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Men, masculinities and diabetes

A qualitative research on the everyday life of men with a chronic illness

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Abstract

National and international epidemiological data show a general male disadvantage in health, and the dominant explanation for men's poorer health status usually points to men's belief and behaviours in relation to health and illness: men, it is suggested, disregard health and mismanage illness in order to fulfil social expectations around masculinity. The present research responds to a call for empirical studies that explore men's health and illness practices not through biomedical or behavioural explanations, which tend to homogenize and oversimplify men's experiences, rather with a critical approach that would allow to go beyond the idea that "masculinity is dangerous to men's health." Masculinity is here intended not as a fixed, universal, biological trait, but rather as a configuration of practices that are accomplished in social action and, therefore, can differ according to the specific gender relations existing in different social settings. This critical perspective allowed studying men's experiences of health and illness by taking into account also its complex relation with gender construction, but also with structural differences and relational contexts. This research explored, through the conduction of 40 in-depth interviews, the experiences of men living with an intrusive chronic illness, autoimmune diabetes. This condition requires a series of self-management practices in everyday life that could be considered as emasculating (e.g. eating healthy, body discipline and self-monitoring) and that may pose specific challenges to dominant assumptions of masculinity such as bodily strength, control of the body and of emotions, independence and resistance to pain, and for this reason it has been considered as particularly appropriate for exploring the complex intertwining of chronic illness and gender. More specifically, the analysis focused on three areas: namely, the impact of chronic illness in the everyday life; the multiple ways of "doing" masculinity in the context of the "doing" of autoimmune diabetes; and, lastly, the impact of diabetes and of the medicalization of male sexual health on sexuality and intimacy practices. Overall, the empirical material allowed for great insight into men's experiences of illness and depicted a complex picture, very different from the monolithic description offered by the majority of studies previously conducted on this issue.

Ricerche nazionali ed internazionali hanno recentemente messo in evidenza un generale svantaggio maschile nell'ambito della salute, che è stato solitamente attribuito ai comportamenti e alle credenze degli uomini nei confronti della salute e della malattia: secondo buona parte della letteratura sul tema, si ipotizza che gli uomini mettano in secondo piano la propria salute e che non gestiscano adeguatamente le malattie al fine di adempiere alle aspettative sociali relative alla costruzione della maschilità. La ricerca presentata in questa tesi risponde alla necessità di esplorare empiricamente le pratiche di salute e di malattia messe in atto dagli uomini attraverso un approccio che non si basi su spiegazioni biomediche o comportamentali, che in entrambi i casi tendono ad omogeneizzare e a semplificare eccessivamente l'oggetto in studio; bensì, attraverso una prospettiva che permetta di andare oltre all'ipotesi patologizzante secondo cui "la maschilità nuoce alla salute" e che affronti invece la maschilità tenendo conto delle sue dimensioni di pluralità e dinamicità, come una configurazione di pratiche compiute attraverso le interazioni sociali nella quotidianità dei vari contesti attraversati. Questo approccio ha permesso di studiare gli uomini e le loro storie di malattia tenendo conto della pluralità e della complessità delle esperienze, così come anche delle differenze strutturali e relazionali che ne hanno determinato gli orizzonti. Questo lavoro di ricerca ha esplorato, attraverso la conduzione di 40 interviste discorsive, le esperienze di uomini che convivono con una malattia cronica intrusiva e degenerativa, ovvero il diabete di origine autoimmune. Questa condizione non può essere curata ma unicamente gestita nella sua manifestazione sintomatica quotidiana. In particolare, è stato selezionato il caso del diabete perché ritenuto particolarmente valido per lo studio della relazione tra costruzione della maschilità e gestione della malattia: infatti, le pratiche di autogestione che la malattia richiede nel quotidiano (come per esempio l'adozione di una dieta salutare, di pratiche di cura di sé, di automonitoraggio e disciplina del proprio corpo, etc.) possono interferire con una performance di maschilità tradizionale dominante. Nello specifico, l'analisi si è soffermata su tre ambiti: ovvero, sull'impatto della malattia cronica nella vita quotidiana; sui molti modi di "fare" la maschilità nel contesto del "fare" diabete; e, infine, sull'impatto del diabete e della medicalizzazione della salute sessuale maschile sulle pratiche connesse alla sessualità e all'intimità. Nel complesso, il materiale empirico ha permesso un'analisi articolata delle esperienze di malattia degli uomini diabetici, di cui ha mostrato un'immagine multidimensionale ed eterogenea, i cui tratti segnano la distanza dalla descrizione monolitica offerta dagli studi quantitativi che hanno affrontato questi temi in passato.

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Chapter I

Introduction

The present research explores the experiences of men living with autoimmune diabetes and draws on biographical narratives that have been collected through in-depth interviews. In Italy it is estimated that more than 3 million 200 thousand people suffer from diabetes, which represents 5% of the Italian population (Istat 2017).[1] Among those cases, the 10% refers to type 1 diabetes, whose onset usually occurs during childhood or adolescence, more rarely during adulthood. After diagnosis, individuals living with autoimmune, insulin-dependent diabetes need to engage in a series of self-management and self-monitoring practices that involve (at least) four times a day blood-glucose monitoring; insulin replacement through multiple insulin injections, which are usually administrated up to six times a day or through the continuous subcutaneous therapy with the insulin pump (see Appendix I for illustrative pictures); as well as the adoption of a healthy diet and eating plan, associated with regular physical activity. A constant diabetes self-management has the main aim of minimizing the risk of experiencing diabetes-related complications in the long term (such as neuropathy, nephropathy, retinopathy etc.) and in its acute manifestations (such as hypoglycaemia, hyperglycaemia, diabetic coma etc.). Diabetes is nevertheless a complex experience, characterized by a combination of bio-psycho-social dimensions: it involves the malfunctioning of the pancreas and the presence of the abovementioned bodily symptoms (in Twaddle terms, the dimension of *disease*); the subjective experience as self-perception of the adequacy of bodily functioning (dimension of *illness)*; and, lastly, it entails consequences on the social level, in the ways diabetes is signified and institutionalized in society (dimension of *sickness*).

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[1] Retrieved from: https://www.istat.it/en/files/2017/07/Report_Diabetes_En_def.pdf?title=Diabetes+in+Italy+-+24+Jul+2017+-+Full+text.pdf last view 27/09/2018.

The onset of diabetes may pose specific challenges to dominant assumptions of masculinity such as bodily strength, control of the body and of emotions, independence and resistance to pain. At the same time, the need to adjust to a potentially marginalizing and emasculating condition could make more evident how health-related practices are signified in terms of gender practices, as well as how they intertwine with broader hierarchies of power relations.

In this introductory chapter I shall give a brief outline of the theoretical framework I draw on, and I shall specify how this study is located within broader work on gender and health; I will then discuss the main aims of the research and their relevance for gaining further knowledge about the object under analysis; lastly, I shall provide an overview of the main points of this dissertation and anticipate the structure and content of the chapters that compose this thesis, together with the methodology that informed the construction and analysis of empirical material.

1.1 Studying gender in the context of health and illness

During the last decades, there has been a growing interest in men and masculinities[2] in the context of health and illness (Gough & Robertson 2009). National and international epidemiological data show a general "male disadvantage" in health, in terms of lower life expectancy, higher rates of specific diseases and higher risk of injuries, accidents and binge drinking (Baker & Shand 2017, Istat 2017). Research on gender disadvantage in health highlighted the impossibility to attribute the origin of those differences to mere biological factors (Butland *et al.* 2014). On the other hand, the majority of explanations for men's poorer health status usually pointed to men's belief and behaviours in relation to health practices: health care services seem to be more likely accessed by women rather than by men (Bertakis *et al.* 2000), and more in general men are found to adopt less healthy lifestyles than women, to have a stoical approach to pain, to

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[2] Throughout this dissertation, I shall use "masculinities" in its plural form, in order to underline the connection of this concept with the broader theoretical approach to gender - and especially to masculinity - that takes into account multiple and dynamic types of masculinities and femininities that are in relation with each other and that are performed in the everyday life as a dynamic and historically situated configuration of gender practices (Carrigan *et al*. 1985; Connell 1995).

engage in risky behaviours and not to comply with medical recommendations (Courtenay 2000). According to this approach, health-related attitudes and behaviours are to be understood as means for enacting and demonstrating femininities or masculinities, which are sustained and (re)produced by social and institutional structures (Ibidem).

However, explaining gender health disadvantages through men's and women's trends of behaviours and attitudes may result in underestimating the complex and sometimes contradictory nature of masculinity (Gough & Robertson 2010) that has been described in literature on men and masculinities (e.g. Connell 1995, Connell & Messerschmidt 2005). In order to explore how gender and health interact together to produce and shape lived experiences, it is crucial to also take into account differences in terms of social structures: in terms of ethnicity, social class, age, level of education, dis/ability, (co-)morbidity, in terms of *habitus* (Bourdieu 1984) and in terms of how men – as well as women – understand health/illness-related practices as a form of social distinction.

Therefore, the research project presented here responds to a call for empirical studies that explore men's health and illness practices not through biomedical or behavioural explanations – which tend to homogenize and oversimplify men and women in dichotomous and universal categories – but rather through a critical approach that takes into account also structural differences and relational contexts.

In this regard, Connell (Carrigan *et al.* 1985; Connell 1987, 1995, 2001, 2005) provided one of the most comprehensive and influential theoretical frameworks that allowed for an understanding of gender that took into account its relational dimensions, and considered not only the system of hierarchical relations that informs women and men's interactions, but also the ones that structure relations among men and men, and women and women. Masculinity, thus, is not conceived as a biological trait, nor a fixed and universal variable, it is rather a "configuration of practices that are accomplished in social action and, therefore, can differ according to the gender relations in a particular social setting" (Connell & Messerschmidt 2005: p. 836). The ways in which masculinity is performed may vary across time, culture, social grouping and even in the same individual through time (Connell 1999). In this dissertation, I thus intended masculinity as an embodied dimension of the self that is located in larger social structures of power relations.

The fact of approaching health and illness-related practices as specific forms of "doing gender" (West & Zimmerman 1991) that are embedded in a multiplicity of social structures and power relations had a significant impact on the way I designed and conduced this research. The object under analysis here is how men experience a chronic illness, namely autoimmune diabetes, which may pose a series of challenges to the construction of masculinity. In fact, the most idealized configuration of practices of masculinity in contemporary Western society, that Connell named *hegemonic masculinity,* entails ideals of bodily strength, potency, independence, rationality, aggressiveness, self-reliance and resistance to pain. On the other hand, it has been argued (see Robertson 2007) that body self-care practices are traditionally considered as feminine, and that "health" is a realm from which men try to distance themselves in order to construct an adequate masculine self.

In the case of diabetic men, it should be noted that they construct their bodies and selves with a potentially conflicting double bind: that of masculinity construction and that of illness management. Diabetes may suddenly manifest specific symptoms on men's bodies and this, in a way, "serve[s] as a continual reminder that they are at odds with the expectations of the dominant culture" (Gerschick & Miller 1995: p. 183) because the need of insulin injections for survival, the possibility of health complications, the constant need medical examinations and the potential sudden unreliability of their bodies may constitute an emasculation factor. In fact, both the weakening of their bodies and the risk of losing control of themselves during hyper- or hypoglycaemia episodes may threaten the above-mentioned cultural values of hegemonic masculinity.

Diabetic men can respond to those challenges in many ways. What I want to stress in this initial paragraph is that looking at illness-related practices through "gender lenses" might be extremely useful in order to better understand how individuals deal with their conditions: this is something that goes beyond the dichotomy of compliance/non-compliance practices, and it is more related to *how* men signify and understand their personal ways of being – or not being –

compliant with medical treatment. Self-managing diabetes necessarily entails a reflection about how the (male) body is presented during social interactions, and which are the practices and conditions that should be disclosed or disguised in order to construct and perform an adequate masculine self. The underlying assumption, which will be further developed in next chapter, is that within a patriarchal society the category of "men" holds a position of power with respect to women, and in order to enjoy the benefits that derive from belonging to the dominant gender group, male individuals have to present themselves to others as a specific social being, men (Schrock & Schwalbe 2009: p. 279), and this essentially is a dramaturgical task (Goffman 1977, West & Zimmerman 1987, Schrock & Schwalbe 2009). In order to be recognised as a man, it is thus necessary to master a set of practices, those "manhood acts" (Schwalbe 2005, Schrock & Schwalbe 2009) that need to be performed during social interactions and that, in turn, have an impact on the way they construct "male" bodies, on the way men incorporate definitions of the self as "masculine" and on the way gender inequality is produced and reproduced over time, also in the context of health. According to the hegemonic ideal of masculinity, health-related practices are considered as potentially emasculating factors, and this has been posited as one of the behavioural reason why men usually are non-compliant to medical treatment.

However, recent literature about changing masculinities (i.e. Bridget & Pascoe, 2014, Arxer 2011, Demetriou 2001) pointed out that the dominant form of masculinity might actually change over time through the negotiation and appropriation of practices that appear as counter-hegemonic, just as those concerning body-care, or illness management. It is thus interesting to explore how diabetic men position themselves with respect to hegemonic ideals of masculinity, and explore whether they take illness as an "opportunity" to renegotiate masculinity or if more traditional gender conceptions prevail.

Overall, previous studies on gender and diabetes have developed mainly in two fields of study, that of medical and epidemiological research, that mainly focussed on aetiology, risk factors, compliance to treatment and diabetes-related complication (i.e. Legato 1997, Summerson *et al.* 1999, Vespasiani *et al.* 2005, Bianchi *et al.* 2016); and sociological and psychological literature, that explored attitudes and behaviours of women and men that had been diagnosed with diabetes (i.e. O'Hara *et al.* 2013, Broom & Lenagh-Maguire 2010, Redman *et. al*. 1988, Lemone 1996). When considered, gender has been found to be a substantial factor in dealing with the disease, highlighting the main differences among men and women. It should be considered that, overall, literature on gender and diabetes often entailed a dichotomous approach to gender and, as Broom and Lenagh-Maguire (2010) and O'Hara and colleagues (2013) claimed, further research on this issue is needed in order to consider different and more complex variations in the way gender interacts with illness and health practices, for instance considering other elements of social structure – such as age and class – that multiply the possibilities of embodying masculinity and illness.

1.2 The aims of the research

Overall, the primary purpose of this thesis was to critically explore men's experiences of autoimmune diabetes, with a specific focus on their everyday life practices, on their embodied experiences of self-management and on their sexuality and intimacy. The questions that this work sought to answer are the following:

- How do men understand diabetes through time?
- (How) does diabetes impact on men's everyday life?
- How do they "do" masculinities while "doing" diabetes?
- How do they respond to the docile and "healthy" diabetic body ideal proposed by medical knowledge? How does this intertwine with masculinity construction?
- How do they understand diabetes-related sexual changes, and how does this impact on the way they perform masculinity(ies)?

The relevance of this study rests on two main points: the first one is the innovative focus on men's accounts of health and illness, which contributes to fill the gap in the actual sociological knowledge of gender and health – which usually focuses on women's experiences and women's bodies –; a second aspect that contributes to make this thesis relevant is its multidimensionality in terms of the illness experiences collected: usually, the literature on chronic illness focuses only on samples based on childhood-onset or adult-onset diabetic participants, while in this case the comparison of different experiences of life with illness allows to go beyond the "biographical disruption" (Bury 1982) approach and expand sociological knowledge in this regard. Furthermore, empirical findings may also provide valuable insights to health professionals and policy makers, in order to critically inform clinical practice and to guide policies in order to reduce (gender) inequalities in health.

1.3 Outline of the dissertation

After this introductory chapter, the dissertation begins by offering an overview of the theoretical background relevant to the object under analysis (Chapter II). The remaining chapters are organized as follows. Chapter III describes reflexively the research design that guided the research process and illustrates how empirical material has been constructed. Chapter IV, V and VI are dedicated to the presentation of empirical findings about men's experiences of diabetes. They are structured with an initial review of the specific literature relevant for the topic under analysis. Lastly, the main conclusions of this research are summarized and critically presented in Chapter VII.

More specifically, the next chapter shall provide a review of the literature concerning the social construction of gender and specifically of masculinity(ies); following that, I then review literature on sociology of the body, with a particular emphasis on the embodiment of masculinity and on the embodiment of illness. Subsequent to that, some background information on the specificities of autoimmune diabetes is considered, in order to better understand its possible implications for men who experience this condition. Finally, the literature that addresses the interrelation of diabetes and gender has been outlined, in order to have an overview of what has been already done on this issue and what instead still needed to be covered. I decided to position the more specific reviews of the literature at the beginning of each empirical chapter.

Chapter III offers a detailed account of the methodological path that has been followed in order to conduct this research, and it is structured in sections that go through the typical traits of qualitative research: the first paragraph is dedicated to the research questions and to their relevance for sociological research; I then discuss the qualification of the research context, subsequently defining the theoretical basis that informed the sample design and the recruitment of the 40 participants that took part in the research; then I focus on the research technique that I adopted in order to construct the empirical material – namely, in-depth interviews – and justify their relevance for the object under analysis; then I offer a reflexive account about my positioning, by considering how my personal characteristics and that of participants may have contributed to the co-construction of empirical material. Finally, the last paragraph of chapter III provides a discussion about the ethical considerations that emerged during each stage of the research process.

The first empirical chapter (Chapter IV) explores men's complex experiences of autoimmune diabetes from a biographical and interactional perspective, by analysing the discourses produced around their illness trajectories. In this chapter findings are organized around three common "stages" that characterized the illness narratives – namely, the onset, diagnosis process and the process of coming to terms with diabetes – which are contextualized and analysed in their multiple dimensions and explained through relevant literature on the topic. These three stages are described in detail by considering illness in a diachronic perspective, and by simultaneously focusing on physical changes, on illness meanings and on the performance of everyday life practices. Illness is conceived as a dynamic process, a "trajectory" (Corbin & Strauss 1988: p. 162) that cannot be predicted in advance but only reconstructed in retrospect. Where it emerged as a relevant dimension, masculinity has been here considered for how it has intersected with the narration of illness experience.

Chapter V further examines the interconnection of diabetes and masculinity by focusing on how illness practices are imbued with gendered meanings, and how talking about one's experience of illness in the context of an interview might turn into an occasion for enacting specific performances of masculinity. The many ways in which participants understand and "do" diabetes in this sample are here analysed by taking into account how and if they incorporate contemporary imperative of healthiness and self-discipline – which in the case of diabetic individuals is exacerbated by the need of self-managing and self-monitoring their bodies for survival – with responses that range between uncritical compliance to resistant lay expertise. I have thus organized empirical findings around three ideal types – namely, the “Diabetic Quantified Self,” the “Athlete” and the Free Spirit” – that describe the main patterns of relations emerged from the analysis.

A different aspect of the intertwining between masculinity and illness is explored in the third empirical chapter (Chapter VI) by focusing on men’s accounts of sexuality and diabetes. The sexual health standards legitimized by medical knowledge in the specific context of diabetes are critically read with reference to the theoretical works and reflections on the medicalization of male sexual health which are described in the literature review proposed at the beginning of the chapter. According to such literature, sexuality is considered as a crucial arena of practices for masculinity construction, and in the case of diabetes it could be challenged in many ways by an organic and psychological impact of the illness on the body. I have thus analysed the main representations of sexuality emerged form participants’ narratives, their main explanations of sexual difficulties and their different responses in relation to such experience. This chapter offers insight on how men dealing with diabetes experience sexuality and its changes and how this intersects with broader processes of masculinity construction.

Finally, in the last chapter (Chapter VII) I critically discuss the main empirical findings of this research and how they contribute to further the knowledge of studies on men, masculinity and illness. To conclude, I consider the limitations and some implications of this work.

Since the main objective of this work was to study the embodied experiences of men with diabetes, I have examined the biographical narratives of 40 men who received – in different moments of their lives – a diagnosis of autoimmune diabetes. As I have anticipated before, empirical material has been constructed through in-depth interviews and participants have been selected following a specific research design that has been constructed and adjusted throughout the research process in order to answer in an accurate and sound way to the research questions. Overall, I chose to use a qualitative approach, because I considered it more appropriate for the specificities of the subject under analysis. I thus focused on diabetic men living in Italy, and the sample design that guided me during the recruiting phase was obtained through the equal subdivision of cases in four main configurations. Such typology has been constructed through the intersection of two main socio-demographic dimensions: individuals' age and their social class, both justified by their relevance for the research questions. To sum up, recruitment criteria included (a) male gender; (b) being diagnosed with autoimmune diabetes; (c) requiring insulin injections for survival; (d) being aged between 20 and 60 years; (e) belonging to a working/middle class background. The final sample is very heterogeneous and such heterogeneity has been further sought with respect to participants' age at the moment of the onset, the severity of the disease, the presence/absence of diabetes-related complications and sexual orientations, under the assumption that these dimensions could contribute to potentially create heterogeneity in discourses and in experiences. The main recruitment techniques, as will be further explained in Chapter III, relied on contacting dedicated associations, on Internet recruitment and on snowball sampling. An innovative tool for recruiting participant that I decided to use and that proved to be extremely successful was that of Facebook advertising, that allowed me to reach a specifically targeted population that fitted research recruitment criteria and to collect illness stories produced by men that would have otherwise been impossible to reach because they did not engage in patients' associations nor in online communities.

As mentioned before, empirical material has been constructed through single in-depth interviews, in some cases enriched by the temporary presence of participants' partners. Interviews conduction took place from May 2017 to July 2018 and resulted in 57 hours of audio recording – with a mean of 1.42 hours per interview – and in 2048 pages of *verbatim* transcription.

Overall, the final thesis is the result of successful strategies as well as of failed attempts: I started with a precise research project that entailed participant observation in a urological clinic but, over time, I had to adjust it to the actual opportunities and possibilities offered by the fieldwork. After encountering some obstacles, I opened to the "unexpected," and the richness of information that emerged from participants' stories of diabetes has been really surprising. I am extremely grateful to all participants for entrusting me with their precious stories. Uncertainty, loss of body function, disrupted identities, challenges, embodiment, reconstructed trajectories, risk, change, opportunity, self-discipline and self-monitoring are themes that recur across this dissertation. The constant intersection of empirical material, theoretical references and analytical dimensions allowed for the construction of a rich and articulated report of research, which aimed to contribute to further problematizing masculinity in relation to chronic illness experience.

Chapter II

Literature Review

2.1 Introduction

The objective of this chapter is to provide a theoretical basis for studying the intersection of masculinity construction in the context of health and illness. At the beginning of each empirical chapter (Chapter n. 4, 5, and 6) an introductory paragraph with more specific literature review will be provided. Until recently, gender and health have been mainly studied with a focus on women, rather than on men. In the attempt of bridging the gap in this specific literature and provide a theoretical framework for the research, this chapter addresses men's experience of health and illness drawing on different fields of sociological investigation and theorization. This object of analysis in fact offers a challenging opportunity to establish and enhance the communication among different literatures and approaches such as the theorizing around gender, the area of sociology of the body and that of sociology of health and illness.

Despite the fact that both gender and health concern and highly influence the existence of everyone in such a way that individuals become intelligible especially through the gendered and corporeal performances of their bodies, in the everyday life the conscious awareness of gender and that of the body is mostly silenced by the assumption of naturalness that surrounds their normative expectations. This is especially true for individuals that, more than others, embody dominant and idealized features such as – within our Western social context – whiteness, healthiness, physical/mental ability, masculinity and heterosexuality. Those mentioned above are indeed privileged forms of experiencing bodies and living social world. As such, they are generally taken for granted and often overlooked. Health is indeed a key factor that shapes the quality and duration of our lives, however, and with the exception of the extreme case of healthists, the majority of individuals consider health as a 'natural' condition that does not need much attention (Cardano 2015). Usually, health emerges as an issue only when it is replaced by its alteration, illness (Ibidem), and it becomes an object of social action and specific consideration especially when illness disrupts significantly the individuals' everyday life and when it is expected to last over a long period of time (Gadamer 1994). As a matter of fact, living with a chronic condition may disrupt ordinary inattention to health and it may have a substantial impact on daily living, perception of self, social relationships and physical functions. In fact, social life is usually structured under the assumption of a certain bodily normativity and a supposed and predefined condition of "healthiness," that is disrupted by individuals that do not meet such ideals of normalcy. In this context, the sick individual "is sick not because of the absence of a norm but because of his incapacity to be normative" (Canguilhem 1978, or. ed. 1904: p. 106). Unintentionally clashing against normative social expectations makes social norms more evident, and makes the sick individual in a reflexive position with respect to his self-perception, his awareness of the body and his understanding of health and illness. As we shall see in further detail later in the chapter, health, illness and the body are therefore brought into –more or less-conscious awareness when normative assumptions of bodily presence and bodily reliability are disrupted by a "critical situation," as Giddens (1979) would define it.

Something similar also happens to individuals that occupy the most privileged position within the gender order: namely, men. Heterosexual masculinity unquestionably holds a hegemonic and privileged position within Western gender order and this has led to a general inclination to take it as a natural, a-historical and homogeneous concept that results from presocial, innate and biological characteristics. The onset of a long-term illness may breach taken-for-granted assumptions of an idealized masculinity: as a matter of fact, the "stuffness" of the body, as Turner (2008) defined it, shapes the concrete possibilities of experiencing life and influences the way people perceive themselves and engage in social interactions.

Chronic illness could be perceived not only as a deviation from an expected health norm, but also as an "innovative experience in the living being," as Canguilhem

(1978, or. ed. 1904: p. 108) states: “the content of the pathological state cannot be deducted, save for a difference in format, from the content of health; disease is not a variation on the dimension of health; it is a new dimension of life.” This new dimension of life may bring some changes in bodily functioning and this in turn may pose specific challenges to dominant assumptions of masculinity such as bodily strength, control, independence and resistance to pain. At the same time, this disruption of ordinary habits and the need to adjust to a potentially marginalizing and emasculating situation makes more clear how health practices are signified in terms of gender practices, as well as how they intersect with the construction of different forms of masculinity. In this regard, gender is here intended as something individuals do, rather than a fixed entity imposed through socialization or determined by biological traits of individuals (Connell 2005). Masculinities are thus actively performed, negotiated and sustained by individuals that are embedded in specific social and cultural contexts, as well as situated in particular webs of power relations. Their multiple positions within structural relations, as we will see in more detail in this chapter, indeed affect the ways in which men understand and engage with health and illness.

Being socially classified as male or female, healthy, sick or disabled contributes in producing specific social identities and in assigning to individuals a specific position within the social order, with specific rights or limitations. Individuals are shaped by different social and cultural expectations, different exposure to vulnerabilities and different possibilities of overcoming unexpected life events. This consideration points out to the social and cultural dimensions of both gender and illness, which are here intended not only as determined by biophysical factors or personal motivations, but rather as culturally, socially and historically situated. From this perspective, this research aims to add empirical knowledge to the recent theoretical calls to consider the biological and material dimension of the body within an embodied sociology of health and illness that considers the “stuffness of the human condition” (Turner 2008: p. viii) with a critical perspective that avoids the risk of oversimplifying the body to his mere anatomical and physiological aspects (Robertson 2006, Williams 2002). In this sense, the approach adopted in this work resides in finding a way of studying the body and the processes of embodiment that takes into account both its physical/biological and social/cultural dimensions, as suggested by Shilling (2012). Hence, men's bodies are here considered as both material and representational (Robertson 2006), as influenced by the culture in which they flow and as shaped by social expectations related to their age, social class, ethnicity and position in the gender order.

With respect to the intersection of masculinity and health, it has been adopted a critical perspective that sought to problematize gender in relation to illness by going beyond the simplistic approach that "masculinity is dangerous to men's health" (e.g. Harrison 1978): here masculinity has been rather conceived as a multiple, situated and sometimes contradictory dimension of the self which is interactionally performed. Overall literature on men's health gives a rather different picture. Gough (2006) analyzed discourses around men's health in the media and highlighted that they usually revolve around a set of claims: that nowadays there is a real men's health crisis because men seem to be more vulnerable than women with respect to a range of health problems; that men do little or nothing to maintain and improve their health; that "masculinity" should be blamed for men's poor health status; and that it is needed dedicated research and policy in order to solve this problem (Ibidem: p. 2477). Just as in media discourses, "masculinity," in its relation to health, has been often reduced to a single dimension, often relying on the "stereotypical macho" (Ibidem: p. 2477) type that is used to explain the supposed "crisis" the men experience in relation to health. As it will be further explained in the following paragraphs, in this work masculinity will be studied in relation to health and illness in its plural and dynamic dimensions, taking distance from the reductive approach of men as an homogeneous group that disregard health and mismanage illness and also from the essentialist conceptions of masculinity that relies on a dichotomous, biological difference among the sexes that do not do justice to the complexity of men's health experiences.

This chapter aims at providing a review of the literature concerning the relationship between male gender and men's health and illness, with an emphasis on theories and studies dedicated to the social construction of gendered identities, specifically on masculinities. Subsequently, literature on sociology of the body is considered, with specific attention given to the embodiment of masculinity and to the embodiment of illness. Finally, some background information on the specificities of diabetes as a disease is provided, focussing on its relevance for the study of men's health and by providing an overview of the literature that has already explored this chronic condition with a gender perspective.

Even though the aim of this chapter is to offer an outline of the works on masculinities construction and men's health and illness, not all the issues that are currently debated in men's health literature will be outlined in detail here. Nevertheless, additional and more specific literature regarding masculinity and health shall be examined and discussed within the chapters dedicated to the analysis of empirical material.

2.2 Overview of the studies on men, masculinities and health

The study of men and masculinities and the importance of exploring male experiences in relation to health have only recently begun to receive sociological and popular attention. Since the 1990s, men's health has gained more attention in the media with regards to decline in fertility, to the use of Viagra and its successors, to obesity problems, to prostate and testicular cancer and to men's reluctance to seek for medical help: all these issues have contributed to fuel the growing debate about the state of men's health (Watson 2000).

Men's health studies have, in the last decades, systematically analysed men's health and illness taking gender and gender health equity into theoretical account, drawing from different fields of knowledge such as epidemiology, sociology, psychology, medical anthropology, feminist research and theory and men's studies (Sabo 2000). At the same time, studying the health of men does not in itself constitute a novelty: in fact, after the Word War II, the majority of academic medical research was dominated by men, most physicians were men, and people selected for medical research studies were also men. As a result, studies did not distinguish women's and men's health practices and outcomes and simplified personal and cultural aspects of men's life to statistical and biological categories (Sabo 2005). The way in which gender and health has been studied had radically changed through time, and in the following paragraphs I will take into account the main changes, while outlining the theoretical framework that has informed the whole research process.

2.2.1 The male sex role and its criticisms

During the 1960s something began to change and early theorizing around gender was informed by theoretical framework of the so-called *sociocultural model* (Sabo & Gordon 1995). This framework overcome the biological determinism and reductionism of the so-called *biomedical model*: it had criticized the excessive and simplistic focus on biological and physical processes and had claimed the relevance of the role of social and cultural factors in determining the perception and experience of health and illness. In this initial phase, scholars approached gender as it was just an additional demographic variable, and this has indeed been crucial in epidemiological research because it allowed to calculate differential rates of illness between females and males and also made it possible to subgroup males according to variables such as socioeconomic status, race, ethnicity and geographical area of residency (Ibidem). For instance, this kind of descriptive research has highlighted that men had a shorter life expectancy than women, they had more life-threatening illnesses and they were less likely to contact doctors for their health problems.

The intersection of health and gender has been more broadly explored during the 1970s and the 1980s, mostly through the work of feminist scholarship that, supported by women's health movement, challenged the male-dominated health system and raised awareness of gender (power) relations. Some of the issues that have been investigated included, for example, how gender socialization processes influenced perception of illness and adjustment to death, gender inequalities in health professions and how sexism and gender inequality were taught to be the cause of misdiagnosis and of women abuse (Sabo & Gordon 1995). Furthermore, feminist philosophers of science emphasised how medical knowledge was characterized by patriarchal and androcentric biases (Daly 1978, quoted in Sabo & Gordon 1995). Lawrence and Bendixen (1992) published an interesting review of anatomy texts for U.S. medical students used between 1890 and 1989 and noticed that in those texts the human body had been represented almost in the same way: namely, both its illustrations and the text depicted male anatomy as the standard against which female specificities were compared. Even the most recent anatomical texts have followed the historical conventions typical of the classical and modern periods in which the male anatomy was considered as the basic model for the human body (Watson 2000). Moreover, Martin's (1989) criticism of scientific discourse pointed to highlight how medicine constructed the knowledge of the (female) body. Interestingly, Martin studied and compared lay and medical accounts of menstruation, childbirth and menopause and observed that, through the appropriation of medical science, the female body came to be understood as fragmented and objectified. She demonstrated that (male) Western medical profession has used metaphors of production and alienation to describe female bodily processes (Watson 2000). Just as Lawrence and Bendixen (1992) highlighted, she discussed the persistence of a dominant male ideology of women's bodies in medical practice and textbooks. For instance, when she compared women's lay accounts about self and body representations to that of medical knowledge it emerged a tension between the two: for example, medical descriptions of childbirth appeared more objectified and technical if compared to the more subjective accounts proposed by women. Such contrast has been explained with the different nature of the two discourses, with the asymmetry of power which characterize them and with the attempt of a "male" medical profession to prescribe order to female bodies: an imposition to which women opposed resistance. However, Martin does not use a social constructivist perspective: she rather focused on the different interpretations that have been given to the same "physiological reality" by lay and medical accounts, without actually questioning its legitimacy.

Martin's criticism of medical knowledge was part of a broader feminist critical approach that intended to unveil the gendered construction of science and to question its supposed "neutrality:" Keller (1985), for instance, claimed that Western science is based on the equivalence of maleness and the dominant scientific worldview (Watson 2000). In fact, the author (1985) argued that women had more marginal roles in the production of medical knowledge as a form of cultural activity, both because of a cultural congruence between objectivity and masculinity, and because of the higher cultural value socially attributed to what is considered as masculine and what is defined as scientific (Ibidem). Thus, feminist criticisms mainly highlighted the impact of a “gendered science” on the lives and health of women, this way bringing attention to the specificity of women’s experiences and needs, and revealing maleness behind the construction of the universal and supposedly neutral subject of knowledge.

Even though gender became soon an essential factor for understanding sociocultural dimensions of health and illness in many disciplines such as epidemiology, medical sociology and psychology, a limitation of this early work was that “gender and health” have been intended as a synonymous of “women’s health and illness,” this way leaving critical study of men’s health unexplored.

Successively, the study of men’s health was fuelled by the reflections and academic dialogue among different fields of analysis referred to as “study of men and masculinity,” “men’s critique of gender” or the “new men’s studies” (Sabo & Gordon 1995). A focus on men’s health was also encouraged by the growth of men’s movements in many Western countries, such as gay rights activism of the 1980s which promoted awareness of the health risks connected with some sexual practices in response to HIV diffusion.

During these years, “sex role” theorists highlighted how the socialization to a traditional masculinity model increased the risk of experiencing injuries and specific illnesses for boys and men. This framework for understanding men’s health has been defined as the “deficit model of men’s health” (Sabo 2005: p. 327), whereas the “male role socialization” and “sex-role related behaviours” (Harrison 1978: p. 81) were thought to be responsible for the higher mortality rate of men. The socialization to traditional masculinity “role” was in fact associated with specific masculine behaviours that elevated health risks, such as: drinking, smoking, fighting, career-related stress, competition, concealing emotions and symptom denials. Over this period, social psychologists approached masculinity as a set of traits that could be measured: among them, we can mention some the most influent such as the Bem Sex Role Inventory (BSRI, Bem 1974) and the Personal attributes Questionnaire (PAQ, Spence *et al.* 1974). In line with sex role framework, scholars have therefore identified specific gender expectations that were associated with the socialization to male ‘role’, for instance psychologist

Robert Brannon (1976) in his article *The Male Sex Role* outlines the following four major characteristics:

> (1) *No sissy stuff*: it requires men to be different from women;
> (2) *Be a big wheel*: that invites to become successful in order to be superior to others;
> (3) *Be a sturdy oak*: it indicates the imperative to be independent and self-reliant;
> (4) *Give 'em hell*: this refers to the expectation to become more powerful than others, if it is necessary, even by force. This specific aspect may imply the adoption of behaviours that put boys and men at risk of illness or death such as binge drinking and fast driving, and this is especially true for the construction of masculinity of male adolescents (Sabo & Gordon 1995).

Critical feminist scholarship began soon to critique the basic assumptions of "sex role" theory: for instance, Lopata and Thorne (1978) argued that the term "sex roles" was "sociologically illogical" (Ibidem: p. 718) and that the very term "role" was not appropriate for describing gender. Gender, understood as a learned behaviour determined on the basis of biological sex, they claimed: "Is not a role in the same sense that being a teacher, sister, or friend is a role" (Ibidem: p. 718). The concept of role instead did not consider essential dimensions such as social contexts, history, phases of the life cycle or culture. Furthermore, they contended that the concept of "sex roles" implied static and unchanging behaviours and expectations for women and men, and furthermore they observed that, with good reason, this had not been the case, for example, of "race roles" or "class roles," that unlike "sex roles" have never entered the sociological discourse (Ibidem). Moreover, critical feminist authors claimed that sex role approach did not account for relations of power and privilege among sexes, nor for ethnicity, sexuality or class. Some of the first studies on masculinity (e.g. Fasteau 1974 and Farrell 1975, quoted in Rosenfelf & Faircloth 2006) questioned the appropriateness of sex role theory, pointing out that it did not consider – and it rather normalized – existing gender order. Another significant insight was that, despite exploring masculinity in relation to health (see, for example, the abovementioned Harrison 1978), this literature actually tended to frame it in medical terms and to pathologize it (ibidem).

2.2.2 The "Doing gender" framework and its contribution to gender studies

This thesis is informed with a constructivist approach to gender, that draws on West and Zimmerman "doing gender" approach, an "ethnomethodologically informed, and therefore distinctively sociological, understanding of gender as a routine, methodical, and recurring accomplishment" (West & Zimmerman 1987: p. 126). This symbolic interactionist "doing gender" framework argued that gender was something women and men "did," rather than an inner property of individuals. The performativity of gender and this (de)constructionist approach reminded, to some extent, that of Judith Butler (1990), an American third-wave feminist philosopher that developed further the theory of gender performativity: she argued that gender is performative and that such performances contributed in constructing the illusion of stable gender identities because they are (re)produced through time.

A few years before Butler's publications, West and Zimmerman stressed the importance of the interactional and institutional arenas for the understanding of gender, which, they claimed, is always a situated conduct, a property achieved keeping in mind the – virtual or actual – presence of others. In order to better explain their approach, the authors proposed a conceptual distinction among *sex*, *sex category* and *gender*: Firstly*, sex* had been defined as "a determination made through the application of socially agreed upon biological criteria for classifying persons as females or males" (Ibidem: p. 127). Such criteria included biological distinctions (external genitalia) at the moment of birth or chromosomal typing before birth, and they could be discordant to each other. With respect to *sex category*, it was indeed applied through sex criteria, but it depended also upon the displays enacted by people in their everyday life, that establish one's membership in one of the two categories. Finally, they defined *gender* as "the activity of managing situated conduct in light of normative conceptions of attitudes and activities appropriate for one's category" (Ibidem: p. 127). West and Zimmerman argued that it is essential to distinguish between these three dimensions in order to account for the “interactional work involved in “being” a gendered person in society” (Ibidem: p. 127).

West and Zimmerman focused on how gender – and, thus, masculinity – is represented into everyday practices and in interactional and relational contexts.
The relational and situated dimensions of gender have been further explored by Raewin Connell, who developed a crucial framework that is considered as essential for the study of men and masculinity. The next paragraph will take into account and further explain her approach and the main criticisms that have been successively made.

2.2.3 Connell’s hegemonic masculinity theory

In the same years, critical feminist scholars claimed that gender relations and health outcomes were deeply informed by social inequality and power differences, that permeated relations between men and women, but also between women and women as well as between men and men (Sabo & Gordon 1995). During this fertile period, Raewyn Connell, with her *Toward a new sociology of masculinity* (Carrigan *et al*. 1985), *Gender and Power* (1987) and *The Men and the Boys* (2001), *Hegemonic Masculinity, Rethinking the Concept* (Connell & Messerschmidt 2005) and *Masculinities* (1995) developed one of the most comprehensive and influential theoretical accounts of gender and especially of masculinity: it had a great impact on the field of gender studies and it has been acknowledged as a real “modern classic” (Giddens & Sutton 2017: p. 630). In her theory of “hegemonic masculinity” which informed the design and conduction of this research- Connell merged a critical feminist approach with elements of social constructionism, this way combining Gayle Rubin’s (1975) analyses of the sex/gender system with the approach to hegemony developed by Gramsci (1971, or. ed. 1932). This framework also provided a link between the field of critical studies on men, sociological theories of gender and feminist accounts of patriarchy. While the majority of literature on gender had focussed on women and femininity, Connell’s theory was the first theoretical account that specifically aimed at better understanding the construction of masculinity. It has been essential in overcoming sociobiological and “sex-role” theory essentialist and deterministic explanations of men and their social practices, which – as I have outlined above - had prevailed in sociological research on men since the 1950s. Connell, instead, proposed a relational model, within which gender was conceived as a system of relations not only between men and women, but also between men and men and between women and women, focussing mainly on the structures that permeate gender relations (power, labour and cathexis). As she pointed out:

> Gender is a way in which social practice is ordered. In gender processes, the everyday conduct of life is organized in relation to a reproductive arena, defined by the bodily structures and processes of human reproduction. This arena includes sexual arousal and intercourse, childbirth and infant care, bodily sex difference and similarity. (Connell 1995: p. 71)

She formulated the concept of "reproductive arena" instead of "biological base" in order to highlight the cultural and historical processes that co-produce different understandings of the body, instead of conceiving it as a fixed array of biological elements. Connell argues that masculinity is not an isolated object of analysis, but it should be rather located in a larger structure that takes into account different types of masculinities and femininities and the relation they have with each other. The concept of masculinity is thus defined as a "configurations of practices that are accomplished in social action and, therefore, can differ according to the gender relations in a particular social setting" (Connell & Messerschmidt 2005: p. 836). Connell thus recognized a multiplicity of masculinities that may vary across time, culture, social grouping and even across the same individual through time (Connell 1999). According to this perspective, masculinities are not essentially determined by biology, nor by the mere process of socialization: they are "configurations of practices," at the same time embedded in hierarchical social relations and located in different structures of relationship, always liable to internal contradiction and historical disruption (Connell 2005). As she stated: "To recognize more than one kind of masculinity is only a first step. We have to examine the relations between them" (Ibidem: p. 76). More specifically, in the current Western gender order she identified different practices and relations among men that resulted from hegemonic processes of marginalization and domination, which she summarized in three ideal types: hegemonic, subordinated and complicit masculinities. Connell argued that there were also different expressions of femininity, which were all located in a position of subordination to hegemonic masculinity and that she distinguished in subordinated, emphasized and resistant femininity. At this point it is indeed essential not to oversimplify: Connell made it clear that there was not only one subordinated form of masculinity, nor only one complicit masculinity, and so forth. As she suggests: “A focus on the gender relations among men is necessary to keep the analysis dynamic, to prevent the acknowledgement of multiple masculinities collapsing into a character typology” (Ibidem: p. 76). Masculinities are in fact configurations of gender practices that may intersect with other factors such as class, ethnicity, sexuality, healthiness and able-bodiness. The figure below (figure 1.1) summarizes the main relational patterning of masculinities “ideal types” in the current Western gender order, which highlights how they are stratified and how privilege and power are distributed among them:

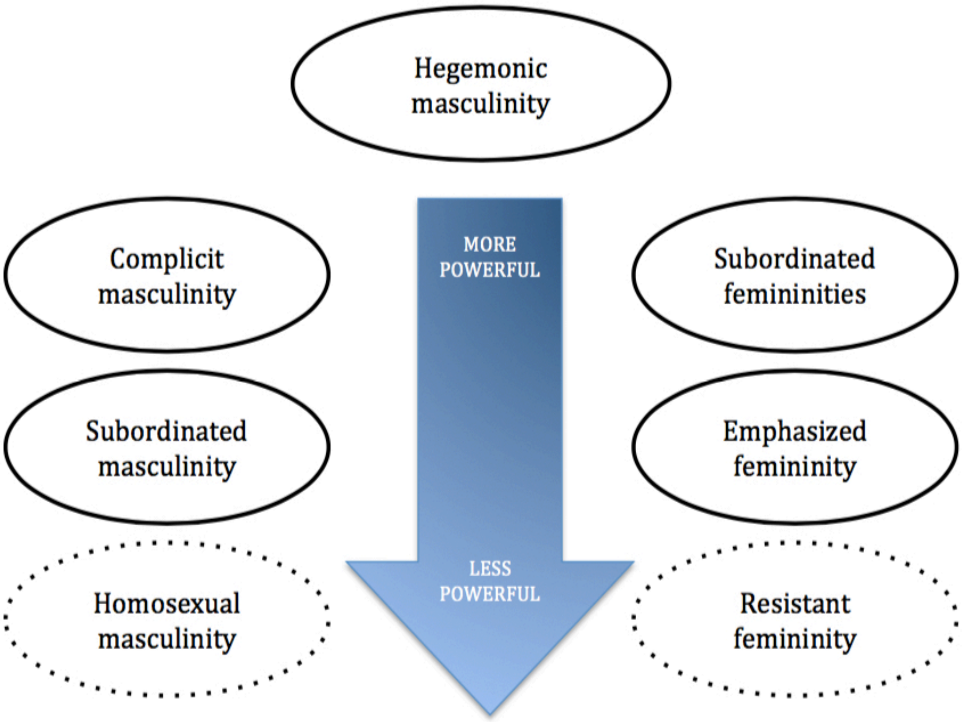

Figure 2.1 Connell’s gender order

As it is outlined in the image above, at the top of the gender order we find *hegemonic masculinity*: this ideal type is the most powerful element of the hierarchy and it is dominant over all other forms of masculinities and femininities. As Connell put it:

> Hegemonic masculinity can be defined as the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women (Ibidem: p. 77).

Connell and colleagues (1985) used Antonio Gramsci's concept of "hegemony" in order to theorize the process of stratifying masculinities: namely, it referred to the cultural dynamic by which a social group holds power and maintains a leading position in social life. Hegemony is usually exercised not through brute force, but rather through a correspondence between cultural ideal and collective institutional power. Hegemonic ideologies tend to legitimate and naturalize the interests of the social group that holds the power, this way subordinating and marginalizing the interests of other social groups. The concept of "hegemonic masculinity" referred to one specific ideal form of masculinity, which is not a fixed character type, but it is rather historically and culturally variable. It occupies the hegemonic position in a given pattern of gender relations and, in the case of Western gender order, it implies being white, heterosexual, wealthy, powerful, physically strong and healthy. It is constructed through the subordination of women and through the marginalization and subordination of alternative forms of masculinity. A good example that illustrates the ideal type of hegemonic masculinity could be the former American actor and governor of California, Arnold Schwarzenegger. Hegemonic masculinity is the dominant and more influencing enactment of masculinity because it is socially sustained, but is not necessarily embodied and performed by the majority of actual men. At the same time, it is normative enough to require men to fit for it or to position themselves in relation to it. Connell's concept of hegemonic masculinity, formulated three decades ago, has been extensively used in the literature and in empirical research in many different fields, from education (e.g. Skelton 1993, Martino 1995) to criminology (e.g. Messerschmidt 1993), from media representations of men (e.g. Jansen & Sabo 1994) to health (e.g. Sabo & Gordon 1995).

Next in the gender hierarchy is *complicit masculinity*: the majority of actual men don't actually meet the idealized standards of hegemonic masculinity, yet they are complicit in sustaining it and in benefitting from what Connell defined as the *patriarchal dividend*, that is to say, "the advantage men in general gain from the overall subordination of women" (Connell 1995: p. 79). Complicit masculinity referred to the cases in which men didn't embody hegemonic masculinity, but yet this did not prevent them from realizing the patriarchal dividend without the tension and risk of being "the frontline troops of patriarchy" (Ibidem: p. 79). As Connell (1995: p. 80) defines it:

> A great many men who draw the patriarchal dividend also respect their wives and mothers, are never violent towards women, do their accustomed share of the housework, bring home the family wage, and can easily convince themselves that feminists must be bra-burning extremists.

There are then a number of masculinities and femininities that exist in a *subordinated* relationship to hegemonic masculinity. Connell (Ibidem) identified the most important case – within contemporary European/American society - in the dominance of heterosexual men over homosexual men. Gay men are perceived as the opposite of the "real men" and their subordinated relationship to hegemonic masculinity goes beyond cultural stigmatization of homosexuality, because it includes a variety of material practices. These include "political and cultural exclusion, cultural abuse (in the United States gay men have now become the main symbolic target of the religious statutes), street violence (ranging from intimidation to murder), economic discrimination and personal boycotts" (Ibidem: p. 78). Homosexual masculinity ranks at the bottom of the gender hierarchy among men, mainly because it is assimilated to femininity: gayness often embodies those traits that are expelled from the hegemonic ideal that range from the marked taste in home decoration to the desire of receptive anal pleasure (Ibidem). With regard to the issue of health, in addition to being subordinated to the "leading position" in the gender order, physical or mental differences may challenge even more the norms and demands of hegemonic masculinity and this could result in what Connell defines as *marginalised masculinities*. Unlike homosexual masculinity, in this case there may be no direct threat to some specific expression of masculinity, yet they may be excluded from full participation in society by material practices (Robertson 2007). Finally, different configurations of hierarchical masculinity practices have indeed an impact on men’s health practice, while at the same time they are influenced by them (Ibidem). Despite the fact that marginalized men may engage in hegemonic practices, they might nonetheless be excluded from the opportunities offered to others.

With regards to femininities, according to Connell, as for masculinity, also for femininity different ideal types can be identified, but in this case there is not an hegemonic form of femininity because they are all in a subordinated relationship with hegemonic masculinity, even the most powerful one. The ideal type of *emphasized femininity*, in particular, is an essential complement of hegemonic masculinity: it refers to the ideal of women as accommodating the needs and desires of men, with sexual receptivity among young women and with motherhood and care among adult women. Connell proposes Marilyn Monroe as an exemplification of this ideal type and highlights that this normative ideal of femininity still informs the representation of women used in the media and advertising. As for hegemonic masculinity, also emphasised femininity may be dangerous for women’s health, for instance it is the case of eating disorders such as anorexia or bulimia. On the other hand, the ideal type of *resistant femininities* represents those women that resist and reject the norms of emphasized femininity such as lesbians, feminists and spinsters. Connell claims that the experiences of this last group of women tend to be ignored in society. In order to emphasize their distance from an essentialist approach to the body, Connell and Messerschmidt (2005) observe that the concept of hegemonic masculinity does not need a male body to be applied; in fact researches have also investigated masculinities enacted by female bodies (Halbestram 1998, Messerschmidt 2004).

Many researchers have recently explored health inequalities adopting Connell’s gender relations approach. A small selection of them includes men’s understanding of their health (Robertson 2007), men's experiences of consultation in relation to their constructions of masculinity (O’Brien *et al.* 2005), men’s experience of arthritis (Gibbs 2005) prostate cancer (Chapple & Ziebland 2002, Broom 2004), sexual health (Oudshoorn 2004, Rubin 2004, Persson 2012), depression (Emslie *et al.* 2006, Valkonen & Hänninen 2013) and mental health (Addis & Cohane 2005). Studies overall did suggest a widespread endorsement of hegemonic masculinity among men, who might often put aside healthy behaviours in order to fulfil social expectations and enact a proper masculinity performance. For instance, Courtenay (2000) is an author that has applied the concept of hegemonic masculinity in his studies: in his *Constructions of masculinity and their influence on men's well-being*, he examines a body of research carried out in the United States about men and men's health. He noticed that, according to his secondary data analysis, it was usually more likely that men – rather than women - adopted behaviours and beliefs that put them at a higher risk for chronic conditions or even death. Courtenay highlights that men, in order to adhere to ideals of manhood, need to reject what is considered as feminine or feminised, such as self-care or healthy practices. That is why many men decide to disregard them: they do so in order to avoid stigmatization and marginalization, in this way maintaining their social privileges. As Courtenay observes, also resisting hegemonic ideals of masculinity may produce negative outcomes: "Marginalised men may also attempt to compensate for their subordinated status by defying hegemonic masculinity and constructing alternative forms of masculinity" (Ibidem: p. 1391). These "hypermasculine" alternative forms of masculinity may also be dangerous or self-destructive (Meineke 1981, quoted in Courtenay 2000). Courtenay observes that, although health outcomes and longevity are influenced by a variety of factors such as economic status, ethnicity and access to care, these dimensions fail to completely explain sex differences in health. In an attempt to demonstrate femininities and masculinities, individuals engage in specific health-related beliefs and behaviours. Why should men commit to social practices that expose themselves and those around them to greater risks and to poorer health outcomes? As Scott (2015) argues: "[I]t is in the pursuit of power and privilege that men often do harm to themselves and others" (Ibidem: p. 543), this legitimises them to perceive themselves as the '"stronger" sex and to eschew the risk of marginalization. Other studies attempt to explain health inequality through a gender relation approach (i.e. Sabo & Gordon 1995, Watson 2000, Robertson 2007, Broom & Tovey 2009) and they succeed to draw attention on how gender interactions encourage or prevent health or illness (Scott 2015).

2.2.4 A selection of critiques to Connell's hegemonic masculinity theory

So far I have considered the usefulness of Connell's theory of hegemonic masculinity, but it is nevertheless necessary to consider also the criticisms and some of its further theoretical elaborations. In fact, although in the last thirty years Connell's theory of hegemonic masculinity has been crucial in the study and analysis of masculinities and it has provided a theoretical insights for critical studies on men, it nevertheless has been the subject of a number of criticisms (cf. Connell & Messerschmidt 2005). From the perspective of discursive psychology, for instance Wetherell & Edley (1999) argued that the first formulation of hegemonic masculinity theory (Carrigan *et al.* 1985) failed to fully account for the more complex and contradictory social psychological reproduction of male identities. They posited that men could ascribe hegemonic masculinity and at the same time distance themselves from its ideals. In their words:

> Recognized social ideals (such as macho man) can act both as a source for invested identity and as an 'Other' to position oneself against. This confusion – men may be most involved in reproducing the hegemonic when they position themselves against the hegemonic masculine ideal – is resolved if we accept that the organized forms of intelligibility which make up the hegemonic in any particular social site and period are multiple, varied and much more complex than current accounts of hegemonic masculinity suggest (Ibidem: p. 351).

Drawing on empirical material from interviews with a sample of men from a range of ages and from diverse occupational backgrounds, they focused on how men position themselves through discursive practices, recognizing that "complicity and resistance can be mixed together (Ibidem: p. 352). They posited that "complicity" or "resistance" are not labels for certain types of men, but rather labels used in order to describe the way that men position themselves through discursive strategies mobilized in different social settings.

2.2.4.1 Hybrid masculinities theory

Demetrakis Demetriou (2001) proposed a critique of the concept of hegemonic masculinity, claiming that "hegemonic masculinity is not purely white or heterosexual configuration of practice but it is a hybrid bloc that unites practices from diverse masculinities in order to ensure the reproduction of patriarchy" (Ibidem: p. 337). He formulated the concept of "hegemonic masculine bloc" in order to elaborate Connell's hegemonic/non-hegemonic masculinity dualism. Furthermore, he argued that the dominant form of masculinity was "in a constant process of negotiation, translation, hybridization, and reconfiguration" (Ibidem: p. 355). That is to say, hegemonic masculinity is indeed a flexible and culturally situated concept, as Connell claimed, but it reconfigures itself through hybridization processes that could be also incoherent and contradictory:

> [T]he hegemonic block changes in a very deceptive and unrecognizable way. It changes through negotiation, appropriation, and translation, through the transformation of what appears counter-hegemonic and progressive into an instrument of backwardness and patriarchal reproduction (Ibidem: p. 355).

Hegemonic masculinity, according to Demetriou, may thus also incorporate elements that are at odds with Connell's definition. For instance, he mentioned the case of adopting traits that are considered as typical of gay subcultures, such as earrings for men and dressiness, which make traditional and dominant masculinity seem more "feminised." Hegemonic masculinity may thus be constructed not only through the distancing from competing and alternative forms, but rather also with its hybridization and incorporation of counter-hegemonic elements. Within Demetriou's theorization, hegemonic masculinity does not necessarily need to be characterised by aggressive and non-effeminate configuration of gender practices. In this way, dominant form of masculinity (re)creates new forms that allow men to maintain and reproduce patriarchy, while incorporating social attributes conventionally identified as "feminine" or associated to marginalized and subordinated masculinities. The point becomes, then, not only the analysis of possible forms of marginalization or negation, but also that of the many ways of negotiating and articulating pre-existing hegemonic masculinities, the ways in which they are enacted and idealized, and their construction in combinations of original complicit forms (Rinaldi 2016: p. 40).

Steven Arxer (2011) continued the work of Connell consistently with Demetriou's criticisms and adopted his concept of hybrid hegemonic masculinity in order to empirically study heterosexual men involved in homosocial interaction through participant observation in a college bar. He highlighted the importance of taking into account elements of subordinated and marginalized masculinities for the construction of hegemonic masculinity, claiming that this is essential in order to “better capture the various expressions of patriarchy” (Ibidem: p. 417) and simultaneously try to destabilize it.

Bridget and Pascoe (2014) provided a systematic review of the literature, whose main aim was to account for recent transformations in men and masculinities through the use of the concept of “hybrid masculinities.” They argued that hybrid masculinities function in ways that, on the one hand, reproduce inequalities based on gender, race and sex, and on the other hand they “obscure this process as it is happening” (Ibidem: p. 247). Drawing form the literature on hybrid masculinities, Bridget and Pascoe identify three recurring consequences related to these “gender project and performances” (Ibidem: p. 250):

- *Discursive distancing*. The hybridization of masculinity often operates in ways that produce some discursive distance between White, straight men and hegemonic masculinity. At the same time, even if they frame themselves as distanced and outsiders from current system of privilege, they often also align themselves with it. As an example, the authors mention the work of Bridges (2010), who observed men’s interaction during the Walk a Mile in Her Shoes, namely the International Men's March to Stop Rape, Sexual Assault and Gender Violence where men wear high-heeled shoes the length of one mile. Whilst, on the one hand, the fact that men were standing with women and wearing their clothes distanced them from sexism typical of hegemonic standards, on the other hand the observation of men’s interaction highlighted “reiterate[d] forms of gender inequality that undergird domestic violence” (Bridget & Pascoe 2014: p. 250). For instance, one form of discursive distancing that aligned them with hegemonic masculinity was to joke about their ability to walk with heels, and about same-sexual desire;
- *Strategic Borrowing*. As the authors define it: “Research on hybrid masculinities documents the way that men who occupy privileged social

categories strategically borrow from Others in ways that work to reframe themselves as symbolically part of socially subordinated groups" (Ibidem: p. 252). In this regard, they mention Demetriou's (2010) example of hybridity of heterosexual-identified men that adopt typical traits of gay subculture, such as fashion or aesthetic care of the body. This way, as explained above, they incorporate elements from marginalised or subordinate 'Others' while preserving the structural position of power;

- *Fortifying boundaries*. As Bridget and Pascoe describe it: "[H]ybrid masculinities work to fortify symbolic and social boundaries between (racial, gender, sexual) groups – further entrenching, and often concealing, inequality in new ways" (Ibidem: p. 250). As an example of this specific hybridization strategy, they mention the case of the recent change in fathering practices and expectations. Whilst spending much time with their children and being more emotionally available for them may seem to be feminist and progressive, they simultaneously "can also reify gender inequality" (Ibidem: p. 255), as the study of Heath (2003) on the Promise Keeper has highlighted.

2.2.4.2 Inclusive masculinity theory and its criticisms

Another interpretation of change in masculinities is that offered by Erik Anderson (2009) who proposed a critique to Connell's gender theory by expanding it in an alternative framework, defined as *inclusive masculinities*. He developed the Inclusive Masculinity Theory (IMT), arguing that in contexts such as the US, UK and other Western countries witnessing a decline in homophobic attitudes, there has been a substantial change in masculinities. In order to account for this process, he coined the concept of *homohysteria*, which refers to "the fear of being socially perceived as gay" (Anderson & McCormarck 2018: p. 2). Within a homohysteric society, homophobia polices gender practices, as men feel threatened by the stigma of being publicly homosexualized through the infringement of the strict boundaries of heteromasculinity. According to Anderson (2009), in this context Connell's gender order (1995; with Messerschmidt, 2005) can be applied, with a multiplicity of masculinity types hierarchically stratified and one hegemonic form on the top of it. Conversely, according to IMT

(Anderson 2009), in societies where levels of homohysteria decrease, Connell's hegemonic masculinity theory –that applied in periods of high homohysteria typical of the twentieth century- cannot be functional anymore. When homohysteria decreases, he claims that stratification of masculinities becomes less hierarchical and a multiplicity of masculinities become equally esteemed, legitimized and culturally valued. In a context where cultural homophobia is absent, Anderson (2009) argues that hegemonic masculinity theory fails to account for the multiplicity of less oppressive masculinities that emerge without stratification and without one form holding a hegemonic position over the others. As Anderson (2011: p. 733) states: "[A] variety of once-stigmatised gendered behaviours will proliferate when there is a lack of homophobic policing. In such a culture, multiple masculinities will proliferate *without* hierarchy or hegemony. Multiple masculinities will co-exist, and the gendered behaviours of boys and men will be less differentiated from girls." IMT contends that in a context where homohysteria is decreased but it is still present, two forms of masculinity can be distinguished: inclusive and orthodox (McCormack 2012). *Orthodox masculinity* represents the more conservative performance of masculinity: men categorized in this ideal type engage in homophobic practices but don't hold hegemonic control over other forms of masculinity. The second category is defined as *inclusive masculinity*: men in this group are shown to perform masculinity in a more inclusive and pro-gay way. None of the two normative forms of masculinity hold a hegemonic position (Ibidem). In sum, IMT aims to provide a theoretical framework for understanding changing masculinities in social contexts where levels of homohysteria are decreased, a goal that, Anderson argues, Connell's gender theory fails to accomplish.

I agree with Bridges and Pascoe's (2014) criticisms to Anderson's IMT theory: the authors highlighted that, within this framework, "inclusivity" is similar to "hybridity" with respect to the incorporation of masculinity performances that are considered as "Other" from hegemonic masculinity, but they offer very different interpretations of this phenomenon. On the one hand, Anderson explains inclusivity as a measure of decreased sexism, homohysteria and erosion of patriarchy. Therefore, "Anderson theorizes hybrid masculinities (which he calls ‘inclusive masculinities’) as endemic and as a fundamental challenge to existing systems of power and inequality” (Ibidem: p. 248) On the other hand, Bridges and Pascoe contest the idea that contemporary masculinity would be characterized by greater equality and less hierarchy. As they stated:

> Rather than illustrating a decline in gender and sexual inequality, scholars suggest that hybrid masculinities work in ways that perpetuate existing systems of power and inequality in historically new ways (e.g., Demetriou 2001; Messner 1993, 2007). Thus, this body of research is at odds with Connell and Messerschmidt’s (2005) analysis of the significance of hybrid masculinities and with Anderson’s (2009) consideration of the consequences. (Ibidem: p. 248).

In addiction, in my opinion Anderson’s inclusive masculinity theory could not apply in a context like Italy, were homophobia and homohysteria are still present not only in the context of sport, were he conducted the majority of his research studies, but also in a more structural and institutional level. Furthermore, on a more methodological ground, I would also argue that Anderson’s theory, in order to be more sound, should also be applied (and should also prove to be functional) in working-class contexts: he has observed a decline of homohysteria and an increased acceptance of counter-hegemonic behaviours (such as touching or kissing among heterosexual men) in middle-upper class contexts, where it was probably more likely to find inclusive behaviours and where the “costs” of transgressing boundaries were probably lower than elsewhere. In order to demonstrate that hierarchy among men does not exist anymore and that masculinity has become more “inclusive,” I think that more research that adopts this framework should be conducted where it would be more likely to find the opposite result, perhaps using more intersectional samples, and including also non-white, non-middle/upper class participants in the research.

This research draws on Connell’s relational framework, and illness-related practices have been interpreted as being part of the construction of a masculine self, both in the everyday life and in the interactional context of the interview, as a set of discursive strategies. Furthermore, it has been argued (see Robertson 2007) that body self-care practices are traditionally considered as feminine, and that “health” is a realm from which men distance themselves in order to construct an adequate masculine self. However, in this regard the abovementioned literature about hybrid masculinity (i.e. Bridget & Pascoe 2014, Arxer 2011, Demetriou 2001) maintain that hegemonic masculinity might be "hybridized" over time through the negotiation and appropriation of practices that appear as counter-hegemonic, such as body care or other practices that have traditionally been considered as "feminizing." It is thus interesting to use such framework in order to explore how diabetic men's incorporation (or the discursive distance from) of illness-related self-disciplining practices affects their positioning with regard to hegemonic expectations of masculinity. Although talking about the "doing" of masculinities as well as of "performance" or "enactment" of gender and health might appear as the result of an individualizing view, it is then worth clarifying – in order to avoid any possible misunderstanding – that throughout this dissertation I have considered the construction of masculinity not as a fixed entity that resides in an innate male biology, nor in a set of practices performed in a "cultural vacuum." On the contrary, as we have seen, the "doing" of masculinities refers to a configuration of practices that are accomplished within social interaction and, as such, they may differ depending on the historical, social, economical, cultural, situational and relational context. Studying the construction of masculinity in the context of health necessarily means taking into particular account the structural dimensions of social practices: Connell (1995: p. 54), for example, observed that "the construction of masculinity through body performance means that gender is vulnerable when the performance cannot be sustained – for instance, as the result of physical disability. (…) So a wide range of responses can be made to the undermining of the bodily sense of masculinity. The one thing none of these men can do is ignore it." Nor we can ignore how the "doing" of masculinity is necessarily the product of incorporated social structures that unconsciously shape men's tastes, beliefs and behaviours. With Bourdieu, we know that the gendered *habitus* depends on individuals' specific positioning in the social structures and it is embodied through early socialization: the specific incorporation of male *habitus*, in fact, guides and shapes also health-related practices, as well as food tastes, attitudes towards self-care, and illness management.

Exploring further the interrelation of masculinity and health, the next paragraph will be dedicated to an overview of theories on embodied masculinities and health, under the assumption that they provide a crucial framework for studying how masculinity and health interrelate with each other and how they both become embodied within interactions.

2.3 Gender, health and the body

In recent years, there has been a growing recognition of the human body as a central object of sociological analysis. As Turner (2008: p. 34) states: “Human being have, and to some extent are, bodies.” Nevertheless, bodies are most of the time taken for granted and silently inhabited, muted by the absence of a legitimate reason to put them into words. The experience of pain, illness, weakness, loss of control of one’s own body necessarily leads those who experience them to recalibrate the attention towards her/his corporeality: that is when the body “comes into conscious being” (Lupton 2003: p. 22). The way we experience life, emotions, and interactions is necessarily mediated by our –and others-corporeality, with its own characteristics, limits and possibilities. In Western societies, body and bodily practices have been “invested with instrumental rationality, being disciplined as an instrument for work and labour, a utility, a function, while continuing to operate as the paramount symbol for the subject to demonstrate his or her being self-possessed, civilised or otherwise valuable” (Sassatelli 2010: p. 1). Furthermore, the body may also symbolize a way of resistance and it may express alternative definitions of reality and identities (Ferrero Camoletto 2015). Therefore human body and embodiment deserve a proper space in the sociological imagination, because they offer an opportunity for theorizing social commonality, social inequalities, and the (re)production of differences (Shilling 2012).

Only just recently sociology of health and illness has acknowledged the importance of taking into account the corporeality of human life, which has previously tended to be ignored because of the emphasis being placed mostly upon social structures and individual subjectivity (Lupton 2003, Shilling 2012). Sociology has in fact embraced, throughout its initial development, a “disembodied approach to its subject matter” (Shilling 2012: p. 21) that privileged an idealistic approach with a "predominance of the social-mind on the biological-body, excluding the latter from its field of study" (Ferrero Camoletto 2015: p. 552).

Modern sociology has been inclined to approach "nature" as a cultural system or a mere social and disembodied construct, perhaps in order to avoid the biological determinism typical of the "hard" human sciences (Turner 2008). However, Turner argues: "The tension between the body as a living organism and as a cultural product continues to underpin the sociological understanding of, and debate about, the body and embodiment" (Turner 2008: p. 1). Whilst Shilling's (2012) reflections highlight an "absent presence" of the body within early sociology, it was nevertheless recognized as too important to be completely omitted. Therefore the work of the "founding fathers" such as Karl Marx, Max Weber and Emile Durkheim, has in some way taken into account human body, although it was not the centre of their attention. Shilling (2012) reviews some of the possible reasons in order to account for this, and her final observation seems to me particularly apt to the topic under analysis in this paragraph, as she argues: "[I]t is relevant to note the obvious but important fact that the "founding fathers" were embodied as men. (…) This is not to suggest that knowledge is reducible to immediate bodily experience, but it is to acknowledge an integral connection between knowledge and embodiment" (Ibidem: p. 27). Consequently, she posits that if Marx, Simmel, Weber and Durkheim had been women at that point in history they might have considered the body and features of embodiment more extensively, especially when reflecting on the risks women faced during pregnancy and childbirth.

The initial sociological theorising around the issue of health is most commonly traced back to the work of Talcott Parsons (1951, 1958), one of the most influential sociologists of the last century. Although he stressed the importance of cultural and social norms in determining what was considered as "disease" and how it was treated, his analysis supported and reinforced the normative and asymmetrical power of medical profession, whose legitimacy paradoxically relied on a claim to biological knowledge. The individual experiencing illness was thus conceived as a patient that was expected to cooperate and comply with doctors' instructions in order to regain health. Despite the fact that Parson's formulation of the sick role has been very influential, it has also encountered criticisms, among which its inability to properly capture the experience of being ill and its failure to acknowledge the corporeality of the human body.

One of the earliest accounts of the body was provided by the anthropological work of Marcel Mauss (1973) who observed that each society produced specific traditions around the use of the body, and every aspect of bodily behaviour reflected hierarchies of inequality. Mauss formulated the concept of "techniques of the bodies," namely "the ways in which from society to society men know how to use their bodies" (Mauss 1973: p. 70). Human bodies therefore embody the "special habits" of their own society that, as he states: "These 'habits' do not just vary with individuals and their imitations, they vary especially between societies, educations, proprieties and fashions, prestiges" (Ibidem: p. 73). In this regard, Mauss uses the term *habitus* in order to account for the process of incorporating societal meanings that inform the activities of the body such as resting, talking or walking. As we shall see in a while, this concept has been then taken up by French sociologist Pierre Bourdieu, who put the body at the centre of his theory.

The anthropologist Mary Douglas (1966, 1970) is considered one of the main influential authors that have explored the social construction of the body. She laid down groundwork for the study of the symbolic value of the body, that she considered as deeply connected with the social system in which it is necessarily embedded. Douglas claims that the social body influences the way the physical body can be experienced, and that the physical body, in turn, supports a specific understanding of society (Ferrero Camoletto 2015). In her words:

> The social body constraints the way the physical body is perceived. The physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society. There is continual interchange between the two kinds of bodily experience so that each reinforces the categories of the other. (Douglas 1973: p. 93; quoted in White 2017: p. 109)

Socio-cultural factors are thus central in determining the symbolic meanings of the body and its possible uses, its normative boundaries and their realizable transgressions. Individual body becomes a metaphor of societal body, this way uncertainties in social relations and social environments are transferred to a concern with the body (Shilling 2012).

Another significant contribution on the social construction of the body is provided by the work of Erving Goffman, who has studied the body as a component of action in public places (1963), in the management of stigma (1968) and in the presentation of self in everyday life (1969). In his work, Goffman places great importance to the body, which is considered an essential aspect of interaction that allows people to flow in their everyday life tasks and performances. Goffman proposes a perspective on the body that somehow entails an idea of embodiment, even if he does not develop it further, as Bourdieu will do through his concept of *habitus* (Sassatelli 2017).[3] Although Goffman is not usually considered among the authors that have extensively theorized about gender, he nonetheless examined this issue on a number of occasions, for instance in order to exemplify the settings of ceremonies that inform interactions (Sassatelli 2017). In Gender Advertisements, Goffman (1976) analyses the ways in which men and (mainly) women are represented in advertisement, showing how these representations might be useful in understanding actual gender behaviour. Through an analysis of photo advertisement, he identifies a number of "genderisms," a set of bodily gestures, face expressions, and scenic choices that allows the audience to read the (gendered) meaning "at a flash" (Ibidem: p. 27). Commercial photos have thus been analysed in order to highlight how femininity and masculinity are usually displayed. For instance, men are usually depicted with "greater girth and height" (Ibidem: p. 28) in order to express male's higher status over women; usually, they are depicted while standing, acting in a confident pose and generally located in a higher position than women's, in order to symbolise their "high social place" (Ibidem: p. 43). On the other hand, women are often represented in a subordinate pose, with a smaller body size, often lying more than men on the floor or on the sofa, frequently used in order to "decorate" objects and

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[3] This reference refers to the speech of prof. Sassatelli on occasion of the Seminar *Corpi di Genere. Una Prospettiva sull'Incorporamento e la Soggettività*. 18/10/2017 at the University of Turin.

depicted as vulnerable, powerless, child-like, submissive and in need of men's protection.

The body is thus approached by Goffman as symbolically important for understanding ceremonial rituals that inform social interactions; how the body moves in social spaces and how its expressions are interpreted by individuals interacting with each other is highly mediated by cultural and social contexts. As Turner notes: "It is possible therefore to reinterpret Goffman's sociology as not the study of the representation of the self in social gatherings but the performance of the self through the medium of the socially interpreted body" (Turner 2008: p. 39). Bodily performances, according to Goffman, are controlled and monitored by individuals in their social interactions and relations through the exercise of human agency, which allows people to manage their movement and appearances (Shilling 1993). Individuals cannot control all aspects of interactions: this is the case, for instance, of the "body idioms" that Goffman defines as "dress, bearing, movements and position, sound level, physical gestures such as waving or saluting, facial decorations, and broad emotional expressions" (Goffman 1963: p. 33; quoted in Shilling 1993: p. 72). Non-verbal communication is crucial in public interactions and it is understood according to a shared vocabulary of body idiom that let individuals classify information deriving from bodies. According to Goffman's approach, human bodies are at the same time property of individuals and signified and valued by society.

In the same years, Michel Foucault addressed the issue of the body by highlighting the processes of discipline and surveillance that are enacted by institutions of social control such as the prison, the school, the clinic and its medical gaze. Therefore, as we shall see in more detail in chapter n. 5, Foucault's work was crucial in outlining an historical perspective on the body, intended as a socially and politically constructed self-regulating entity (Rosenfeld & Faircloth 2006).

As Shilling (2012) observes, sociological theories began to acknowledge the importance of the body only since the mid-1980s, and among the most important works we can find that of Elias (1982), Turner (1984), O'Neill's (1985), Freund (1988) and Frank (1990), Feher, Naddaff and Tazi (1989), and Featherstone and colleagues (1991). The body has been progressively considered as an essential part in sociology studies, especially in the processes of identity formation, stabilization and transformation (Sassatelli 2002). On the one hand, some theories –following Giddens' (1991) approach- argue that in late modernity the body has become an object of choices, a *project* on which the individual works in order to construct his/her sense of self-identity (Shilling 1993). According to this approach, the self has become a *reflexive project* that results from multiple choices and that supports a coherent and constantly updated biography. However, as Sassatelli (2002: p. 430; my translation) states: "If we consider more carefully how different body care and transformation practices are practically organized, which are the meanings that participants assign them and what is their actual institutional context, the limits of similar perspectives on reflexivity, action and corporeality become clear." In fact, such approach is likely to reproduce the body/self dualism that entails a conception of the body as an object that can be monitored, rather than an essential part of the self (Ibidem). A different approach to the body is the one elaborated by the French sociologist Pierre Bourdieu, who focused on the body as the place where individuals incorporate social meanings and, at the same time, they express them through their everyday practices. In this perspective, the body is a form of capital and a mean of distinction. Social structures are in fact embedded within individuals and influence their understandings of the world, their tastes and their interests. This is illustrated in his influential elaboration of the concept of *habitus*, which developed further Mauss' first theorization. *Habitus* is one of the key concepts of his framework and cornerstone of sociology, and it is intended as:

> [s]ystems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them (Bourdieu 1977: p. 53).

According to Bourdieu, *habitus* is a set of unconscious dispositions –such as bodily conducts, ways of talking, thinking and acting- that occurs during socialization processes and depends on the specific social groups and classes in which individuals live. It is naturalized and, therefore, individuals are mostly unaware of its effects. This concept is particularly useful because it allows us to explore the links between social structures and individual actions, where action is conceived as, at the same time, influenced by external structures and also reinforcing them, because actions actively contribute to (re)create social structures. In fact, the *habitus*, the specific bodily socialization, implies the assimilation of specific schemes of perception and classification that at the same time consider physical differences, participate in their existence and naturalize them through their reification (Ferrero Camoletto 2015). The division of sexes provides a good example of this. As Bourdieu (1998: p. 8) states, it “appears to be 'in the order of things', as people sometimes say to refer to what is normal, natural, to the point of being inevitable: it is present both - in the objectified state - in things (…), in the whole social world, and in the embodied state in the habitus of the agents, functioning as systems of schemes of perception, thought and action.” In *Masculine Domination*, Bourdieu observes that in social perception and in language the masculine gender is often conceived as neutral, non-marked, while the feminine gender is instead clearly characterized. The awareness of this androcentric vision allows detecting the strength of the masculine order that, he claims, informs the social order which “functions as an immense symbolic machine tending to ratify the masculine domination on which it is founded: it is the sexual division of labour, a very strict distribution of the activities assigned to each sex, of their place, time and instruments, it is the structure of space, with the opposition between the place of assembly or the market, reserved for men and the house, reserved for women” (Bourdieu 1998: p 9). The body is, according to Bourdieu, constructed by society as a sexually dichotomous defined reality which is subject to principles of “a mythic vision of the world rooted in the arbitrary relationship of domination of men over women” (Ibidem: p. 11). The biological and anatomical differences between the sexed bodies might thus be perceived as the basis that legitimizes the dichotomous differences between the genders and this, in turn, might lead to perceive as ‘natural’ specific social division of labour. As Bourdieu observes, the construction of masculinity “remains indissociable, tacitly at least, from physical virility, in particular through the attestations of sexual potency – deflowering of the bride, abundant male offspring, etc.- which are expected of a 'real' man" (Ibidem: p. 12). Masculinity, as well as femininity, is perceived as a specific *habitus*, as a set of disposition that differs depending on the positioning that the individual occupies within social organization system of classification. The body is thus perceived as the point of contact of nature and culture, and the embodied gender inequalities are, according to Bourdieu, naturalized as a form of "symbolic force" (Ibidem: p. 38) that takes for granted what is, instead, arbitrary (Sassatelli 2017).

Moving on to a more general overview, Shilling (2012) observes that there has been a significant shift in the social significance attributed to sociological reflections on the body, from being signified by national governments to being considered as a cornerstone of self-identities construction. Many factors are thought to be involved in this substantial change of perspective, among others: demographic changes and increases in longevity, which has led to a sociological focus on how symbolic values are attached to the concept of "youth" -usually associated to a slim, muscular, sexual body - and "old age" – which, on the contrary, is usually out of the public eye. According to Shilling, another factor that has brought attention to the body and the processes of embodiment is the rise and diffusion of the so-called consumer culture. As Sassatelli (2005, 2007) examines in depth, this resulted in assigning great symbolic value to consumer practices and discourses that, in turn, are deemed to be essential in order to construct and negotiate social and personal identities. Bodies became thus increasingly important in performing specific identities and this implied devoting substantial amount of time to the preparation and presentation of them throughout physical exercise, a balanced diet, individually-tailored health programmes, leisure shopping etc.

Finally, Shilling emphasizes the role of "second wave" feminism in increasing the focus on the body: it has in fact brought attention to women's bodies, in an attempt to draw attention to issues regarding the control of fertility, abortion rights and the more general problem of gender inequalities and oppression. Furthermore, feminism scholarship has been essential in problematizing the concepts of gender by questioning the ontological basis of the dichotomy female/male, woman/man and femininity/masculinity. Feminist work did not exclusively focus on women's bodies, but they rather considered both men's and women's bodies as intimately related, together with the dynamics of power that inform(ed) their relationships. The focus on men's bodies and masculinity(ies) embodiment processes was then fuelled by the development of men's studies in North America and in the UK: despite the fact that the majority of this work has received criticisms for paying too much attention to what men *are*, instead of what men do, it has been important for putting the (male's) body in the spotlight of researchers' reflections. One of the reasons why there has been the need to focus on gender in general and on men and masculinities in particular, is, as Hearn and Morgan (2015: p. 9) write: "The danger of reification, essentialism, and reductionism that arise when using such categories as "women," "men," "femininity" and "masculinity." In some cases, for example, there may be a danger of importing taken-for-granted understandings of masculinity – men as competitive, striving, future-oriented and aggressive – into our analyses or re-analyses of existing texts." Hearn and Morgan (Ibidem: p. 10) furthermore observe that a large part of early studies on men and masculinities "remained somewhat disembodied" and encouraged scholars to include the body and bodily processes in society as well as constructions of gender and gender identities in their work.

Seidler (1994, 1997; quoted in Robertson 2007) explored the role of Cartesian mind-body dualism in assigning different meanings to women's and men's bodies: women have been historically associated with the body and nature, while men have been associated with mind and reason. Therefore women are supposed to be more embodied than men, while men – especially from Enlightenment thinking on - are though to be less sensitive to the needs of their bodies, and this is reflected in professional literature where men are often believed to have a "mechanistic" conception of their bodies (Robertson 2007).

However, as Connell (1995) points out, "true masculinity" is often perceived as something that cannot be changed, because it originates directly from men's body. As she states:

> True masculinity is almost always thought to proceed from men's bodies – to be inherent in a male body or to express something about a male body.

> Either the body drives and directs action (e.g. men are naturally more aggressive than women; rape results from uncontrollable lust or an innate urge to violence), or the body sets limits to action (e.g. men naturally do not take care of infants; homosexuality is unnatural and therefore confined to a perverse minority). (…) So the first task of a social analysis is to arrive at an understanding of men's bodies and their relation to masculinity. (Connell 1995: p. 45)

She further observes that in the last decades discussion on gender and body has been characterised by two prevailing approaches: within the first one, the body is perceived through the metaphor of a "natural machine that produces gender differences" (Ibidem: p. 45). A "machine" whose functioning is understood through biological elements, in the case of masculinity that includes masculine genes, hormonal difference and the different role of the sexes in reproduction. With a sociobiological perspective, men thus "inherit," with their bodies, the propensity to be aggressive, competitive, promiscuous, and so on.

The second approach to the body, on the other hand, addresses the issue of the body as it was a "neutral surface or landscape on which a social symbolism is imprinted" (Ibidem: p. 46). It is often inspired by the work of Michel Foucault, who argues that essential aspects of the body must be considered as historical and cultural product. Foucaultian work has thus allowed the body to become an object of study going beyond a conception of it as a mere product of nature, but rather accounting for its social construction within the context of gender, sex, class and ethnicity, and their structures of legitimation and domination. Shilling (2012), after reviewing the main works and limitations of both standpoints, claims for an approach to the body that accounts simultaneously for both biological and cultural dimensions.

Although social constructionists' work on the body (e.g. the works of Foucault, Goffman and Turner) has been fundamental, something was missing. As Shilling points out: "The body is present as an item for discussion, but absent as an object of investigation" (Shilling 1993: p. 87). Even less empirical research is dedicated to embodiment processes and health (Robertson 2007). In this respect an important contribution is that of Watson (2000), that in his book *Male Bodies: Health, Culture and Identity* offered a useful framework for the understanding of male embodiment and health, the so called "male body schema" within which he identifies four differing ways of embodying masculinity in relation to health. This approach allows considering at the same time the material and representative dimensions of male bodies as well as how these two spheres are interrelated in respect to men's practices and perceptions of health and wellbeing. The table below presents a brief summary of Watson's theorization:

Normative embodiment	'Normal', 'standard' or idealized accounts of bodily shape(s).
Pragmatic embodiment	The functional use of a 'normal everyday body' in order to fulfil specific tasks ('father', 'husband', 'worker') required in different social contexts.
Experiential embodiment	The point of contact of social and physical boundaries, the primary site for experience of emotion and physicality.
Visceral embodiment	The indirect biological processes, usually unconsciously experienced, that support bodily function and, to an extent, determine bodily shape.

Table 2.1. Male body schema, as summarized in Robertson (2006: p. 68)

Watson (2000), in his empirical work on a "well-man clinic," observed that health professionals often focussed mainly on underlying physical processes – that is, what Watson defines as *visceral embodiment*, a set of information collected indirectly through medical reports and anamnesis – while they overlooked the pragmatic mode of embodiment, that, in contrast, was the most relevant for the men interviewed (Robertson 2007). In an attempt to expand Watson's framework, Robertson (2006) employed his "male body schema" and explored more in depth "how, when and where these elements interact with each other, and with the men's conceptualisations of health, to influence health practices and health outcomes" (Ibidem: p. 450). His research on lay men's and community health professionals' attitudes towards masculinity and preventative health care was carried out in the northwest of England and showed that men interviewed did not privilege the *pragmatical embodiment*, as Watson suggested. They rather "showed a nuanced and complex understanding of the relationships and interactions between health practices and the representation, form, experience and utilisation of bodies in their everyday lives" (Ibidem: p. 450). The issue of identity (including its gendered aspects) emerged as important in mediating the material and the representational dimensions of the body.

The present research, as already mentioned above, focuses on men's health by exploring the embodiment of a specific bodily condition, chronic illness, which is the subject of the next paragraph.

2.4 An overview of the literature on health and chronic illness

> One day my body broke down, forcing me to ask, in fear and frustration, what's happening to me? Becoming ill is asking that question. The problem is that as soon as the body forces the question upon the mind, the medical profession answers by naming a disease. This answer is useful enough for practicing medicine, but medicine has its limits.
>
> Medicine has done well with my body, and I am grateful. But doing with the body is only part of what needs to be done *for* the person. What happens when my body breaks down happens not just to that body but also to my life, which is lived in that body. When the body breaks down, so does life. Even when medicine can fix the body, that doesn't always put the life back together again. Medicine can diagnose and treat the breakdown, but sometimes so much fear and frustration have been aroused in the ill person that fixing the breakdown does not quiet them. At those times the experience of illness goes beyond the limits of medicine. (Frank 1990: p. 8)

The current predominant way of understanding health and illness is the product of a specific system of knowledge developed in the 19th century, prior to which there have been a series of subsequent stages which progressively replaced transcendental interpretations with natural origins of disease and healing (Williams 2003b). Over the centuries, scientific methods supplanted religious authority and the hospital became the place specifically devoted to the treatment of the sick. In this context, in more recent times health care has been intended as the specific patient-doctor interaction, where the latter has received a university medical training and is supposed to apply medical standards of care to patients, and the former is expected to take responsibility of his/her own health.

Contemporary Western medicine is based on the so-called "biomedical model," intended as the predominant approach to disease (Gabe *et al*. 2004) which relies on five basic assumptions (Nettleton 2006). The first one assumes that there is a *body/mind dualism*, which informs more broadly medical knowledge. In the second place, the biomedical body is understood as a machine that can be repaired, a specificity that Nettleton (2006: p. 2) defines as a “mechanical metaphor,” where doctors are intended just as engineers that can fix what is considered as dysfunctioning. As a consequence, the third assumption is that technological interventions are often overemphasized and medicine responds to a “technological imperative” (Ibidem: p. 2). The fourth assumption is that biomedicine simplistically focuses on biological changes, while it overlooks social and psychological dimensions. Lastly, this reductionist approach was subsequently favoured by the development of the “germ theory” of disease, according to which each disease would be the result of the contact of the body with a particular, identifiable agent such as a virus, a parasite or bacterium: this approach is referred to as the “doctrine of specific aetiology” (Ibidem: p. 2). Atkinson (1988; quoted in Nettleton 2006: p. 2) efficiently summarized the biomedical model as follows:

> It is reductionist in form, seeking explanations of dysfunction in invariant biological structures and processes; it privileges such explanations at the expense of social, cultural and biographical explanations. In its clinical mode, this dominant model of medical reasoning implies: that diseases exist as distinct entities; that those entities are revealed through the inspection of ‘signs’ and ‘symptoms’; that the individual patient is a more or less passive site of disease manifestation; that diseases are to be understood as categorical departures or deviations from ‘normality’.

Until recently, anthropologists and sociologists of health and illness took biomedicine’s framework for granted, without considering the cultural and historical influences that impacted on its development.

During the seventies, medical anthropologists began to approach medical knowledge not as an unquestionable lens through which to interpret illness experiences, but rather as a specific and situated knowledge that can be subjected to criticism. In particular, during those years Arthur Kleinman, an American psychiatrist and a professor of medical anthropology, with a group of other scholars founded the so-called “Harvard school”: according to them, biomedicine should have been considered as a particular ethnomedicine, and illness as a concept defined by cultural norms that associate a specific state of being to a medical problem (Quaranta 2006). In this perspective, medical knowledge is not conceived as to be in possession of an incontrovertible truth, but rather as an hermeneutical process that interprets a cluster of bodily "signs" by correlating their functional and structural causes to respective pathologies, thereby accomplishing their main aim: namely, producing a diagnosis and providing a rationally appropriate treatment (Good 1999). On the one hand, biomedicine claims that illnesses have a biological and universal nature: their distribution may vary according to social and ecological contexts, while medical knowledge remains fixed, indiscriminately effective and universally applicable. On the other hand, Kleinman (1988) and Good (1999) refer to the medical system as a specific cultural system with a particular cultural language and to illness not as a separate and independent entity, but rather as an explanatory model. Illness, therefore, belongs to culture, more precisely to the specialized culture of medicine.

In fact, when we deal with health and illness there are many different dimensions -such as the medical, personal, and social ones- that are all closely intertwined with each other rather than the merely biological one. Since the 1950s, many authors (e.g. Kleinman, Eisenberg, Good, 1978; Fabrega & Manning 1972; Feinstein, 1967; Parsons, 1951, 1958) have proposed the distinction between *illness* and *disease*, in order to recognize and distinguish between the perspectives, respectively, of the patient and the physician. The illness-disease distinction has been indeed a fruitful one, but a more complex version has been provided by the doctoral dissertation of Andrew Twaddle (1968) who developed the well-known triad *disease, illness* and *sickness* that has been then further elaborated and widely applied in the sociology of health and medical anthropology. According to Twaddle:

> - Disease is a health problem that consists of a physiological malfunction that results in an actual or potential reduction in physical capacities and/or a reduced life expectancy;
> - Illness is a subjectively interpreted undesirable state of health. It consists of subjective feeling states (e.g. pain, weakness), perceptions of the adequacy of their bodily functioning, and/or feeling of competence;
> - Sickness is a social identity. It is the poor health or the health problem(s) of an individual (Twaddle 1994: p. 8).

Concisely*,* *disease* is thus ontologically understood as an organic malfunction as conceived by medical profession and it is considered to be independent of subjective experience and social context. On this basis, it is assumed that it is measurable by objective means. *Illness* is, instead, identified as a negative bodily occurrence for how it is perceived by the person him/herself. It can be detected only by the subject and can be understood through his/her report of symptoms. The third and last component of Twaddle's triad is *sickness*, which refers to the way other people define and understand this specific health condition. Being socially defined as "sick" means to become holders of a new set of rights and duties. Moreover, social representations of illness are very influential in shaping individuals' perception of it. As Colombo (2001: p. 150; my translation) states: "All diseases are different from each other and, in our culture, (…) having diabetes, circulatory disorders, intestine or lung cancer, cirrhosis of the liver or HIV involve substantial differences in the way other individuals will behave with the sick person, as well as in the attribution of responsibilities for being ill and in the social consideration concerning the morality and identity of the sick person."

According to Twaddle, typically the three dimensions succeed one another chronologically: at first, an underlying organic malfunction – disease - makes the individual experience symptoms – illness -, which is subsequently socially recognised –sickness - (Maturo 2007).

Social and cultural contexts in which individuals are embedded have thus a significant impact on morbidity and mortality (for a systematic and comparative review about social inequalities in health, see Cardano 2008) as well as on the way they experience, define and understand illness, and this is particularly relevant in the case of incurable, life-long illnesses. The present work focuses on this particular condition, namely chronic illness. As Gabe, Bury and Elston (2004: p. 77) state: "Sociological interest in chronic illness has in part stemmed from the limitations of medical treatment for chronic disorders. While some forms of treatment are very effective, for example, hip replacement and cataract surgery, many disorders can only be treated palliatively, to relieve pain and to help physical functioning." Chronic illness, as the etymology of the term "chronic" evokes, refers to a long-term health condition that may be permanent, and whose symptoms might be more or less invasive, painful and constant over time.

Early sociological work on chronic illness began in the 1960s and 1970s, and most of it concentrated on the consequences of living with such condition. Gabe and colleagues (Ibidem) identify Strauss and Glaser's book, *Chronic Illness and the Quality of Life* (1975) as the most significant publication of the 1970s on this issue. With an interactionist approach, the authors address chronic illness not just as a biological malfunction that entails social dimensions, but rather as a reality that is negotiated and mediated by many figures (patients, doctors, etc.) that constantly interact.

2.4.1 Chronic illness as a "biographical disruption"

In 1982, Michael Bury conceptualised chronic illness as a form of "biographical disruption" (Ibidem: p. 169), claiming that experiencing a chronic condition may disrupt "the structures of everyday life and the forms of knowledge which underpin them" (Ibidem: p. 169). In his classic study on rheumatoid arthritis he observed that the onset of this disease implied the experience of chronic pain, suffering and the recognition of the possibility of death, which are usually perceived as remote possibilities by individuals that don't experience such condition. Bury identifies three dimensions of disruption that characterised the impact of chronic and severe symptoms in the everyday life: "First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries" (Ibidem: p. 169). In this first stage, the individual gives attention to new bodily states and takes into consideration the different possibilities of help seeking. In a second stage, as Bury (Ibidem: p. 169) writes it: "There are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved." Lastly, the final stage involves the mobilisation of resources in order to cope with the "critical situation," in Giddens's words (1979). In this regard, Bury highlights that occupation and social class are indeed important factors because they impact on the distribution of resources and thus on "the ability of individuals to compensate for the effects of disability and thus offset economic and other handicaps" (Ibidem: p. 177).

The disruption of chronic illness overall implies the redefinition of a planned trajectory through expected chronological phases, to a situation of uncertainty and, possibly, danger (Ibidem). Daily routines might be disrupted and conditioned by pain, or even interrupted to make room for care activities (Cardano 2007). In an attempt to manage and adapt to this new condition, Bury (1991) distinguish between three different dimensions that are simultaneously involved: coping, strategy and style. *Coping* refers to "the cognitive process whereby the individual learns *how* to tolerate or put up with the effects of illness" (Ibidem: p. 460). Throughout coping, the individual maintains a sense of coherence and self-worth while coming to terms with the new bodily condition. *Strategy*, unlike coping, "directs attention to the actions people take, or what people do in the face of illness, rather than the attitudes people develop" (Ibidem: p. 461). It refers to what people do in order to manage their situation and how this has an impact on what Goffman (1959) defines as strategic interactions, that is to say, the features of everyday encounters. Lastly, the term *style* refers to "the way people respond to, and present, important features of their illness or treatment regimens" (Bury 1991: p. 462). Living with a chronic condition implies the adoption of different possible ways of presenting their altered physical appearances, as well as the decision of disclosing or disguising symptoms and their effects. We can detect differences in style by analysing discourses about the body and about the self, within which they are embedded (Bourdieu 1984, quoted in Bury 1991). For instance, Bury observes that "middle-class values towards the body and health may be expressed in more abstract terms, particularly about the self, as a means of communicating social distance or "distinction" from instrumental roles, whereas working class accounts may stress more practical values in terms of being able to carry out tasks and roles, though the dangers of a reductionist approach to style, class and communication is recognised" (Ibidem: p. 463).

2.4.2 Critiques to the concept of chronic illness as "biographical disruption"

Williams (2003) proposes a critical approach to the notion of chronic illness as a "biographical disruption." In his chapter *Bodily Dys-order: Chronic Illness as Biographical Disruption?* he reviews some of the many critiques that have been advanced to the biographical disruption model and he subsequently outlines a set of observations in order to develop it further. The first one refers to the fact that this concept relies on an adult-centred model of illness, within which it is assumed that the onset of an illness occurs in adulthood or otherwise later in life. Therefore, it does not account for conditions from birth or early childhood, where the guiding principle is continuity, rather than change. A second observation concerns a set of so-called “normal” crises, that arise in conditions of general adversity and material deprivation and that are somehow expected as part of life. In this regard, class and age are two crucial dimensions that need to be taken into account when studying chronic illness, as well as gender and ethnicity, all factors that are so far under-researched (Ibidem). As some studies have observed, in particular contexts –especially where individuals experience hardship and adversity- chronic illness might be biographically anticipated or planned-for event. As Williams (Ibidem: p. 104) states: “[T]iming and context, norms and expectations, alongside our commitment to events, anticipated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow them”.

Furthermore, Williams mentions the study of Carricaburu and Pierret’s (1995) on HIV-positive men infected through homosexual relations or medical treatment for haemophilia. In this study, it is highlighted how in some cases the meanings given to being HIV-positive brought elements of “biographical reinforcement” (Ibidem: p. 65), that arose when they reinterpreted their individual and collective pasts. In the case of haemophiliac, for instance, HIV infection simply confirmed their lifetime experience of illness. On the other hand, in the case of homosexual men it reaffirmed their struggle as gay men, both individually and collectively. The notion of biographical reinforcement thus described better their illness experience, rather than that of biographical disruption.

With respect to the subject under analysis, Williams’ critique to the concept of biographical disruption could be useful in order to include and recognize also those illness stories that are not characterized by a disruptive event –as it is subjectively reconstructed- for example in the case childhood onset of autoimmune diabetes. What these two theories have in common is the occurrence of a turning point, the onset of an illness, which might have different impacts on different people. In fact, illness is never merely a private experience. It rather involves also people whose biographical trajectories intersect that of the ill person. For this reason, even if "biographical disruption" as a concept may not be useful in order to describe all juvenile-onset diabetes experiences, it could nonetheless represent the experience of the caregivers (for example, the parents) who experienced the onset of diabetes of their child. For this reason, I shall consider those approaches not as mutually exclusive, but rather in a combination of elements in order to analyse illness as a complex and multidimensional phenomenon.

2.5 Constructing masculinities in the context of chronic illness

The biographical disruption of chronic illness (Bury 1982) can pose a number of challenges to masculinity construction, from challenging taken for granted ideals and expectations to real "identity dilemmas," as Charmaz (1994: p. 269) defined them. The onset of a serious chronic illness may lead to experience a number of physical and mental effects that interfere with the ideals of physical strength, independence and resistance to pain that characterize the dominant ideal of masculinity; its management in the everyday life may also require specific care of the body and medical diet regimes, all practices that are usually associated to a feminine sphere. Therefore, it is certainly interesting to explore the ways in which men cope with physical and emotional vulnerability and with the risk of marginalization.

As Giddens (1979: p. 123; quoted in Bury: p. 169) points out: "We can learn a good deal about day-to-day situations in routine settings from analysing circumstances in which those settings are radically disturbed." The diagnosis of a chronic illness might be a biographical disruption (Bury 1982) or a "critical situation" (Giddens 1979; quoted in Bury 1982: p. 169) that affects perception of the self and influences the enactment of masculinities in everyday life: I assume that observing the (re)negotiation of male embodiment in a context of serious chronic illness might shed light on more broad processes of male embodiment and masculinity construction, because, in a way, it would break taken-for-granted assumptions of body control and "healthiness" that inform ideal conceptions of masculinity and, thus, it would make normative assumption around male bodies more evident. To what degree men refer to health services or comply with medical prescriptions, how they signify their changes and losses, how they cope with reduced bodily functions, how much they are willing to modulate their routine habits (such as work load or unhealthy eating): these are some of the significant elements to be considered in exploring the intersection of male embodiment and men's health and their experience of illness, in parallel with the consideration of their social, cultural, and economical situatedness.

There is a paucity of research that focuses on embodied masculinity and health (i.e. Cameron & Bernardes 1998, Chapple & Ziebland 2002, Charmaz 1994, Elgie, 2002, Gijsbers Van Wijk *et al.* 1999, Grogan & Richards 2002, O'Brien *et al.* 2005, Robertson 2006, Watson 2000, White 2001, Williams 2000). Charmaz (1994) highlights that, after the onset of a chronic condition, "[i]dentity dilemmas result from losing valued attributes, physical functions, social roles, and personal pursuits through illness and their corresponding valued identities, i.e. positive definitions of self, including socially conferred and personally defined positive identities" (Ibidem: p. 269). Men living with chronic illness may feel, on the one hand, the demands of embodied hegemonic masculinity ideals and, on the other hand, the marginalization and stigmatization caused by their illness. As I have already mentioned, hegemonic ideals of masculinity prescribe to men expectations of physical strength, courage, independence, risk-taking, athleticism and career orientation, all expectations that men with a chronic condition or disability may not be able to meet or, rather, may be actually able to meet, but at the cost of worsening their – actual or future - health. Physical limitations and social stigma may thus prevent access to hegemonic masculinity ideal standards and when this happens, men are often marginalized and stigmatized. Marginalization occurs because chronic illnesses and disability destabilize the symbolic value of the male body, which is an essential part of how men define themselves and how others define them. Given the difficulty (or impossibility) to accomplish the demands of hegemonic masculinity, they may experience what Murphy (1990) calls "embattled identities" (Ibidem: p. 104, in Gerschick & Miller 1997) and Charmaz (1994: p. 269) defines as "Identity dilemmas."

Further insights can be obtained from the literature on men with disability. In order to account for how men with disabilities (re)negotiate their masculinities, Gerschick and Miller (1995) developed the "Three R Framework" (Gerschick & Miller 1997: p. 457), identifying three recurrent coping strategies in relation to hegemonic masculinity ideal standards: reformulation, reliance and rejection. *Reformulation* refers to the strategy of redefining hegemonic characteristics of masculinity in their own terms; *reliance* entails the (hyper)sensitive adoption of specific attributes of hegemonic masculinity; lastly, *rejection* represents the coping strategy of foregoing these hegemonic standards followed by the creation of their own principles or even the denial of the importance of hegemonic masculinity for their sense of self. Gerschick and Miller (1997) make clear that they propose an heuristic tool developed to analyse men's response to physical impairment, acknowledging that these coping strategies may indeed be enacted in more complex combinations by each man. The 'three R framework' has also been proven useful in relation with chronic illness, as in the case of Lisa Gibbs' research on men's experience of arthritis (Gibbs 2005).

2.6 Doing masculinities in the context of autoimmune diabetes

The present research aims at exploring the embodied experiences of men with one specific chronic condition: autoimmune diabetes. Diabetes mellitus is a term that refers to a group of metabolic disorders of multiple aetiologies that are characterized by chronic hyperglycaemia, which results from defects in insulin secretion, insulin action, or both. Some of the earliest mentions of diabetes have been found in an Egyptian papyrus of 1500 BC (Tattersall 2009) but first systematic description of the disease and its symptoms was provided by Aretaeus "the Cappadocian," who is considered to be the greatest physician of Greco-Roman antiquity after Hippocrates (Laios *et al.* 2012). Aretaeus coined the term "diabetes" and added it into medical nomenclature: the term stems from the Greek verb *διαβανω* (diabaino) that translated means "to go or run through" (Ibidem: p. 113). In fact, one of the symptoms that lead to the diagnosis of diabetes is that of polyuria (that is, an abnormally large production of urine), which is caused by chronic hyperglycaemia (that is, high blood sugar).

In most cases, diabetes can be classified in two main etiopathogenetic categories: type 1 and type 2 diabetes. Type 1 diabetes, formerly known as insulin-dependent diabetes, has usually (but not necessarily) a juvenile onset and results from pancreatic islet beta-cell destruction. It is an unpreventable and incurable autoimmune process that usually leads to an absolute deficiency of insulin secretion: therefore, most times people experiencing type one diabetes need insulin treatment for survival throughout their lifetime, in order to prevent the development of ketoacidosis (that is, high levels of blood acids which are defined as ketones) that may lead to coma or even death.

Type 2 diabetes, formerly known as non-insulin-dependent diabetes or adult-onset diabetes, has its onset usually later in life and it is the most common form of diabetes. It is not an autoimmune disease; it rather results from insulin resistance and may also have relative (or absolute) insulin deficiency. People with type 2 diabetes in the first period after the onset –and often throughout their lifetime- do not necessarily need exogenous insulin to survive. In order to treat it, they are strongly encouraged to make radical changes in their lifestyle in terms of healthy eating and physical exercise. Depending on the stage of the disease, they may need to take oral medications or insulin.

When we eat, most of the food is turned into glucose (or sugar) in order to let our bodies to use it for energy. The pancreas is an organ located in the abdominal cavity near the stomach that produces several hormones, including insulin, which helps glucose getting into the cells. During a conference, in order to better illustrate to a non-expert audience the substantial difference between type one and type two diabetes, doctor Lorenzo Piemonti[4] proposed a metaphor that I found particularly effective: insulin action may be compared to a key that facilitates cellular glucose uptake, while the sensitivity of tissues to insulin may be thought as the lock in which the key operates. In the case of type 1 diabetes, the problem resides in the mechanism of turning the key and letting the glucose in the cells, because it doesn't function properly. While in type 2 diabetes the problem is not

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[4] Doctor Lorenzo Piemonti is the director of the San Raffaele Diabetes Research Institute in Milan and this quotation refers to his speech at the Conference "Diabete: Bergamo apre le porte alla conoscenza. Convegno Medico Scientifico" held in Bergamo (Italy) on 6 May 2017.

the “key,” but rather the functioning of the “lock,” and this makes the cells unable to use the insulin being produced. This metaphor is exemplified in the image below:

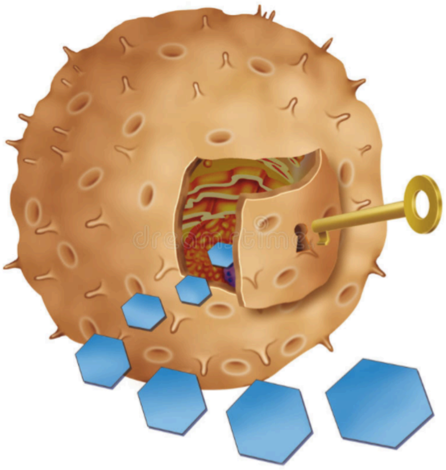

Figure 2.2: Insulin as a key. (Source: google images)

In Italy more than 3 million 200 thousand people reported suffering from diabetes, which represents 5% of the overall population (Istat 2017)[5]. Over the last thirty years, the number of people with diabetes has almost doubled, and this increased prevalence is likely to be due to the aging of the population and other determinants, such as unhealthy eating, sedentary lifestyle, but also earlier diagnosis and an increased survival of diabetic people.

Among different chronic conditions, I have selected autoimmune diabetes because I believe its characteristics make it particularly apt to the purposes of this research. This chronic condition may affect people in different ways, in terms of invasiveness and severity of symptoms and physical complications; overall, its disruption –that Kolling (2012: p. 93) termed *diabetic disruption* - may present specific challenges to masculinity construction, as it requires self-care, lifestyle changes, managing uncertainty, regular check-ups and it frequently causes, as a common complication, erectile difficulties. Managing diabetes and its

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[5] Retrieved from: https://www.istat.it/en/files/2017/07/Report_Diabetes_En_def.pdf?title=Diabetes+in+Italy+-+24+Jul+2017+-+Full+text.pdf last view 3/02/2018.

consequences could be even more challenging in a context such as Italy, where construction of masculinity is still influenced by the legacy of virilism, "an ideology emphasising gender differences and hierarchy" (Ferrero Camoletto & Bertone 2012: p. 434) that was mainly adopted during the fascist era and entailed an ideal representation of manhood that "celebrated the cult of youth, duty, sacrifice and heroic virtues, strength and vigour, obedience, authority and physical and sexual potency" (Spackman 1996: p. XII; quoted in Ferrero Camoletto & Bertone 2012: p. 434).

Unlike other chronic conditions with a higher impact on everyday life, diabetes might leave some room for negotiation and compensatory practices. Furthermore, the occurrence of physical complications (such as retinopathy with potential loss of vision, nephropathy potentially leading to renal failure, peripheral neuropathy causing gastrointestinal, genitourinary, and cardiovascular problems) depends mostly on individuals' adherence to lifestyle changes (healthy eating and physical activity) and compliance to medical treatments. More specifically, management of type 1 diabetes requires daily (usually, at least four times a day) blood-glucose monitoring; insulin replacement through multiple insulin injections, which are usually administrated up to six times a day or through the use of an insulin pump; the adoption of a healthy diet and eating plan, associated with physical activity. A regular diabetes self-management hopefully will minimise the risk of experiencing diabetes-related complications.

Overall, literature on diabetes can be divided into two general approaches: researches with a clinical focus and others exploring attitudes and behaviours. In the first case, research with an epidemiological background has investigated the distribution, the incidence, complications, risk factors and adherence to medication (i.e. Legato 1997, Summerson *et al.* 1999, Vespasiani *et al.* 2005, Bianchi *et al.* 2016). Other research has focussed on sexual functioning and reproductive health of people having diabetes (i.e. Redman *et al.* 1988, Lemone 1996). Although in epidemiological terms diabetes is not gender-specific (except for gestational diabetes), men have usually been found to be at a higher risk to develop the disease, in Italian studies as well as in foreign ones. Research on social and psychological aspects of diabetes included adherence and compliance (i.e. Cramer 2004, Lerman 2005), personal experiences of living with diabetes (i.e. Hernandez 1996, Paterson & Thorne 2000), coping strategies (i.e. Grey & Berry, 2004, Coelho *et al.* 2003), depression in adults with diabetes (i.e. Lustman & Anderson 2000, Barnard & Skinner 2006), gender differences in the psychological adjustment to diabetes (Enzlin *et al.* 2002, Ponzo *et al.* 2006). When considered, gender has usually been found to be a substantial factor in dealing with the disease, highlighting the main differences among men and women. For instance, Peel and colleagues (2005) with a discursive psychology approach explored how newly diagnosed type 2 diabetic women and men constructed their dietary practices. They concluded that women, in their study, "tended to construct dietary practices as an individual concern, while men presented food consumption as a family matter" (Ibidem: p. 779). It should be considered that, overall, literature on gender and diabetes often entails a dichotomous approach to gender and, as Broom and Lenagh-Maguire (2010), as well as O'Hara, Gough, Seymour-Smith and Watts (2013) claim, further research on this issue is needed in order to consider different and more complex variations in the way gender interacts with illness and health practices, for instance considering other elements of social structure -such as age and class- that multiply the possible embodiments of masculinity (and femininity).

Future research on the intertwining of gender and chronic illness could focus on another crucial dimension that has a significant impact on both illness experience and gender performance: namely, sexual orientation. In this regard, Crip Theory gives some theoretical tools for questioning the norms that informs everyday social interactions as well as the majority of the literature published on these issues. The combination of disability studies and LGBTQ studies has given rise to Crip Theory,[6] that drawing from queer theories focuses on the importance of destabilising the hegemonic ideal and imperative of bodily normalcy in terms of heterosexuality – which has remained often unquestioned and invisible in academic as well as in public discourses – and in terms of able-bodiness, which

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[6] See Robert McRuer (2006), *Crip Theory: Cultural Signs of Queerness and Disability*, New York University press, New York and Alison Kafer (2013), *Feminist Queer Crip*, Indiana University Press, Bloomington, Indianapolis.

has been considered as a non-identity even more than heterosexuality. In this perspective, “compulsory able-bodiedness,” in a sense, “produces disability” (McRuer 2006: p. 2) and it is intertwined with the system of compulsory heterosexuality that results in the production of queerness. In fact, heterosexuality is somehow expected for able-bodied individuals and vice versa (Ibidem). In the 19th century society divided humankind in “normal” and “pathological” bodies, and the danger of the degeneration of the so-called “race” promoted by eugenics theories lead to the segregation and exclusion of “abnormal” individuals (Casalini 2016). Both homosexuality and disability share a medicalized past, and in that period heterosexuality and able-bodiedness were the legitimate form of being and had been constructed through the “need of embodied, visible, pathologized, and policed homosexualities and disabilities” (McRuer 2006: p. 2). In the present time, the current economic and cultural system of neoliberal biopolitic produced the coexistence of dominant identities together with nonpathological, marginal identities which are visible and, at times, spectacular: in fact, neoliberalism needs heterosexual, able-bodied subjects who visibly tolerate queer and disabled subjectivities (Ibidem). In this context, Crip Theory points to the subversive and transgressive potential of non-conforming bodies, and their ability to exceed normalcy ideals: just like the term “queer” has been adopted and resignified by lesbian, gay, bisexual and transgender community, the term “crip” has undergone the same political process and within disability community it has been used to rewrite the derogatory term “cripple,” claiming that disable identities should not be separated from the subjects who identify in them and should rather be recognized and celebrated. Although Crip Theory focuses on disability, and despite the fact that autoimmune diabetes is labeled as “chronic illness,”[7] it might be nonetheless a useful lens through which understanding the experiences of chronically ill LGBTQ subjects in so far as it puts into the picture the broader processes of construction of normative (and “healthy”) bodies, as well as considering the multiple forms of discriminations in different social contexts that

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[7] I am aware that the boundaries that divide chronic illness from disability are blurred and ever changing, and that although many long-term conditions are defined as “chronic illness” even if they are disabling in their consequences. For a critical overview of the chronic illness/disability debate see, for example, Williams (1999).

they have to face, the lack of representativeness in contemporary culture, the stigmatization that affects both queer and ill/disabled bodies.

Chapter III

Research design

3.1 Introduction

The previous chapter provided an overview of the theoretical background that informed this research, whose main aim was to explore men's experiences of a chronic illness, namely autoimmune diabetes. With this purpose, I have analysed the biographical narratives of 40 men who had been diagnosed with autoimmune diabetes mellitus. Participants have been selected according to a specific sample design, which had the main objective to answer in a convincing and sound way the research questions that guided from the beginning this research process.

This chapter will account for the methodological path that has been followed in order to conduct this research, and it is structured in sections that aim to cover the typical traits of qualitative research: the first paragraph is dedicated to the research questions and to their relevance for sociological research; I then discuss the qualification of the research context, subsequently defining the theoretical basis that informed the sample design and the recruitment of participants; I will then focus on the research technique that I adopted in order to construct the empirical material – namely, in-depth interview – and justify their relevance for the object under analysis; I will then offer a reflexive account about my positioning, by considering how my personal characteristics and that of participants contributed to the co-construction of empirical material. Finally, the last paragraph provides a discussion about the ethical considerations that emerged during each stage of the research.

For the present research I have used a qualitative approach that, for its specificities, was considered as the most appropriate for studying men's accounts of illness. In fact, qualitative research allows exploring in depth participants' experiences by listening to their own voices and, when it is possible, to enter their private worlds. Qualitative research is useful for grasping the meanings and representations that men assign to everyday life practices, to chronic illness and to their male identity. The focus on social practices made it possible to study illness and gender as two deeply inextricable, embodied dimensions of the self: in fact, subjects construct their bodies on a daily basis through the enactment of practices mainly determined by their specific *habitus*, according to the social expectations around their being males or females, healthy or sick, "normal" or "pathological."

Overall, this thesis aimed to explore how autoimmune diabetes was experienced by men and how it impacted on masculinity construction, with a specific focus on everyday life practices, on participants' embodied experiences of illness self-management, and on the impact of diabetes-related sexual difficulties on their intimate relations.

3.2 The definition of research questions

In recent times there has been an increased interest from the media, policy makers and researchers on the topic of men's health issues (Gough & Robertson 2009). Traditionally, men's worse health outcomes and higher mortality rates reported by national and international surveys have been explained through their supposed desire to meet social expectations around dominant forms of masculinity (i.e. Harrison 1978) according to which men do not seek for medical help, they have a stoical approach to pain, they engage in risky behaviours and they are not compliant with medical recommendations. According to this perspective, "health" and its related practices would be imbued with feminizing meanings and men, in order to have recognised their membership in the "male" category, need to distance themselves from this domain by engaging in a set of "unhealthy" practices through which the male identity is recognised within social interactions. In fact, hegemonic ideals of masculinity construct men as the quintessential neoliberal citizen: namely, able, strong, autonomous, in control, independent and rational (Goodley & Runswick-Cole 2013, Connell 2005). Often, illness – as well as disability – is perceived as undoing the main characteristics of such model. While dominant ideals of masculinity are difficult to achieve for everyone, chronic illness implies a significant threat to hegemonic standards of embodiment, and so does diabetes with all its related bodily uncertainties and bodily maintenance practices.

As Robertson (2007) highlighted, more recent qualitative research on men's health has uncovered the oversimplistic assumption that underlies the ideal that "masculinity is bad for men's health," positing that masculinity is much more complex than that and it actually might be, at times, even contradictory in its embodied performances.

In line with this critical approach to the study of men's experience of health and illness, and within the theoretical framework outlined in the previous chapter, a first objective of this study was to observe how men signify the onset of diabetes, how they represent its presence in their everyday life and how different social contexts and social expectations contribute in shaping different illness experiences. A second aim of this work was to explore male embodiment in relation to diabetes-related practices by looking at how men understand and manage their diabetic bodies in order to deal with chronicity and bodily uncertainty. Finally, a third objective of this study was to analyze men's experiences of diabetes-related sexual difficulties, by focusing on how they signify such problems in light of the contemporary medicalization process and in light of the great relevance of sexual performances for masculinity construction.

The relevance of this study rests on the innovative focus dedicated to men's accounts of health and illness, which contributes to fill the gap in the actual sociological knowledge of gender and health – which usually focuses on women's experiences and women's bodies – and may also provide valuable insights to health professionals and policy makers, in order to critically inform clinical practice and to guide policies in order to reduce inequalities in health.

3.3 The context of the research

After defining the questions that guided the whole research process, in the next subparagraphs I will explain in details and justify the appropriateness of the empirical context where I conducted my fieldwork, which has been selected in order to answer appropriately to the initial research questions.

In order to study men's experiences of autoimmune diabetes, the general population that have been selected is that of men who were diagnosed with such condition and who resided in Italy. In this context it is estimated that more than 3 million 200 thousand people suffer from diabetes, which represents 5% of the

Italian population (Istat 2017).[8] Among those cases, the 10% is diagnosed with type 1 diabetes, which usually occurs during childhood and adolescence. In general, diabetic subjects are difficult to reach, because they are (mostly) invisible and they usually do not interact with each other. The fact that men are also more difficult to access compared to women and the fact that, once accessed, they are even more difficult to interview on health issues (Brown 2010) made participant recruitment quite time-consuming and very challenging. In what follows I will specify in details the selection of cases and participant recruitment strategies.

3.3.1 Sample design

The final sample is the result of an accurate methodological reflection and of one year and a half of relentless fieldwork. The profile of the cases has been designed in order to construct a sample that could answer the research questions in the most accurate and sound way possible. The sample design that allowed me to move to the recruiting phase has been produced through the equal subdivision of cases in four main configurations. Such typology has been constructed through the intersection of two main socio-demographic dimensions: individuals' age and their social class, both justified by their relevance to research questions and the desire to ensure heterogeneity with regard to men's experiences of illness. Within the obtained four quotas, I have sought to maximise their heterogeneity on the basis of age of diabetes onset, degree of compliance, presence of diabetes-related complications, sexual orientation and ethnicity. Unfortunately I was unable to explore the last dimension and compare participants with different ethnic origins, because all participants where white and Italian of birth.

To summarize, inclusion criteria for participating in the research included: (a) male gender; (b) being diagnosed with autoimmune diabetes; (c) requiring insulin to obtain or preserve satisfactory glucose control; (d) being aged between 20 and 60 years; (e) belonging to working/middle class backgrounds. Sample design is summarised in the table below:

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[8] Retrieved from: https://www.istat.it/en/files/2017/07/Report_Diabetes_En_def.pdf?title=Diabetes+in+Italy+-+24+Jul+2017+-+Full+text.pdf last view 27/09/2018.

Social class / Age	Working Class	Middle Class
Young adults (20-40 yrs.)	10	10
Adults (41-60 yrs.)	10	10

Figure n. 3.1: Description of sample design

Individuals are simultaneously embedded in a number of social hierarchies that influence their way of experiencing the world: the way they feel, their aspirations, their tastes, but also the way they can signify an unexpected event such as the onset of a chronic illness, as well as the actual possibilities they have to cope with its consequences. For the purposes of this study, the sample design stands at the crossroads of three systems of social stratification: namely age, social class, and gender.

The relevance of "age" in structuring the experience of illness is perhaps evident: it has been shown that age might influence the perception of illness as a biographical disruption (Williams 2000), in fact according to some empirical studies (e.g. Faircloth *et al.* 2004) age determines how people could minimize the actual impact of an intrusive condition; age could also determine individuals' actual agency and competences in respect of illness management in their everyday life. With respect to social expectations that surround masculinity, ages matters too: Raewyn Connell (1995, 2002) characterizes hegemonic masculinity – the most idealized model of masculinity within a specific social context – with heterosexuality, marriage, authority, paid work and physical strength. Thus, recruiting participants within their young and adult stages of life allow exploring how diabetic men responded to the challenges posed by chronic illness in all the five abovementioned dimensions within a period of life where social expectations around masculine identity are particularly high.

Social class is indeed a crucial dimension that intersects, and shapes, experiences of health and illness. Structural factors such as the organization of production and the distribution of resources in society are crucial in determining patterns of inequality in health. In fact, different positioning within class hierarchies are associated with different mortality rates, different incidence in chronic diseases, and differences in access to health services (White 2017). Social class is also crucial for studying gender and masculinity. As Connell (1995) highlighted, conceptualizing gender as way of structuring social practices means that it inevitably intersects with other social structures, among which social class is one of the most relevant ones. As Connell (Ibidem: p. 76) stated: "To understand gender we must constantly go beyond gender. The same applies in reverse. We cannot understand class (…) without constantly moving towards gender. Gender relations are a major component of social structure as a whole, and gender politics are among the main determinants of our collective fate." Typical models of masculinity interact with social hierarchies related to social class (Morgan 2005), and different ways of "doing" masculinity might be reinforced by differences in occupations and in communities of practices.

Finally, as I have anticipated before the sample design took into account three social hierarchies: that of age, of social class, and that of gender. As explained with greater detail in the previous chapter, Connell (1995) proposed to approach gender as a crucial way of organizing and structuring social practices through the reproductive arena. Masculinities are thus historically situated and dynamic configurations of gender practices that are positioned in a given pattern of gender relations. The sample design sought to expand its heterogeneity through taking into consideration cases that were distributed along different positions in current Western gender order, including for example "subordinated" masculinities such as gay men. Hegemony, subordination and complicity are thus considered as the main reference to structuring relationships between masculinities. Within this framework, men with a chronic condition are not necessarily subject to a marginalization process. If we maintain the focus on gender relations, chronically ill men might *in some cases* become marginalized from men occupying a hegemonic position in the gender order by precluding their full participation in society in terms of material practices (Robertson 2007). But they could however be complicit in benefitting from the hegemonic privilege, what Connell defined as patriarchal dividend. This has been "translated" into designing a sample that was heterogeneous in terms of the severity of illness impact, that ranged from a "mild" impact on diabetic men's bodies and selves to a "high" and disabling one; heterogeneity within the four outlined quotas has been also sought in marital status and type of occupation.

Although this research – as qualitative research in general – relied on a small sample size, I assume that the comparative potential (Barbour 2008, quoted in Cardano 2011) provided by this sample design could offer the possibility to answer soundly to the research questions that guided the research process.

3.3.2 From "cases" to "real people": multiple strategies for participants recruitment

In this paragraph I will describe in details the strategies adopted in order to recruit participants for this study, that is to say, how I moved from the sample design outlined in the previous subparagraph to the actual group of participants that engaged in this research, whose characteristics will be described in details in the next subparagraph. This research has been usually presented to mediators and gatekeepers in person or by phone. As the subparagraph 3.3.3 will show in details, this has been also supported by leaflets, posters and on line presentations.

As a general rule, I did not offer any economic reward for engaging in the interview in order to prevent people to participate in the study only for economic reasons and thus incurring the risk of creating a "biased" sample. It could be argued that the economic reward would have facilitated participants' recruitment, especially in the case of people living in less favourable economic conditions. This issue has been considered in the initial research design: in fact, in order to deal with it I managed to guarantee the accessibility to participating to this research with the possibility of me going wherever the interviewees felt more comfortable to meet me, or through the possibility to talk through video calls. In one case I personally reimbursed travel expenses to a university student that could not afford them and who desired to meet me at the University.

At this point, one could possibly ask: what kind of recompense does the participant get from participating in a time-consuming activity such as an in-depth interview? On this issue, Cardano (2011) mentioned a series of possible rewards: first of all the emotional one, which results from having the opportunity of participating in an interaction where the interviewee is at the centre of the attention and can express himself freely, without the risk of being contradicted or silenced. This kind of reward is indeed higher for those who are less used to receive public attention, and it is particularly the case for chronically ill people, who usually complain for the lack of consideration given by their doctors and the lack of spaces where they can share their feelings about the condition they live with. It should then be considered the cognitive reward, the one derived from realizing a work on the self: through the questions and observations of the interviewer, the interviewee in fact has the chance to look critically to his life and his daily routines and to elaborate some “otherwises” that would not have come to mind outside of this occasion. Lastly, a final reward concerns the opportunity to share, through the interview, the complaints for a malfunctioning of the health care system, or to divulge the personal strategies developed for filling in the gaps of – or improve the – medical treatment, in the hope that this could ameliorate other people’s lives.

On the other hand, an economic reward is also possible, but I intentionally decided to avoid it. In our capitalistic society, money seems to be the privileged mean to purchase everything: goods, services, emotions and relations. When used in social research for recruiting participant, it should nevertheless be considered that it would have a significant impact on the kind of sample it would allow to obtain. In fact, as Cardano (2011: p. 151, my translation) observed: “If the sample is composed of people who agreed to engage in the interview only for obtaining the [economic] reward which has been promised to them, the soundness of the findings risks being seriously compromised.” At this point it might be argued that without an economic reward some people could be intrinsically excluded from participating to the research, for example people living in situations of extreme poverty and social deprivation. It is true. But this was not the aim of my research: the heterogeneity of diabetic men's experiences has been sought through the intersection of two specific dimensions: social class (namely, working and middle class) and age (namely, young and adult), under the assumption that both were relevant for answering in a sound way to my research questions. The final sample, as it will be explained in more detail soon, presented a quite balanced and heterogeneous composition, and this proves, in my opinion, that the plural and creative forms of recruitment that I have selected were adequate enough to fulfil the research objectives.

3.3.2.1 Engaging with Associations dedicated to diabetic individuals

Overall, an initial observation is that the population of diabetic individuals is invisible and difficult to access for privacy reasons: in fact, it was not possible for me to obtain a list with their names and personal contacts. Since I was not only looking for diabetic people, but I needed to recruit diabetic *men* differentiated for *ages* and *social backgrounds*, this dimensions further complicated the recruitment process. An additional challenge was given by the fact that, as Brown (2001: p. 192) observed: "Men are not used to talking about health, as it is not normally part of their day to day discourse." Many assumptions have been made in order to explain men's reticence to engage talking about health, and one of them is that men would refuse to participate in such interviews as a way of doing masculinities, as a means of affirming their independence, rationality and control (Butera 2006, quoted in Oliffe 2009). With the objective of finding men willing to talk extensively about their health and illness experiences, I relied on a numer of different "mediators" (Cardano 2001: p. 176; my translation), because according to the literature (see Oliffe 2009: p. 71) a third-party endorsement could serve as a form of "authorisation" for men to engage in this "atypical and perhaps suspect activity."

With that in mind, first of all I contacted the main associations dedicated to people with diabetes in Milan and arranged a meeting with the representatives that I thought could play the role of mediators and let me connect with prospective participants. Interestingly, at this stage I only met women. One of them warned me that it would have been very difficult for me to recruit diabetic men within the context of associations dedicated to diabetic patients, because, in her experience, they were mainly composed by women: by diabetic women indeed, but also, surprisingly, by "non-diabetic wives of diabetic men." This information, in my opinion, gave already an initial interesting clue about the role of gender in organizing care activities within the family context. This is well illustrated in the next excerpt of an informal interview conducted with a diabetic woman that managed the activities of one of the biggest national associations dedicated to diabetic individuals:

> **You were saying [when the tape recorder was turned off] that often women help their husbands…**
> Yes, because they are the ones that cook. Especially for elder people, it has always been the woman who cooks. This is why many [diabetic men] came, and still come, with their wife because it's her that buys groceries. I also know some of them who know every drug their husband takes, what he eats… And [diabetic men say to me]: "Well, you should speak to my wife because she is the one who knows." (Maria)

Despite the fact that the potential mediators that I met in this initial phase enthusiastically helped me by disseminating the recruitment message of my research in their associations' contexts, nobody actually contacted me for participating.

Meanwhile, I took part in formative activities and conferences organized by associations dedicated to diabetic people: in those occasions, during pauses and lunch breaks I approached informal groups of diabetic men and presented them my research. Although many of them expressed interest, and despite the fact that I gave them dozens of leaflets with the presentation of my research that they said they would distribute to their associations' members, this did not prove to be a fruitful method of participants' recruitment because, again, nobody replied.

3.3.2.2 Engaging with social media and on-line communities

In a couple of occasions, during medical conferences about diabetes issues, I was lucky enough to meet Elisa, a non-diabetic woman that administered an on-line community for people with autoimmune diabetes, who began her engagement in such activity in order to help and support her diabetic brother. She really helped me many times by spreading the interview invitation through her personal contacts, on her website and through several Facebook pages dedicated to diabetes issues. This attempt has proved to be very successful and I was able to recruit 8 people that fitted recruitment criteria. Subsequently, after reading my recruitment invitation, other on-line communities administrators (again, women) contacted me in order to have more information, and when they approved (after a series of "suspicious" and "investigatory" questions) the aims of my study, they helped me in spreading the recruitment invitation through their personal channels.

After gaining visibility especially in the social media, a journalist contacted me and interviewed me about my research; she then wrote an article on diabete.net (see appendix H) that has been spread though social media and resulted in the recruitment of others participants.

Since it had proved to be a fruitful channel, and given the overall difficulty in recruiting participants, after receiving the authorisation from my Ph.D. coordinator and supervisors I decided to continue using the Internet to publicise my work, using different social media such as Twitter and Facebook or on line forum and communities. In fact, a very successful an innovative strategy has been that of using Facebook targeted advertising. It has been a low-cost, efficient strategy that allowed me to reach in a very short period of time a vast amount of potential participants (246 people joined the personal Facebook profile page[9] dedicated to this research and 217 people "liked" the public Facebook page[10]). Facebook advertising consisted in, first of all, selecting a range of preferences for the target population: for example, male sex; the age range (20-60 years); the geographic distribution (I began with Milan and Lombardy region, then I progressively extended it throughout Italy); "liking" Facebook pages related to diabetes and, with the aim of covering an higher heterogeneity of the cases, also "liking" Facebook pages dedicated to diabetes-related technologies, diet, but also LBTQ issues, ethnic minorities and sport pages. I selected the cheaper option (2 euros per day) and test it for one week. This allowed me to reach several hundreds of people through banner ads that appeared in the Facebook home pages of the targeted population. The banner ads showed just some short sentences, in order to

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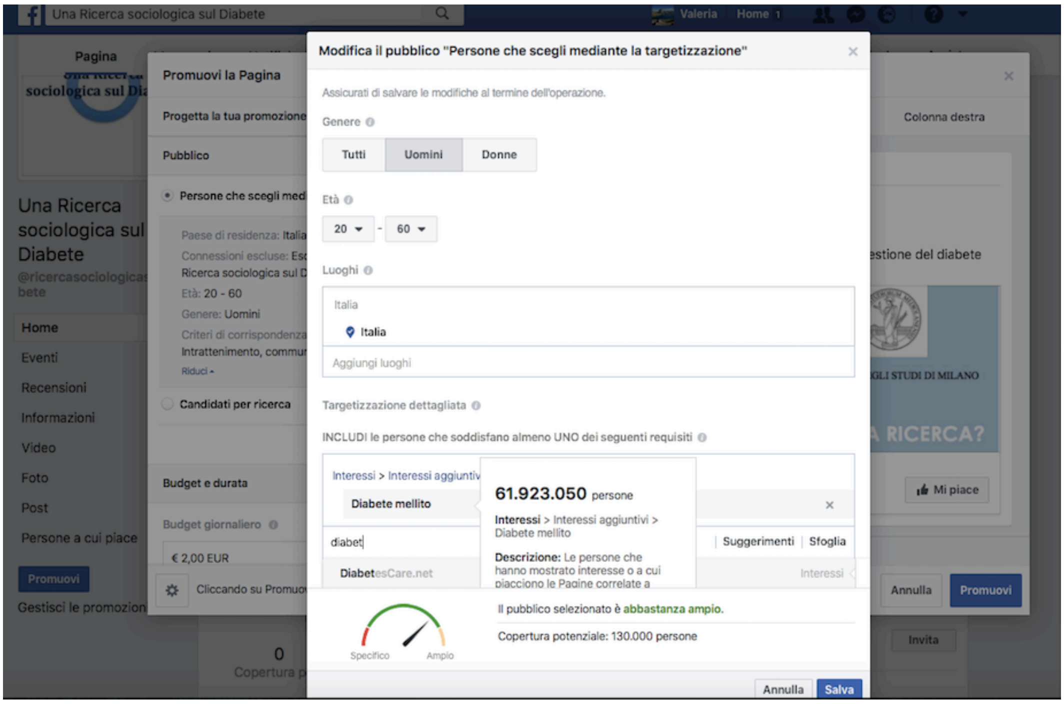
[9] Retrievable at: https://www.facebook.com/ricerca.suldiabete.7 last viewed 27/09/2018.

[10] Retrievable at: https://www.facebook.com/ricercasuldiabeteuniversitadimilano/ last viewed 27/09/2018.

get people attention. When somebody clicked on it, they were automatically directed to the public page of the research, where they would read in details the aim of the research and the different modalities of participation. The public page did not allow the administrator (me) to engage directly with the people who "liked" it, unless they had already interacted somehow with the page (by "liking" or commenting on some posts, or by writing a private message). Out of 16 followers that interacted with the Facebook page, 5 of them accepted to participate in the research and some of them gave me other contacts of diabetic acquaintances. Since the Facebook page had some limitations in terms of interacting with followers, I decided to create a Facebook "profile" dedicated to the research that has been added to the possible contact information in the recruitment invitation. Some of the interviewees, as well as some colleagues, friends and tutor helped me in finding new Facebook contacts and spreading the recruitment invitation. From this Facebook profile I managed to recruit other 6 participants, and some of them in turn gave me the contact of some of their diabetic acquaintances and it was possible to continue the recruitment through snowball sampling. Although this has been a fruitful recruitment tool, it was not without limitation: despite the fact that the 11 participants who joined the research through Facebook where heterogeneous in terms of age and social background, one can reasonably imagine that Facebook users usually tend to be young, better educated and wealthy enough to have access to internet and modern technologies. Another weakness of this research tool is that it is very time-consuming: many of the diabetic men that answered to the initial advertising banner through liking the pages, or through private messages, emails or phone calls were not actually available to engage in an in-depth interview – they would have preferred an online questionnaire or a phone interview rather than a video call or an in person interview –; others did not even have diabetes, but they had a diabetic friend, child or family member and hoped that they could be interviewed in order to talk about their experience; lastly, despite my recruitment message was clear enough about the male sex as a recruitment criterion, I received many messages from diabetic women that wanted to participate in the research. Furthermore, as often happens, also in this case some men that initially declared their willingness to participate in the research changed their mind afterwards and never showed up at the appointment (virtual or in person), and this could have being facilitated by the distance and anonymity provided by the Internet.



Modifica il pubblico "Persone che scegli mediante la targetizzazione"

Assicurati di salvare le modifiche al termine dell'operazione.

Genere: Tutti | **Uomini** | Donne

Età: 20 - 60

Luoghi: Italia

Targetizzazione dettagliata

INCLUDI le persone che soddisfano almeno UNO dei seguenti requisiti

Interessi > Interessi aggiuntivi > Diabete mellito

diabet

61.923.050 persone

Interessi > Interessi aggiuntivi > Diabete mellito

Descrizione: Le persone che hanno mostrato interesse o a cui piacciono le Pagine correlate a

Il pubblico selezionato è abbastanza ampio.

Copertura potenziale: 130.000 persone

Paese di residenza: Italia

Età: 20 - 60

Genere: Uomini

Budget giornaliero: € 2,00 EUR

Figure n. 3.2 Screenshot of Facebook Ad construction

3.3.2.3 Final recruitment strategies: bringing gender into the picture

Access to another association (A.N.I.A.D., Associazione Nazionale Italiana Atleti Diabetici) was gained, at first, by contacting the President of such association through email and presenting him my research; when, after few weeks, the father of a colleague of mine that knew him personally asked him if he could support my research project, he spread my recruitment invitation in their national mailing list and this resulted in 3 individuals willing to participate in the research. Interestingly, this was the only case in which the President of the association was male and the only case in which contacting an Association dedicated to people with diabetes actually resulted in successful recruitment of male participants.

Finally, I continued by using the recruitment strategy of snowball sampling, asking to the previous interviewees to publicize my research project among their acquaintances that could meet the criteria for participation in the study. In this regard, it has been extremely important the role of another woman, Carla, the partner of Francesco (a 51 years old man with diabetes from the age of 3 who participated in this research) who was in turn diabetic and that was very popular within the diabetic community. After asking many questions about my research, after verifying that I knew the difference among type 1 and type 2 diabetes, and after making sure that I would give voice and "support" type 1 diabetic experiences, in different times she connected me with no fewer than 8 diabetic men that fitted my sample criteria perfectly, and all of them confirmed their willingness to participate in the research.

In sum, recruiting diabetic men has been a difficult and time-consuming task that consisted in numerous unsuccessful attempts (in this respect, see paragraph n. 3.6) but also in fruitful strategies. Looking at this process through "gender lenses," I found it interesting that the main gatekeepers that "monitored" my access to specific associations were all women, as well as the majority of members of such associations (diabetic women and wives of diabetic men), and this supported the hypothesis that the care role is still considered a feminine responsibility. As mentioned before, also the two most important mediators I encountered, Carla and Elisa, were also women, and their endorsement has been crucial in order to find participants for the research. The only man that played the role of mediator was, not surprisingly, that of an association dedicated to diabetic athletes, and this could be interpreted as a more "acceptable" way for a man of engaging in support activities.

3.3.3 Presenting the research to participants

In order to present the research to prospective participants, I used a series of strategies that I explain in details in the following subparagraphs. In sum, I created a printed leaflet and a poster that I have distributed and attached in different places, in order to gain prospective participants' attention. Afterwards, I will describe how I engaged with social media, and with Facebook in particular, in order to recruit participants through online recruitment.

3.3.3.1 Presenting the research through printed documents

First of all, I created a *leaflet* (see Appendix A) where prospective participant would find: (i) and explanation of the main aims of the research; (ii) a specification of participation modalities; (iii) anticipation of the topic of the conversation; (iv) and privacy protection.

(i) When explaining the main aims of the research, I have mainly focused on diabetes self-management. I decided not to explicit my interest in analysing masculinity issues because I though that this would discourage men even more from engaging in talking about their illness experiences. However, I have made explicit this dimension of the analysis when participants phoned me and asked for further details of my research design, because they were curious about the reasons why I decided to recruit a sample composed only by men. In writing research's aims on the leaflet I decided to be clear and concise in order to facilitate the reading and to increase the possibility of raising interest in the study;

(ii) Participation modalities included *how* the interview would take place, the estimated time, the possible locations and the alternatives for those that I could not meet in person. As regards to the time, I preferred to anticipate that the interview would require from one up to two hours, in order to make sure that prospective participants would decide to engage in this research knowing in advance the time that it would take and thus could organize themselves accordingly. With respect to the possible locations I decided to let them choose whether they preferred to meet at the university, at their own house or elsewhere. According to where they came from, I also gave them the possibility to meet at the University of Turin of Milan, where I had at my disposal a room where we could talk in private. Furthermore, Skype, FaceTime or Whatsapp video calls were also proposed as a possibility if the distance or other contingencies would make it difficult to meet in person;

(iii) In the leaflet I also made explicit the topic that would be the object of the conversation, in order to make sure that they would feel confident enough to engage in an interview about their personal experience of diabetes where they would play the role of "experts." It seemed important to me to clarify that the questions would be open-ended, in order to set, from the beginning, the typical rules of in-depth interview. Since this is a sensitive topic, I explained that they would have the opportunity to decide not to answer to my questions, if they wanted to, in order to make them feel as free as possible;

(iv) Since the object of the interview was sensitive, I considered it crucial to explicit in the leaflet that the information collected would be used only with scientific purposes and it would be protected by rules of confidentiality (see paragraph n. 8).

Since recruiting participants has proved to be very challenging, I decided to use more creativity and create a sort of poster (see Appendix B), with a text content similar to the leaflet but with a more "catchy" lay out. From this poster, prospective participants could directly get a ticket with my contacts written on it. I distributed posters in pharmacies, libraries, shops and GP clinics. I tried to attack it in some hospitals' notice boards, but unfortunately I could not because I was not allowed to.

3.3.3.2 Presenting the research through social media

As a recruitment strategy I also entered an – as far as I know – uncharted territory (at least in Italy) and I used Facebook in many ways (Facebook Ads, personal profile of the research, and a public page dedicated to it) and I produced a personalised "Ad" with a simpler text, and more colourful lay out (see Appendix C) and with a content similar to the other two presentations, in order to attract prospective participants' attention.

UNIVERSITÀ DEGLI STUDI DI TORINO

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UNIVERSITÀ DEGLI STUDI DI MILANO

SOMET Sociology and Methodology of Social Research

HAI IL DIABETE?
TI INTERESSA PARTECIPARE A UNA RICERCA?

Secondo le ricerche, il numero di persone che scopre di avere il diabete cresce di anno in anno. **Lo scopo di questo progetto è di contribuire allo studio di questa malattia cronica in Italia**, dando voce a chi ne fa un'esperienza più diretta.

LA RICERCA È RIVOLTA AGLI UOMINI DI ETÀ COMPRESA TRA I 20 E I 60 ANNI CON UNA DIAGNOSI DI DIABETE.

LA PARTECIPAZIONE CONSISTE IN UN'**INTERVISTA** SINGOLA (DI PERSONA O VIA SKYPE) CHE DURA CIRCA UN'ORA. GLI ARGOMENTI DELL'INTERVISTA RIGUARDERANNO LE **ESPERIENZE E LA GESTIONE DEL DIABETE NELLA VITA DI TUTTI I GIORNI**, LE DOMANDE SARANNO APERTE E I PARTECIPANTI POTRANNO PARLARE LIBERAMENTE DELLE LORO ESPERIENZE. Le informazioni raccolte verranno utilizzate in modo anonimo a solo scopo scientifico, nel rispetto delle normative vigenti in materia di protezione e valorizzazione della proprietà intellettuale e in materia di privacy (L. 196/2003).

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Figure n. 3.3 Picture used for advertising on Facebook

3.3.4 Final sample

As summarised in this paragraph and specified with greater detail in the Appendix M, the sample obtained in this research is quite heterogeneous. In figure n. 2.4 it is described the final sample as compared to that of the initial research design:

Social class / **Age**	**Working Class**	**Middle Class**
Young adults (20-40 yrs.)	**9**/10	**9**/10
Adults (41-60 yrs.)	**9**/10	**13**/10

Figure n. 3.4: Characteristics and main dimensions of the final sample

As shown in the table below, all men interviewed had been diagnosed with a form of autoimmune diabetes, the majority of them (33 out of 40) were diagnosed with the more common “type 1 diabetes,” while a minority of them (7 out of 40) were diagnosed with LADA diabetes, the form of autoimmune diabetes that usually has its onset in adulthood.

Total number of participants		**N**
		40
Diagnosis	**Type 1 diabetes**	33
	Latent Autoimmune Diabetes in Adults (LADA)	7

Table n. 3.1: Descriptive characteristics of the overall sample by type of diagnosis

In this sample, diagnosis occurred to participants in different points in life: 12 of them experienced a childhood-onset, the 10 of them had the onset during their adolescence or early adulthood, while the largest proportion of participants – 18 of them – suffered from diabetes later in life, namely after 25 years of age. This is summarised in the table below:

Total number of participants		**N**
		40
Age of the onset	**Min**	3
	Max	52
	Mean	20.35
	SD	13.36
	Childhood (0-11 yrs.)	12
	Adolescence / early adulthood (12-24 yrs.)	10
	Adulthood (25 yrs. - and older)	18

Table n. 3.2: Descriptive characteristics of the overall sample by age of onset

Overall, the 40 men interviewed ranged from 23 to 59 years of age, with an average age of 41.6 years and a standard deviation of 10.8 years; age distribution was similar through different age groups, with a slight majority of people aged more than 40:

Total number of participants		**N**
		40
Age	**Min**	23
	Max	59
	Mean	41.6
	SD	10.8
	20-30 yrs.	8
	31-40 yrs.	10
	41-50 yrs.	11
	51-60 yrs.	11

Table n. 3.3: Descriptive characteristics of the overall sample by age

In the overall sample, only one participant reported having a low level of education, 2 participants reported having a Ph.D., 10 participants a degree and 27 participants high school:

Total number of participants		**N**
		40
Education level	**Middle school**	1
	High school	27
	Degree	10
	Ph.D.	2

Table n. 3.4: Descriptive characteristics of the overall sample by education level

The table below describes the distribution of the actual sample in terms of occupation, and the details of the single participants are listed in the Appendix M.

Total number of participants		**N**
		40
Occupation	**Retired**	3
	University Student	1
	Unemployed	1
	Unskilled[11]	2
	Partly skilled	2
	Skilled-manual/non manual	16
	Managerial	10
	Professional	5

Table n. 3.5: Descriptive characteristics of the overall sample by occupation

Moreover, all participants were white, and all but two were heterosexual. Despite the fact that I have sought to augment heterogeneity through sending the recruitment invitation to specific associations dedicated to LGBTQ people and migrants, this strategy was not efficient and nobody replied. Two non-heterosexual participants were recruited through on-line strategies of recruitment.

3.4 In-depth interviews as main research technique

Single in-depth interviews have been a useful research instrument that allowed to access participants' biographical reconstruction, their most important life events, their main turning points and their ever-changing relationship with diabetes. This research drew on 40 illness accounts of diabetic men that have been collected through the conduction of in-depth interviews. The 40 individual interviews took place from May 2017 to July 2018. At the end, this resulted in 57 hours of audio recording, with a mean of 1,42 hours per interview, and in 2048 pages of interview transcriptions.

In-depth interviews are a fruitful instrument for studying men's experiences of illness: within this special conversation, participants do not narrate their biography as it was a static collection of events, a museum with an ordered,

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[11] Although I found this subdivision not completely satisfying, I found it nevertheless useful for the purposes of this chapter. It corresponds to the British Registrar General's classification of occupations (Leeye & Fox 1977).

unaltered exposition of past experiences to be enumerated: it is rather a dynamic process that takes shape during an interaction, where meaning are (re)constructed and identities are (re)produced. Narratives *construct* illness and illness experiences (Good 1994): while talking about their condition, participants *represent* their experience through an ordered and coherent set of events, that are recounted along with the experiences related to them and with the associated meanings. Illness narratives combine the present of the interview interaction, the reconstruction of the past experiences, and direct them towards the future of their desires and projected objectives. The interviewer is like an active and empathetic listener, and the interviewee recount his illness story in the attempt to take the researcher into his private world, even for a little while. But, as I said before, listening to the past illness experiences of participants within the context of an interview is not like admiring works of art in a museum: narratives, in fact, "succeeds by subjunctivizing reality" (Ibidem: p. 153) and allow the interviewer to explore the indeterminacy of reality. Illness narratives have subjunctivizing elements because interviewees – men with diabetes, in this specific case – are *doing* diabetes and they are *doing* masculinities in the same moment that they are *doing* the interview. In fact, they are in the constant process of making sense of their ever-changing situation, in an attempt to deal with a troubled present and an uncertain future. For this reason, illness stories are always open "horizon" (Ibidem: p. 157), and this openness regards the future, but also the possibility of new interpretations, and the eventuality of changes.

Thus, collecting diabetic men's stories may provide a valuable amount of information and despite the rising interest in men's experiences of health and illness, and despite the growing attention dedicated to masculinities, to date there is a paucity of research that draws on men's own account of illness. In-depth interview as a research technique allows going beyond the biomedical conception of *disease*, of diabetes as a metabolic disorder that provokes high blood sugar levels and a series of health complications. Men's experiences of *illness* explain that it is not only the body that deals with uncertain outcomes: it is rather their whole life. Maintaining a constant glucose control means controlling their bodies, but it also results in controlling their lives and shaping new selves. In fact, after the onset of an illness, “[t]he self, as well as the body, is shattered, and narrative is the only tool that can be used to build a new link between present and future, the only tool that can make sense of the experience of illness” (Cardano 2016: p. 66). Furthermore, men’s health literature highlights the usefulness of in-depth interview as a valid research instrument also for exploring masculinity construction. Connell (1995) clearly stated that “Life histories give rich documentation of personal experience, I ideology and subjectivity. (…) But life histories also, paradoxically, document social structures, social movements and institutions. (…)” (Ibidem: p. 89).

3.4.1 Interview guide

After having identified the research technique that I would use, I then constructed an interview guide (see Appendix F) that would allow me to elicit participants’ stories around some themes that I considered as relevant for answering the research questions. During the interviews I tried to “give voice” to participants, letting them recount their illness stories with their own words, but at the same time directing the conversation towards the topics that interested my research.

After testing the first draft of the interview guide with pilot interviews, I progressively redefined and shortened it. Overall, in all interviews I tackled the same key themes, with a high degree of flexibility in their formulation and in the order in which they have been raised within the conversation. All the questions were open-ended, in order to access as much as possible the complexities of men’s experiences of illness. Some interviewees gave rich accounts of each theme specified in the interview guide, while others focussed more on some themes at the expense of others. Across the interviews, sometimes I have formulated the questions in the same way, in other occasions I changed them and at times the participant talked about same theme without the need of asking him to.

The interview guide was structured drawing on Corbin and Strauss’s (1988, 1991) illness-trajectory framework (see table n. 3.6). The “Corbin-Strauss-Model,” as the authors (Ibidem: p. 156) stated: “[I]s a conceptual model built around the idea that chronic conditions have a course that varies and changes over time.” This model approaches the study of chronic illness – and of diabetes, in this specific case – in a diachronic perspective, it allows grasping fluctuating adherence to treatment over time, it focuses simultaneously on physical changes and on the performance of everyday life practices. Within this framework, illness is not conceived as a fixed, universal concept. It is depicted as a dynamic process, a "trajectory" (Ibidem: p. 162) that, inevitably, entails in its own definition the possibility of change and different degrees of uncertainty. Its potential course cannot be predicted in advance, it can only be reconstructed in retrospect.

For the same illness, there can be multiple "trajectories projections" (Ibidem: p. 162), by which Corbin and Strauss mean the different "visions" that characterize each individual who comes into contact with illness and its management. These are constituted by different meanings attributed to illness, its symptoms, the time and the biography of the individual. In the following table it is summarized the definition of the phases of the Illness Trajectory:

Phase	Definition
1) Pretrajectory	Before the illness course begins, the preventive phase, no signs or symptoms present;
2) Trajectory onset	Signs and symptoms are present, includes diagnostic period;
3) Crisis	Life-threatening situation requiring emergency/ critical care;
4) Acute	Active illness or complications that require hospitalization for management;
5) Stable	Illness course/symptoms controlled by regimen;
6) Unstable	Illness course/symptoms not controlled by regimen but not requiring hospitalization;
7) Downward	Progressive deterioration in physical/mental status characterized by increasing disability/symptoms;
8) Dying	Immediate weeks, days, hours preceding death.

Table 3.6: Trajectory Model's phases (Corbin & Strauss 1991: p. 1963)

When talking about their diabetes, participants may recount in retrospect the precedent phases, they talk of the actual phase in which they are living and may express their fears, or hopes, for the phases of the future. During the interview it is elicited the trajectory projection, which is often compared from the interviewees to that of others: their loved ones as well as other diabetic people, who could have different visions of the same illness.

As can be observed in the final interview guide (Appendix F), there are only few questions that consider explicitly the issue of masculinity. This is the result of a gradual restructuring of the interview guide according to fieldwork experiences. In fact if, on the one hand, the high majority of the interviewees had developed over time a self-reflection about their illness and its impact on their lives and on their selves, on the other hand this was not the case of masculinity, which in most of the cases was considered as a taken for granted, invisible and incorporated dimension. An exception to this trend was given by the cases that, more than others, deviated from dominant masculine norms: namely, non-heterosexual participants and – to a lesser extent – heterosexual participants whose body shape somehow "transgressed" hegemonic expectations of bodily strength because they were perceived as "too thin", or because they did not have sculpted muscles, or for their perceived weakness caused by illness.

Overall, masculinity was not detectable with direct questions such as: "Do you think men and women are expected to behave differently with respect to eating/expressing emotions/performing sex?" or: "Do you think diabetes had an impact on the way you perceive yourself as a man?" or, again, "how do you position yourself with respect to the stereotype of the "manly man", the one you may see in TV, which is strong, with muscles, does not have fears (etc.)?". Such questions have usually resulted in disoriented participants responding vaguely, changing the topic of conversation, often returning to a medical/biological framework and eventually talking about hormonal differences that characterize men and women and that might influence diabetes experience. As I mentioned before, the two gay participants gave rich and detailed accounts of their position as men with respect of the hegemonic ideal, and this is probably because they experienced being at odds with it since their early childhood.

Given these difficulties, I detected masculinity and its intersection with health in a more implicit way. As Catherine Kohler Riessman (1990) observed, in the process of the interview a particular self is constructed, which is determined by the presence of a listener that has specific characteristics and whose presence contributes in the creation of that specific reality. Considering the strategic uses of narratives in the presentation of self and illness, masculinity is here observed as discursively and actively performed throughout the interaction with the (female) interviewer. The original interview guide has been modified and direct questions concerning masculinity have been reduced in number. However, masculinity has been studied in diabetic men's accounts through the implicit reference to everyday life practices that endorse social expectations of manliness, the difficulty/impossibility to fulfil stereotyped ideal of masculinity because of illness consequences, or even the masculinity performance enacted within the specific context of the interview and the interaction with the female interviewer.

3.4.2 Men talking about their illness experiences

It has not been easy to find men available to talk about their illness experience, and it has not been easy to make them talk about it extensively. Overall, the majority of men were surprised – and looked quite lost - when the interview began with a very open question. Making a brief comparison with my precedent research experience, where I interviewed gay and lesbian people, I observed a substantial difference. Gay and lesbian activists are used to talk about themselves, they regularly produce autobiographical narratives for politic activities and they do so as a collective practice. Being overtly "deviant" from the heterosexual norm calls for biographical questions: when did you find out? How did you know..?

On the other hand, interviewing chronically ill men that have been mostly recruited outside the context of associations meant eliciting stories that have sometimes never been told before: very often, after the interview participants thanked me for making them "reflect" on issues that they never considered before, and expressed the desire to have more occasions to do it. Diabetic people usually talk about their diabetes experience in the context of regular check-ups with their diabetologist, and in this situation they reported being questioned only about numerical parameters (mainly glycaemia levels and glycated haemoglobin) and physical symptoms, in a compressed length of time that usually did not exceed 15 minutes.

Thus, according to the literature, the majority of men rarely talk about self-health "outside the familiar zone of fact-finding and problem-solving" (Oliffe 2009: p. 74) and, usually, they become interested in health researches only when these relate to the cause and cures of disease, but they are not used to nor interested in talking about their illness experience (Ibidem).

According to this experience, men in this research were not used to talking about themselves, nor about their illness. But after some first minutes of "warming up" all 40 men talked for, on average, 1 hour and 40 minutes each. The most illustrative case is that of Paolo, a 32 year-old man who had diabetes onset at the age of 20. The person who gave me his contact said to me: "He is a very shy and diffident person, I don't know how much you can make out of the interview with him." As a matter of facts, at the very beginning he gave me monosyllabic answers, as can be read in the *incipit* of his interview:

> **Ok. Well, I would like to ask you to tell me your story with diabetes, starting from where you prefer..**
> Um, /are questions that open?/ (Says while laughing with embarrassment)
> **I will also ask you some questions, later**
> Yeah, that would be better, because I am not very talkative actually, you know..
> **Don't worry, I'll begin. Do you remember when you found out you had diabetes?**
> Yes, in 2006. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

After few minutes, his answers progressively became richer and richer, and by the end of the interview we were eating together and this turned out to be the longest interview of the entire sample, as well as one of the richest in details and critical reflexivity.

The literature highlights the difficulty in making men talk about their health and illness, and this is often assumed to be related to their need to perform a "silent" and tough masculinity, and to distance themselves from feminized domains. According to this research experience, men actually seem willing to talk about their health and their experience of illness, and their accounts are rich and complex. The point, probably, is learning to construct a "safe space" in order to let them disclose and talk freely about their experience, their ups and their downs, their compliance and their resistance, without being judged or criticised about it.

Overall, participants seemed at ease in talking about themselves. The only topic that was more difficult to explore was that of sexuality and diabetes-related sexual difficulties: despite the fact that the majority of participants reported having experienced to some extent sexual difficulties related to diabetes, only a minority of them felt comfortable enough to talk about it extensively, and this proved that there is still some reticence in talking about sexuality issues, because if on the one hand participants provided a rich reflection on diabetes and its effects on the sense of self, this was not the case of sexuality difficulties and their effects on the (masculine) self.

3.5 Analysis of the empirical material

After receiving the consent from the interviewee[12], all interviews have been tape recorder and, afterwards, transcribed *verbatim* through the "notazione Atb" (Cardano 2011: p. 301, see Appendix E), which had the main aim of giving an account of the relevant communicative features that characterised the interactions among the interviewee and the interviewer, as well as among other possible people during the conversation, also indicating the elements of the background that are implicitly or explicitly recalled within the interview process (Ibidem).

I have analysed the interviews transcripts with the aim of exploring the meanings participants gave to their experiences with diabetes, to its impact on their "practical routines of social life" (Connell 1995: p. 92). In the very first step of the analysis it has been useful to read the fieldwork notes that I wrote after each interview, after meeting key informants or participating to events. This allowed me to have an overview of the fieldwork and to start reflecting on the impact of my presence – and my personal characteristics - on the construction of the empirical material.

The analysis followed three different stages: the segmentation of empirical material, the coding of each identified segment, and the identification of the relations among the attributes assigned to different segments (Ibidem). I coded the transcripts following concepts drawn from relevant literature, but I also allowed

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[12] In the case of traditional interviews I received a written authorisation through the signature of an informed consent, while in the case of video call I asked for and received a verbal authorisation after explaining the main aims of the research and after guaranteeing participants' privacy (see paragraph n. 8 for a more detailed explanation).

new themes to emerge. In some cases I had already began the coding while transcribing, and in this cases I have adjusted the coding in a more uniform and updated way after finishing the coding for all other interviews. After the coding process, I have compared each segment of one interview with the segment with the same coding of other interviews and observed similarities and differences among them. I then used an excel matrix in order to observe in a concise way how different dimensions interacted with each others and this was helpful for identifying emerging relations.

Subsequently, I considered participants' accounts in groups, in order to identify similarities and differences among them: initially I explored the identified relations within the most eloquent cases, when those were confirmed I extended the analysis to the other narratives. During this last part of the analysis I constantly kept in mind the common themes and looked for the major similarities and differences among them. The transcripts were re-read several times in order to identify similarities among the different groups in relation to diabetes experiences and to masculinity performances.

Finally, this dissertation is organized around three main domains that emerged as relevant from the analysis: the impact that diabetes onset has on men's everyday lives, how they "do" diabetes while "doing" masculinities in embodied everyday practices and, lastly, I focused on how they experienced one of the most common diabetes complications: namely sexual problems.

3.6 Dealing with the unexpected: a reflexive account of the research experience

The research process has been much less linear than what it may seem reading the previous paragraphs. Thinking about it while reconstructing the whole process, it looked more like a roller coaster: I alternated moments of great discouragement with others of high enthusiasm. It began with enthusiasm. In the very beginning my research project envisaged a participant observation within the context of a urology ward, and with that purpose in mind I spent a fair amount of time looking for a doctor with whom I could collaborate. At the beginning, nobody replied to my emails, nor to my phone call requests. I thus decided to "break into" the field skipping the phone/email first passage. Apparently, it seemed to have worked. Without being announced, during the visiting hours I went to urology ward of the Policlinico di Milano, I walked in with family members of the patients hospitalized, and I asked to the head nurse where I could find the referring urology doctor. At that moment I found a young postgraduate doctor, who kindly listened to me and gave me precious information about the doctors that could better fit my needs. He phoned to a senior doctor, an andrologist, a woman that in addition to being a doctor had also a specialization in psychology, and arranged a meeting for me. We met, we talked, and she agreed to work with me and to let me conduct a participant observation there. But, first, there was the need to obtain the ethical committee approval. From here, it began for me the "discouragement" phase. We then met several times in order to go through all the bureaucratic obstacles: once she found the (enormous amount) of forms to be filled, there was the need to adapt them to a qualitative, sociological research, because they were all structured for medical trials and required information that I did not have (for example, the authorization of AIFA for drug administration, that of course I would not need). I thus re-wrote my research project adapting it to this situation, prepared the informed consent form, the interview guide, my CV and filled the dozen of forms in order to get everything approved from the ethical committee. After several weeks of "bureaucratic" work and meetings in which we found a proper way to collaborate together and work on a future joint publication, we send the forms to the ethical committee. Unfortunately, we never received an answer in time.

On the other hand, I was also having some difficulties in recruiting participants from the context of associations, and that was the moment when I decided to proceed with more "creative" sampling strategies. Since from the literature it emerged that men were more likely to engage in quantitative studies rather than qualitative ones, I prepared an online questionnaire on SurveyMonkey, that would have been useless in terms of data collection, but that had the only objective of attracting prospective interviewees. In fact, at the end of the questionnaire, together with a sentence that thanked participants for their time, there was the invitation to participate in a further interview, and after that I left my contacts. I decided not to ask their email in this stage because I thought that this could lead them to think that their privacy would not have been guaranteed despite the fact that this was assured at the beginning of the questionnaire. However, this strategy did not have any success. Despite the fact that 76 men completed it, nobody contacted me afterwards. It has been very difficult to spread the link of the questionnaire: despite the fact that many on-line forums are public and open, I found out that non-diabetic "outsiders," and especially "researchers" need to have the authorization of the forum administrators that works as a "gatekeeper" (also in this phase, I have always interacted with women as virtual gatekeepers) and this has been really difficult to obtain, because many of them were skeptical and were afraid that my project could have an hidden commercial purpose.

Luckily enough, the flexibility of qualitative research allows harmonising the research methods to the contexts or the cases to which it is applied, and the fact that at the end of the research process the methodological path that has been followed was not the one that had been prefigured at the very beginning "is not considered as a distortion, a mistake that undermines the rigour of the study" (Cardano 2017: p. 163), it is part of the story of the research process, with its successes and failures.

Finally, the original research project did not distinguish among type 1 and type 2 diabetes. After conducting the first pilot interviews that involved participants affected by both pathologies, and from a closer analysis of the first empirical material, I then decided to focus only on autoimmune diabetes, because despite the fact that the term "diabetes" is the same, it actually entails, in its different forms, very diverse practices of maintaining and monitoring diabetic bodies and selves.

3.6.1 Writing myself in: reflecting on personal characteristics of the researcher and the researched and their mutual influence on the interview interaction

In this paragraph I propose a reflexive account with the main aim of exploring how the characteristics of the "observer" influenced research practices (Altheide & Johnson 1994, quoted in Cardano 2013: p. 2). As I have explained in detail in the previous paragraphs, for this research I have adopted in-depth interview as main research technique. This specific instrument allows to construct empirical material in a dynamic and interactive way, where researcher and researched co-construct knowledge interactively. For this reason, it is fundamental to give an account not only of *what* the researcher knows, but also how s/he came to know it (Reinharz 1992, quoted in Oliffe 2009) because this made it possible to the reader to have sufficient information about how the empirical material has been constructed. As Oliffe (Ibidem: p. 69) observed, the interviewer, the person asking men to talk about their health, is accountable for much more than interviewing and asking questions. Reflexivity, said Robertson (2006: p. 302), "assists with evaluating how intersubjective encounters within research influence data collection and analysis and can increase integrity, trustworthiness, rigor and thereby research quality." Many authors have highlighted the impact of the qualitative researcher's biographical profile on the research process (e.g. Cardano 2011; Oliffe 2009; Robertson 2006; Finlay 2002; Broom *et al.* 2009; Arendell 1997). My positioning as a sociologist, white, lesbian, able-bodied, non-diabetic woman from a middle-class background in the North of Italy has inevitably influenced the whole research process.

For example, it is possible that the perception of me as a doctoral student doing research in a "privileged" context such as university may have had some influence in the research process, especially with younger participants or with participants with a lower level of education, that not infrequently were confused by the assonance of "doctorate" with "doctor" and expected me to be a diabetologist. Indeed, in those cases I presented myself one more time as a sociologist and better explained what my research was about. My role as a Ph.D. student and the university room as the setting for some interviews may have been, in a way, "intimidating" and challenging to some participants and may have played some role in "biasing" their answers with social desirability. An example was Pasquale, a 47-year-old man with Diabetes LADA from the age of 30, who was very controlled during the interview, measuring words and often correcting himself hoping to be able to give "the correct answer," the one he thought I was looking for. This was even clearer when, immediately after turning off the tape recorder, he anxiously asked me: "How did I do? How were my answers if compared to that of the others? Were they correct?".

In some cases, I got the impression that instead of me they were expecting somebody older, and may be dressed and presented more "doctor-like" or "university-professor-like." Furthermore, diabetic individuals are often familiar with another kind of research, that of medical trials or medical quantitative research. When they came into contact with a young(ish), female researcher that posed them open-ended questions, they sometimes expressed surprise and it took some time to negotiate a balanced interaction.

3.6.2 Gendering the interview: the researcher and the researched as gendered subjects

Ann Oakley (1981) was one of the first feminist authors that discussed methodological problems of traditional criteria for interviewing applied to the context of female researchers interviewing women. In this paragraph, I will consider the case of the present research, where a female interviewer interviewed male participants. As Bagilhole and Cross (2006: p. 38) stated: "Gender has an effect on interview relations for what is disclosed or withheld, pursued or neglected." In this research, I considered men's illness practices as, at the same time, influencing and influenced by gender, but I also took gender "seriously" (McKee & O'Brien 1983) and considered fieldworking and researching as a dynamic set of gendered practices. Empirical material is indeed constructed following a research design developed by the researcher, but it is nevertheless created through the active participation of respondents that tell their stories through social interactions. In fact, in-depth interviews are an interactive process of co-construction of knowledge, a particular form of conversation that, as well as all other form of social interaction, is necessarily gendered.

Reflexivity in sociological research has been deeply influenced from its feminist legacy and many women have reflected on how their own gender influenced research process and outcomes (for example, Gair 2002; McCorkel & Myers, 2003). Recent work has also focussed on women interviewing male participants (i.e. Pini & Pease 2013, Broom *et. al.* 2009, Bagilhole & Cross 2006, Golombisky 2006, Pini 2005, Arendell 1997, Hearn, 1994, Green *et al*., 1993, McKee & O' Brien 1983) and, drawing from this literature, I tried to reflect on the possible implications of my gender for empirical material construction.

My gender inevitably affected the construction of empirical material. As an example, I can compare the current fieldwork experience to that of my MA thesis, where I interviewed 30 gay and lesbian people and 20 heterosexual parents with gay sons, in order to explore the construction of non-heteronormative identities. Traditional gender codes in interaction applied more frequently in the context of the present research, which has mostly included heterosexual participants. Whilst in my previous experience it has been taken for granted that I would pay the bill when meeting with participants at cafés (in both the case of gay and lesbian participants),[13] in the current study I never manage to pay even my drink or food, because in all cases –regardless of their age or social class-[14] they insisted to pay the bill as an act of chivalry. While I was examining critically my gender positioning with respect of the interview context, I tried to ask myself: what would have changed, if anything, if I were a man? If I were a man, probably I would not have received physical compliments in the middle of the interview (such as "You know that you have a nice smile?") or questions regarding my age or my marital status, as it has been actually happened frequently and as the following interview excerpt well illustrates:

> My brother-in-law went for bone marrow aspiration and they [the doctors] inadvertently punctured a vein, and then they had to operate him in order to fix the vein. So, [I have] zero confidence [in doctors], no confidence at all. How old are you?
> **Me? I am 32**
> NO WAY! Really? You don't look it at all, you look like a little girl, actually I was saying: "You must have just finished university," I said.
> **Actually I finished.. Anyway,..**
> Eh, some years ago. Are you engaged? Married?
> **Engaged, not married**
> Is him a good boyfriend, a good husband?
> **Indeed**
> I'm so glad, because many men today, when I hear: "Killed the wife, killed the girlfriend"... (Donato, 57 years old, type 2 diabetes, onset at 46 years)

This excerpt is part of a pilot interview that I conducted at the very beginning of my fieldwork; as I have already mentioned before, I subsequently focused on

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[13] While all the interviews with heterosexual parents had been conducted at their homes.
[14] I cannot compare this situation to that of homosexual participants because in both cases the interview has been conducted at the university.

autoimmune diabetes and I did not consider type 2 diabetic participants, but I nevertheless used his interview in this paragraph only with an illustrative purpose. In this case, I did not disconfirm the normative assumption of my heterosexuality, and this was mainly due to the fact that the interviewee had just talked about his wife "cheating with another woman" and the profound impact that this event has had on their relationship. Instead, I came out as lesbian with both the gay interviewees when I perceived their difficulties in talking about their affective/sexual relationships with other men: after my coming out, they appeared more relaxed and talkative, and this has been useful in order to build trust and contributed to offer a "safe environment" that facilitated participants' disclosure.

My age, together with my non-medical profession and more importantly my gender and the fact that I did not have diabetes, might have resulted in participants perceiving me as an "outsider," a naïve listener that needed to be "lectured" from them about diabetes and its characteristics. This was the case, for example, of Leonardo, a 52-year-old man who lived with diabetes since the age of 4 years and had a scientific background:

> You know, then for me it is not a big problem to correct a mistake on a vector, right? I just need to find the time to do it. But for a common housewife[15] it would be [a problem]. The point is that this thing now eeh … in giving, it doesn't only give you a result, like the glucometer, yet it gives you a curve, so it gives a trend (…) [These data] are downloadable on the computer and they can be analysed by any nerd as much as they want to. (…) Put simply, if I had to explain this to a child I would say: "Lots of not-accurate measurements are better than only 3 accurate measurements [in a day], because they give me the trend." (Leonardo, 52 years old, T1D, architect, onset at 4 years)

In this excerpt, as well as during the interview, Leonardo described his illness experience through the enactment of his know-how that derived from his technical/scientific background and resulted in his ability in understanding charts, medians, means and modes. He had a mansplaining approach to the (female) interviewer, discursively opposing his 'technological predisposition' with a

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[15] The original Italian version was "la casalinga di Voghera", which in the Italian language is an idiomatic expression that refers to an imaginary housewife, with low level of education, that lives in a little town. It is usually used in a derogatory way as a (sexist) stereotype.

supposed numerical incompetence of an imaginary housewife/child or even the interviewer, all intended as potential naïve listeners.

The context of the interview provides a rare occasion in which there is an attentive listener, who is interested and who values the interviewee's experience, and helps him reflecting upon his life through and external and different perspective. Precisely because of my personal and gender characteristics, many interviewees reported feeling more at ease in talking about sensitive issues. Even if, as I mentioned before, this was a difficult topic to tackle, the interview has also been an occasion for some participants to talk and reflect about the sexual difficulties caused by diabetes, a topic that sometimes resulted difficult to address with their doctors. Despite the fact that this happened several times, the person that more than others gave an illustrative account of this within the context of the interview was again Donato. For example this emerged when, after talking about diabetes-related sexual difficulties, he stated:

> So, I don't trust doctors. [May be] if I'll find one that I can feel I can trust, and I see that he cares about the person in front of him, just like you do… It looks like you care, may be because of the type of research you are conducting, because you allow me to express my issues to you, issues that with a woman I would have some difficulties telling, but with you it was easy. And I have never told to my doctor anything about that. (Donato, 57 years old, type 2 diabetes, onset at 46 years)

Or in the case of Leonardo: when he was talking about his "erectile dysfunction," he said: "This is the first time that I actually talk about this with someone."

I reasonably assume that the way participants told their stories in this research within the context of the interview would have been different if the interviewer were male, of if there were other male participants present in that moment in the room (for example, in the context of a focus group instead of an interview). So, in the end, "Why put sex and gender into health research?" asks to the reader Lorraine Greaves in her essay (Oliffe & Greaves 2012: p. 3). Basically, because every human being is sexed and gendered, and because these two dimensions have a significant impact on the way people engage with health practices, as well as on the way they represent their illness experiences and on the way they interact with the researcher.

3.7 Personal safety doing fieldwork: does gender matter?

Green and colleagues (1993) compared their research experience with that of other fieldworkers and concluded that the technique of in-depth interviewing, their age, their gender and that of the male interviewees, as well as the particular topic of their research (HIV-related risk behaviours), made them "particularly vulnerable to being sexually harassed during fieldwork" and that "all fieldworkers are potentially vulnerable" (Ibidem: p. 1993).

Interviewing men, often in their own house, often after recruiting them on the Internet, in a country like Italy were every three days a woman is killed by a man and violence against women is an incredibly widespread and common phenomenon (Istat 2014) made me think about my personal safety while doing fieldwork. I was aware of the risks that this entailed, and I knew that talking about sexuality issues in these circumstances could put myself at a higher risk: as Green and colleagues (1993) observed, within their research practices in different occasions this was in fact perceived by male heterosexual respondents as "provocative" and led to over or covert sexual harassment. In order to protect myself I have always phoned to participants before scheduling an appointment, and asked few informative questions about their illness with the purpose of figuring out their suitability to the study and also to get an idea of the degree of their actual interest in engaging in the research. As a general rule, I have always left a folded note on my desk with the address where I was going to conduct the interview, and asked a colleague to text me after three hours and a half from the beginning of the interview in order to check if everything was fine. Actually, everything went fine. With the exception of recurrent compliments on my physical appearance, some dinner invitations, and a participant that texted me repeatedly for some months asking me out, the majority of participants were highly engaged in the interview topics and during subsequent contacts and meetings we had after the interview we mainly talked about my research project and possible future collaborations with them, with diabetologists they knew and with associations dedicated to people with diabetes.

What I wanted to briefly highlight in this paragraph is that dealing with personal safety while doing fieldwork has – in my opinion - in turn affected the construction of the empirical material: for example, when I decided to meet some interviewees in a university room rather than their own house because I considered it a more appropriate setting, I actually missed the opportunity of interviewing with the intimacy of their own house, where I could gain a better picture of their socioeconomic profile and where I could explore the "front stage" and "backstage" (*sensu* Goffman) of their private worlds. As Sin (2003: p. 305) observed: "The intersubjective dialogic exercise through which identities and knowledge are constructed exists in a dialectic relation with the 'place' of the interview. The *in situ* nature of interviewing should not be overlooked." For example, when Pasquale, a 47 years old diabetic man, phoned and texted me several times - and also late at night - in the week before the interview, I considered it more "safe" to meet him at university, because this made me feel more at ease. When, for my MA thesis, I interviewed 50 non-heteronormative participants, I never received an unwanted physical compliment within the context of the interview, nor a persistent dinner invitation, but I instead have always felt that my role of researcher had been valued and highly recognised. As a woman, I am used to live in a patriarchal society were women are constantly undervalued and objectified, but I think it is crucial not to underestimate it, not to take it for granted, not to silence it, because gender power relations have a great impact on our everyday lives and they also silently inform our research practices. As Broom and Tovey (2009: p. 51) observed, gender can be "both resource and delimiting factor" in research practices, and it should always be considered in how it mediates the production and analysis of qualitative data (Ibidem).

3.8 Ethical considerations

Lastly, some ethical considerations. The men who participated in this research entrusted me their precious stories, and I am very grateful for their time and for the knowledge they shared with me. In order to guarantee their privacy, I resorted to different strategies: first of all, they have been informed in advance of the study's aims, on what their participation entailed, and on how their anonymity would have been protected within the whole research process. Confidentiality was assured through the use of fictitious names and through the omission of identifying details. I have tried to narrate their stories without revealing either their identities or those of individuals they mentioned during the interview. I have been very careful to omit such information while preserving the sense of their discourses and the important information that they gave to me.

An informed consent form (see Appendix D) has been signed by interviewees that I had the possibility to interview face-to-face, while an oral consent has been requested in the case of Skype interviews. Before beginning the interview, I have asked for permission to tape record it. Throughout this dissertation, for clarity reasons I have shortened the interview quotations and (partially) edited them in order to facilitate the reading, but all the *verbatim* transcriptions are stored in the original form, with all the non-verbal communication and repetitions. Unfortunately, the interviews excerpts have necessarily been translated into English, although they were originally produced in Italian. The process of translation, *ça va sans dire*, modifies -at least in part- the content of the original quotation, even if I have certainty done my best in order to maintain the original meanings and structure of the sentences.

Chapter IV

Experiencing diabetes into the everyday life

> Experiencing chronic illness means much more than feeling physical distress, acknowledging symptoms, and needing care. It includes metaphor and meaning, moral judgments and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles. (Charmaz 2000: p. 277)

> Serious illness is a loss of the "destination and map" that had previously guided the ill person's life: ill people have to learn "to think differently." (Frank 1995: p. 1)

4.1 Introduction

In Italy there has been an increase in the prevalence of diabetes, which has doubled in the last 30 years (Istat 2017). In 2017 it was estimated that over 3 million people were living with this condition, about 5% of the total population (Ibidem). Among them, approximately 90% were affected by type 2 diabetes and 10% by type 1 diabetes. Gender analysis highlighted greater diffusion of this condition in men, regardless of the type of diagnosis (Ibidem).

This study focuses on type 1 diabetes, an unpreventable autoimmune chronic illness caused by a selective destruction by the immune system of β-cells in the islet of Langerhans - located in the pancreas - that suddenly (or progressively) stop producing insulin. The aetiology and pathogenesis of this disease is still unknown, while its diagnosis is definitive and its framing and management relies predominantly on a biomedical approach.[16] Its onset usually occurs during infancy or young adulthood and, since for this autoimmune disorder there is no cure yet, people that experience it need to manage its symptoms regularly during the day

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[16] In the case of diabetes, the biomedical approach to illness is rarely questioned. In the sample analysed in this research, only one informant (partially) refused medical treatment and relied on alternative understandings of this condition.

throughout all their life. This means regular self-monitoring of blood glucose levels (with a glucose meter or a continuous glucose sensor); self-administering insulin injections several times a day (with insulin pens or by wearing an insulin pump); eating healthy food and engaging in regular physical activity (AMD SID 2018).

Since the main symptom of type 1 diabetes is high or low glycaemia (the level of glucose in blood), the principal aim of diabetes management is to maintain – every day and during the day – glycaemic levels within a range of values, in order to minimize and delay the possibility of the emergence of health complications caused by the disease (e.g. neuropathy, nephropathy, retinopathy, heart disease).

Sociological literature on chronic illness has devoted attention to the lived experience of individuals with chronic conditions (Strauss & Glaser 1984, Kleinman 1988, Bury 1982, 2001, Corbin & Strauss 1987, 1991, Kelly & Field 1996, Kelly & Dickinson 1997, Williams 1999, Williams 2003, Faircloth *et al.* 2004). Experience of diabetes have been studied in Italian researches by focusing on the point of view of fathers with diabetic children (Fornasini *et al.* 2018); on the point of view of diabetic children (Favretto *et al.* 2017, Diasio & Cozzi 2017), on the potentials and limits of the apps related to diabetes self management (Moretti & Morsello 2017) and on the experience of diabetic teenagers (Miele & Piras 2016).

International research on diabetes has focussed on the experience of men with type 1 diabetes (O'Hara *et al.* 2013); on the diabetic disruption to masculinity and sexuality in Brazilian diabetic men (Kolling 2012); on the psychological repercussions of diabetes (Watts *et al.* 2010); on the lived experience of adhering and not adhering to diabetes treatment (Ingadottir & Halldorsdottir 2008); on young women with type 1 diabetes' management (Rasmussen *et al.* 2007); on gender differences in the psychological adjustment to diabetes (Enzlin *et al.* 2002, Ponzo *et al.* 2006); on adherence and compliance to diabetes treatment (i.e. Cramer 2004, Lerman 2005); on coping strategies adopted to deal with it (i.e. Grey *et al.* 2003); on adolescents and young adults with type 1 diabetes (Schur *et al.* 1999); on personal experience of living with diabetes (i.e. Hernandez 1996, Paterson & Thorne 2000); on patterns of diet-related self-care in adult men and women with type 1 diabetes (Maclean 1991) and on coming to terms with diabetes (Kelleher 1988).

The aim of this empirical chapter is to explore how men construct new maps (Frank 1995) and new meanings of their (new) lives with autoimmune diabetes. I have asked 40 men diagnosed with this condition to talk about their experience with diabetes through in-depth interviews. Illness accounts that compose the rich empirical material collected for this research are complex life stories, where illness trajectories are retrospectively (re)constructed by organizing memories around significant events, and where events are sequentially narrated with a coherent order along participants' life trajectories.

The analysis of empirical material has highlighted a typical way of narrating diabetes stories: participants usually started their accounts from the moment just before diagnosis, when they recall having felt that "something was wrong" with their bodies. Thus, the "onset" of diabetes with its unknown ill feelings, has been identified as the first stage of illness narratives, an initial account that opened to the interviewer a window on participants' worlds. As Frank (1995: p. 164) metaphorically observed: "The illness story begins in wreckage, having lost its map and destination." In fact participants talked about an initial interruption, an on-going transformation, a corporeal change. After being shipwrecked by the storm of disease (staying with Frank's metaphor), participants recalled being affected by unfamiliar sensations of feeling unwell from which they could not recover. The prolonged unwell feelings led them to search for medical assistance: a second stage that all narratives had in common in fact concerned the description of the diagnosis process. On the one hand, giving a name to an altered body condition served as a cognitive tool that legitimized its existence and provided a solution for its destabilizing effects. On the other hand, participants recalled being told that their bodies were ineluctably failing: their immune system was progressively destroying pancreatic cells that produced insulin and they should have needed to replace this hormone with daily insulin injections for the rest of their lives in order to survive. For this reason, participants talked about diagnosis process in an ambivalent way: on the one hand, their unknown malaise had a name; but, on the other hand, they had to come to terms with its incurable consequences. The intrusiveness of diabetes symptoms and its chronicity over time often questioned the participants' sense of self and imposed them a reorganisation of their everyday life on many different levels. Coming to terms with this condition and the many ways of incorporating its manifestations and treatments into the day-to-day life characterised the third stage of diabetes narratives. Diabetes symptoms entailed the risk of losing body control, fainting, experiencing coma or even death. This implied the need to constantly monitor and discipline their bodies and acquire specific technologies of the self (Foucault 1988) in order to survive and in order not to break social expectations of bodily normativity, which in their narratives emerged as not less important.

These three stages were the "buoys" around which participants recalled having navigated their lives along with diabetes; their stories depicted storms and shipwrecks, but also successful repair works, unexpected travel directions and the acquisition of new skills in order to handle heavy sea with an unexpected ship equipment. This chapter attempts to reconstruct this adventurous journey by giving direct voice to the captains of those ships: the people that live in person with this condition, and their many and complex ways of experiencing diabetes.

4.2 Narrating the onset: from bodily signs to symptoms

The relationship with our bodies is, most of the time, unproblematic and taken for granted: they are usually a marginal presence that allows us to act freely in the material and social world (Williams 1996). They become object of our attention and problematized only when things begin to "go wrong" (Ibidem: p. 24) and when their silent presence turns into a loud interference with our routinized and predictable everyday life. In the case of diabetes, the altered body "signs" experienced in the initial phase were usually not immediately recognizable as such, and individuals experienced a progressive transition from a state of general well-being to a state of feeling sick and experiencing altered physical functioning. Those initial "warning signals" did not usually appear as a real and complete disruption of everyday life, they rather implied a disruption of the accomplishment of some basic bodily functions, whose manifestations appear 'excessive' (Favretto *et al.* 2007), such as increased hunger, increased thirst, frequent urination and fatigue. With regard to the initial phase of bodily discomfort, the majority of narratives had in common a number of bodily signs that, retrospectively, were read as incontrovertible disease indicators. It was not uncommon that participants retrospectively reported initial altered bodily sensations by defining them as 'symptoms' of diabetes, and by using terms and descriptions typical of the biomedical knowledge, a language and perspective that they progressively had incorporated over the years in their personal narrative.

All interviewees placed this initial sense of ill being (or the lack of it) in the *incipit* of their diabetes stories, organizing their accounts from what was supposed to be the chronological starting point. As Simone, a 53-year-old men that had the onset of diabetes at 4 years, stated: "We started that way. And we never finished, that's it."[17] The initial phase of the 'natural history' of diabetes experience therefore entailed a variety of altered bodily signs. They are synthetized in the table below with, in the right column, the corresponding number of occurrences:

Altered bodily signs experienced in the first stage	**n. participants**
None	5
Fatigue	9
Increased urination	21
Increased thirst	23
Vision problems	2
Psychological difficulties	4
Erectile difficulties	1

Table 4.1: Initial altered bodily signs as reported by participants

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[17] Throughout this dissertation, interviews excerpts have been used as illustrative examples. The original quotations have been translated from Italian into English. Despite the fact that the content has been reported as much similar as possible to the original form, there could be some minor differences between the two versions.

The majority of the participants reported having experienced multiple symptoms at the same time, while 5 of them did not recall being affected by any symptoms, and they rather found out they had diabetes from routine blood tests.

The experience of diabetes' onset, as recalled in participants' stories, seems to differ significantly according to the age and the life stage at which the onset occurred. On this basis, participants' narratives can be divided into three different subgroups: childhood onset (0-11 years of age at the moment of onset); adolescence and young adulthood onset (12-24 years of age at the moment of onset); and, lastly, adult onset (25 years of age and older at the moment of onset).

Childhood-onset diabetes occurred in 12 cases out of 40. The table below summarises the main information of this specific subgroup:

Name	**Age at the moment of the interview (2017-2018)**	**Age at the moment of onset**	**Diagnosis**	**n. years with diabetes**	**Education**	**Occupation**
Alessandro[18]	46	3	T1D[19]	43	High school	Employee
Cristian	43	10	T1D	33	High school	Manager
Diego	23	4	T1D	19	High school	Confectioner
Edoardo	53	3	T1D	50	High school	(Non manual) labourer
Francesco	51	3	T1D	48	High school	Employee
Ilario	28	5	T1D	23	High school	Shop assistant
Leonardo	52	4	T1D	48	Degree	Architect
Martino	34	8	T1D	26	Middle school	Farmer
Massimiliano	40	4	T1D	36	Ph.D.	Chemistry researcher
Matteo	58	5	T1D	53	High school	Retired (ex labourer)
Simone	53	9	T1D	44	High school	Tourist guide
Tommaso	53	3	T1D	50	High school	Employee

Table 4.2: Main biographical information regarding the childhood-onset subpopulation

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[18] In order to protect respondents' privacy, throughout this dissertation all identifying characteristics -such as real names, detailed occupation and cities- have been modified.

[19] In the next pages, I will use the short form 'T1D' instead of 'Type 1 Diabetes'.

The narratives of this subgroup have in common that they are not usually based on personal memories: they rather rely on information that – due to the young age at the time – have been told to participants by their parents. It is in particular the mother that emerges as parental figure to which is assigned the primary role of care since this very first stage. From participants' narratives emerged that their parents were the fist ones who recognised that something 'was wrong' with their children and who decided to search for medical help. The initial signs of a possible transformation of their bodily condition were not retrospectively signified as a complete fracture in the everyday life, but rather as a disruption concerning the fulfilment of some essential bodily functions, characterized by some 'excessive' events (Favretto *et al.* 2017: p. 109) such as increased thirst and increased urination. Consistent with the findings of Favretto and colleagues (Ibidem), the analysis of childhood-onset narratives highlighted that participants described themselves at the moment of onset as mute bodies experiencing a transformation, a change to whom they did not give any form of personal interpretation. Below, some illustrative examples:

> Obviously during the best time… ever, I mean every year more or less, we would go on holiday with my parents with our caravan, we'd go to Sardinia, (…) …and we were travelling, …during the trip, and so… mmm… it was during the night, and also during the trip, I had to keep stopping, and [go] to the toilet, etcetera, it was quite… sudden, in that moment I was weak… (…) they [the parents] talk to me about these things. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

> So, my story with diabetes starts in 1985... When I was ten, when my mother... She had figured it out. Especially at night, I used to call her, especially at night, I used to call her very often because I needed to go to the bathroom, and then immediately afterwards I needed to drink. If I'm not wrong, little time before that she had just heard on television that this symptomatology could be diabetes. Then they got me tested and in fact I had high blood sugar. And pretty soon, I think the same day or the day after, I don't remember, (…) I went to the hospital and then the day after I was hospitalized. (Cristian, 43 years old, T1D, manager, onset at 10 years)

> So I… I've been a diabetic since the age of… since I was exactly 5 years old. And initially… I urinated during the night, and so I had certain behaviours … a little strange, because I would also go during the day, it happened… often to go to the toilet, frequently, and… this was because I had too much sugar in my blood… I discovered after a little while, and… I was hospitalised straight away, in order to understand… what this anomaly was, that was observed by my parents. (Ilario, 28 years, T1D, shop assistant, onset at 5 years)

> Well, my story with diabetes started when I was 3 and a half, so back in 1968/'69. As a matter of fact, I don't remember a time before diabetes,

> because I have no memory of that time. (…) I was told that since I kept drinking and losing weight, they realised this weird thing, that I kept drinking, they even told me that I wanted to drink so badly that I would go drink the water from the dog bowl in our yard, because. So they thought of taking me to a doctor. (Tommaso, 53 years, T1D, clerk, onset at 3 years)
>
> And let's say that I'll start from, it's a long time ago, (he laughs) because I'll start from when… when it began. That is, I was 3 years old, basically, and… 1974, (…) At the time, my mom… by the way, I was very young so my mom… suffered a lot because of it, (…) basically, what happened? (…) I was losing weight, I urinated a lot and I had stopped using nappies and I started wetting myself again, so… Then they took me to hospital, and they found this thing, so nothing, then after I went to a diabetologist… (Alessandro, 46 years, T1D, employee, onset at 3 years)

The second subgroup is composed of the 10 participants who experienced diabetes onset during adolescence or young adulthood (12-24 years of age). Participants' main information is summarized in the following table:

Name	Age at the moment of interview (2017-2018)	Age at the moment of onset	Diagnosis	n. years with diabetes	Education	Occupation
Alessio	42	13	T1D	29	High school	Employee
Elio	29	24	T1D	5	High school	Shop assistant
Emanuele	43	16	T1D	27	High school	Employee
Enzo	40	15	T1D	25	Ph.D.	Physics researcher
Filippo	34	14	T1D	20	Degree	Nurse
Gioele	39	12	T1D	27	Degree	Employee
Liam	24	18	T1D	6	High school	Shop assistant
Nicola	23	13	T1D	10	Degree	University student
Pietro	27	16	T1D	11	Degree	Musician
Vito	30	23	T1D	7	High school	Employee

Table 4.3: Main biographical information regarding the adolescence and young adulthood-onset subpopulation

Compared to the first subgroup, participants that experienced diabetes onset during adolescence seem to clearly remember the ‘signs of the body’ that they retrospectively qualified – as they have been educated to – as typical symptoms of diabetes. Parents tend to disappear from these narratives and they use the first person singular in order to describe their experience. They present some elements in common with childhood-onset narratives: although it was not their parents that detected and interpreted their altered bodily functioning, parental figures are still crucial in deciding to immediately seek for medical help.

These narratives also share some commonalities with the adult-onset ones: informants have in fact direct memory of onset symptoms, and they almost immediately developed the awareness that 'something was wrong' with their bodies. When I asked them to tell me about their onset, here it is what some of them replied:

> In '93 I had my diabetes onset. I was 15 years old and I realised it like everyone else, that is, through the normal symptoms, that is… I lost weight, about 15 kilos, I ate like crazy and I started to lose weight. I would fall asleep when sitting, I wouldn't sleep, I mean, I wouldn't sleep because I kept waking up to go to the toilet. (Enzo, 40 years old, T1D, researcher, onset at 15 years)

> Well, so, mmm, maybe it's strange but I didn't have… a terrible relationship with my illness, or better, the memory… of my illness was being unwell, so blood tests and… and having started… being unwell, being sleepy, always sleeping. (Alessio, 42 years, T1D, employee, onset at 13 years)

> There were many symptoms: sleepiness, significant loss of weight, 11 kilos in a month, an increase in thirst… I drank up to, despite it was August and it was very hot, I drank up to 11 litres of water a day and… and I was so hungry, very hungry. The combination of these symptoms, hunger and weight loss, drinking a lot, made me think that somehow there was something wrong. (Emanuele, 43 years, T1D, clerk, onset at 16 years)

> So. I'll start from the beginning, when I started… mmm with this pathology, living with this, let's say, with this pathology, in 2008, … it was, well, the year of the diagnosis, in the summer of 2008, … So I was 14, 15 years old. I was born in '94, … about, yes, 14 years old. … And mmm I managed to find out because mmm I didn't feel well at all, physically, I was really tired, … then obviously the classical symptoms of polyuria, excessive thirst… (Filippo, 34 years, T1D, nurse, onset at 14 years)

> I mean, basically the day I began to live together [with my girlfriend], my / mom / (laughing) makes me take a blood test, and I found out I had it [diabetes]. / So ok / (whispering) so ok [I was] 23 years old… Well, then- no more- … more than anything it was that I had my partner, with whom I was going to live, who'd already had it [diabetes] for ten years. So it was… it was a bit of a shock at the beginning. (Vito, 30 years, T1D, employee, onset at 23 years)

The third subgroup is that of participants with an adult-onset diabetes. Compared to the other two subgroups, many participants seemed to experience milder symptoms of their condition, at least in this first stage. This is particularly true in the case of interviewees that were diagnosed with diabetes LADA (Latent Autoimmune Diabetes of Adults), also known as type 1.5 diabetes, which is an autoimmune form of adult-onset type-1-diabetes that usually has a slower development, if compared to childhood-onset type 1 diabetes. Initially, diabetes LADA can be mistakenly diagnosed and treated as type 2 diabetes,[20] but insulin is required at some point in time after the onset, just as for type 1 diabetes. As illustrated in the table n. 4, overall 11 participants were diagnosed with type 1 diabetes while 7 participants received a diagnosed of diabetes LADA:

Name	**Age at the moment of interview (2017-2018)**	**Age at the moment of onset**	**Diagnosis**	**n. years with diabetes**	**Education**	**Occupation**
Alberto	43	28	T1D	15	Degree	Employee
Amedeo	50	30	T1D	20	High school	Realtor
Damiano	58	33	T1D	25	High school	Manager
Flavio	41	36	Diabetes LADA	5	Degree	Psychoterapist
Giovanni	32	31	T1D	1	High school	Unemployed
Igor	31	28	T1D	3	High school	Shop assistant
Ivan	52	27	T1D	25	High school	Manager

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[20] It is worth recalling that type 2 diabetes is not an autoimmune disease, it rather identifies a condition where the cells of the body do not respond properly to the insulin which is –unlike type 1 diabetes-produced by pancreas.

Lucio	38	36	Diabetes LADA	2	High school	Entrepreneur
Manuel	28	16	T1D	12	High school	Precarious employee
Massimo	59	30	T1D	29	High school	Retired (ex employee)
Paolo	33	20	T1D	13	High school	Labourer
Pasquale	47	30	Diabetes LADA	17	Degree	Architect
Patrizio	44	38	Diabetes LADA	6	Degree	Employee
Raimondo	57	37	Diabetes LADA	20	High school	Retired (ex military)
Renato	56	37	T1D	19	High school	Entrepreneur
Ronaldo	46	39	Diabetes LADA	7	Degree	High school teacher
Sebastiano	33	31	T1D	2	High school	Surveyor
Silvio	50	35	Diabetes LADA	15	High school	Employee

Table 4.4: Main biographical information regarding the adult-onset subpopulation

As the following narrative excerpts highlight, in the case of diabetes LADA sometimes individuals did not experience any symptoms at all and they happen to find out about diabetes after routine blood testing. In these cases, they described themselves in this initial phase as bodies unexpectedly experiencing altered blood parameters:

> So ok, I found out I was diabetic... five years ago. And mmm I did some blood tests- I did some blood tests, and mmm... to... mmm well I mean, not

> because I wasn't feeling well, but because I had to... and I had to have an operation, so I had my blood taken for this operation, and it came out that, well, this data is a little off, and after that I went to a diabetologist, I found out I had this... this problem. I don't know since when. I think it was recent because I had lost a lot of weight... in only a few months. (Flavio, 41 years, T1D, psychotherapist, onset at 36 years)

> Well I would start from... from when, let's say... I had my onset, because I had it not when I was young, but... at the age of thirty. No- yes. Thirty... And... Now I'm 47. And I started, ok, with my diabetes... it's a bit strange. In the sense that... I am a type 2, let's say, but insulin-dependant basically since always. And I started with... and (he laughs) I started with high glycaemia, because I had to undergo an operation, and the doctor told me: "Oh well, you'll see, it'll go away, it was probably the cortisone you took", (...) I didn't even notice- I didn't- no, I didn't have symptoms, a few tests were at stake, and this high glycaemia came up, because in the mean while I had to have an operation for a herniated disc. So... after the operation I was hoping... that it all returned as it was before... how- how it was, while it never went back to how it was. And that's when the, how can I say, ordeal began. (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

Within this subgroup, some other participants described themselves at the moment of onset as bodies whose functioning were altered, but unlike the other two subgroup they often provided an initial and personal interpretation of their uncommon situation. As Lucio remarked:

> I found out I was... diabetic relatively recently... January 2016. And... I realised it because I had... or better, the symptoms I had were a... very... very frequent urination. I went to the doctor because... I was afraid I had problems with my prostate, or something like that, the doctor had me take my blood tests... the glycaemia was found to be off the scale, and my GP told me: "You have diabetes". (Lucio, diabetes LADA, 38 years, entrepreneur, onset at 36 years of age)

If compared to the other two subgroups, adult-onset participants mentioned – in addition to more common symptoms – also different altered body functions such as vision problems, urinary infection and erectile difficulties:

> Yes, I started having a bit of... I lost a lot of weight, I kept eating and lost a lot of weight. I then had a problem, a urinary infection that they kept treating. I would get better then after a while, obviously [it came back], because sugar in the urine probably caused some imbalance. When it got better and then after a while it would keep... coming back, this problem. And then the doctor, but not even my doctor, it was the... the... a, a specialist, a doctor who treated my infection... [She had me take] a blood test and the

> first thing was glucose, 350 of glycaemia... (Amedeo, 50 years, T1D, realtor, onset at 30 years)
>
> I remember 2011, or something like that, well ok. Anyway... It was the summer, and... I... I have my glasses on, and I tell you, from a distance, ...I told you: "Well, it seems a bit strange". I mean, "I- I'll have to go to the optician's (...) because my eyesight has changed". Well, I'm older... eyesight, ...it makes sense... Then, ...the- drinking, you see, ...and July, August, ...it was so hot, ...exaggeratedly. So, ...you don't even think- you don't even think about it. You don't.... then, ...in my family nobody has diabetes... I mean, my father has it, but it's type 2. (...) It was an advantage, ...that, because there was a glucose monitor in the house. That's true. (...) But, ... I'm telling you, in September, ... let's see, August, September, ...I found myself, ...I was on the floor, playing with... with my son, who is ... 5 years old now, so he was younger, ...I tried to get up, and, ... mmm I barely made it up. I mean, ... everything was spinning, I was really unwell. And my father, I called my father, I told him: "Look, measure my [blood] pression, ...because I must be really low", I... I've never had it high, 60 106, 60 116, maybe 60 120... He measures it and tells me: "Actually, it's fine", and I say: "Shit, strange, I feel really unwell". He said: "Look, I have the glucose monitor, let's measure your glycaemia" ... He measures it, and it was 575... So then I said... he told me: "Did you eat anything?" I said: "Look, normal, not- it's 4 in the afternoon, 5, I mean..." ...So I went... straight... to my doctor. (Patrizio, 44 years, diabetes LADA, clerk, onset at 38 years)
>
> ... So at that time I had a life that was... let's say, not normal. And basically... I had a very intense sexual life... you know. And basically the... I realised it [the onset of diabetes], because I changed partners often, I even had two or three partners a day, and I realised that... at a certain point I wasn't able to perform. (...)
> **This in the sense of... problems of... erection, or...?**
> Exactly. And basically I realised that... I had this erectile dysfunction... Yes. (...) ... Well, but statistically not even 10 per cent of diabetics... notices it, because in fact then others have different symptoms... And nothing. Well basically since ...we couldn't understand... the cause, also because for the kind of life I lead at the time, ...all women were the same to me, still I was popular and so... I had to serve them. And as a consequence it came up like this, you say: "But why?" I went to the doctor's and the GP made me notice I have a family history of diabetes... (Ronaldo, 46 years, diabetes LADA, high school teacher, onset at 39 years)

Often, early signs were not interpreted as synonyms of diabetes, and sometimes they were considered not to be a cause of concern at all (for example, increased thirst was initially interpreted as a consequence of a particularly hot summer). As Bury observed (1982: p. 170) in his research on individuals suffering from rheumatoid arthritis: "[C]ommon sense partially furnished the answer, particularly in terms of the immediate external environment." In the present research, only one participant was able to immediately decode the first bodily signs as indicating diabetes, this mainly because of his high familiarity with this condition.

Acknowledging that "something was wrong" was just an initial stage, a phase that marked the beginning of an important transitional process: from experiencing the world with a "silent" and taken-for-granted body, they where undergoing a change and their bodies suddenly required special attention and responded to different rules. The following phase was that of searching for an explanation of such altered body "signs" and for a name that could define the situation. To this second crucial step is devoted the next paragraph.

4.3 "You have diabetes": narrating the process of diagnosis

In our society, the most common types of illness are temporary: when we get a cold or we get flu, we might be tempted to rest at home and not go to work, maybe to take some aspirin and wait for our body to recover and then go back to normal routine. Unlike acute illness, in the case of diabetes and chronic diseases in general, symptoms are not short-lived but they are rather, by definition, long-term or even permanent (Nettleton 2006). When the symptoms persist and the body does not return to the previous state of wellbeing to which the individual was used to, the next step is to seek specialised help, usually a medical one. In the case of early-onset diabetes, the search for medical help was a decision usually undertaken and guided by parents, who noticed the initial body signs and decided to search for an explanation. Usually, it was the mother – rather than the father – who was more involved in caring activities since the beginning and it was again the mother who has been described by childhood/adolescence-onset participants as having reacted with a more emotional response to their diagnosis, as the following two excerpts highlight:

> I was 9 years old, I had just turned nine, and nothing, I was brought to hospital, urgently, and there... thank God, despite being in '74 they tested my glycaemia, now I couldn't... I couldn't tell you what level of glycaemia I had, because I didn't... I know- I only remember my mother cried, cried, cried, and cried, she had it already figured out... well, that's when we started basically. Never ended. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

> I wasn't at home, relaxed, eh, but I was also in quite a... delicate moment, when my parents realised, my mother went a little... crazy, because of this. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years).

Unlike early onset subgroup, in the case of adult-onset diabetic narratives, participants recalled that seeking for medical advice was a decision that they had always made on their own. In this subgroup there was a tendency to discursively distance themselves from the realm of the "sick" by pointing out that, before the onset, not only they were unfamiliar with blood tests or medical examinations, but they also describe their past selves as 'healthy' and not particularly prone to engaging with medical assistance. This sort of contradiction – namely, diligently searching for medical help while at the same time presenting themselves as men that "don't care" about health issues – is consistent with Robertson's findings (2009) that point to complex ways in which men understand and narrate health issues. On the one hand, this might reflect dominant discourses that depict health issues as being "women's business," implying that men are less keen on seeking for medical help and suggesting that men are strong, stoical and that they usually do not express concern for their state of health. In their words:

> I was thirty- …one, more or less (…) it's 24 years I have diabetes, since they found it. Mmm, so, weight loss, etcetera, etcetera… then I went to have my tests done, probably the first blood test of my life… (Damiano, 58 years, T1D, manager, onset at 33 years)
>
> … Ok, so the story with diabetes, it starts with some symptoms, so... in fact, I didn't even know what... I was going towards... and so I felt unwell, and weight loss, and constantly tired, especially my legs, let's say, almost immobility, not immobility, but doing... I don't know, 30 metres was already... a small struggle, and... loss of weight... I lost 5-6 kilograms over a time of 10 days, ...thirsty, thirsty, and still thirsty, so very thirsty. And need to go to the toilet, as a consequence, so the symptoms that, I imagine, you have already understood... so then I decided to have my blood test done, to... better understand, you know? Because I started to sense that something was not right. Because... luckily I've always... I've always been fine... And usually, I am one of those people who... struggles to decide- I mean, as soon as they have something, it's not as if I run... to the hospital, so yes... (Giovanni, 33 years old, T1D, unemployed, onset at 31 years)

Or as in the case of Sebastiano, a young man that waited for one month before searching for medical help:

> So about... a year ago, let's say September. In September, let's say a few months before, I started to be thirsty, ...and I urinated a lot, and ... if- I felt a bit strange, let's say, dry mouth, ... so, ... I imagined, imagined that was it [diabetes], but I didn't want to believe it... Because I had a... a significant family history [with diabetes], because I had my father, my grandma (...) so... I had the symptoms. I didn't want to believe it, I convinced myself that it couldn't be it, but then it went on for a month... even a little bit more, then... after that, mmm one night I couldn't sleep anymore, because... I would get up to urinate, and let's say the last day I went for a run, I couldn't physically make it, I am... an- an athlete, I practise a lot of sport, the last day I couldn't make it, and... the night I felt unwell, the day after I went to my mother, who had an... old people's home, and I measured my glycaemia, and I had it at 500... Then after that... and ok well, I was hospitalised straight away. (Sebastiano, 33 years, T1D, surveyor, onset at 31 years)

On the other hand, narratives are deeply informed by a moral conception of health (Williams 1998, Lupton 1993), according to which in order to present oneself as "good citizen" it is needed to show some interest in one's own health (Robertson 2009). With the purpose of complying with hegemonic ideals of masculinity, men could thus find themselves in the "don't care and should care" dilemma (Ibidem: p. 5) that consists in feeling the pressure to conform to two contradictory social expectations.

The process of diagnoses, for the majority of participants, was quite straightforward and lead to an immediate period (from one week to several months) of hospitalization. However, a minority of participants were at first misdiagnosed and their path towards an understanding of symptoms has been more tortuous, as in the case of Simone, Amedeo and Paolo:

> And... I started being unwell, ... on the day of my birthday, my birthday was- it still is the 2nd of August, and eh more or less around those days I started being unwell, we're talking about '74 though, eh, so a few years ago. And... we had our GP who claimed it was probably... it was a... a particular kind of flu, because... I began to lose some weight – not a lot, initially. But I was losing weight, I was already quite skinny, I mean. But I kept losing weight. And as the weeks went by, so it was around September, in September, second half of September, I started being really unwell... and my parents... also, and rightly so, trusting the... the doctor, but since I couldn't eat anything anymore, I couldn't have anything, they kept giving me sweetened tea, which obviously didn't- didn't help with the situation. And the tea, I obviously throw it up... after a few minutes obviously, at that point I had lost, I was already skinny as I was, I lost 10 kilos in two weeks... I was 9 years old, eh, so well, not much. At that point I was 9 years old, I had just turned nine, and nothing, I was brought to hospital, urgently. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

> ...I'll start... well, I am fifty years old, I turned fifty this year, and I've had diabetes from... about thirty years, so quite late. I struggled a bit to have it diagnosed, in the sense that I went about six months without, without managing to understand what... what I had, then obviously it was diagnosed. (Amedeo, 50 years, T1D, businessman, onset at 30 years)

> Eh, in 2006, 11 years ago. More or less, because they didn't diagnose me it [diabetes], I mean, they told me they were panic attacks. Eh, I felt unwell in general, fatigue more than anything, weakness (…) then a bit at the time, everything else came along, so… you know, losing weight, then I went to the toilet every two minutes, the usual symptoms, but more than anything I felt… pressures in the chest and… weakness. So I ate sugary things to feel better (he laughs) plus, well, then I had started taking different medications because my GP had prescribed me a few medications: benzodiazepines, antidepressants… Eh, I went on like this for a year. And then… I kind of got to the end, I was going down and… (…) Nothing, they called the ambulance and first thing they injected me glucose, just to be sure. Then (he laughs) once I got to the hospital, since I had 900 of glycaemia, they said: /"Maybe you have diabetes"/ (ironically). (Paolo, 32 years old, T1D, labourer, onset at 20 years)

In the case of Enzo, he was diagnosed and treated for type 2 diabetes, instead of type 1 diabetes, and thus he was advised to take metformin tablets (a drug that serve to reduce the amount of blood glucose released by the liver and helps enforcing how body cells respond to insulin) instead of insulin injections:

> In '93 I had my diabetic onset. I was 15 and I realised it like everyone else, that is, through the normal symptoms, I mean... I lost weight, about 15 kilos, I ate like crazy and I started to lose weight. I would fall asleep on my chair, I didn't sleep, I mean I couldn't sleep because I would keep waking up to go to the toilet... to go pee... I drank constantly... So basically I had all the symptoms. Just that I had wasted time, because my GP still mmm (he laughs) kept giving me metformin, in fact. So they'd say "Take these tablets (...)" They were wrong, and after a month, I think... so all my [islet] (...) they were going to hell. I never had the honey moon period at all, because I broke all the... mmm... islet, so nothing, then I they sent me to xxx (name of a town in the South of Italy)... I lived in the province, so I went to the hospital, in the diabetes department and I didn't get out for 15 days, that is, because they measured my first glycaemia, it was 463, I remember this number very well, so they hospitalised me immediately, they told me: "You're not going anywhere." I stayed there 15 days. (Enzo, 40 years old, T1D, researcher, onset at 15 years)

Difficulties in receiving a correct diagnosis have been found in most of participants affected from diabetes LADA, who were initially diagnosed with type

2 diabetes and treated as such, this way postponing the moment of finding a proper solution for their ill-being, as Lucio recalls:

> I went to the doctor because... I was afraid I had problems with my prostate, or something like that, the doctor had me take my blood tests... the glycaemia was found to be off the scale, and my GP told me: "You have diabetes". They immediately prescribed... hypothesising it was a type 2 diabetes... metformin tablets, to control my glycaemia and told me to buy... a device to monitor my blood sugar, for self-monitoring... I bought it straight away... then, at the same time I... started to... book specialist examination, as requested by my GP, and... I immediately noticed that, for me, metformin had a few... side effects, especially in the stomach, digestion... initially, I struggled to manage... to manage my illness, my glycaemia, my meals. (...) And... I insisted to see a (...) diabetologist... and... let's say that she prescribed me another... another... blood test, to... detect antibodies, to exclude a type LADA diabetes... She had told me already that she was pretty sure mine was a type 2... In fact, after... about three months, very late, since it was a rather long analysis to perform... And the result came back positive. So actually I wasn't a type 2 diabetes- I'm not a type 2 diabetes, but a LADA diabetes. So autoimmune. It's a sort of type 1 diabetes, that... occurs... later in life. (Lucio, 28 years, diabetes LADA, entrepreneur, onset at 36 years)

Receiving a diagnosis might entail contrasting feelings. On the one hand, it is often experienced as a relief, because naming an unknown and unpleasant condition helps indeed to identify a possible solution for altered body functioning. In this respect, Pietro gives an account of his positive reaction to diagnosis:

> If I think about it now that 10 years have passed, to be honest I romantically see it as an almost positive period. Because, anyway, this was an improvement. One month- one month before… Ok, I won't tell you, because everybody else sure has already told you...
> **No, please, tell me**
> Still, it [diabetes] is really annoying. Because you feel so much sick that... I mean, it isn't normal to hurt so much. Because you hurt everywhere, you've got sore feet, your hands hurt, your mouth, and… the thirst... then you don't see anything, because I didn't see anything. My dioptres have changed. With the fact that this glycaemia has been up to 6-700 for a very long time... Then I was thirsty, so what did I do? I bought Coca-Cola and put it in the freezer... Or otherwise I ate an ice cream. And I was even thirstier, and I didn't understand why, I mean. (…) [The diagnosis was] a major improvement. (Pietro, 27 years old, T1D, musician, onset at 16 years)

But, on the other hand, the communication of a diagnosis always brings with it some sort of ambivalence: first of all, diagnosis is a cognitive tool that allows to give a name (Good 1999) to an unknown bodily discomfort and to act accordingly in order to cope with it and to feel better. In fact, diagnosis is a cornerstone for the practice of medicine and for the subsequent (re)construction of the new self. The act of naming a disease "represents the time and location where medical professionals and other parties determine the existence and legitimacy of a condition" (Brown 1995: p. 38), and in this case it marks the beginning of the "diabetic career."

On the other hand, the newly diagnosed is suddenly catapulted into a new and unfamiliar world where, most importantly, he comes to know that initial bodily signs and unwell feelings that he experienced where not transitory symptoms of an acute illness, and that there is no definite cure for his condition, which instead can only be monitored and managed.

> [There was] an initial... disorientation, because at the beginning you think that... not knowing the pathology, that it could be cured. Then after... a while, (…) I realised that it wasn't something that could be cured, so I had to... manage it, somehow. (Renato, 56 years, T1D, entrepreneur, onset at 30 years)

The feeling of ambivalence regarding the diagnosis process clearly appears in Igor's narrative:

> And mmm well, so they told me: "You have diabetes" and they hospitalised me. I was... very, very surprised and... I don't mean: "I was disappointed," because I knew little, very little, maybe nothing of the problem. But still it was better than I thought because I, also considering the problem with my eyes, I thought it could be anything... I didn't know. But on the other hand, I knew it was an illness that would live with me for the rest of my life, so... I took it... well and badly. It depends on how I looked at it. (Igor, 31 years, shop assistant, onset at 28 years)

After searching for medical help, the diagnosis process usually continued with a – shorter or longer – period of hospitalization, where participants where socialized to medical knowledge. This was a crucial moment for at least two main reasons. Firstly, this was the context where individuals usually received the official diagnosis and their initial "unwell feelings" were "translated" into specific symptoms of a particular disease. Secondly, the time spent in the hospital allowed diabetic people understanding the meanings assigned from the biomedical knowledge to their symptoms in order to recognise them in time and to treat them properly in the future, so as to prevent health complications and blood sugar fluctuations. The hospitalization period and the socialization to diabetes self-management was narrated as quite an homogeneous process with respect to the different socioeconomic backgrounds of participants: in fact, all respondents reported referring to public hospital and being taught the same standardised procedures of self-monitoring and self-managing illness. In the majority of the narratives, the hospitalization is represented as the starting point of a "new life." As Diego, a 23 years old men that was diagnosed at 4 years, stated: "That is when the, let's say, the adventure began, in the hospital. Let's call it an adventure..."

An analysis of the narratives revealed that during the days – or months – that participants spent in the hospital, an actual transition of status took place – more or less consciously – in which the 'diabetic identity' began to be acquired. A new language was learnt, as well as the use of medical devices designed to monitor one's own body's parameters. This moment could be thought of as an "initiation" and as the learning of bodily rituals that would be repeated everyday, for the rest of their lives.

> There was a whole procedure: they gave me - they told me what to do, they gave me the device for [measuring] glycaemia, and all... the rest, so from that moment, basically, I was initiated to... to diabetes, yes. (Giovanni, 32 years, T1D, unemployed, onset at 31 years)

We can observe this moment of transition more closely through the words of Cristian, a 43-year-old man, who at the moment of the interview was married, had a son and worked as a manager for a big company in Central Italy. At the age of 10, his mother noticed that his thirst was increased and that he went often to the toilet, especially during the night. Being afraid that this could be due to diabetes, she took him to the hospital, where they performed the necessary tests and, since they found very high sugar levels in his blood, he was hospitalised. This is where a very detailed narrative began: Cristian remembers that he went to a special hospital, a "hospital by the sea," which had a section dedicated to diabetic patients. He recalls that, before becoming a separate diabetes department, this was known as "diabetario,"[21] namely a place run from nuns where diabetic children were accommodated, often for years. When Cristian was there, the "diabetario" did not exist anymore, but somehow the atmosphere of an isolated reality – of a "special department," as he called it – had persisted over time. As he described it, in this place parents, doctors and children interacted with each other in order to let the newly diagnosed learn to live with their new bodily condition:

> It was a special department. In the sense that... well, the whole hospital was special. Because... well, first of all, it was a hospital by the sea, which is something... something very characteristic. And moreover with access to the beach. (...) ...So, already a particular situation. And at the time, that hospital, had accommodation for children's parents, especially for diabetic children, because they were the ones who needed to have their parents nearby, especially during the beginning of their hospitalisation. (...) There were three doctors (...) and all the nurses of the department, some [of whom] were diabetic. This was another characteristic, (...) and they taught an approach, aimed at self-management, and at teaching children, and their moms, to self-manage themselves. (Cristian, 43 years old, T1D, manager, onset at 10 years)

In his story, the hospital almost appears like a magical place, a place where the doctor-patient relationship seems less asymmetrical and where also gender and generational boundaries were put aside in favour of living together – albeit momentarily – among different subjectivities. In this context, the mothers were described as the protagonists of the care role towards their children (Lupton 2012, Favretto *et al.* 2017) and they also learnt how to use the medical devices that served for managing their children's disease. In an almost surreal context, they were described to experiment new recipes suitable for diabetic children by cooking side-by-side with the healthcare personnel:

> There was a great degree of spontaneity, within this department, ... it was a department in which there were children but also adults, male and female, all together. So yes... let's say that it was set up as... the department seemed like an actual community, ... I mean, in those 15 days, in that week you were there, and you lived, ... with the doctors, nurses, and adults, boys, girls, mothers, ... and the first 15 days they had a school set up. Every afternoon, that lasted from two to four hours per session, in which they explained everything, from A to Z, (...) Then, ... there was the attitude of... of all these people I had around me, the doctors, once the lesson was over, the lesson

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[21] The term "diabetario" in Italian language reminds that of "lebbrosario" (Leper colony in English), a place where lepers where placed in order to protect society from their disease.

> could have been of a scientific kind, in which they would explain some things in more detail, but it could also simply be about food, or... the explanation of a few recipes, ... I remember one of the nice things that... and let's say that I was immediately fascinated, ... was that as the lesson ended, the doctor who had led the lesson would go into the kitchen with the moms and they would prepare a snack, ... Maybe they- they would stay there and maybe make dessert, or... you know, making sandwiches, or fruit salad, or things, eh, ... at the time there were few sweeteners that could be used instead of sugar. So, ... if you wanted to make a bundt cake, you had to be careful, otherwise something like chewing gum would come out, instead of a bunt cake... So, they would go to the kitchen, the doctors, actually also supported by the nurses, ... but they were the ones who... who taught... but, ... more than teaching the recipes, they taught the behaviour- the attitude, the behaviour, the search for alternative... ways, that however, ... would be viable, ... and let's say, also similar enough, ... to the life that all people lead. (Cristian, 43 years old, T1D, manager, onset at 10 years)

In his account, sharing spaces with other diabetic adults affected by diabetes-related complications seemed, retrospectively, to have worked as a future reminder to maintain a high adherence to treatment, an image engraved in memory, like a constant warning of the possible consequences that could occur if he did not take care of himself:

> You could be hospitalised with forty-year-old people, I mean... What was the point? That many of those who didn't accepted the illness and didn't take care of themselves were in the department, ... with, let's say... I can't think of how to say it. ... with consequences, due to the fact that they weren't taking care of themselves, that they didn't take enough care of themselves, that they had certain lifestyles that were... inadequate. Overweight, some blind, ... or maybe they only saw shadows, ... others might be missing a piece of a limb. Yes, because if ... if you didn't take care of yourself like you should have, ... these were the complications. Well, this induced me, ... immediately, an mmm an idea, ... in the sense that I didn't want to end up like that. (...) But in fact, living in this situation, with all these incentives and with the comparison with what it could have happened to me, if I'd have behaved in a certain way, ... was really good for me, because on the other hand, there also were all the positive comparisons, you know? So you learnt from all those who behaved well, you learnt from the doctors, the nurses, ... but in a way you also learnt from those who didn't behave well. (Cristian, 43 years old, T1D, manager, onset at 10 years)

Getting to know other people that were affected by the same condition was a recurring theme within the narratives, and it also seemed to be an important opportunity for the (re)construction of a (diabetic) self. Another illustrative example is that of Matteo, a widower and a retired man who was diagnosed with diabetes at the age of 5. Matteo grew up in a working class context, his mother used to take care of him and she used to try – often in vain – to take shots of insulin to him through the equipment used at the time: two daily injections administered through a glass syringe, that needed to be boiled and strained each time. The stigma attached to illness and to injection practices made him refuse insulin treatment for many years. Although the hospitalisation in the case of Matteo did not occur at the time of his onset, but rather after a few years where had been mismanaging his condition, this two-years period of hospitalisation in a "diabetario" has been crucial for his construction of a (diabetic) self. His account expressed more clearly than others how the time spent in this institution with other diabetic peers could provide the opportunity to integrate the illness within his masculine identity through the interaction with (non) diabetic others.[22] This, as will be further explored in the next empirical chapter, reminds the concept of community of practices (Wenger 1998), where people sharing the same interest (in this case, diabetes self-management), become progressively members of a community where the "novice" diabetic individual learns from experienced diabetic others how to deal with this condition. After a few years in which he had frequently avoided insulin treatment and after his mother became sick and could not take care of him anymore, Matteo was forced to become a guest of the 'diabetario' when he was 10 years of age:

> My friends made fun of me because my mom would run after me with a syringe, ... something like that, then I got home, I remember it well, and I told my mom: "No, ... I won't take insulin anymore". Poor thing, now you know, ... who knows what she went through, (he laughs) (...) There, well, "I won't do it, I don't want it done", she must have run after me all day, ... and-and I woke up the following day in hospital, in a coma, ... I open my eyes, I remember, ... I open my eyes and I say: "What am I doing here?" (He laughs)
>
> **So this... happened because you had decided to, let's say...**
>
> I didn't want to take my insulin. (...) So... Then, I... then let's say that I didn't take care of it, I did nothing whatsoever until thirty years of age. Except, yes, ... this is something that maybe... by now... few of us exist yet: at the time only- since my mom then was ill with a tumour, unfortunately, you know? So then, at the time, who managed diabetes, there were only two centres in the whole of Italy. (...) Yes, ... it was called "diabetario", more

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[22] In other cases, also the experience of "camps" proposed to diabetic teenagers served the same purpose.

> than a... diabetes centre, it was a real leper colony! (He laughs) (Matteo, 58 years old, T1D, retired, onset at 5 years)

In his narrative, the "diabetario" became the opportunity for a learning process in an alternative way to the more conventional path of non-diabetic peers: the institution in which he was staying was very far from his home town and this implied that at the young age of 10 he was forced to move away from the world he was familiar with. In this unexpected and new context, his social identity was influenced by different experiences: on the one hand, in the context of middle school, attended by both non-diabetic students and by some who, like him, were hosted in the diabetario, his identity was "spoiled" by the stigma attached to illness. On the other hand, the immersive experience of the "diabetario," where he ended up living for years, provided him with an opportunity for living in a situation where being affected by diabetes was actually considered as the "normality," since also everybody else was. In terms of identity construction, he recalled performing a stigmatised and marginalised identity within non-diabetic contexts, while at the same time enacting provocative and resisting performances within the context of the "diabetario" (e.g. revolting against the tough regime imposed by the nuns, trying to evade from the facility, becoming a "gang leader" with other diabetic peers). In his words:

> **And- and how did [the diabetario] work? Do you remember?**
> Oh, yes, yes, holy crap. Yes, because it was my first, ... how can I say? My first... my first trauma. Not because of diabetes, but- ... just going there, (he laughs) (...) I finished the last two years of middle school. There. And that time, yes... I basically was a boy who was always out and about, a little... a little naughty, even there, with the nuns, ... and you know, you couldn't eat, you couldn't- you had to eat the- the traps they wanted you to, so and so, ... after a year, I told the doctors: "I'm not staying here". (He laughs) I took... I warned a friend of mine, this was the damn problem, I remember... And I told him: "Look, I'm not staying here, it's no place for me. I'm going home" ... And I went to catch the bus, (he laughs) the only thing is, I had told him, and they busted me. In short, they caught me. There... Well, anyway, it's been... it was around 1970, about that time, you know? And this was the diabetario. More like a leper colony, than a diabetario, because they didn't understand a damn thing about diabetes.... You did your glycosuria [he probably means the urine glucose test] once a month, just about, you know... oh but we were amazing because then... It was obvious that if... you took insulin once a day, by then you know how treatment is, no... It's obvious that if they find that your glycaemia is high, I mean, not even glycaemia, glycosuria, because there were no devices, they tested it in hospital and

> that's it, ... and if they found that it was high, then they gave you more insulin, or twice a day, no? So, since we were smart, we watered- watered down our... our urine (he laughs) (...) And- you know, since- ... thirteen years of age, I did the third- the third- second and third year of middle school. / More or less. / (whispering)
> **So how long did you stay there?**
> Two years. It was only... school you did. You know, I mean... Obviously we were "the ones from the diabetario," I mean, it wasn't a good... "Poor things," you know... something like that, more or less. (...) After a while, since I wanted to get away from there, I became the gang leader, I mean. It was a... also a... to see it positively, it was, how can I say... A good ... like military service was once seen, a good thing of life, you feel a... good, ... it teaches you to live these things. There. (Matteo, 58 years old, retired, onset at 5 years)

Many of the narrative segments about the hospitalisation period could be read with a greimasian actantial perspective, as a sort of formative process in which, through the diabetes onset, the diabetic "subject" was separated from an initial condition of wellbeing. Subsequently, he was asked to control and manage this situation, in order to reach the lost balance and wellbeing, considered as his "objects" of value. The diabetologists were the main "senders" of the action and the nurses (together with the parents, in the case of children) were the main "helpers," that is to say, those who help accomplish the action (compliance to treatment) by providing the right tools, support and information.[23] Reaching the object has usually required an obstacle course, where the main opponent – diabetes and its glycaemic swings – interfered in reaching the objective. The majority of interviewees had an initial period of hospitalisation, especially those with a childhood or adolescence onset. It was not something they all remembered in detail, often the ones who were the youngest only remembered through second-hand stories told by their parents, which they hardly mention in their narrative.

For some, the experience of hospitalisation was very different from the idealised story of Cristian, it was rather concentrated in a short period of time and the necessary information were limited to the "basics":

> My mother would tell me that it was what we unfortunately still hear about,

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[23] Cardano (2007, 2011) used the greimasian model as a tool to segment illness narratives. In this study, it was only used for illustrative purposes since not all the narratives collected provided the description of the hospitalisation period and, among those who did, only some of them could be segmented with the actantial model.

> like: “That’s your son, this is insulin, that’s the exit.” (Leonardo, 52 years, T1D, architect, onset at 4 years)
>
> Well, when they teach you how to do the injection, that’s wonderful... To me, a rough nurse -and I mean really rough- she brought me down to an examination room, ... she said: / “Syringe, needle, screw, unscrew, you do. Do it!” / (In an authoritarian tone) (Pietro, 27 years old, T1D, musician, onset at 16 years)

In other cases, the days spent in hospital and the often painful and violent medicalization of the body caused real traumas, and those stories where very different from the gradual learning processes described by those who entered, in a way, the diabetic “community of practices” as previously mentioned. For example, Francesco recalled:

> Look, the first memory [of diabetes] I have, maybe has influenced me, ... it still influences me now, when I have my blood tests, because I tend to faint. Because... I remember that I was surrounded by doctors and nurses who kept me still on a... bed, to cut me, ... to get to my vein, I don’t know whether it was to rehydrate or to administer insulin... Well, as a matter of fact, it was... rather traumatising... Finding myself held down by many adults, on a bed, to cut my arm, and then I had- I still have a scar on my arm... I mean. So even now, despite... and also the day after tomorrow I’m going up to xxxxxx (city name) to have a blood test. Me, I have my blood tests lying down, because I’ve sometimes tried to have them done while sitting, but... /half the time I faint/ (laughing). (Francesco, 51 years old, employee, T1D, onset at 3 years)

Even before participants realised what “being diabetic” really meant for them, in the majority of cases they reported undergoing to repeated intervention on their bodies by health care professionals (such as drips or blood tests) and having to learn themselves how to handle medical instruments such as insulin pens (or glass syringes, in the case of elder informants), glucose monitors etcetera. The process of incorporation of illness (Csordas 1994) progressed slowly: they learnt how to obtain a blood drop from their fingertip (by piercing it and putting the blood drop on the lancet of the glucose meter), how to measure glycaemia, how to interpret the measurements, how to keep track of them in a daily diary and how to inject insulin according to the blood glucose level observed. They would have to perform this self-management “rituals” several times a day, every day, for the rest of their life. In this initial stage diabetes was mainly framed within their narratives in a biomedical way: interviewees talked about symptoms, treatments, glycaemia measurements, glycated haemoglobin (that is a blood test that reveals the three-month average of plasma glucose concentration) and the necessity of acquiring medical skills. As Manuel described:

> I would start from... the onset, so January 2007. So... I had to have an operation (...) a routine operation. So... I had my tests done, the usual tests, ... and the value turned out to be changed, so the next day I went... straight to hospital, hospitalised for one week, ... obviously, immediately with a control of glycaemia, then with the tests ... constant glycaemia tests, ... and then, the insulin... pen (...) ... then... I started... I got to the hospital with 446 [glycaemia], and slowly... in about one week, we managed to calibrate it, ... let's say, in a... in the correct range. (...)
> **And what do you remember of this week?**
> I remember the... well, the first memory I have is surely this... little device, I called it, that is the... for measuring glycaemia, and the first... the first... injection I did, with... me- moreover, ... they had shown me once, the second time I already... /vial, needle/ (he mimes the act) ... actually on my own, (he laughs). As if I had been a nurse for years... So I learnt straight away... (Manuel, 28 years old, T1D, employee, onset at 16 years)

In this context, participants referred learning how to deal with sudden bodily malfunctions and the risks that this entailed: conditions such as glycaemic swings forced them to compensate with the use of treatment and medical devices:

> [There's the need] to take care of yourself 24 hours a day. That is, doing the work of your pancreas, full time. (Alberto, 43 years old, T1D, employee, onset at 28 years)

This is how the beginning of life with diabetes has been narrated in the accounts collected. The challenges related to the necessity of (re)building the self and the everyday life, as a matter of fact, continued after walking out of this safe environment, the hospital, where somehow the identity of "ill person" was institutionalised, taken for granted and built on repetitive and shared rituals. The challenges of diabetes multiplied as soon as living with the illness was experienced also in the contexts where participants used to live "before" diabetes. At the end of the diagnosis process, a transformation and adjustment of the everyday life was needed, as well as the (re)construction of the personal and social identity and the relational changes that concern both the diabetic individuals and the significant others. A number of participants echoed Elio, who said: “And then, /this new life begun!/ (Smiling).” And it is to this “new life” and to its many possibilities that the following paragraph is entirely dedicated.

4.4 Coming to terms with diabetes in the everyday life

What does it mean to live with autoimmune diabetes? How does it impact on the everyday life? How do men manage their diabetic bodies in order to maintain or (re)construct social relations? How did diabetes affect their embodied sense of self? In this section of the chapter, I propose an analysis of biographical accounts of diabetes experiences by “examining how the everyday world is systematically subverted or ‘unmade’” (Good 1994: p. 124) by the onset of this chronic condition. Medical knowledge and practices usually focus on the specific dimension of *disease,* namely the altered physiological state that causes actual or potential alteration of physical capacities (Twaddle 1994, Maturo 2016). Drawing from sociological and anthropological alternative perspectives on chronic illness, the analysis of empirical material took into consideration both the dimensions of illness – the personal experience – and sickness – the way other people interpret this condition. The diabetic body is here considered not merely as a physical object or physiological state but rather as an essential part of the self. The body is in fact “the very ground of subjectivity or experience in the world” (Good 1994: p. 116) and diabetes narratives open to the possibility of analysing how diabetic bodies act as real agent for experiencing life. The role of the body in the construction of the self and in social interactions is crucial. We experience the world through our body, and its (mal)functioning influences the concrete possibility to structure and live our everyday life. Biological changes such as the onset of a chronic condition can alter the flow of daily living and can complicate social relationships, as well as shaping the construction of social and personal identities. But individuals are not passive recipient of bodily (im)possibilities, they rather actively contribute in shaping their bodies and in assigning different meanings to the same conditions. Whilst subjects are not entirely defined from their mere materiality, it is indeed important to note that only some of all the variables that compose their self construction are accessible to an active projectuality of their bodies (Sassatelli & Ghigi 2018, Bourdieu 1984). In fact, on the one hand, individuals shape their bodies through a process of reflexive individualisation, where subjective individuality emerges as a value principle; on the other hand, as Bourdieu highlighted, within the everyday life the embodied construction of subjectivities is somehow an unreflexive process that is influenced by different power relations in which individuals are embedded (Ibidem).

Bodies, in each time and culture, are subjected to specific systems of social rules and meanings, and the work of Erving Goffman (1959, 1963) in this regard has been illuminating with respect to the impact that illness could have on the sense of self and on social interactions. Contemporary Western culture emphasizes youth, beauty and healthiness, most of the time ignoring aging, disability, chronic illness and death, that have all been mostly precluded from the everyday life and have been increasingly regulated and medicalized (Turner 1998). The possible disruption brought from the onset of a chronic illness reveals much about the tacit and taken-for-granted ways in which people engage in social interactions and structure their everyday life (Gabe *et al.* 2004). Overall, in our contemporary cultural context illness is a potentially discrediting attribute that constitutes a discrepancy among the individual's virtual social identity and his actual social identity (Goffman 1963) and the greater this discrepancy is, the more the attribute in question is stereotyped and stigmatising. All interviewees reported having experienced some degree of stigma, mainly because diabetes is frequently taught to be a condition caused by physical inactivity or overindulgent food habits (that actually do not play any role in the onset of autoimmune diabetes). Thus, often participants referred being blamed for their own disease. For example, Tommaso said:

> Today people still think that diabetes is that illness that occurs to people that eat too much, to those that do not engage in physical activity, to those that eat too many sweets, because basically they identify diabetes with type 2 diabetes. Not type 1 diabetes. In fact, I went to some meetings of blind people association at xxxxx (city name in the North of Italy) and there was a psychologist, and during the group discussion I said I had diabetes and she said: "Why diabetes? You eat too much, too many candies." So, I explained, I said: "No, that one can occur, but it's type 2 [diabetes], but that doesn't necessarily mean that this is the reason why. Mine is type 1, it's an autoimmune diabetes and therefore the antibodies –nobody knows why- got angry and ate pancreatic cells." (Tommaso, 53 years, T1D, employee, onset at 3 years)

Diabetes is, most of the times, an invisible condition. Hence, many participants reported that often people around them did not fully understand what living with this condition really entailed. Often hypoglycaemia episodes could occur during the night, keeping them awake and suffering, and the day after their fatigue has been confused with indolence or with a hangover:

> **Do you think that people that don't have diabetes understand what it is like to have it?**
> I don't think so. They don't understand it, in my experience. Because when you say in the morning that you woke up tired, they immediately reply: "You should have gone earlier to bed yesterday night". (…) It doesn't matter if your fatigue is the result of hyperglycaemia or hypoglycaemia. And you wake in the morning that you are (he laugh) messed up, you are tired, you know. But, as I said, at first people say (…): "You should have gone earlier to bed yesterday night" (He laugh) people say: "You shouldn't have partied too much, you should have drunk less" (…) without knowing that actually you have your problems, you had a rough night. (…)
> **And when you tell somebody that you have diabetes, which are the stereotypes that you had to deal with? I mean, what do people think when you say you have diabetes?**
> (He laughs) "Well, you don't look sick!" (He laughs) (…) Young people say: "Well, you don't look sick!". Older people, they say: "Who knows what you have eaten when you were young!" Because they think about type 2 diabetes. But, let's say, people my age, they say: "But you don't look sick, this is not true." And instead… Unfortunately (he laugh) unfortunately there is. (Martino, 34 years, T1D, farmer, onset at 8 years)

Along with victim-shaming, the practice of injecting insulin also may convey potentially discrediting information because of its associations with drugs addiction and heroin injections. For example, Gioele recalled:

> I started injecting [insulin] with syringes, you know, finding oneself (…) suddenly holding a needle is not nice even for me, besides, being mocked, being called "junkie," things like that. (…) Then, there have been some unfortunate episodes experienced in restaurants… I was in a restaurant, in order to eat something with a friend, and I went to the bathroom to get an insulin shot before eating, with the syringe. Since the toilets where all taken, I've done it next to the sinks. A man probably walked next to me while I was performing the thing [injection] and after that he went to the restaurant owner and he said that there was a drug-addict in the bathroom and... Basically, they wanted to kick us out from the restaurant (Gioele, 39 years, T1D, employee, onset at 12 years)

Indeed, diabetic individuals are not only "diabetic" people; they are carriers of multiple and shifting identities. They, as everybody else, are placed in dense networks of social relationships and complex social hierarchies that are the result of the possession (or the lack of it) of determined social classifiers. By trying to observe social world through intersectional lens, I have sought to let other forms of oppression and other minority statuses emerge during the interviews, giving them space and voice and trying to analyse how these dimensions could be intertwined with illness issues. Two interviewees defined themselves as homosexuals, and they compared the stigma attached to homosexuality and that attached to illness, producing different discourses: when I asked to Elio, a 29 years old man that has been living with diabetes for 5 years, if it was easier for him to "come out" as gay or as diabetic, he replied:

> It would depend from the context, because… I think it's easier to say that I am gay than diabetic. I mean, I guess… the first thing that I say, it's that I'm gay. Then I also say that I am a diabetic (he laughs). But… May be this could be due to the fact that some people see from the outside that I'm gay. Anyway, I'm not a crazy queen, but I see that people notice it. (Elio, 29 years, T1D, shop assistant, onset at 24 years)

To the same question, Amedeo – a 50 years old man that had diabetes onset at the age of 30 – replied differently:

> Absolutely that I am diabetic.
> **So their reactions are more... I mean, less...**
> Yes. I have to say, their reactions are more… calm, but, I mean, with people that I meet for the first time, I would not say: "I am diabetic and homosexual" (he laughs) neither the first one, nor the second one it's something that I would say, obviously. But it can happen that I say it, in both cases. Let's say that in the second case I prefer that it comes up as it happened that it came up [in this interview], spontaneously. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

Autoimmune diabetes is usually an invisible condition, and the narratives collected suggested that it could became "visible" in different ways: it could be actively disclosed by individuals, or it could unintentionally emerge because of a hypoglycaemic episode, because of the use of specific medical devices for its monitoring and treatment, or even because of work/sport mandatory medical inspections. The visibility of a diabetic body transgresses the normative expectations of "healthiness" that inform and orient social relations and, therefore, it increases the vulnerability of the subject to the scrutiny and judgement of others. With the aim of going back to their everyday life, their occupation and their social relations, participants disciplined their bodies and re-negotiated social routines according to their desires, needs and actual possibilities.

All participants experienced – although in different ways – some degree of stigma because of diabetes and all of them reported alternating disclosure to concealment strategies and having the impression that the information about autoimmune diabetes where scarce and inadequate and usually non-diabetic people underestimated the impact of this condition in their everyday life, or even mistook their condition for the more common type 2 diabetes, which is more discrediting because it is usually caused by a combination of genetics and lifestyle factors.

In addition to stigma, autoimmune diabetes may affect everyday life in many ways: the body changes due to hypo/hyperglycaemia, to diabetes health complications, the need to dedicate time during the day to diabetes self-management, the constant risk of ketoacidosis, coma or even of death, and the uncertainty that all this projects to the present and the future. I have thus analysed how participants discursively constructed their "diabetic careers," how they talked about adapting to new body conditions and how their did (or did not) normalize it into their everyday life.

According to the empirical material collected, social routine appeared, in some cases, profoundly disrupted, in other cases only temporary altered, while in others cases the narrative proposed by participants depicted an almost unchanged situation, were diabetes was incorporated into the everyday life without altering it in a substantial way. I have analysed how diabetes has impacted and has been incorporated into the everyday life of participants by looking at how they talked about it in terms of disruption, fluctuation or continuity of their social routine over lifetime. The disruptiveness of illness on participants' routine seemed to depend mainly on the age at the moment of the onset, the severity of the disease, the social context participants were living in, the degree of (physical and psychological) demand of their occupation, and the amount of control they had for scheduling their time around their needs. I draw on Karasek and colleagues' (1981) job strain model (reported below in Figure n. 4.1) as an illustrative tool for taking into account the environmental characteristics that influenced participants' lived experience of diabetes:

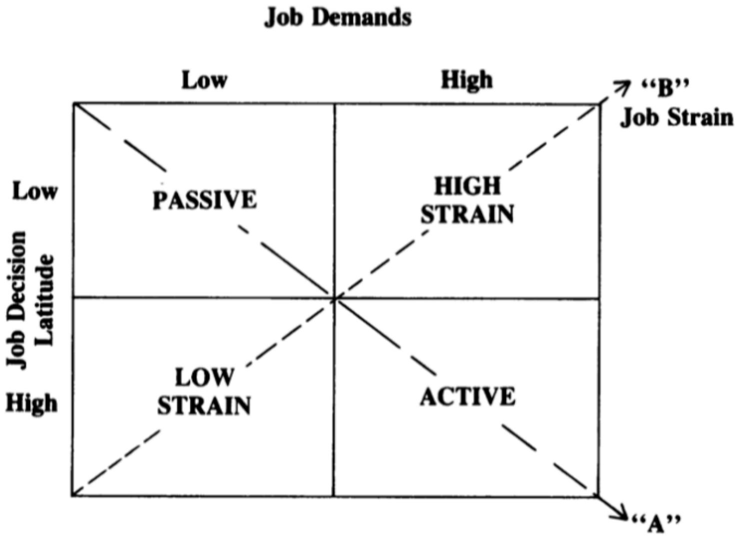

Figure 4.1: Job Strain Model (Karasek *et al.* 1981: p. 695)

Based on the dominant discourses participants produced around their everyday life – in terms of biographical disruption, fluctuation or continuity – three narrative 'forms' were identified, whose main patterns are exemplified in the figures below and considered individually in the following subparagraphs.

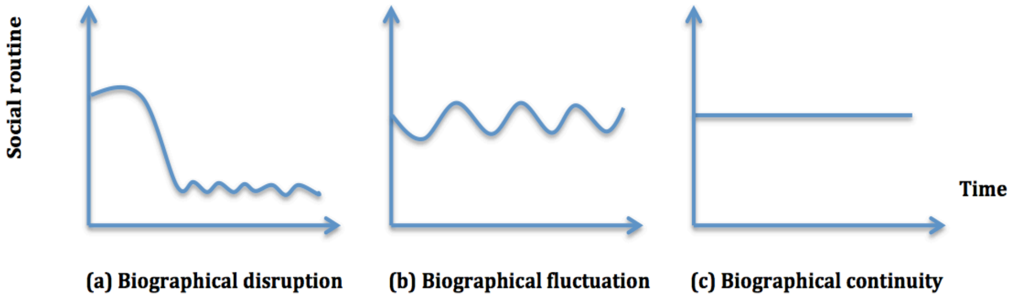

Figure 4.2: Typical forms of diabetes biographical narratives

4.4.1 “Diabetes changes everything”: chronic illness as biographical disruption

Five participants out of forty described their experience with diabetes as profoundly disruptive. Biographical disruption is here intended as an abrupt change in social routine and in the sense of self, a “major kind of disruptive experience, or, using Giddens's (1979) term, a 'critical situation'” (Bury 1982: p. 169). In Bury’s (1982) original formulation, biographical disruption was considered to be a single event located at the beginning of the illness trajectory, while here it is approached as a significant change in the social routine and in the construction of the self that persists over the biographical career. The analysis of empirical material highlighted that a minority of narratives has been discursively organized around the unsettling impact that diabetes had on the general structures of participants’ everyday life: in those accounts, the onset was described as a fracture that – with different degrees of severity – affected irremediably their routine and shaped their present as well as their plans for the future. Within these accounts, disruption is described as a persistent process rather than a single point in time: it is the embodied experience of engaging in social practices through the mediation of an illness that is perceived as intrusive. As shown in the (oversimplistic, but still useful for illustrative purposes) graph (a) in fig. 4.2, illness narratives that can be categorised as “disrupted” present a significant shift in how social routine is experienced. In fact, the curve declines steadily at the moment of onset and immediately after; in some cases, the way they experienced everyday life was stable over time, in other cases it showed more fluctuations. But in all five cases, it never increased up to the initial level: they never managed to restore their life as it was before the onset, and this was attributed to the intrusiveness of their condition. An influencing factor in determining the degree of disruptiveness of diabetes in the everyday life was that of the age at the time of the onset: all five accounts were produced by participants with adult-onset diabetes. Social structures and occupation characteristics were crucial in determining the degree of disruptiveness: using Karasek (and colleagues, 1981) job strain model, we could say that a physically/psychologically demanding job where the decision latitude is low increased the risk of experiencing diabetes as a disruptive presence. Although there were not flesh and blood “ideal types” of disrupted biographies, five biographical accounts were dominated by the recurrent reference to the disruptiveness of illness, that in different ways “unmade” their daily routine, their sense of self and their present experience of time. An intrusive illness such as autoimmune diabetes meant that its effects did not simply disrupt ill people’s lives temporarily, they rather continued over time. It also meant that they were forced “to accommodate to it, or to suffer the consequences, which can be both immediate and devastating” (Charmaz 1991: p. 42). As follows I will illustrate this process by reporting some particularly illustrative stories.

In the narrative of his experience with diabetes, Silvio recalls when he noticed the initial signs of illness: he reminds the occurrence of common symptoms such as substantial weight loss and increased thirst, bodily alterations that, at a certain point, made him look for medical help. At the moment of the interview he was 50 years old and the onset of Diabetes LADA occurred when he was 35 years old. According to his narrative, the unusual need of medical assistance marked an initial, and significant, rupture with the past self:

> **Silvio**: It’s tough, I got it fifteen years ago… It’s LADA diabetes… the famous diabetes one point five. Everyone calls it in their own way. (Long pause) and, [I was] thirty- …five, thirty-four, thirty-five years old. [Now] I’m fifty. And I have lost about… twenty kilos, … I drank about five litres of water a day, together with classic consequences… (Long pause) of the emergence of the illness, basically. (…) It didn’t go well in the sense that I didn’t want to… I was someone who, unlike now that I have a blood test every three months, back then I never had them done. So it wasn’t good. I mean…
> **Wife**: He didn’t accept the illness, in short.
> **Silvio**: I struggled with it. I struggled a lot. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

For him, diabetes changed everything: from being a dynamic, independent and hard worker man, after the onset of diabetes Silvio had to rethink his whole life. The illness, and the changes that it entailed, disrupted his physical and emotional life as well as his plans for the future, which became threatened by the severity and unpredictability of diabetes’ symptoms. His account is characterised by the recurring reference to the disruptiveness of his condition, which was present in his lived body and which significantly influenced his everyday life. In his words:

> It [diabetes] changes your life... It turns your existence upside down, actually. It changes your life; this is why at the beginning it has been incredibly hard for me. (Silvio, 51 years old, employee, onset at 35 years)

When I asked him to what extent diabetes had an impact on his life and in what way diabetes could be considered as disruptive, the narrative that followed represented an attempt to give words and shape to the pervasiveness and oppressiveness of his condition in his everyday life:

> Uh, it changes everything to you: it changes your diet, your lifestyle, it changes… I always say that having diabetes is a [full-time] job. Because… /monitoring oneself every day, paying attention to counting carbohydrates, and the blood glucose metre that doesn't work, so you have to call the company, and the insulin pump that b- / (chanting) so… It never leaves you. It's not… a… for heaven's sake, all illnesses are bad, but diabetes never leaves you. In the sense that you have to deal with it twenty-four hours a day. … And this is a little tough. (Silvio, 51 years old, employee, onset at 35 years)

One of the greatest causes of disruptiveness of diabetes in his everyday life was found in his adult age at the time of the onset, as he stated:

> Now I'll say something bad- I mean, bad. Something that one could say that it's absurd. But if- if glycaemia [diabetes] arrives when you're young, not that it's better, absolutely, it's worse, it ruins you… but still [you] grow up [with it], if it comes when you're thirty years old, then, I mean, for thirty years you've led a certain life, the next day they tell you: "That's it. That's not your life anymore." And- and- it gets tough… (Silvio, 51 years old, employee, onset at 35 years)

In Silvio's account, illness is represented homogeneously over time as a burden that requires continued attention, allotted time and forced accommodation (Charmaz 1997, Corbin & Strauss 1988). In order to encourage him to talk about his story, I asked him: "Can you tell me how is your typical day?". And below there is part of his answer:

> I get up in the morning at quarter to seven, twenty to seven, you measure it [glycaemia], you calibrate the sensor… you eat… I have an hour-long bus ride [to work], …at ten o'clock… you re-calibrate the insulin pump, at half

> past twelve before lunch you re-calibrate it again… You eat, counting the carbohydrates (he laughs). At four o'clock you re-calibrate the insulin pump again… I can't feel my poor little fingers anymore. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

The time of the day is ordered through the reference to the constant self-management, which punctuated and structured his routine. And it is the need of constantly monitoring glycaemic swing and managing uncertainty that caused his inability to continue his past occupation, considered as a crucial component of his previous sense of self. At the time of the onset, he was working as a technician, often travelling and operating in outdoor places. He still recalls the period before diagnosis, when diabetes' effects began to appear on his body:

> **Silvio**: I remember at work, I was at work… back then I travelled for work, because back then I was a technician around different places, and I remember that I started to sweat incredibly, I sat on the steps… of a… of a… And I don't know how I got home. But now… clever car, for her [he indicates his wife, with his eyes], the car was clever enough to take me home.
> **Wife**: (She smiles)
> **Silvio**: Because really I don't know… I don't have a clue. Really. If I had to say how I got home, I don't remember. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

Working as a technician was physically stressful and demanding and it entailed low decision latitude, which is why his ability to carry out his occupation was abruptly interrupted when diabetes symptoms became too intrusive:

> Well, at work I've had some problems because before I was a technician, so I travelled, and [after the onset] I couldn't anymore. In the end, well, [now] I only work in the office, obviously I couldn't… I couldn't be fainting around (he laughs). (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

As mentioned before, unlike other diseases diabetes is an "invisible" condition most of the time, and this complicates the social recognition of a changing identity. Silvio's colleagues, that were used to perceive him as a dynamic person, did not understand easily this sudden change and the new situation was misinterpreted as indolence, rather than an effect of his debilitating illness. His changed social identity is reaffirmed through the struggle for receiving a proper recognition of his new status:

> My colleagues initially thought that I didn't- I didn't want to do things anymore because I didn't want to do it, not because I couldn't manage [the situation]. Eh, it was tough. The early days… even then, I… Eh, now it sounds bad to say that I told… them to go to hell but, I mean, at that point I had to tell them to go to hell because if I tell you nicely, but you don't want to understand, I have to tell you a bit more… by crook. A little ruder. /But…/ (whispering) then in the end they understood… Also because everyone, they were- people are still ignorant about the illness, everyone thinks all diabetes are the same. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

These changes caused a fracture not only in his everyday life, but also in his sense of a coherent – and masculine – self, described as an active, independent and hard worker man "before" the onset, and as an ill and dependent person "after" the advent of diabetes. The loss of the "previous" self is described as an effect of the advent of illness, and as Charmaz (1997: p. 257) observes, illness disruption often entails "being involuntary dispossessed of former attributes and sentiments that comprise one's self-concept, as well as the actions and experiences upon which they are based." For Silvio, it also implied losing the self-definition with which he had most identified in the past, this way becoming vulnerable to the appraisal of others. In Western social context, "holding down a job," as Rissman (1990: p. 1198) observed, is "a core component of masculinity and yet the role that illness most often interferes with." As well as being a crucial context for masculinity construction, the occupation represents also a circumstance where the instability of the diabetic body necessarily faces the concrete difficulties of controlling blood glucose swings and self-administering insulin without complications. As Charmaz (1995: p. 273) notes, after the onset of chronic illness men acknowledge that their body is changed and they need to come to terms with uncertainty in many respects: "Uncertain episodes, uncertain treatment effects, uncertain complications." Our society requires from its members to manage uncertainty and keep a certain body control, and its loss might imply the stigmatization of the individual (Goffman 1963), the possible shift in the participation in the gender order and a corresponding loss of self. As Silvio stated:

> **Silvio**: Sometimes, (…) the bad thing is not much knowing that you're always ill, but seeing the people around you getting used to seeing you ill. I don't know what is worse. (…)
> **Interviewer: That is, seeing that people get used to…**
> **Silvio**: Getting used to seeing you ill. I mean, in the sense that, if I fall on the floor, neither her [his wife] nor my son worry anymore. (…) But it's a fear you have, eh, this one, of habit. And this is a thing that mmm leaves me a little… (…)
> **Wife**: These are just his /quirks/ (laughing), at least, I think so!
> **Silvio**: Yes… and as a matter of fact everyone says it's not true, I mean, the people closest to me, but I think… they often pity me. Even though everyone says they don't, but deep down I think that a little pity…
> **Interviewer: And what bothers you about… this?**
> **Silvio**: Well, I mean, I wasn't someone like this. (He laughs) I wasn't someone to pity, before. (…)
> **Interviewer: How were you before?**
> **Silvio**: Well, I worked, yes, I worked a lot, maybe too much, but I was always mmm I worked, worked, worked a lot, I mean. So basically I was always… busy. Now… the routine is what it is… You have to reach- you have to reach a compromise with yourself. This is a little… (…) … Eh, it's tough. I keep saying it's tough… Then I don't know what others say to you. But I say it's tough. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

Another informant, Paolo, a 32 years old man who lives with diabetes from the age of 20, gives an account that reveals how diabetes might be disruptive in the context of a precarious and physically demanding job. For him, the period that followed diabetes onset had been particularly difficult, not only for the discomfort caused by the bodily signs that prelude illness, but also because the situation was complicated by a misdiagnosis: in fact, his GP initially misinterpreted his altered body signs and thought that they were caused by panic attacks, and thus he treated them as such for more than a year. The process of giving a name to his condition was not disruptive in itself, and the diagnosis was in fact considered as a relief after a long period of undefined ill feeling:

> Well, ok, the news came as a relief because I didn't know… I didn't know what I had. So to classify it as something (he clears his throat) was, yes, let's say good news. At least I knew where to start. More than anything, I knew I wasn't completely crazy, just a little bit (he smiles). (Paolo, 32 years old, T1D, labourer, onset at 20 years)

The sensation that everything would be different began when he was discharged from hospital, when he realized that a “new life” was about to begin:

> I was in the hospital for about a month, several weeks… And then when you get out, it’s a mess, because it seems like you’re in another world, you know? In the end, I mean, you have a new life, you have to, you have to organise everything… scheduling time. A mess. (Long pause) Find another job… You know, it took a while for me. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

The reference to biographical disruption dominates Paolo’s narrative and one of the first social contexts where it was experienced the most was that of sport. This context clearly entails a situations were the body is highly engaged, and especially for men this is a crucial context for the construction of a gendered self since physical strength and competition are two key elements of hegemonic ideal of masculinity (Connell *et al.* 1985). Diabetes may cause a profound bodily and psychological disruption, as it happened to Paolo, a fracture that led him to quit altogether every physical activity in which he was engaged:

> I am very competitive, especially in sports, because I was good… Well, I played basketball, and I break danced (…)
> **You stopped because you felt, I mean, you were weaker than before?**
> Well, the year I was unwell, I closed myself in the house, I mean, I couldn’t even walk! I spent a year in which… Yes. I tried to go running, just to see, I mean, to try overcoming my depression, my… anxiety, you know? But I didn’t manage to stay standing, I mean… I didn’t do anything at all, I, I stopped doing everything! And then, between one thing and the other, in the end a few years went by (…). So in the end two years went by and, after those two years I was scared – and I still am – that I had lost the chance to be good in that sport. Well, I mean, I still stand by my choices, eh! Because I wanted to be the best in that, and, if I am not, it makes no sense to do it, (he smiles) that sport.
> **Break dance and basketball…**
> Break dance. Basketball, well, I would have never been the best though (he laughs). Then break dance takes place in quite a closed community, I mean hip-hop and all that – now less so – it was a rather niche environment. I mean, either you’re part of the group or you’re out. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

As mentioned before, from the analysis of the empirical material, working context emerged as an important sphere with respect to impression management and information control: this could be due to the fact that disclosing or disguising illness and its symptoms within social interactions with colleagues and employer can have a profound – and possibly disruptive – effect on the maintenance and coherence of the self, as well as on the actual possibility of performing working tasks and being able to maintain one's job. The process of information control took different forms and meanings according to the socio-economic context in which it was experienced. Continuing, as a way of example, with the case of Paolo, from the moment of the onset to the time of the interview he had been engaged in jobs that were characterised by high physical demands and very low decision-making freedom within a working class context, and this had possibly influenced the way he presented and constructed his self in relation to illness. More specifically, he reported disclosing about his condition in the majority of social contexts except for the occupational one, because the "costs" of this potential "coming out" would have been too high. In his words:

> **Paolo**: I have never worried much about hiding it, saying it, how to say it, if I should say it or not… (…) The only concerns I had were related to the workplace. Many [concerns] at work.
> **Partner**: At work, it's not only a concern, it's that if you say you have a problem..
> **Paolo**: …You don't work. I have lost a job because of diabetes, you know? I worked in a foundry. (…) I didn't pass the medical examination, I mean, the doctor said: 'No, from now on you don't work here anymore'. (…) I never disclosed [my condition] again. (…) Nowhere. Well, like, before starting in factories, I worked off the books, so... I built sheds, I've always done rather dynamic jobs. I built sheds, worked construction sites. And well...
> **Partner**: You worked your butt off!
> **Paolo**: Yes, because then in the summer, under the sun, in the winter, in the cold...
> **Partner**: 14 hours!
> **Paolo**: Yes, also. Long days. Oh well, there... there I would eat just about everything and I didn't even take my insulin. (...) In the factory, I never said it.
> **Interviewer: Oh ok, so you didn't take your insulin because it was...**
> Because if I took my insulin there, it was difficult to manage myself. Because I tried taking it, insulin, even taking less, even much less than what I should have taken – I had hypoglycaemia straight away. Because adding the physical activity to insulin, even though it wasn't much, probably the physical movement made it work too quickly, compared to food. I couldn't work then. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

Dealing with high job precariousness and high physical demands, Paolo decided to keep diabetes invisible and to neutralize its unpredictability by maintaining high blood sugar levels (hyperglycaemia) and, at times, even avoiding insulin administration. Despite the fact that hyperglycaemia in his future could have been dangerous to his health and significantly increased the risk of incurring in diabetes-related complications, it nonetheless prevented the risk of hypoglycaemia in the present, which would have affected his bodily strength and his work performances in that moment:

> **Ok. So as for food, your diet, [while at work] did you manage to follow a specific diet?**
> Well no, I ate everything. I mean I ate… back then, I mean, I had the wrong approach (…) I mean, I understood that I couldn't take insulin, but I thought: "Well, I'll eat all I can" (he laughs) "I'll fuel up and in one way or another, I'll burn it". /It didn't work that well/ (laughing, ironically). I was never unwell, I mean, because of high glycaemia, so, maybe I had symptoms like dry mouth, a little tachycardia, going to the toilet every two minutes, passing litres [of urine], but other than that, no. I mean, I could still work, I was in good shape. Also, I mean, compared to other non-diabetics. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

The impact of prolonged ill feelings, together with the disruptiveness of diagnosis in his everyday life, had been very intrusive and destabilising. After some months of struggling, Paolo became addicted to drugs. After one year from the onset, he participated to a rehabilitation programme and progressively stopped using drugs. Retrospectively, today he and his current partner (that occasionally joined the interview) attributed responsibility of drug addiction to diabetes:

> **Paolo:** Like, well, I used intravenous (…) I did a bit of everything… (he laughs) So, like cocaine (…) heroin (…)
> **Partner:** (…) many drug addicts have diabetes. Because I think [diabetes] causes it.
> **Paolo**: Yes. No! For the diabetes-injection-insulin association (he laughs).
> **Interviewer: What do you mean?**
> **Partner**: Not everyone. Maybe who tends to…
> **Paolo**: Also the fact of being addicted to a substance… I mean, not only the gestures, but also…
> **Interviewer: Being addicted to a medication?**
> **Paolo**: Yes, giving in to an actual dependency… I mean, saying… "Oh well, I'm already addicted to this, so… I dunno, I'll just go ahead…"
> **Partner**: The true addiction of a drug addict who takes a hit is the act in itself.
> **Paolo**: The act.
> **Partner**: The act. I mean, the act… you inject insulin…
> **Paolo**: Yes, it's a completely different injection but still now, when I do it in my arm – and the act is much more similar, also the grip, no? That is just

> like… [he mimes the action] freeing your arm [from your clothes]… Gives me a different feeling from when I do it on my belly (…) I mean, the correlation was that, for me, the fact that you'd say mmm… I mean: "What's the difference, at this point, since I already like it, no?" "What's the difference between insulin and heroin?" So then making the following steps: "What's the difference between heroin and cigarettes? What's the difference between heroin and pasta? What's the difference between heroin and desserts? What's the difference?" You go on like that and it's all over-justified addictions. Why can't mine be justified? (…)
> **Partner**: I think also part of… of becoming a drug addict brought diabetes to you. If they hadn't diagnosed you with diabetes, I think, you wouldn't have… you wouldn't have been…
> **Paolo**: No, probably not…
> **Partner**: You would have never done that life.
> **Paolo**: Probably not. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

At the moment of the interview his occupation was that of labourer, often working the night shift. Over time, Paolo changed his approach to illness and at that moment he was highly engaged with self-management and he had developed specific technologies of the self (Foucault 1988) in order to keep a balance and sustain physical work demands. His narrative is characterised by an overall altered social routine that, in his perception, could never be restored. Diabetes is represented as a burden, as an illness that damages irreversibly the body, as a weakness of the body that distances even more the subject from the dominant ideal of a masculine self:

> So, yes, anyway, one of the first things I thought: "[Since] when I have diabetes, I won't be able to pick up a woman with my arms and run through a field"
> **And how... how come this thing came to mind?**
> Eh, I don't know. I don't know. Thinking of an exaggerated situation that will never happen and thinking that you can't do it, so you're not who you used to be, but you've never been that person... (Paolo, 32 years old, T1D, labourer, onset at 20 years)

The focus of the accounts that can be categorised in this narrative type is on the experience of an altered body, with its physical changes and diminished bodily functions. They often compare their current "damaged" body to the one they had before the onset, assessing the differences between the present and the past, and this entails a radical fracture of body and self. As Charmaz (1995: p. 662) observes: "The body once viewed as a taken for granted possession to control and master has spun out of control. At best, the body is now a failed machine, an obstacle to be repaired, overcome, or mastered. At worst, it has become a deadly enemy or oppressor."

4.4.2 "Good days, bad days"[24]: diabetes as biographical fluctuation

Within the narratives included in this category, informants retrospectively reconstruct life with diabetes as a "fluctuating normality" (Sanderson *et al*. 2011: p. 625), and illness narratives are organised through a pattern of changing understandings of diabetes, discontinuous engagement with its management and intermittent impact of its consequences in their everyday life. In these cases, diabetes might be described as a non-disruptive event with serious and permanent implications for social interactions and for the sense of self. It can rather be perceived as a part of participants' on-going health history, being disruptive and critical as far as their body or they lives undergo physical or social changes over the years. Faircloth and colleagues (2004) have formulated the concept of biographical flow "as a way to better understand the process of illness as a part of an on-going life," and drawing from this perspective, in this study whether diabetes played a large or small part in the participants' lives greatly depended on a number of factors. Based on the empirical material collected, 19 out of 40 participants organised their narratives on the basis of alternating periods of crisis and stability with repeated transitions caused by the occurrence of a variety of different turning points. These last were used as narrative anchors for discursively reconstruct their biography. Generally, the main turning points that have punctuated the illness narratives of participants corresponded with the moments relating to some "expected transitions" (Bonica & Cardano 2008: p. 20; my translation), and in particular (a) the transition to adult age, (b) the beginning of a stable relationship, and (c) the beginning of working life. At the same time, the "unexpected transitions" (Ibidem: p. 21; my translation) that majorly influenced the development of the biographical trajectories were (a) the emergence of more or less severe health complications related to diabetes, (b) passing from more 'traditional' self-monitoring tools, such as insulin pens and the glucometer for the

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[24] Besides being a quotation from Simone, an interviewee, this is also the title of Kathy Charmaz's book (1991).

measurement of glycaemia, to medical devices such as the insulin pump and the continuous blood glucose sensor.

The story of Simone, a 53 years old man who was diagnosed with type 1 diabetes at 9 years of age, clearly illustrates how the relationship with diabetes can vary and fluctuate over time. At the moment of the interview Simone worked as a tourist guide, he was married and had two children. At the time of the onset he lived in Switzerland, where his parents migrated in order to look for a job. Despite the tight diet regimen he was subjected to ("I always [used to] eat the same things, at the same time"), the first years with diabetes were hard for Simone and his parents, because of strong hypoglycaemic crises that made it difficult to perform self-management:

> Many problems… I remember… I remember, especially at night, that I had these very violent hypos, and my parents very worried… and… I don't know if poorly educated… maybe also panicking in the moment, because they told me that- they… told me for many years that during the… hypos I was bouncing on the bed, because I had really weird contractions, and they tried to make me eat the sugar, unsuccessfully, … more than once they broke my lips, … a couple of teeth, trying to introduce sugar in the mouth. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

In his biographical reconstruction, he retrospectively considered racist his diabetologist of the time, because he recalled him having discriminatory behaviours towards people who migrated into Switzerland. In his case, the doctor had encouraged his family to consider the possibility to go back to live permanently in Italy, motivating this recommendation on the basis of a presumed betterment of Simone's overall wellbeing observed during his summer holidays in his home country:

> Then, I have to be honest, … I had a diabetologist, a (…) … can I use a blunt term?
> **Absolutely.**
> A son of a b- … a son of a bitch, because he convinced my parents, … a year and a half after the illness onset, … a year and a half more or less, yes. And he asked my parents, who were workers, … I describe them as ignorant, in the sense that they ignored, what the illness entailed, … and he basically asked my parents how I felt during the summer, when I came to Italy, to… to stay with my grandparents, … and my parents answered that… eeh I was better, … I was compensated better, my need for insulin was significantly

> reduced, much more stable values, and this doctor, obviously a well-known … he was not well-known at the time, but I understand… I understood a few years later, he didn't particularly like… immigrants, and he convinced them that it was a matter of climate… so… my parents, in order to meet my illness' needs, on… the first of April of '77, …came back… to Italy… It's true that the climate helped, but for two or three weeks, until one- eeh gets used to the climate, and then… and then… unfortunately you go back to the old trends. As a matter of fact, on the first of May, exactly one month after being in Italy, I ended up… I ended up in hospital, in short. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

After moving as a child, Simone stayed indefinitely in Italy, up to the moment of the interview. His childhood was characterised by a rigid adherence to treatment and, despite this, by a difficult management of the symptoms of diabetes. When his parents' control was loosened and left space to a higher autonomy during adolescence, the regularity of illness management became discontinuous and food – previously eaten almost "therapeutically" at regular times and in controlled quantities – became rather an occasion to obtain a momentary pleasure, it became "comfort food," assumed to counterbalance the frustration derived from an adolescence marked by his "diversity": diversity in terms of health, but also in terms of social background. Adolescence is a delicate life stage in which boys and girls construct their ways of "doing" masculinities and femininities. When illness got into the way, this process became more complicated: in the case of boys, the reference to bodily strength and to a "healthy" normativity might be even more pressing, and transgressions are sanctioned with stigmatization and marginalization. In his words:

> But I, eeh… insulin and all, I did it, I mean, I certainly didn't follow what you'd call an appropriate diet, ok I mean, I ate a little too much, … (…) causing… eeh let's say, one problem after another (…) I made a lot of mistakes, by all means, because one might think they're completely indestructible. (…) Since I came back from school at half past two in the afternoon, and my parents both worked, I never ate with my parents. (…) In that sense, I was autonomous. The problem is when you're too autonomous, and you don't realise you're doing some things that are huge nonsense, you tend to eat what you shouldn't, so… in the summer, for example, I… eeh… I was a huge fan of ice creams, also packaged ice cream, I would make it disappear, (…) it's all things that have an impact on blood sugar, on weight, on the management of diabetes… I was basically causing one mess after the other… I have to say, the- most difficult thing for me was… that I was part of a social class, I was… my parents were poor, let's say. They faced- I mean… they made sacrifices to sign me up to a private high school

> obviously… And the context is that of xxxxxxx, (city name in the North of Italy)… at the beginning of the ‘80s, … north-eastern rich city, I had classmates of another… another social class, so, yes… Let’s say that… I wasn’t completely marginalised. But I still wasn’t part of… of the circle they belonged to, then… I have to be honest, they kind of eeh… they saw me as a loser, as a diabetic, in short. Because I had my problems that I created for myself, you know, it’s not that they gave me problems with the diabetes, I mean… I, at the time, eeh … I tried to access this group of people, … and… I didn’t- I didn’t manage, maybe it wasn’t only my fault, but… but I- … I realise now that… the frustration of not managing to do it, because at that age, you rightly look for a group that will support you… of which you can be part of, because we all want to be part of the pack. At that age… It pushed me… I say, without prob- without drawing a line probably, to eat like a… eeh… like a hog, then, once I got home. To… Let out the frustration, probably. (…) Then, there’s the revolt against the illness, you begin to make mistakes, mistakes, mistakes, and you think you’re immortal. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

During adolescence and in the following years, Simone “put up… an unspeakable amount of weight,” “even more than 25 kilos per year,” reaching a weight of 129 kg at the age of 29. In his narrative, “good days and bad days” – as he defined them – were alternated, he talked about periods of time in which he could manage diabetes in a more regular way and other ones in which the stress related to family and work issues brought him to find solace in food, with the refrain: “Yes, an exception today, an exception tomorrow, what could possibly happen to me?”. Unfortunately for him, diabetes-related health complications arrived soon, and with these, at the age of 29, an initial turning point to his approach to the illness took place: in fact, a potentially fatal complication – diabetic ketoacidosis[25] – and other diabetes-related problems temporarily stimulated his adherence to treatment:

> And then in ’94, it came- I had problems with my eyes, laser therapy, and the inability to use both my thighs… to inject the insulin, because I had mostly used them… to… to inject my insulin, so since ’94… I simply haven’t used my thighs anymore as… as a place to inject my insulin, yes. And I couldn’t use them anymore. Although 24 years went by, there hasn’t… there hasn’t been a way to use it. (…) When they hospitalised me for a… for an acidosis coma, eeh … and there, the immediate fear made me lose some weight. However, never managing to… to go below 100 kilos of weight. Let’s say that… My weight always varied between 100… and 105,

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[25] This is a condition that can be cause by different factors, one of which is poor adherence to insulin treatment. If not treated, it can lead to coma and death.

> maximum 110 kilos, yes. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

A further incentive to adhere to treatment arrived when he met his wife, and his account of that period highlights a dichotomous and stereotyped conception of gender with respect to care activities:

> Then my wife came along, that saint of my wife, in ’97, … and eh she pushed me like all women push men who are unable to do anything good, (he laughs) she initially pushed me to… to do exercises, so I managed to go down to… 90 kilos, and doing physical exercise, going cycling basically, and… Having your heart busy is useful… Is useful to… It makes you do things that before were unthinkable, but okay, this- this is a good thing, eh, a good thing, I won’t argue... (Simone, 53 years, T1D, touristic guide, onset at 9 years)

His narrative continues with other family struggles, various stressors, and relapses in terms of adherence to treatment and illness management. His biographical account is often summed up in numerical terms, with reference to the rotation of lost kilos and gained kilos, as well as to glycated haemoglobin values, which are used as a parameter that sums up the glycaemic development of the previous three months. He described himself through fluctuating values, numbers that enclose within them the value of a life that is subject to change, of changing situations and of a body experience shaped by the situations in which he found himself into: “But… I continued… to go-… not as much as I wanted, basically. Glycated never over 10, but never significantly under 10.” Finally, the last turning point in his narrative concerned a twist in the sphere of self-management, when he decided to change the use of insulin pens with that of the insulin pump:

> …And then at a certain point… I let myself, how can I say? …I put two and two together, since I liked my children, I liked my family, I liked my life, … and… I did some research on the Internet, I said: “I want to start using the insulin pump.” (Simone, 53 years, T1D, touristic guide, onset at 9 years)

And that is how in 2010, at the age of 45, Simone showed up in a new hospital, he met a new diabetologist and decided to sign up to the course to learn how to use the insulin pump. This became an opportunity to learn new forms of illness management – such as carbohydrate counting – and from this moment started what he defined as his “second life as a diabetic.” Motivated by the general betterment, Simone also introduced with greater conviction the third “pillar” of diabetes management: physical exercise. In his words:

> Up until 2010, I knew nothing, …and… I did everything well, on the 25th May 2010 they attached me to the insulin pump for the first time, … and since then, I have never been off it, and… at the beginning of June of the same year, I said: “Ok, yes… I am getting better, … let’s see if I can make a further breakthrough” …I started… first of all… by going for fast walks, then I added some running, more running, even more running, I mean… I went down to… under 80 kilos, of… I basically lost 20 kilos in three months. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

At the moment of the interview, Simone was working as a touristic guide within an international company. This work context has always been very inclusive towards his condition and he has been given all the freedom he needed for managing his illness. But it has not always been easy for him, because he also experienced many rejections because of diabetes. For example:

> In ’86, I applied for working in a bank where I used to live. I was invited to the job interview, and… during the interview it also came up –I don’t know- the discourse that I was diabetic. And… once they found out… there were two people interviewing me… Once found out that I really was diabetic, in that moment they finished the interview, they said: “No, thank you.” (Simone, 53 years, T1D, touristic guide, onset at 9 years)

The body is not a separated entity, unconnected with the mind and with the circumstances of life. The body is actively built and shaped by experiences in life, by the social contexts; it is marked by the flow of life’s different seasons and its ups and downs. Simone’s account illustrates the variability of experiencing an illness through time, the never-ending search for a balance, as well as the vulnerability to unexpected life events:

> Then I gained some weight again… for some problems due to the death of my in-laws… to managing the family and so on. And every now and then life hits you, and you’re not always… entirely ready to face it. I mean, the stress is… is what then affects the blood sugar levels and all… But then, I had promised myself: “Never again more than 100,” that is, never again more than 100 kilos, and… at Christmas, not the last one, but two years ago, eeh I went on the scale, I saw 99 point 9… and I said: “Remember you told yourself: <<Never again more than 100>>”, I immediately stopped

> everything I was doing, I started to… to walk again, to… and now I've started running again, I went back to 79 kilos basically, yes. So now, one metre and 83, for 79 kilos… I- I'm quite satisfied, yes. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

Also in the case of Leonardo, a middle-aged man who lives with diabetes from the age of 4, his everyday life is narrated as intermittently influenced by diabetes and subjected to consistent changes over time. Today he is a married man with a 12-year-old son, and he runs an architectural firm, where we met to talk about his experience with diabetes. He reported that for most of his life he had been disinterested in managing diabetes, and that he had frequently disregarded both medical recommendations and treatment.

But his approach to illness radically changed when two significant events occurred, almost simultaneously: the emergence of the first diabetes-related complication (retinopathy), and the possibility of monitoring its chronic condition through highly technological devices (continuous glucose monitoring sensor for glycaemic control and insulin pump for insulin administration). Since he runs his own architectural firm, his job is very demanding, especially in terms of working hours and commitment. But it is also characterised by a high degree of control, which allows him to freely manage his diabetes during the day, without fearing possible repercussions on his career.

During his youth and for most of his life, he has had an approximate approach to the management of diabetes, replacing the precise measurements of the glucose-monitoring tool with the rough ones based on the experience of physical sensations:

> More or less at eighteen, one feels invincible, so you do fucking stupid things, but you come out of them alive, so "Who can kill me?" So mmm I don't, why should I do 72 analyses every day, bringing the stuff along in a little brown purse? (He laughs, ironic) I'm joking obviously but, I mean, this gives you the idea, eh! Every now and then I would have a look and then even the pretence, yes, I think you will find this again in other people who've had it for a long time, to say: "I know it… because I can feel it" And because, this is not completely mad because one can feel, I, one knows if…/ their blood sugar is going down or not, it's a thing…/ (quietly) [that] you feel on your body, there are signals, some people more than others. I was one who could understand and say: "Gosh I'm high in sugars." (Leonardo, 52 years old, T1D, architect, onset at 4 years)

According to his biographical reconstruction, for most of his life Leonardo used strategies of denial of his illness as a coping strategy to face the stigma attached to it and in order to compensate the potentially emasculating aspect of illness. During adolescence and young adulthood, he recalled having to deal with a body that was considered weaker than others', and in his reconstruction he reminded having reacted by denying this bodily difference and even trying to negotiate a more normative ideal of masculinity through resistance and competition:

> I don't exactly remember the individual episodes, but there have been a few in which for a male boy, whether it's right or wrong (…), or at least, for my generation it happened that also standing up for yourself, in a certain way, was also a matter of physical performance, either because when I was fighting with someone, or I took place in a race, or playing football, at a certain point I stopped playing well because eeh [he mimes with his hands as to say "I went down"] and these things [affected] a little… (…) But I didn't… then maybe this should be placed in another… context, in the sense that for my generation, one thing that now is different, but there was a mixture of… need rather than cultural heritage, a mix of these two things, to tell oneself or others: "This thing is not a problem." I mean: "I'll smash everything up, you know, just you see, I'll show you!". (…) Because I said that it was also a bit of a need, because really at that age, in those years, you would sign up to the gym and someone would say: "Oh, oh ok, you're diabetic, so you'll do the easiest things". And I wanted to say: "No, if I feel unwell, I'll tell you, so if you tell me: '50 pushups' and I say: 'at the 30th I'll stop' you better not bust my balls." But it's not as if you have to give me 20 to start with, no? So, let's say, a little because of widespread ignorance, ok, not knowing the problem, there was also a bit of a need to assert… in a certain sense, a… maybe misplaced, but an idea of normality. (…) I mean, the key word is ignorance, people don't know. (…)
> **What are the diabetes stereotypes you happened to face?**
> Well, of inability, I mean, of no potency in general, "No, no, so you're diabetic, you can't do that, what do you expect a diabetic to do…" Then clearly maybe we, because of our generation or cultural heritage, I don't even know if that's the right word, but we'd say: "The fuck are you saying? I could even be an astronaut!" (Leonardo, 52 years old, T1D, architect, onset at 4 years)

In the first segment of his biographical account he described himself as reluctant to adjust his everyday life to illness, he rather attempted to live just as everyone else, just as non-diabetics did. In his reconstruction, this first segment was characterised by adhering to diabetes regimen just to the bare minimum, and this entailed discursively – but also physically, as he recalled – distancing himself to the objects that were understood as a proxy for illness:

> It often happened to me that I would say: “Come on…” what do I c[are]… I mean… After that, as a matter of fact, I… mmm… I think there are things I found out about myself that I discovered very… very recently, like, at the end I’ve been someone who for years, too many years, mixed ignoring the problem…
> **And this was at what age, more or less?**
> From adolescence to, more or less, last Thursday! (He laughs, ironic) No, now I’m, it’s obviously a joke, but mmm…
> **What did ignoring the problem meant for you?**
> … A sort of subliminal denial of the thing. (…) Something that has always bothered me mmm of the world around diabetes was… mmm I mean, I don’t know how to say, everything… mmm… that had to do with diabetes like tools, medical devices, technology… I’ve always found this something that made me say: “No, put this stuff on yourself, you! I mean..” [Some people] also proposed to me -now I say this to take the piss- but /the practical little purse…/ (he says it chanting, in a feminised tone). I mean, one would see these things and [say]: “The fuck is this?” (He laughs). (Leonardo, 52 years old, T1D, architect, onset at 4 years)

His current job is one of great responsibility, as well as being highly psychologically demanding. Even though he is self-employed and there is no risk for him to get fired (thus, he actually holds high control), he still prefers to conceal from others his disease most of the time, especially from clients, in order to preserve his status and to avoid the risk of marginalization, implying that illness could be perceived from others as a form of weakness and impinge his professional reputation. As he puts it:

> I tend to avoid that others need to know it, because working on my own and living in a viper’s nest, bla bla bla... I mean, let’s suppose that there is the biggest bastard of all, why should I give him one more weapon [against me], so he can say: ‘Holy shit, our Italian delegate is a sick person...’. It is a matter of discretion... (Leonardo, 52 years old, T1D, architect, onset at 4 years)

This meant that for most of his life he concealed his condition from his colleagues and that he usually ‘passed’ as non-diabetic, managing insulin treatment in a private space (the bathroom), this way keeping illness apart from his social identity. He referred that he had, for most of the time, led a lifestyle unsuitable for diabetic people, prioritising work or his career over the proper management of the illness, often working overtime and eating without any restrictions.

In the last few years, however, his approach to diabetes and to its management has radically changed. The occurrence of the first diabetes-related complication has been a real turning point for him. At a certain point in his life, diabetes forcefully started to impose its presence, breaking into his everyday life, redefining the boundaries of his self-perception and undermining the sense of invincibility the had characterised the previous chapter of his illness narrative. The emergence of invasive health problems has never been a neutral element in the life of participants. As Leonardo points out, complications for him are synonym of the vulnerability and the mortality of the body, both elements that (healthy) people usually tend to forget. Illness complications reminded Leonardo the possibility of losing his independence, of the possibility of irreversible functional losses, as well as the need to come to terms with a body that was experiencing another change.

> In the meanwhile, a small thing eeh I had some complications, which were not enough to [be perceived as] a significant warning bell. (…) I am obviously a stupid person because, well, I risked losing an eye. (…) And that's also an, well ok, that was also a moment when I felt a… In a different form, my fragility.
> **Mm mm and do you want to tell me more about it?**
> (long pause) Yes, in the sense that, I mean, I define this fragility: it's the fragility of man, who feels small compared to the possible events of his destiny, no? So, "my body that is starting to go into pieces, oh God!" and "if I lose my eye, I can't drive anymore… do this certain thing, etcetera". And "I have this weakness, I need assistance" in the sense that, also here maybe it depends a bit on how you're set up, I… bragging to myself abilities that I may not even have. But I think, for now I think I can get better, how can I say then, how can I say, this… this nuisance, how can I say: "Then the holidays will arrive" no? This is a thing that's always been with me, but that I hadn't ever really… elaborated. And in those moments you feel, I mean, it's a bit more than breaking your leg and "I'll have a limp for a month", you say: "Shit, my eye, mmm", as a matter of fact, we say: "[Something] is as precious as eyesight", I know it's not exactly (he laughs) the newest of sayings, no? So there's an actual fragility of: "My body is fragile, I'm not… a decay has started", well ok, something that… that, ok, get younger, nobody gets younger, with diabetes getting old is a little, how can I say, catalysed towards an acceleration especially, especially or exclusively if you don't take care of yourself, if you don't manage yourself properly. (Leonardo, 52 years old, T1D, architect, onset at 4 years)

Leonardo proposes an interesting analogy: when his everyday life was altered by retinopathy, he reported having felt like Giuseppe Corte, the protagonist of the novel “Seven floors” by Dino Buzzati (1942). To sum up the novel: Buzzati tells the story of a lawyer who admits himself into a hospital that is specialised in the treatment of the illness he suffered from. The hospital was structured on seven floors, which were organised in order to accommodate patients in a progressive way, from the least serious in health conditions (seventh floor), to the more serious (ground floor). Initially hospitalised on the seventh floor – because his condition was considered as a non-serious one – the main character saw himself progressively and inexplicably transferred to the lower levels, accompanied by a feeling of surprise, concern, and relentlessness, because he actually did not perceive his condition as worsening. Leonardo feared something similar could happen to him, and that his retinopathy could be merely the first sign of an imminent physical decay: “Yes, so I thought I had entered a loop and, (…), a similar process with my eye.” The fear of a domino effect due to subsequent possible complications provided the necessary incentive to radically change his approach to the illness. This is put into practice through a change in diabetes self-management with the implementation of the insulin pump and of the continuous glucose monitoring sensor, which somehow brought together the necessity of constant glycaemic monitoring with his “predisposition to technology” inherited from his scientific background. Unlike the traditional glucose monitoring device, the new medical devices did not need a “little brown purse” to be transported – that perhaps was considered as a feminizing object and that rather stimulated his technical competence. This, as a result, increased his compliance with treatment:

> I also had a little distance, I perceived a distance and if they made a machine [I would not be interested, in the past]… As you’ve probably understood, I’m an architect and therefore I have a predisposition to technology, maybe working with numbers, so (…) I got kind of more involved in diabetes [management] from the moment this object came out [he lifts his shirt and points to a tiny round object, attached on his belly]: this is a continuous glucose monitoring sensor, meaning that it measures [blood glucose] in the interstitial fluid (…). This has interested me as far as I said: “Ah, maybe I can take back control of that thing.” (…) When I put this instrument [a device that looks like a mobile phone] next to it, it downloads the last 8 hours [of measurements], if I need it. Up to eight hours of data, in which then, with a normal cable, this one with which I charge my phone, I can [download] the data on the computer (…). This here is a historical innovation, in my opinion. But then there are some… there are some apps… You know, then for me it is not a big problem to correct a mistake on a

> vector, right? I just need to find the time to do it. But for a common housewife[26] it would be [a problem]. The point is that this thing now eeh… in giving, it doesn't only give you a result, like the glucometer, yet it gives you a curve, so it gives a trend (…) [These data] are downloadable on the computer and they can be analysed by any nerd as much as they want to. The other thing is that one goes to the doctor, he downloads the data, has a look and says… he also sees a trend and… if you're curious, I'll show you a graph as an [example].
> **Eh sure, that would be nice, thanks**
> [The interviewee goes to the next room and comes back with some papers with graphs printed on them] Now I don't know how much of a math lady you are, but (…) this is what I, sticking this object in the computer, it has a software, in fact this is something that someone who is familiar with these things does with Excel, you know? (…) Well ok, here [showing a point on the graphs to the interviewer], this is the famous [glycate] haemoglobin value, in this case it's not high, 6.5 would be a good value, so this is not much, but this is the actual mean, this is the deviation from the same mean… (…) Put simply, if I had to explain this to a child I would say: "Lots of not-accurate measurements are better than only 3 accurate measurements [in a day], because they give me the trend." (…) The real innovation is being able to work on the given trends, on the curve, (…) here I can have a trend while with the glucose monitor I can't. Unless I pricked [my finger] at regular intervals, but even in this case a consideration should be made, because there is here a problem of data interpolation…(Leonardo, 52 years old, T1D, architect, onset at 4 years)

Leonardo describes his changed approach to illness through the enactment of his specialised – and gendered – *savoir faire* (Diasio & Cozzi 2017), that derives from his technical/scientific background and results in his ability in understanding charts, medians, means and modes and in setting accordingly the units of insulin in the pump. When asked about his diabetes management, he focused on technical details and numerical data, thereby "showing off" his technical expertise and enacting a "quantified self" (Lupton 2016, Maturo 2015: p. 1). His account was – throughout the whole interview – informed by a mansplaining approach to the (female) interviewer, discursively opposing his "technological predisposition" with a supposed numerical incompetence of a imaginary housewife/child or even the (sociologist) interviewer, all intended as potential naïve listeners.

A particular case is represented by the fluctuating narrative of Francesco, a 51-years-old man who was diagnosed with type 1 diabetes at the age of 4. He is now

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[26] The original Italian version was "la casalinga di Voghera", which in the Italian language is an idiomatic expression that refers to an imaginary housewife, with low level of education, that lives in a little town. It is usually used in a derogatory way as a (sexist) stereotype.

married with a diabetic woman and works as an employee in a public office. His experience is told with a progressive incorporation of diabetes into his everyday life: having received diabetes diagnosis during infancy, his ups and downs were soon embodied as a “normal” flow during the day, something with which he has always had to deal with. Sporty ever since he was a child, he described his childhood and adolescence as a time in which he overall lived serenely with his illness: “I liv- lived it… peacefully, I managed it peacefully.” Growing up, he started to perceive diabetes as a burden that weakened his physical and mental abilities. Throughout his narrative, he reported alternating times of adherence to treatment to others in which, as he puts it: “In which… I didn’t even measure my blood sugar levels, monitoring…” and, soon enough, “…the damage started to occur, from that point of view.” As a matter of fact, Francesco today holds diabetes responsible for his failures in sports, those at university, and also those related to his past love life:

> And after school, let’s say, I signed up… to university, and there I had to realise that… I wasn’t able to… to face university exams. Because moreover, I really liked chemistry, I had signed up to chemistry, not exactly… an easy subject. I struggled when doing my exams… I mean, with… let’s say, the first year exams… But… the second exam of inorganic chemistry, the first exam I decided absolutely not to be the easiest, on the contrary, in the second year (…) you basically need to learn it off by heart. And I didn’t learn things off by heart… I could read the same- the same four pages four times… and I would always start again from the… (He laughs) Well, but I also found myself do- studying with other… colleagues… when they didn’t understand something, I would explain it to them, with the book in front of me, and when I had to repeat it, I wouldn’t- I would go silent. (He laughs) And so… at that point… after… a few more months spent there, and… inorganic chemistry I failed the second exam, I failed the second physics exam, subjects on which- that I liked, on which I thought I was … and let’s say there was no need to continue, yes. (long pause) And … and so let’s say I had this uncertainty… on memory, … and as far as the… relationships with women, let’s say that also there… I had a certain insecurity, that was more-… was even stronger than the insecurity I had with… eeh in friendships. So… let’s say, I lived rather (he laughs) closed in myself. (…) For me… [diabetes is] a real pain in the neck. (He laughs) … And (long pause) I think that… it affected me in life… both physically and mentally. Physically, because as I said… probably if I hadn’t been diabetic, in terms of sport I would have managed to do more. And mentally because… probably if I hadn’t been diabetic, some of my limitations, wouldn’t have been so… blatant. (Francesco, 51 years old, T1D, employee, onset at 3 years)

The second segment of his biographical account, the one of young adulthood, was mainly informed by the limitations imposed by diabetes, and by the struggles he faced to overcome them in order to adjust it within his everyday life. What affected him the most, aside from what was mentioned above, were the frequent hypoglycaemic crises. As for the majority of interviewees, also for Francesco hypoglycaemia implied the necessity to balance low blood sugar levels and the subsequent sense of weakness on his own, often declining support of others in an attempt to keep up with the masculine ideal of independence and strength, even at the cost of risking his life. This is well illustrated in the following episode:

> Once… I went to visit a friend (…) And … I had dinner at his place (…) I end up in hypo, …during dinner, …and I eat all I can there, I keep getting lower and lower, I say goodbye, I get out of there, with a very strong hypoglycaemia, I take the motorway, I stop after two kilometres, at the first tollbooth, I buy myself a pack of sweeties, I eat a pack of sweets sitting there for a quarter of an hour, twenty minutes, …[But] the blood sugar does not increase. I leave again, (…) and I go another thirty, forty metres… huge hypo… at a certain point I decide to pull over [the car] because I can't even see anything. And I crash the car against… the rest area, …I mean, one tire was all bent, and someone stops… Someone who saw… Saw I was there with my car… I go: "All good, all good," I make him go away, I imagine he thinks I was drunk, high, I don't know what else. The adrenaline of that… of the crash, plus maybe all I had eaten, makes me recover, I start going again, with the car (he laughs) wobbling, I go a hundred… I don't know how many kilometres to get to xxxxxx (city name)… I get there with my blood sugar through the roof, and, and well… It's one of those episodes that… I mean, …say what you like, but what makes you- logic, your mind, …can tell you anything, you can say: "In certain situations, you mustn't, you must do this, do that." But then when it happens to you… (Francesco, 51 years old, T1D, employee, onset at 3 years)

The unpredictability of glycaemic swings then became worse when he stopped "feeling" hypoglycaemias, and therefore this brought more difficulties in predicting and managing them. At the time of the interview, Francesco worked as a public employee, a job characterised by low demand in terms of workload and high control in terms of freedom for organizing self-management, medical examinations and medical checks that he performed on a regular basis. This context allowed him to undergo a pancreatic islet transplantation,[27] which was a delicate surgical procedure that marked an important change in his everyday life, since, after a lifetime as a diabetic person, he had the opportunity to live an experience as a "non-diabetic." As he said: "After the first infusion of islets, I've been three, four years without needing insulin." This "travelling back in time" imposed an important transition in his illness trajectory since his experience of the illness was basically interrupted, although only for a few years. Unfortunately, things did not go as he had hoped and, after a few years of "break from diabetes," as he defined it, he began to experience again glycaemic swings, and with them it returned also the need for insulin injections. He therefore experienced a sort of "second onset," which he described as being even more disruptive than the first one:

> Everyone says: "I have no problem accepting my illness" etcetera, …I'd like to say the same thing, although if then when… After a few years ago when I didn't… Need insulin, I had to start taking it again, I had to eh, get back into the process, it was rather traumatic. And it was more traumatic than when I was three [years old], because when you're three… you accept anything. So to speak. (He laughs) (Francesco, 51 years old, T1D, employee, onset at 3 years)

After the "second onset" the hypoglycaemic crises did not allow him to practice intense sports as he would have wanted. This made him take another important decision, which entailed another turning point in his biographical trajectory: starting to use the insulin pump to manage his insulin instead of insulin pens. In his words:

> I had the transplant in 2005, and… Then after a few years I started injecting the long-acting insulin again… After a few years, this long-acting insulin would cause me hypos, to- followed- during sport practise, so it wasn't good anymore, …despite a thousand different strategies, at that point I had to… I chose to use the insulin pump, because it allowed me to- not to use the long-acting insulin, but to stop the administration of insulin… obviously still taking sugar… just before I start running, to have a trend, an increasing trend… (Francesco, 51 years old, T1D, employee, onset at 3 years)

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[27] This is a procedure in which pancreatic islets (that contain beta cells, which in turn in non-diabetic individuals provide the hormone insulin) are transferred from a donor into another person. In Italy this is still an experimental and quite uncommon procedure.

The year before the interview, Francesco tried another pancreatic islet transplantation, hoping that the "break from diabetes" could that time become permanent. Unfortunately, again it did not have the desired outcome. Even though at the moment of interview he could not consider himself as 'cured' from diabetes, thanks to the joint action of the islet transplantation and the use of the insulin pump his self-management had become much less burdensome and the presence of illness in his everyday life much less invasive:

> Now that I am… almost a type 2 diabetic, in the sense that I am insulin-dependent, physical exercise is not enough, a specific diet is not enough, … but I have to still take… Some insulin, about fifteen units a day. But compared to a real type 1 diabetic, who needs to… [before the transplant] I needed 54 units… in the winter, and 35 in the summer. As a boy. And now I take… between 10… and… 17 units a day… And so- but I have swings that are much more contained, as maybe the peak and the hypo, … I get to 40, I get to 250, but they don't last long, and when I make the corrections, …and as if I had a magnet attracting… glycaemia towards decent values. (Francesco, 51 years old, T1D, employee, onset at 3 years)

As Charmaz (1997: p. 198) pointed out: "Chronically ill men and women divide their lives into periods of illness and non-illness, crisis and quiescence, flare-ups and remissions, rigid regimens and convalescence." Narratives described by this category are retrospectively structured as illness chronologies (Ibidem), punctuated by events that, for who experienced them, are considered as particularly important. Recalling these events and inserting them into a chronologically ordered narrative served the purpose of reflecting on the different meanings they assigned to the presence of diabetes into their lives, as well as providing the opportunity for observing how, together with illness experience, the sense of self had in turn changed in alternating directions over time.

4.4.3 "Life grows with diabetes": structuring illness narrative as biographical continuity

The concept of biographical disruption (Bury 1982) has been extensively applied in research on chronic illness. As mentioned in the introductory paragraph, other concepts have been subsequently formulated in order to explain and understand diverse individual responses to chronic conditions. Many criticisms have been made: for example, as Williams (2005) observed, conceptualising the onset of a chronic disease as a disruptive experience usually entails an adult-centred model of illness, that presupposes a substantial shift from a ‘normal’ and healthy state to a state of ill-health. Consequently, it hardly describes the situations in which chronic illness is experienced from birth or early childhood, within which illness is “integral to an individual’s biographically embodied sense of self” (Ibidem: p. 103). Despite the fact that the lives of many chronically ill individuals may seem disrupted if compared to cultural and social expectation of bodily normativity, it is true that, within this third categorisation, half of participants (8 out of 16) had a childhood-onset of diabetes. In this regard, one excerpt from the story of Massimiliano might be particularly illustrative. He is a 40 years old man and he lives with diabetes since the age of 4. In his narrative, he did not talked about a “before” and an “after” illness, yet it only included the memory of his life as it was in his present at the moment of the interview – that is, with diabetes. In his words:

> Before, if I am not mistaken, what you asked me was (…) what changes between before and after. You’ve, you’ve introduced this topic. And… mmm… what I can tell you is this: as far as I’m concerned, …since I had it when I was… 4 years old, I can’t talk about the version /previous version/ (laughing). So eh mmm eh… I’ve thought of this many times, I’ve thought of this thing, mmm and many times we discuss this also… Heatedly, among us [diabetic people], and mmm what …I would not be able to imagine a situation apart from the one I am in. It’s as if you asked a… A blond guy with blue eyes, (…) a blond guy with blue eyes such as myself [the interviewee has brown eyes and brow hair] – you see? – he could not tell you (he laughs) which one it is… and whether he would feel better or worse, or whether he changed for better or for worse, in the [other] condition. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Similarly, Alessandro, a 46-year-old man who was also diagnosed at 4 years of age, said:

> Being very young, I mean, at this point, for me it was an overt thing, I didn’t even (…) So I didn’t… and maybe if you have it when you’re twelve, it’s different. [I remember] very, very little. For me it’s always been this way. There… There has not been a different condition. (Alessandro, 46 years old, T1D, employee, onset at 3 years)

Analogously, the story of Martino – a 34-year-old man who experienced diabetes from the age of 8 – well illustrates how the onset of illness can be narrated not as a disruption but rather as an event experienced within an on-going life that does not change in its overall direction. Martino in fact described diabetes as an integral component of the biographically embodied sense of self to the point of qualifying it as "normality" since its onset. This can already be found in the *incipit* of his interview: he was diagnosed after a period of being unwell, and despite the initial distress due to the hospitalization period, he reported having come to terms with his new condition almost immediately. In his words:

> So. Shall we start from… when I got it? I got it in '92, we found out on the 31st December of '92… And after a long time of pneumonia and whatnot, I carried it with me until we understood a cure, …and the doctor tried… the test, the kit, the test… and we found that I had 890 of glycaemia …brought me straight to the hospital… and from that moment… My life with diabetes began. (…) They let me get out of bed after a week of drips and whatnot… I remember the pain of the drip… And broken veins everywhere, and… so yes, that was… a tough start… but (…) I had always lived in normality. (…) All considered, I accepted it well, maybe because I was very young… I accepted it… Easily…
> **Mmm, do you remember when they told you that it was diabetes, how you reacted?**
> …Well, in that moment, they told me in hospital: "Because you have diabetes" …I wasn't very awake, because with the high level of glycaemia, like that, I was very young, I'd been taking antibiotics for days, so… Maybe I didn't- …I didn't even think… I accepted it normally, (…). Maybe it was more critical for my parents than for me. (…) We can say that my life has begun with diabetes so I would not know.., I mean… Since 8 years onwards with diabetes, so life grows with diabetes, that's it. (Martino, 34 years, T1D, farmer, onset at 8 years)

People that received an early diagnosis learned to live with diabetes symptoms and with its treatment, and they organized their lives incorporating and normalizing such practices. Illness accounts that could be categorised in this narrative type had in common the recurrent use of discursive strategies that minimized the disruptiveness of diabetes upon their everyday lives. To some extent, for them illness had become predictable (Charmaz 1991) and incorporated, thus living with it was often reduced to routinized practices of self-management that overall did not alter their everyday routine. I asked to Martino: "When you went back home [from the hospital] do you remember how… How the routine changed?". Despite the fact that he had always followed a specific dietary regime (as we shall see soon), he answered:

> Well, "changed"… I've always lived in normality. I still ate the same food I ate before… There only was the problem that I had to get my injections before eating, check the glycaemia, but as far as eating is concerned, I didn't have particular problems… Quite the opposite… I still behaved like a normal person, you see. (Martino, 34 years, T1D, farmer, onset at 8 years)

A similar discursive strategy can be found in the words of Pietro, a 27 years old musician with type 1 diabetes since the age of 16, who stated:

> In fact, I didn't… I never changed my lifestyle. Honestly (he laughs). Because, I dunno, …I've always felt fine. And I've always been calm. From that perspective…In fact, I mean- …even- even more than joking, I mean, it was actually something… Extremely normal… An incredible normality, you know? (Pietro, 27 years old, T1D, musician, onset at 16 years)

The narratives that can be placed within this category did not only include participants with a childhood-onset. In fact, there were also a number of people with an adolescence or adult onset. Another characteristic of these narratives is that they described a mostly unchallenged everyday routine, whose retrospective reconstruction did not report any significant changes. Within such accounts, diabetes was not described as causing a fracture at the moment of the onset nor over the years: symptoms were properly monitored and diabetes-related health problems were mild or absent. A fundamental aspect that allowed integrating the illness within one's life without significant interruptions was that of working in a context that actually made it possible. In all 16 cases, participants' jobs had high or low demand, but all of them guaranteed a high control of daily time scheduling freedom. For them this meant being able to accommodate time and tasks depending on illness needs without incurring in negative consequences.

One participant benefited from the possibility to be employed as included in sheltered groups, this way finding a job that would match his needs. In his words:

> Let's say that I looked for a job… That possibly wouldn't have been too… Not too tough. For example, a job as a factory worker or at the mechanical presses would have been too… It would have been critical, because the [glycaemic] ups and downs… more than anything the downs, it's not too much the ups of glycaemia, but the hypoglycaemias… They are particularly

> critical. And let's say that I took the first job that… That chose me, and more than anything, mmm they selected me as an… Eh, as an invalid. I am a civil invalid with the minimum, with 46% due to diabetes… (Edoardo, 53 years old, labourer, onset at 3 years)

Another commonality of these narratives is that illness is represented as not affecting – for different reasons – their actual possibilities of experiencing the world. Unlike Edoardo, who chose a type of job that was specifically considered to be more appropriate to live adequately with his illness, Pietro led the eventful life that is customary of artists, in which not only diabetes did not influence the working hours and rhythms, yet it constituted within itself one of the many elements of eccentricity that characterised his presentation of the self. In his account, Pietro distinguished the continuity of his everyday routine – with its erratic and unpredictable features – with that of diabetic people whose onset has been particularly disruptive:

> …I've heard of men, …who stopped working [because of diabetes]. Maybe they had tough jobs, …and I know that it's not… maybe people who had diabetes further on with age, I know that they stopped working. (…) …Then, it's also true… that I have always… I've always studied… and been a musician. So… I've never worked in a factory, in a construction site, I've never... Knocked down walls, or built houses…
>
> **...And still, being a musician is quite- I mean, it requires a lot… Of energy…**
>
> Yes but eh, it's the context that's different, you know?… In the sense that… I mean, …of work, aside from teaching. Which is something… more standard. But as a job, going to make money in… a place where there's food and drinks… So the context is completely different, because… You need to have professionalism while playing, but… the behaviours you have, …are not- not- not standard. Like those in- in the professional life of anyone else. Because any weirdness of yours, peculiarity, …comes and stays, you know? It's seen as… as something that… it goes together with the fact that you're playing. So it's a completely different world, yes, from that point of view. I think that someone who is a builder, …or maybe who has an eight-hour shift in a factory, actually, if they have diabetes, …a treatment, …I'm not saying a special treatment, but one that considers some of their… the difficulties that they can have, and… maybe they- would go, they would go there, yes. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Within these narratives, diabetes is represented not as a burden or as an intrusive illness, but rather as a specificity that accompanies their existence without infringing the sequentialily of their everyday life. As Martino stated:

> Well, for me it's a nuisance, I mean (…) I live it as a nuisance. I don't see it as illness, or that it is. Because I still see that I live normally… So it's not-not- it isn't a problem that I'm ill, or that it's… Yes, there is, this problem is here, full stop. It's a nuisance, that's it. …For me it's a nuisance and …illness, [for me represents] worse things, let's say… I see- see it as a nuisance. (…) In my case, eh what a person… Who doesn't have diabetes does, I do it too. (Martino, 34 years old, T1D, farmer, onset at 8 years)

Incorporating diabetes into one's life, according to Pietro, was the result of a positive approach to illness, considered as an integral part of his life. As he noted:

> And you shouldn't… be mad at diabetes… You should… act in a respectful way towards your diabetes… But you shouldn't see it as- you see, if it is seen in a negative way, it becomes an enemy. It shouldn't become an enemy, …it has to be a thing, that you know it is your life, (…) you need to respect it. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Experiencing diabetes at a young age and managing a therapeutic regimen for many years results in it coming to be an ordinary part of the everyday life and permeating deeply into the sense of self. This is well illustrated in the following dialogue between Cristian and his wife:

> **Cristian:** I cannot imagine myself without diabetes
> **Wife:** He is the kind of person who says: "If there will ever be a cure for diabetes, I am not sure… [that] I would like it to live without it." /You can't imagine how often he has told me so/ (she talks in a serious tone, looking at the interviewer)
> **Cristian:** Well, it's thirty year- I am forty… I will be forty in January, and in March it will be 33 years of diabetes… For me, it's easier to see myself with diabetes than without. (Cristian, 43 years, T1D, manager, onset at 10 years)

To maintain one's everyday life unaltered is not only an effect of a particularly indulgent illness with mild symptoms that allows for freedom in action and movement. Often participants managed to maintain their everyday life stable over time through a constant work that masked the effects that diabetes could have both in one's own sense of self and in their social interactions. Once diagnosed as suffering from diabetes and thereby becoming "diabetics", participants had to confront matters regarding information control. As Massimiliano pointed out:

> …Sometimes I think… Well, surely it’s possible that this [the management of illness] (…) …maybe one… one difficulty, …not only to deal with diabetes itself, but… to face life outside diabetes, which is… surely… the… the major challenge. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Massimiliano, who at the moment of the interview worked as a researcher at university, recalled how the issue of information control was something that had been specifically addressed from his parents since the onset, which, in his case, took place when he was 4 years old. In his account, he recalls that until the end of his teenage years, he mostly used “passing” strategies in order to avoid his social identity to be spoiled by the stigma associated with illness. This way, his routine could continue unaltered, just as his non-diabetics friends. In the first segment of his biographical account, he drew a difference between his private and his social identity, where the second was characterised by muting the effects of illness within his social interactions:

> So… eeh mmm… my father was a soldier, my mother, even worse, …and mmm… they obviously, eeh, feared this thing, …and mmm they told it, obviously, to the families of the children next door, I mean… they kind of knew each other, but eh mmm let’s say that they had, …from my point of view, the… decency, … to make me choose whether to … say it and… document it or… eh mmm …I’ve always… maybe wrongly so, I don’t know. I’ve always kept it to myself, this thing. (…) And I exploited, let’s say, I’ve kind of always exploited this thing that [diabetes]… wasn’t… was never visible, right? And this is surely, … the… the most important aspect of the distinction you talked about at the beginning. It’s not much the fact that … eh your awareness of being different, you have that, because you know it. But it’s how others see you that… Surely is a decisive thing. And in my case, I exploited it fully. (…) With… with friends, it never happened that I [would say]: “No, I have to go take my insulin, now that I’ve eaten.” No, it wouldn’t happen. I would get up and go to the toilet, or wherever, and I took it anyway. And then I’d come back as if nothing happened. (…) Not because… Because I was embarrassed, but not to eh… eh not to burden the others with something that, after all, I had to solve… And mmm… and… and the same, … even more so, in relationships with… with… girls, with other people, with people with whom… let’s say, with whom I wanted to be with, with friends that were more… mmm … mmm I wouldn’t… I would have never, eh let’s say, if… We had to go out to eat a plate of pasta, at… xxx (name of a mountain), no, eh… others didn’t have to worry about what I had to eat, and if I had to eat one thing instead of another. I ate… what I had to eat, full stop. The others did… The same. (…) And this, let’s say, helped me quite a bit, a lot, to… Have a good awareness of … of my abilities, no, of my possibilities, and also of… maybe, let’s say, also to control it, …with more… more decisively, … no, … without waiting for… eh mmm…

> someone to help you. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Impression-management strategies changed when he became a University researcher. On the one hand, this job was highly demanding in terms of performance expectations and efforts, but on the other hand, it allowed for high control, as far as managing his working hours was concerned and, therefore, also as far as diabetes itself was concerned. The stability of a permanent job acted as a protective factor that made him less vulnerable to the appraisal of others. In addition, Massimiliano referred to the inclusive environment that surrounded him at the workplace, that he counterposed to other "less cultured" work environment where social (diabetic) identity would probably be stigmatised:

> Well now, okay, now… things have changed, because everybody knows it, I talk about it (…)
> **And at work, how… how do you handle your diabetes? …How… do- do you measure, …and the insulin…**
> [In an] untroubled [way], yes, yes, …I measure, …obviously, …I don't do significant physical activity, (he laughs) and there are no significant changes as far as blood sugar swings are concerned, and this is an advantage. Because all considered… I manage to maintain a… a… relatively good control. …(…) every day… in… normal, everyday life, I don't have particularly traumatizing moments, no. And most of all …I can manage, I am lucky I can manage myself, …at least for the time being, eh, with no problem whatsoever. (…) …Now, even in this sense, the culture maybe of who stays in an environment with other people, …not only, …eh… sensitive, from a humane perspective, … but, …also intellectually… well-prepared on many aspects. No? So … eh mmm… the… environment is full of … eeh mmm culture, then, it helps a lot, …what… eeh mmm… to understand, to have the necessary sensitivity. Also… if you have to get informed on some things, … you ask them directly, eh, or … you go, you get informed, eeh… eh. [While] in an environment that is a little more… eeh mmm… less cultured, it could obviously be more complicated. I mean, yes. This is true.… This is true. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Martino's job is very different from Massimiliano's: he is a farmer. On the one hand, his job is highly demanding too – in this case, particularly as far as physical effort is concerned. What they do have in common is the high decision latitude expressed in terms of the freedom in organizing their working hours. After middle school, Martino decided not to go on studying and, instead, joined his family in working as a farmer. The family context allowed him to manage his illness as well as possible and to have sufficiently favourable conditions to make diabetes “disappear” from his thoughts during the day. He incorporated illness related practices in its daily routine and in this way his day rapidly flow, without having to ask for any permission to take a break, or for managing his condition:

> **…So, your teenage years, after middle school…**
> Well, I started working straight after middle school, in my parent’s farm, and… I worked normally… A normal life (…) …During work, well, working on the farm with my parents, so… I can manage my own times…
> **But what… What is your main occupation? If…**
> …We have livestock (…), so feeding the animals, and plus cultivation. Yes, a little tough. Sometimes at night we work, eeh… Work in the fields, at night, but sometimes I manage…
> **Mm-mm… Diabetes often requires… A certain regularity, right? You still manage to…?**
> Well that, that is something I sometimes struggle with, because it’s a job that doesn’t have hours, regular hours, and fixed… sometimes you finish in the evening at 8, other times at 5, there is no fixed schedule. (Martino, 34 years, T1D, farmer, onset at 8 years)

The challenge of the variable and irregular working hours and tasks required by the farm job are compensated by the regularity that structures the rest of his daily routine. Below, an illustrative excerpt of his narrative where he described part of his “typical” day:

> So, in the morning my alarm clock goes off, …at a quarter to six, I get up, (he laughs) every morning my alarm clock goes off at quarter to six. I get up and [have] breakfast… Breakfast with milk and biscuits, anyway… It’s 68 carbs, more or less. (…) Anyway I am a person who more or less… Always eats the same things. Mmm they say routine… Is monotonous. Ok, …but in my case, routine makes me feel good. Because I know… What I have to do, what I don’t have to do… And, but also if I break the routine, I don’t panic, that, you know. (…) However, let’s say, to do the simplest thing, you follow the routine. (…) I get up, I check my blood sugar… And I take my insulin, breakfast with milk and biscuits (…) and… At quarter past six, I’m at work, because I have to walk 30 metres to go to work, so I’m at work, (…) first of all, we take care of the animals, until 9 a.m., half past eight, nine, and then we work in the fields outside. (…) …Always walking until midday, and we walk, and …In any case, until nine, it’s a rather physically demanding job, because we lift the sacks, and… [engage in] physical work. (…)
> **And if you happen to experience hypos during work … (…)**
> Well, aside from the fact that, as I said, I’m- … I’m there working with family, so… In fact, I feel, if I feel the hypo, I go …Drink my juice, then when it’s over, I start again. I don’t have the problem of a boss, so yeah. It’s an advantage. (Martino, 34 years, T1D, farmer, onset at 8 years)

The organisation of meals is fundamental: also in this case, in Martino's account routine seems to prevail. In order to minimize the effects of illness into everyday life reported maintaining a specific dietary regime, with carbs quantified food (i.e. he talks about "90 grams of pasta") that made glycaemia levels predictable and reduced the risk of hypoglycaemic crisis. His mother organised and prepared the meals, and took care of food "rituals" for a specific balanced diet (e.g. such as the rice, which was drained immediately after cooking in order to remove the starch that would raise the blood sugar levels of his son). His mother prepared specific food for him alongside the preparation of meals for the "non-diabetics" members of the family, with a very gendered division of roles:

> … At quarter past twelve, half past twelve, I go home, and I check my blood sugar, I take my insulin again, I eat… my plate of pasta... it's 90 grams of pasta.
> **What kind of pasta?**
> Normal pasta. I don't… I don't eat whole-wheat pasta, or the one for diabetics. Normal… And then I eat my second course, eeh meat, or… or fish. I prefer meat, because with fish my blood sugar tends to go down. Because it has less fat. I always have a second course, though… either chicken, beef, there's always meat, with vegetables, (…). That's my lunch, in total it's 92 carbs more or less… I always eat at home, with my family.
> **And your family, they eat the same as you, more or less, or do they eat other things?**
> My family, well. Eeh… the second course is just the same… The main course… (…) Mine is weighed.
> **… And mmm usually, … who makes… prepares the meals?**
> Well, my mom does it, she prepares- …my mom prepares lunch. She knows, because my pasta, my 90 grams, she has them cooked aside. She has them cooked aside, so she does it aside, she makes my pasta aside. (…) I've never followed my diet precisely, never have. [Then] after lunch, usually I take a nap until two, because otherwise… it's tragic (he laughs) (…) and at two o'clock I go out, we work in the fields a little more, or another kind of work… Mmm work in the fields varies from… fixing… fixing equipment, it's tough work, the same as in the morning, …at seven in the evening, if there's something to do, in the summer, when there is something to so, the day becomes longer… until we've finished, and we're tired (…) yes. Eight… quarter past eight, half past eight, we have dinner… (…) … I go home, check my blood sugar again, …I normally calibrate the insulin pump… And I eat my 90 grams of white rice… Every evening, you could say. Yes, because I'm used to eating my white rice every evening, me, if I don't have my white rice, it doesn't seem like I have dinner. The others tend to eat… either pasta, something else, because when I have dinner, the rest of my family has already had dinner. Because maybe they have dinner at half past seven, eight. I might stop working on one thing or the other, … I always have dinner half past eight, nine.
> **… So your mom prepares it and leaves it there for you, or…?**

> She always prepares my rice aside, she leaves it there for me, when I arrive I eat it. But the rice is not the usu- well… She- she doesn't- doesn't cook it in the usual way, yet before draining it, she… she cools it down with cold water, inside a pot… Then she drains it, she washes it, … and it, I- I eat it… even if it's just been drained, but still cool, almost cold. Because… when washing it- I mean, when cooling it down quickly, you block the starch. Which- … they raise your blood sugar during the night. (Martino, 34 years, T1D, farmer, onset at 8 years)

One thing that should be noted is that, within this category, all interviewees worked in an occupational context in which the "costs" of the visibility of their illness was not excessively high, and being visible as diabetic individuals would not have compromised their career.

Another interviewee, Pietro, gave an account of his everyday life that – a part from the basic structure of biographical continuity – was different from that of others. Although in all 16 cases diabetes was not represented as a disruptive experience, usually participants proposed a narrative characterised by the presence of a highly structured everyday life. On the contrary, in the case of Pietro the element of biographical continuity was given by his unregulated everyday life which characterised both the narrative of his adolescence as well as the narrative of his adult life: it is the account of the hectic life of an artist, in which the illness is marginally considered alongside his multiple activities and diabetes self-management is almost cut off in the presentation of the self that he proposed during the interview.

When we met for the interview, it was 5 p.m. in a summer afternoon. He said to me that he just woke up, because the previous night he had worked and partied until dawn in a town by the sea. While we were walking towards his house, he stopped by a grocery store and bought some beer cans. The interview took place in his house, were he had breakfast with a bitter coffee and were he accompanied the narration of his story by smoking several cigarettes. This was the essence of how he represented himself in his biographical account: an everyday routine without rules and without diabetes-related restrictions. His illness self-management at the time of the interview was reduced to insulin injections that were performed automatically, as an incorporated set of practices, whereas he avoided measuring his blood sugar levels because he trusted his bodily sensations. In his words:

> **Do you want to… tell me what is your typical daily routine?**
> Well, I don't have a daily routine… I mean, a daily routine fundamentally does not exist, because you're never in the same place… So I never eat at… normal times. I mean, for example, today- now I still haven't had lunch. Very wrong- I know, yes, it's wrong, …but I was hungry this morning at 5 a.m., I'd worked all… all night, I hogged a delicious Ligurian focaccia thingy, (…) and then I didn't have lunch, for example. (…) Eh, if I look at one of the past few days, (…) these days have been really… For example, Saturday and Sunday I played [in a concert]… Eeh.… I didn't sleep, … neither Saturday night, nor Sunday night. Monday morning, I went to sleep at 10 and I woke up at 2, I ate at 2, then we had to take back some- some speakers, very heavy stuff, to a service, so we left, we went to unload these huge speakers… I came back… I had dinner, at a normal time, and then I went to sleep, really late, obviously (…)
> **And in all this, how did your diabetes…?**
> … Well, it didn't come up… It didn't come up as a problem (…)… and plus, I have too many things on my mind, so …I tend to forget it a little.
> **And did you take your insulin, or not?**
> Yes, yes, but it's automatic… It's not… it's not that you forget… it's not that you forget. But the insulin is an automatic thing. I mean, it's not that… it's not as if you forget to take it… Because it's something so… so… that it's like that, … you do it … regardless of… of anything. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Despite the fact that diabetes requires constant monitoring, despite the risks associated with blood sugar swings – that could even be fatal –, despite the need of regular visits to the diabetologist, and despite the risk of health complications that could also become disabling, often the difference between this group of participants and other non-diabetic people has been discursively minimised to daily pharmacological treatment, as Pietro suggests in his narrative:

> …Then anyway if… I mean… I can have coffee and not take my insulin, I can eat a brioche… And take my insulin. What makes the difference is that if every morning you eat a cappuccino that's this big, a brioche that's full of sugar and jam, …I can take my insulin, and it's bad for me, you don't have diabetes, …but it's still bad for you too… So all in all, …the only difference is that… The only one... In essence, you have your insulin in your pancreas, and I have to take it from the outside, but then the effects of things are just the same… (Pietro, 27 years old, T1D, musician, onset at 16 years)

In order to reinforce his position of a "successful diabetic," who had embodied the illness without suffering its destabilising effects and without altering his everyday life, Pietro compared his approach to an extremely opposite one: that of middle-class women whom he encountered at meetings dedicated to diabetic people. As opposed to him, in his opinion they had unnecessarily turned their life upside down because of diabetes onset, whose daily management was from him depicted as some sort of numerical obsession:

> But then the… Problem is that (…) your illness becomes your life… And not the other way around. Because the other way around, it would have an excessively philosophical taste (he laughs). But your illness kind of becomes your life, …because you have to really be… if you wanted to be perfect, (…) and to be… excessively controlled, and not to have any problem… (...) These forty-, fifty-year-old ladies, these little ladies who live around here [he lives in a little rural town], who care a lot… only think about themselves, no, …and about their own family, in their own house, …they fall into depression, when they get diabetes. They fall into depression, and (…) for example… [they] call an ambulance for hypoglycaemia, after you've had diabetes for twenty years, it's pure madness, …and there's also… I have heard it told like this… I think… I mean, it's a basic anxious thought, no, to think about… I maybe underestimate certain things too much, but they …instead, they really see them, these ladies… (…) I mean, I couldn't care less if after you've done 300 metres on foot, on a Saturday morning, with your poodle, …you measured your blood sugar before leaving home, [and] it was 74, you came back, it was higher. "But why??" [they ask themselves]… Well, there can be a thousand factors... Instead, the questions they ask are those: "Ah but I went for a walk, like you told me" (…) "but when I came back my [glycaemia] was higher than the one…" it's an obsession for this numerical value.
> **… And you don't have the obsession for this value?**
> I eeh… honestly, in the past months, …I haven't even measured my blood sugar levels. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Something similar – the contrast of an "incorporated" and integrated approach to diabetes to an "obsessive" and disruptive one – can be also found in Martino's account, who, in turn, compared his approach to his condition to that of an acquaintance of his:

> I know a girl (…) and… she completely lives a different life than mine. She is terrorised… completely, I mean. Completely… You tell her: "Let's go out for a walk", she replies to you: "Oh my God, I have diabetes!" …Otherwise her walk is: "Okay, let's go, but I'm eating ice cream [before] because I have diabetes. Otherwise my [blood sugar] levels go down." …And: "I won't do this, what, are you mad? I have diabetes." …If she has to go out, when she has to get the shopping, she goes always the same way, because she had realised that going the same way, her diabetes doesn't bother her. (…) We went away [together] for three days -as friends I mean- … And …I've- I took- I tried to take it, …normally… But she made me anxious like crazy,

> like I’ve never had such anxiety in my whole life. (…) In the morning I told her: “Shall we go have breakfast?” … [She replied:] “What? You must be joking, going out without having eaten anything before??” “I mean, we don’t have to walk for 50 kilometres, we’ll go to the bar under the hotel, and eat” “Oh, but, you know…” And nothing, so she ate- she would have a snack in the room and then we’d go out. (…) The three days I spent… away with her… for me it was stressful… For me it was very stressful… Because I don’t live it like that… I mean, I live… a normal life. (Martino, 34 years, T1D, farmer, onset at 8 years)

Within our society, individuals are expected to present themselves in a proper way, in order to fulfil social expectations and in order not to be considered as “different” and thus stigmatised. Nevertheless, describing one’s own everyday life as mostly unchanged after diabetes did not preserve participants from experiencing some degree of stigmatization, both for being “different” and for engaging in a highly stigmatising practice such as performing injection in public. Overall, participants in this third narrative category described themselves as being resilient to discrimination through the enactment of different coping strategies. Martino gave an account of what it was like for him to experience diabetes-related stigma during childhood, despite him engaging in the same activities of non-diabetic classmates:

> ... It was tough, ... with my classmates... Because they saw you in a different light. They saw you as an ill person, the weak one of the class, ...so there I, eh, they made me uncomfortable, making fun of me, and... like ...eh “You’re a drug addict”, “You need to take drugs” I mean, ... at the time, those things... I have to say that lately this thing has changed a lot though. Because before, even in my town, out of 2000 people, there were only two of us, ...now out of 2000, it’s eight of us, eight, nine guys, who have diabetes. So it’s changed. But at the time, when it was only two of us, it was tough. There wasn’t a good knowledge of it. Especially at the beginning... Until later, during school, ...we studied the human body, the diabetes pathology came up, pancreas, studying it then (...) my classmates understood my situation, ...but by then... let’s say that the discomfort that had been created (...) after, I was always minding my own business, ...although, as I said, if I had to play football, I did it, if I had to play, I did it too (...) (Martino, 34 years, T1D, farmer, onset at 8 years)

Something similar also happened later on, when he was older, when in certain situations social relations were interrupted, according to his narrative, because of diabetes:

> ...So I came across relationships that... excluded me from certain groups of friends, because of that reason, ...when- when they found out I was diabetic, [no] more calls for Saturday evenings, gone from one day to the other, people were gone. (...) Maybe scared of the problem, people who are scared of the problem, and in order to avoid it, they remove- they remove the problem, remove the person, ... (...) ...I was excluded from groups of both male friends and female... somebody understood it, ...because they still see that I live normally, and some others, on the other hand, say: "No, I don't want anything to do with him".
> **...And this is something that... how can I say, a sensation you had? Or someone...**
> Well someone also told me, they told me.
> **What did they tell you?**
> That... I'm an ill person, they don't want to... have to do with an ill person. And ok, I said: "We'll go our separate ways", eh... This thing came up because... I found someone with my same problem, we talked, and the people who were there understood, so after that they asked me, "Yes," I said: "Yes, I have it," and they said: "Ok, then it's better if you don't hang out with us anymore." (Martino, 34 years, T1D, farmer, onset at 8 years)

One solution adopted in order to cope with stigmatization was to re-create an inclusive social context that would avoid the risk of disruption. For example, he reported avoiding situations that could made him feel "different" from the others and potentially obstacle his plans, he thus searched for possible alternatives, as it happened for example in the field of sports:

> ...Well, after six months I stopped [playing football], because my role was that of benchwarmer. Because the coach was afraid to let the kid with diabetes play. Because: "The diabetic kid cannot play because he has diabetes. If something happens, what will we do?" ... He was a little... not-unawareness of the coach. Even though, as I said... I was good at football. (He laughs) So I gave up. I chose solitary sports, ...because at least it was only me, alone, doing it. Also cycling, I go out alone, I don't have anyone forcing me to go out, or not to go out, like running. Eh, team sports penalize you a little, ...if you have diabetes. Because... it could be that your teammates see you... as the weak one of the group, ...being seen the weak one of the group, you might be left aside... and that's it. On the other hand... individual sports, it's you, and you have to deal with yourself and nobody else. (Martino, 34 years, T1D, farmer, onset at 8 years)

In front of others, one of the major challenges that diabetes brings is that of managing the blood sugar swings, which could make the illness visible against the will of the person who experiences it. When hypoglycaemia occurs, interviewees usually reported feeling numb, shaking, feeling like fainting. A recurring strategy that they reported enacting in order to maintain a "normal" performance in contexts of social interaction was that of maintaining very high blood sugar levels (for example, by eating a dessert and not injecting the insulin after), which usually did not bring visible effect in the short term. Despite the fact that hyperglycaemia is usually well tolerated when experienced, it is the major cause of health complications in the long run. To this matter, we can read an episode from the story of Pietro:

> I play, right? … One thing, which is fucking stupid, which I used to do, was before playing, … tending to assume more sugar. Because this way I don't get low blood sugar while I'm on stage. The only two times I went in hypo on stage, …I couldn't even touch the guitar, … and that makes you feel weak, that's true. Because if it… undermines what you do best, … or anyway, if you… you care at all, …about your life, you take it personally. But… then you have- you have all your loopholes, …wrong or right, we all have them, to avoid them, these things… (...) [Hypoglycaemia occurs] when I'm stressed, …and… especially during moments when you're high in adrenalin, when you have to do something because you're tense, …then, in those situations it [glycaemia] decreases a little.
> **...So when this thing happened on stage, what did you do?**
> I finished playing…Very worried, …very worried, …First thing I did, it will make you laugh… We were playing, had beers on stage, I- I saw beer as carbohydrates. So I drank that beer as fast as I could. And it helped… (…) …Let's say that normally, …eeh you drink, …your glycaemia goes up to 11, because it's all sugar, …then two, three hours after you drank, you can sink down. Very strong, and it screws you, you understand that… it's not… it's not this. In that moment, I didn't have sugar, I was playing so, whatever, …I drank it. (…) and it helped me a little. (Pietro, 27 years old, T1D, musician, onset at 16 years)

We can find another example in the narrative of Martino, that recalls keeping his glycaemia levels high in order to avoid hypoglycaemia during social interactions:

> I might have gone out on a Saturday evening, and... being afraid of being unwell, as soon as I felt a few symptoms of hypoglycaemia, I drank my tea, my juice. I kept it secret like that. Then when I got home, my blood sugar was high, but ok, I took my insulin... In order not to be unwell around people, I tended to keep my blood sugar higher.
> **So in this way you avoided having problems with hypoglycaemia...**
> Yes, you'd avoid hypoglycaemia, starting to sweat... that... I mean, [it's not as if you can] be unwell, because of hypoglycaemia, around other people, you know? Maybe it's something that still comes from school, and... Because [at the time] they excluded me when I was unwell... (Martino, 34 years, T1D, farmer, onset at 8 years)

Biographical continuity, for those who experienced diabetes from adolescence or adulthood, meant developing and incorporating a variety of "technologies of the self" (Foucault 1988) that allowed – where necessary – to conceal those bodily signs that could expose them to the stigma attached to illness. One informant, Igor, gave a particularly eloquent account that revealed the amount of "back office job" that diabetes required in order to keep –at least on the surface and in front of others – his everyday life unchanged:

> I wanted to prove that both me and the activities I was engaged with, didn't change, that is, there wasn't a before and an after. I mean, I know what I wanted to do in order to… to manage to do the same things, because if before I ate a pizza and that's it, now I eat a pizza and then there's a whole… a pre-treatment and a post-treatment. But it's something that… I handle… it's a, let's say… let's call it a back office job… But I carry on my life, I mean… my objective is to make sure whoever is in front of me… doesn't perceive this thing. (Igor, 31 years old, shop assistant, onset at 28 years)

4.5 Conclusions

Even though men's health has recently become a prosperous field of research and despite the fact that men are usually found to experience worse health outcomes than women, a paucity of research is dedicated to their experience of chronic illness and among them few have focussed on men's lived experience with diabetes. This chapter addressed the objective of exploring how young and adult men experience autoimmune diabetes, an incurable and degenerative condition characterised by a diminished production of insulin that results in high blood sugar levels and – as a consequence – in a series of altered body functions that cannot be cured but only constantly monitored and managed. The analysis of illness narratives collected conveyed a complex picture in which diabetes was experienced and understood in many different ways and its impact on participants' everyday life varied according to the social contexts in which it was lived, but also according to the age in which this condition occurred, as well as the time in life when it was experienced.

All narratives had in common a chronological structure in which diabetes experiences were ordered in a sort of "illness trajectory," which was punctuated by a number of meaningful events and (un)expected turning points. All participants described initial altered body signs (or the lack of them) that was marked as "diabetes onset": in some cases, this initial stage was experienced during infancy and their accounts relied on their parents' memories, they described themselves as mute bodies undergoing a physical transformation and their parents emerged as crucial figures that became aware and took care of it, searching for medical help. In those cases in which participants experienced diabetes during adolescence or young adulthood, the *incipit* of the narrative was characterised by a direct memory of illness onset, but still they parents were described as a fundamental presence in mediating with medical assistance. Differences were more pronounced in the case of adult-onset participants, where symptoms were more diversified compared to the other two subpopulations and they were initially (in certain cases, also *mis*)interpreted by those who were directly affected by them.

The process of diagnosis has been crucial for all participants: naming and framing unknown and altered bodily signs with a specific and well-known disease served as a cognitive tool for finding a solution to cope with it, determining the existence and legitimacy of the new corporeal condition and restoring a new balance. On the other hand, diagnosis brought a feeling of ambivalence, because it entailed finding out that the initial symptoms were not, as we are used to think, signs of a temporary and acute disease. They rather prefigured a permanent and incurable condition whose main symptoms (hyperglycaemia and hypoglycaemia) entailed a threat to their present and future existence and could not be cured, but rather monitored for the rest of their life. The process of diagnosis, for the majority of participants, was quite immediate. However, a minority of them were at first misdiagnosed and this caused greater discomfort and some difficulties. In the majority of cases, this second stage has been characterised by a period of hospitalization that, in a way, marked the beginning of the "diabetic career" and the socialization to medical knowledge. In this context, participants usually received the official diagnosis and they were taught to understand their "new" body and its different functioning in biomedical terms, as well as to constant monitor and manage diabetes symptoms through medical devices. In the majority of the narratives, the hospitalization was represented as the starting point of a "new life," where the diabetic identity began to be acquired.

The discharge from the hospital and the return to their original social context marked the beginning of a third phase, characterised by the need of coming to terms with illness in their everyday life. Adjustment processes to diabetes were described in different ways, as well as different was the way in which individuals perceived themselves as diabetic people and their being in the world, or how they managed and shaped their bodies during social interactions. Interestingly, the majority of participants reported having experienced some degree of stigma because of their condition and all of them I have analysed how illness has been incorporated into the everyday life of participants by observing how they talked about it in terms of disruption, fluctuation or continuity of their biographical trajectory over their lifetime. Many factors influenced the degree of disruptiveness of diabetes in their social routine. Among them, the most relevant ones were the social and occupational context in which they were living, the degree of (physical and psychological) demand of their occupation, and the amount of control they had for scheduling their time around their needs. Overall, three narrative types were identified: the first one was characterised by the description of a severe disruption in the embodied self, especially when diabetes symptoms were highly intrusive, or when the individual had been constructing over the years a sense of self around masculine ideals of bodily strength and competition, or even when the social context in which he lived at the moment of onset entailed low personal schedule freedom and a high physically demanding commitment.

Social routine and individuals' sense of self have been developed over the years with respect to specific bodily competences and possibilities. A chronic condition might – together with its health related complications – alter both their sense of self and the everyday life but, as happened in the accounts included in the second narrative type, these alterations could be described in terms of a temporary fluctuation within an on-going life, rather than a permanent disruption.

Participants that had experienced diabetes since birth may not have recalled the onset and their life with diabetes as disruptive, many of them in fact do not even have memories of themselves before the onset, and thus they overall depicted their social routine in terms of continuity, rather than change. Also other participants with adolescence and adult onset diabetes did not experience illness as a dramatic alteration of their routine, and this mainly depended on the mildness of symptoms as well as on the social context in which their routine was carried out.

Throughout the chapter I sought to consider, along with a biographical analysis of illness experiences, how male gender could interact with diabetes life as well as with the construction of diabetes accounts. Although this was not the main focus of this chapter, I tried to reflect on how the construction of masculinities emerged in men's accounts of diabetes: as next chapters will explain in greater depth, gender is an embodied dimension that inevitably affects how individuals engage with health and illness practices, as well as how they talk about it during interview interaction. Often, research on health and illness consider gender as a dichotomous variable merely used for the construction of sample design, implying that men and women are a homogeneous group that behave uniformly. As already mentioned in the previous chapter, gender is not a fixed entity imposed through socialization or determined by biological traits of individuals (Connell & Messerschmidt 2005). When they talk about health-related practices, participants do not only describe themselves as diabetic bodies: they also inevitably talk as sexed bodies that are embedded in a web of hierarchical gender social relations. Gender, as well as social class, age, sexual orientation, dis/ability and ethnic origin are intrinsic and inextricable dimensions that co-construct illness experience and that thus deserve to be properly considered when analysing biographical accounts. Designing a sample entirely composed by male participants of different age that live in different social contexts allows devoting more attention to the intersection of illness with gender dimensions, to which next empirical chapters will pay closer attention.

From the analysis of the empirical material proposed in this chapter, gender emerged as a relevant dimension in different circumstances. As already found elsewhere (i.e. Favretto *et al.* 2007), all of childhood-onset participants in this study referred to their mother as the principal (often, the only) responsible figure for childcare and illness management; more generally, mothers were often described in participants discourses as the obvious and principal carers for children needs.

Another example is that, in many cases, participants had the tendency to distance themselves in their discourses from the realm of the "sick" identity by pointing out that, before the onset, they were unfamiliar with blood tests or medical examinations, and often specifying that they used to be reluctant to going to the doctor, even when initial symptoms arose. In this way, they discursively fulfilled the masculine imperative of independence and resistance to pain. Often, diabetes was held responsible for weakening the body and precluding physical confrontation with other male peers during infancy and adolescence, thus imposing a "marginalised" masculinity. As already observed in other researches (i.e. O'Hara *et al.* 2013, Broom 2010) another key context for masculinity construction was that of occupation, which had emerged as a main theme in participants' accounts for both the challenges that diabetes imposed in maintaining participants' occupations and for the difficulties that their occupation entailed in complying with diabetes daily self-management. Participants often highlighted the relevance of their work for their sense of self, mainly describing themselves as privileging career and working overtime over a proper diabetes self-management; or, in other cases, they emphasised the loss of self that was caused by job loss after diabetes onset. Diabetes has challenged masculinity construction with the stigma that is attached to it: hegemonic ideal of strength and potency are put into question as to the debilitating nature of this condition that could affect their everyday performances as well as sexual encounters, that in contemporary western societies is considered as a central part of contemporary masculinity (Tiefer 1986, Ferrero Camoletto & Bertone 2016). Next two chapters will further investigate the complex interplay of gender with illness experience.

Chapter V

Doing diabetes, doing gender: embodied masculinities in the context of chronic illness

5.1 Introduction: understanding diabetes as an embodied experience

The previous chapter analysed men's experience of autoimmune diabetes from a biographical and interactional perspective, exploring how they (re)constructed their everyday lives and (re)negotiated their selves after a potentially disruptive event such as diabetes onset. With the aim of deepening the understanding of men's experiences of this chronic condition, the present chapter intends to examine diabetic men's accounts by focusing on the intersection between male embodiment, masculinity construction and illness management.

Analysing male embodiment and its relation to health and illness experience implies a focus on male bodies, on how they are at the same time material and representational (Robertson 2010), and on how they are simultaneously shaped by and shaping different dimensions of social life such as institutions, culture and social interactions (Ghigi & Sassatelli 2018). The lived experience of disease entails the construction of a body that is, as the same time, influenced by both organic and social processes: it is the result of concrete, historically situated and culturally defined processes that vary depending on different forms of societal organization and classification (Ibidem).

5.1.1 Health society and the construction of the healthy citizen

Contemporary society is defined by Kickbusch (2006, cited in Greco 2009: p. 14) as "health society": in fact, health is something that is expected to be produced and reproduced within all the field of everyday life, and it is universally endorsed as an uncontroversial value to be sustained and promoted (Greco 2009). What are the norms that inform the "healthy citizen"? Which are social expectations that influence male bodies that do or do not conform to healthy normativity? What kind of masculinities are performed, and how, through health-related practices? In this respect – although Foucault made few references to the issue of gender in his work – the concept of *biopower* (Foucault 1976, 1978) might be particularly helpful: it describes "a mode of the exercise of power that recognizes the value of life (and thus health) as a resource, and uses it as a principle of legitimation" (Ibidem: p. 16). In contemporary Western societies, medical authority determines what should be considered as "health" and what should be considered as "pathology," it regulates how a body should be disciplined in order to maintain health or properly governed to manage illness. Contemporary medicine had created the recent categories of the "disabled," the "handicapped" and the "chronic patient," which had replaced the broad category of the "anomaly" used in the past (Arney & Bergen 1983). Once, "anomalies" were marginalized or detained, they were feared and, in some cases, spectacularized; anomalous bodies, within contemporary health society, are instead normalized and subjected to disciplinary processes that ensure their maintenance, their minimum expenditure of public resources, and their ability to "ensure a healthy workforce" (Foucault 2003: p. 239). As Foucault noted: "The play of code and decoding leaves room for chance, which, before being disease, deficit or monstrosity, is something like perturbation in the information system, something like a 'mistake.' In the extreme, life is what is capable of error." (Foucault introducing Canguilhem, 1978: p. 22). Out of error, contemporary medicine created the subject, an "individuated collection of errors" (Arney, Bergen 1983: p. 19) that is disciplined and cured through the incorporation of social and medical control. In our cultural context, people are in fact induced to constantly scrutinize and inspect themselves in order to shape normative bodies and present successful selves according to what is considered as "normal" in their specific social contexts.

Diabetic bodies might be considered as an exemplary case of how the medical gaze construct "healthy bodies" through the development of standard practices of medical care that are incorporated by individuals and that affect the way they understand and discipline their bodies. Autoimmune diabetes is a serious chronic condition, whose symptoms can threaten individuals' survival. Since there is no cure for it but it can only be managed in the everyday life, usually diabetic individuals refer to a medical model of cure. Contemporary self-management of diabetes consists mainly in constant self-monitoring, medical treatment, healthy eating and physical activity. Medical recommendations place great emphasis on individual responsibility for diabetes control (Broom & Whittaker 2003) and for the prevention of its health-related complications. Medical discourses on diabetes self-management are dominated by the imperative of control, body discipline, and self-surveillance that are, in a way, the exacerbation of the "good and healthy citizen" appropriate form of behaviour. Self-surveillance is constructed on the cultural assumption that certain behaviours and attitudes are dangerous or unhealthy to the constitution of the individual as a subject. Diabetic individuals, as well as non-diabetic "good and healthy citizens," embody those assumptions and discipline their bodies so as to maintaining or improving their health and well-being. Contemporary self-discipline society constructed the individual *at risk* (Lupton 1995): in fact, everybody is expected to conduct a healthy lifestyle in order to avoid diseases or, if they have one, to control it properly. Conversely, there is an implicit disapproval of bodies that are not properly managed, "fit" and "healthy," and this implicitly assumes a moral dimension of health practices. In fact, healthism "situates the problem of health and disease at the level of the individual. (…) Further, by elevating health to a super value, a metaphor for all that is good in life, healthism reinforces the privatization of the struggle for generalized well-being" (Crawford 1980: p. 365).

In the case of diabetes, body discipline and compliance with medical treatment allow the control of distressing symptoms such as hypoglycaemia (low blood sugar levels) and hyperglycaemia (high blood sugar levels) and to delay diabetes-related health complications (e.g. renal failure, blindness, heart disease etcetera). In this respect, Anderson (1995) observed that although healthy dieting and undergoing medical treatment may be perceived as a submission to medical authority, this may alternatively be also conceived as constructive attempts to reduce the likelihood of potential suffering. Nevertheless, such norms of conduct might be embodied and become also a way of thinking, lenses through which individuals understand their bodies, and specific “technologies of the self” (Foucault 1988) that inscribe a specific knowledge on living bodies.

Foucault (1991) formulated another useful concept that may help in the understanding of diabetic men’s experiences: that of governmentality. The disciplinary power seeks to render bodies docile, healthy and productive through techniques related to the discipline of the self, through systems of surveillance, hierarchies, mechanisms of control and coercion. It could be argued that people with chronic illnesses in general, and diabetic people in this specific case, “may be subtly coerced into self-care and self-management processes, so to prevent deterioration and reduce the demand on resources” (Wilson 2001: p. 139). Drawing from this perspective, diabetic individuals might be conceived as subjectivities that need to manage themselves in specific ways. Taking extreme examples, the well-managed diabetic jogger is a responsible citizen, whereas the overindulgent, decompensated diabetic individual is a moral deviant, an actual or potential burden on the state.

The way the chronically ill is governed in contemporary society recalls the broader demand for a “care of the self” that characterizes contemporary society (Greco 1993, 2001; Cruikshank 1993) where health is perceived as a responsibility of the rational individual, and the result of their lifestyle and their consumption decisions. Tastes are, as Bourdieu (1984) has broadly illustrated, standardized according to individuals’ social position, and this also includes health practices. As Sassatelli (2007: p. 85) observed: “If we consider the health market, we can clearly see that there are very different attitudes to the body and its state of health which correspond to different forms of health service consumption. The middle classes tend to operate around the idea that they can and must control themselves, their body and their state of health, and so they generally have more medical check-ups, with the result that they effectively have a longer life span. Instead, the working classes tend to adopt a fatalist attitude, (…) with the result that their life-span is less.”

The construction of corporeality might be imagined as subdivided along horizontal and vertical axes: bodies are horizontally differentiated for gender, ethnic origin, and social class; at the same time, they are separated through vertical lines that discern the old and young, the sick and healthy, the normal and pathological (Ghigi & Sassatelli 2018). In this chapter I will focus on the intersection of two axes in particular, that of gender and that of illness, under the assumption that individuals' approaches to health and illness simultaneously interact also with other social identities and social relations.

5.1.2 Health as a gendered issue

Gender is a crucial dimension of the self that should be taken into account when studying health practices: in fact, from an early age bodies are sites of construction of gendered selves and the ways in which they are shaped over time highly influence individuals' approach to health and illness. Through socialization processes, boys and girls are taught to think about their bodies in very different ways: for example, girls are encouraged to avoid physical contact and fight games, while they are expected to minimize the use of the space with their bodies and to learn how to take care of others; boys, on the other hand, learn soon to physically interact with peers, to fight with each other and to take up public space for such purposes (Ibidem). Gender is performative (Butler 2012, or. ed. 1988). It is not a stable identity from which acts descend correspondingly: gender identities are rather constructed through time and across different social contexts, through mechanisms imitation and of social control, and through the constant repetition of normative acts that stabilizes them and that (re)produce two different and dichotomous categories: that of women and that of men (Ibidem). In this sense, "[t]he effect of gender is produced through the stylization of the body and hence, must be understood as the mundane way in which bodily gestures, movements, and styles of various kinds constitute the illusion of an abiding gendered self" (Paechter 2003: p. 69). In this respect, Paechter (Ibidem) explained the production and reproduction of gender through the fruitful concept of communities of practices (Lave & Wenger, 1991): in this perspective, femininities and masculinities regulate their practices in response to local conditions as well as to wider influences. Individuals gradually learn what it means to "be a male" or to "be a female" within particular communities that share the common intent of sustaining specific localised masculinities and femininities (Paechter 2003: p. 71). The progressive learning of masculinity and femininity results in learning a specific set of practices, which is fluid rather than fixed, and that is crucial because the sharing of such practices hold communities together (Paechter 2003, Wenger 1998).

Understanding gender as a configuration of practices does not mean that individuals can choose day to day freely how to perform their masculinities or femininities. As the ideal of community of practices suggests, individuals perform gender in ways that are influenced by social contexts in which they are embedded and by what is intelligible within the gender system in which they live. Individuals cannot avoid considering the existing power relations and gender norms: they have to confront with social expectations on an everyday basis, by conforming or challenging them. Garfinkel's (2000, or. ed. 1967) study of Agnes, one of the first transsexuals of the twentieth century, was ground-breaking in anticipating contemporary feminist perspectives on gender: through the analysis of Agnes' experience, he highlighted how gender was not an internal property of the individual, but it was rather considered as a performance, a "doing" which was accomplished within social interactions and institutional arenas, and that needed to be constantly displayed in order to receive social recognition. Drawing from this perspective, masculinity is here intended as a situated doing, which is carried out in the actual or virtual presence of others who participate in producing and reproducing specific gender orders.

With regard to men, mass culture usually understands masculinity as a fixed, natural and "true" entity that informs men's practices, and this perspective is shared across Jungian psychoanalysts, the mythopoeic men's movement, Christian fundamentalists, sociobiologists and the essentialist school of feminism (Connell 1995: p. 45) and evolutionary psychology. The "real" masculinity is intended to originate from male bodies (e. g. men are intrinsically more violent and aggressive than women) or to be an expression that derives from the nature of male bodies (e.g. child care is naturally women's exclusive domain and not men's) (Ibidem). Connell (Ibidem: p. 45) suggested that "the first task of a social analysis is to arrive at an understanding of men's bodies and their relation to masculinity."

The analysis proposed in this chapter attempts to deepen this knowledge: it does so by looking at masculinity not as an isolated object of analysis, but rather as an embodied dimension of the self that is embedded within a larger structure. Gender is a way of structuring social practice, where the everyday life is ordered according to a reproductive arena consisting of "sexual arousal and intercourse, childbirth and infant care, bodily sex differences and similarity" (Ibidem: p. 71). Gender is a social construction, a configuration of social and collective practices, it is something that individuals *do* with their bodies, rather than a natural component of their selves. It follows that, with Connell, masculinity is not a "fixed entity embedded in the body or personality traits of individuals. Masculinities are configurations of practices that are accomplished in social action and, therefore, can differ according to the gender relations in a particular social setting" (Connell & Messerschmidt 2005: p. 836). Carrigan and colleagues (1985) demonstrated that masculinities were embedded in power relations not only with respect to the subordination of women, but also with respect to a power hierarchy among men, and in this regard they developed the fruitful concepts of hegemonic and subordinated masculinities. According to Connell, hegemonic masculinity is the current most idealised form of masculinity that organizes the way boys and men perceive and act upon themselves, and it structures the social expectations about them. In our contemporary Western social context, it refers to bodily attributes such as strength, potency, rationality, aggressiveness, self-reliance and action. In order to enjoy the benefits that derive from belonging to the dominant gender group, male individuals have to present themselves to others as a specific social being, men (Schrock & Schwalbe 2009: p. 279), and this essentially is, with Goffman (1977) and West and Zimmerman (1987), a dramaturgical task (Schrock & Schwalbe 2009). In order to be recognised as a man, it is thus necessary to master a set of practices, those "manhood acts" (Schwalbe 2005; Schrock & Schwalbe 2009) that need to be performed during social interactions and that, in turn, have an impact on the way they construct "male" bodies, on the way men incorporate definitions of the self as "masculine" and on the way gender inequality is produced and reproduced over time. As Connell (1995) pointed out, in our Western contemporary culture the physical sense of maleness is crucial to the cultural interpretation of male gender: it entails a certain feel to the skin, certain muscular shapes and tensions, specific postures and ways of moving. At this regard, "sport has come to be the leading definer of masculinity in mass culture. (…) In these contests a combination of superior force (provided by size, fitness, teamwork) and superior skill (provided by planning, practice and intuition) will enable one side to win" (Ibidem: p. 54). Sport practices symbolise competition and hierarchies among men and women, among men and men, and among normative and non-normative bodies. Body performances are symbolic and kinetic, individual and collective simultaneously. Sports – whether it is played, watched or used as a theme of conversation with other men – can be a "manhood act," a way of constructing and signifying a masculine self (Messner 1992, Schrock & Schwalbe 2009). As Schrock, Schwalbe (2009: p. 282) observed: "Another lesson for young males is that emotional display must be regulated." Once again, sport offers an opportunity to symbolise the stoicism that is requested for gaining creditability as a man: the ability to control and police one's emotions, according to the assumption that boys and men should not express fear or pain (Messner 1992). Through socialization processes, boys learn that signifying a masculine self means expressing only some of the emotions they feel, while managing and controlling the majority of them through what Arlie Hochschild (1979, 1990) defined as "emotion work," which is the ability to manage one's feelings in order to maintain specific social relations. Social expectations around hegemonic masculinity also involve feeling or expressing sexual desire for women, this way distancing oneself from subordinate forms of masculinity. It also involves "aggression and violence" and "the importance of signifying manhood through displays of fighting spirit" (Schrock & Schwalbe 2009: p. 282). Constructing masculinity through bodily performances means that men that are not able to sustain such body normativity are considered as marginalised and may face special challenges. This vulnerability may occur in the case of disability or chronic illness, when bodies fail to ensure masculine strength, self-sufficiency or independence.

In the present case, diabetic men construct their bodies with a potentially conflicting double bind: that of masculinity construction and that of illness management. The bodies of men with diabetes “serve as a continual reminder that they are at odds with the expectations of the dominant culture” (Gerschick & Miller 1995: p. 183) because the need of insulin injections for survival, the need of constant medical examinations and the potential sudden unreliability of their diabetic bodies may constitute an emasculation factor. In fact, the weakening of their bodies and the risk of losing control of themselves during hyper- or hypoglycaemia episodes threaten cultural values of hegemonic masculinity such as strength, stamina, reliability, autonomy, and invincibility. But as the literature on this issue has shown, men can construct and present themselves in a multiplicity of ways.

Therefore, it seems important to gain an understanding of how men construct and present their (masculine) selves when they are potentially unable to enact fully the hegemonic ideal of masculinity because of a chronic and degenerative condition such as autoimmune diabetes. It is interesting to analyse how they signify the practices of care related to diabetes self-management, how they describe – to a female interviewer – the specific technique of the self that they incorporated in order to discipline their bodies and control bodily uncertainty.

Therefore, drawing from gender studies and sociology of health and illness literature, diabetic men’s self-discipline and management are here observed through “gendered lenses,” and understood as a result of two crucial and inextricable dimensions of the self: gender and health. In this sense, I have analysed the “doing” of diabetes as a way of “doing” masculinity. The male body, Connell observed, “is inescapable in the construction of masculinity” (Connell 1995: p. 56) and as Evans, Frank, Oliffe and Gregory (2011: p. 12) observed, men “have unique considerations in both the construction of their masculinities and how their practices of masculinity intersect with other determinants of health to influence their health and health care practices.” In this regard, Watson’s (2000) “male body schema” (see chapter n. 2) provides a useful model to detect the different male embodiment modes in relation to health.

In conclusion, studying how diabetic men manage their condition is not only about assigning a binary state on dichotomous variables, such as whether participants inject insulin and monitor their glycaemia, whether they eat a healthy diet and whether they engage or not in physical exercises, as suggested by medical knowledge. The important question here is *how* they do or do not so, and what are the meanings that they assign to such care practices – or their lack thereof.

It has been argued (see Robertson 2007) that body self-care practices are traditionally considered as feminine, and that "health" is a realm from which men distance themselves in order to construct an adequate masculine self. However, recent literature about changing masculinities (i.e. Bridget & Pascoe, 2014, Arxer 2011, Demetriou 2001) pointed out that the dominant form of masculinity might actually change over time through the negotiation and appropriation of practices that appear as counter-hegemonic, just as those concerning body-care, or that pertaining gay culture such as gay fashion. As Demetriou (2001: p. 355) stated: "It is precisely through its hybrid and apparently contradictory content that hegemonic masculinity reproduces itself. To understand hegemonic masculinity as hybridity is therefore to avoid falling into the trap of believing that patriarchy has disappeared simply because heterosexual men have worn earrings or because Sylvester Stallone has worn a new masquerade." With this in mind, I have sought to explore how diabetic men understand, self-discipline, and talk about their diabetic bodies, and I have organised the forty accounts collected for this research in three different ideal types: the "diabetic quantified self," the "athlete" and the "free spirit." With regard the use of ideal types, Frank (1997: p. 29) observed: "Real people are not ideal types. Ideal types are puppets: theoretical constructions designed to describe some empirical tendency. Actual body-selves represent distinctive mixtures of ideal types." It is thus worth mentioning that the three ideal types identified here do not actually represent in detail actual participants' experiences, and that they might not have an identical empirical referent. The forty diabetic men's accounts analysed in this chapter were thus ordered according to a fuzzy membership function that, besides the more extreme modes of full and none membership, allowed to a plurality of more partial and nuanced sharing of the ideal type's intensional profile (Cardano 2011). This is a way of ordering a rich and complex reality such as the one analyzed here, in an attempt to overcome simplistic explanations that have informed traditional literature on this issue and, following Robertson's (2007) call, in order to further problematize "masculinity" in relation to health and, in this case, illness. In summary:

(a) *The Diabetic Quantified Self (DQS).* This ideal type describes 16 out of the 40 narratives collected. The DQS deals with diabetes-related body uncertainty by constructing a data-centric discursive representation of the self, which mainly revolves around his ability to measure body parameters, to engage in a rigorous, quantified diet regimes, and to demonstrate his competence in counting and in understanding data. Depending on the meanings that underlie these practices, the DQS is further subdivided in the *Quantified Patient*, who mainly signifies his numerical description/achievement in terms of adherence to treatment; and the *Quantified Lay Expert*, who uses self-tracking and self-quantifying strategies in order to construct an alternative expertise which incorporates medical knowledge and shapes it around personal experience;

(b) *The Athlete.* This ideal type describes 15 out of 40 illness stories, and indicates a diabetic man who narrates his engagement in competitive sport as a sort of counter-discourse that resist to medical suggestion for "moderate" physical activity and rather relies on embodied experiences of sport-related practices that are acknowledged as a learning process and shared within the subcultural word of diabetic athletes as common practices. The main goal, for the Athlete, is to use his active body as main instrument for controlling diabetes, improving its fitness and reducing insulin intake;

(c) *The Free Spirit.* The last ideal type encompasses a minority of narratives -9 out of 40- that mostly distance from the hyper-monitored body of the DQS, or from the hyper-surveilled body of the Athlete. This ideal type equates body control and rigorous self-management practices with excessive prohibition and denial, and describes the DQS of the Athlete as wretched souls, obsessive subjects that dedicate all their life to diabetes and who let diabetes define and control their routine, their bodies, their lives. The Free Spirit discursively represents his body as an instrument for experiencing pleasurable sensations, and this often entails an overall low adherence (or even refusal) to medical treatment.

5.2 The Diabetic Quantified Self (DQS)

> Every time that I eat something I perform the following operations: I check glycaemia. I mentally count the carbohydrates that I will eat while looking at the quantity and quality of the food. (…) I transform carbohydrates in numbers of insulin units. I add [insulin] units in proportion to the actual glycaemic level. I add or take off [insulin] units depending on how much I ate in the last days, depending on the physical activity I will have in the following hour, depending on how much tired I feel (…). Then I inject a certain amount of insulin units and I hope that I got it right and that I will fell fine for at least one hour. And to think that I never desired to become an accountant... Or equilibrist... (Codeluppi 2012: p. 27, my translation)

Diabetes is a chronic illness that causes body uncertainty: it implies the need of managing a series of symptoms on a daily basis, and the necessity of dealing with the life-threatening, but also "social" risks that this entails. The diabetic individual embodies illness through a process of subjectification that implies the internalisation of the biomedical model, as well as the embodiment of technical self-care practices and the ability to act upon himself and upon his social and material environment (Diasio & Cozzi 2017). The "Diabetic Quantified Self"[28] (DQS) narrates his illness experience in terms of his ability of taking control of his body, that he expresses through the constant reference to "numbers." The narrative of the DQS is in fact data-centric and relies on the belief that self-tracking practices allow to increase self-awareness and self-knowledge, and that the collected data make it possible to exert greater control over diabetes symptoms, but also over their future destinies (Lupton 2016).

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[28] The denomination of this ideal type is clearly inspired from the concept developed by Gary Wolf and Kevin Kelly, editors of the *Wired* magazine that in 2007 (Wolf, 2010) created web site (retrievable at www.quantifiedself.com, last seen 7/10/2018) where lifeloggers could share information and increase the "self-knowledge through numbers," as the subtitle of the web site promises. The Quantified Self (QS) movement main objectives are to improve self-knowledge, health and life in general through self-tracking daily practices and biometrics. Such movement emerged for self-monitoring management in chronic conditions such as diabetes, "when physicians began eliciting the assistance of patients in tracking blood glucose levels throughout the day" (Appelboom *et al*. 2014; p. 2585).

The DQS incorporated the neoliberal model of health and considers well-being and health as a personal responsibility and thus engages in a rigorous management of risk, which is realised through constant and rational practices of measurement, self-monitoring, registration and sharing of data regarding visceral processes, that are described during the interview as an individual accomplishment. He incorporates and takes to the extreme contemporary discourses of health, well-being and the body where individuals are "constructed as active consumers of health advice; as responsible citizens with an interest in, and a duty to maintain, their own well-being both to improve health and fight disease." (Crawshaw 2007: p. 1606).

The DQS usually refers to a community of practices whose members share his basic assumptions of health and illness management. He does so through the participation in virtual forums or the attendance to activities promoted by associations dedicated to diabetic people, where he has the possibility to share information and receive support from the most experienced members of the "community" that have lived the same issues and difficulties. The DQS disciplines his body through a rigorous self-surveillance that mainly involves self-monitoring and diet regimes, and discourses produced around those issues become a shared repertoire of stories for management practices (Wenger 1998). The DQS shares with other members of the "community" a common vocabulary: in fact, they mainly talk about diabetes and about their diabetic bodies in terms of "numbers." Numbers related to daily glycaemic levels, or that of the results of common blood test such as glycated haemoglobin, a parameter that "measures" the long-term control of glycaemia and – in a way – gives a concise representation of the last months ability of the individual to keep glycaemia in balance and to avoid glycaemic swings. The DQS discursively distances himself from those diabetic individuals that mismanage their condition, those that have an opposite lifestyle compared to his, such as the "Free Spirit" ideal type. As Broom and Whittaker (2004: p. 2381) outlined: "To be in control denotes power and agency, while being out of control signals chaos, madness, and moral failing."

Those numeric values were considered as the main goal to reach from the DQS, and from the analysis it emerged a further relevant difference in terms of *how* participants managed to reach those goals and what were the *meanings* assigned to the adopted self-management practices. In fact, two sub-types of DQS have been identified, that describe two different disciplinary regimes that were discursively reproduced within the narratives: the "Quantified Patient" and the "Quantified Lay Expert." The former describes those participants that talk about their bodies and the care practices that surround it through an explanatory model grounded in a medicalized understanding, to which they are compliant. They understand *illness* in terms of *disease* (Twaddle 19868) and when they talk about their experience with diabetes they mainly describe it through words that derive from medical knowledge, whose legitimacy is not questioned in its efficacy. On the other hand, the "Quantified Lay Expert" shares with the other subtype the discursive practices of talking about diabetes experience and self-management in numerical terms and in giving high relevance to the self-surveillance and self-discipline strategies that inform their everyday routines. Unlike the other subtype, the QLE incorporates biomedical frame, but he "shapes" it around his personal experience and an individual search for information, this way constructing an "alternative" source of knowledge which, in his perception, improves and fine-tunes the more abstract and universalistic expertise offered by diabetologists and physicians.

5.2.1 The lure of numbers: managing uncertainty through quantification and self-tracking practices

In a world made of uncertainty and instability, numbers – as well as measurements and calculations – help maintaining the sense of control. In fact, self-monitoring and self-tracking practices might be seen as a way of controlling, predicting and managing the "messiness and unpredictability of the fleshy body" (Lupton 2016: p. 77). For this ideal type, the variety of self-care practices that punctuate participants' days and lives is the theme that prevails in their discourses, together with the need of governing their bodies and containing health risks. An illustrative example is that of Alessandro, a 43-year-old man who was diagnosed with type 1 diabetes at the age of 3. His account focused on the importance of intense monitoring and on the need of being constantly aware and in control of the situation. In his words:

> **What does having diabetes mean to you?**
> (Long pause) Ehhh it means... a lot, it means... maybe a life that is... let's say, conditioned, (...) you have to always remain... alert. (…) Let's say that you can never lose control, ... this is something that I've always had, even when... I was a reckless teenager. (Alessandro, 46 years old, T1D, employee, onset at 3 years)

He illustrated the importance of self-management and the need to preserve and maintain wellbeing and glycaemic balance through an example of a recent episode, when he was attending a wedding and despite the solemnity of the occasion he decided to monitor his parameters and considered that it was better for him to rise glycaemic levels instead of staying with the others and attend the marriage ceremony. Thus, "regardless of social conventions," he ate alone, before the buffet even started: "You come before everything else," he stated, because glycaemic balance "is a matter of survival" and relies on a series of "inculcated," embodied technologies of the self that govern the everyday life, the conduct and the body.

The narratives that can be described from the DQS ideal type talked about the management of uncertainty through self-monitoring and quantified-self practices that usually entailed the use of electronic or digital medical devices such as the glucose meter, the glucose sensor, the syringe, the insulin pens and the insulin pump. Diabetic bodies necessarily need to quantify themselves in many daily occasions: when they do blood tests, when they inject a certain amount of insulin, when they eat a certain amount of carbohydrates, or when they deal with hypo or hyperglycaemia. Diabetologists usually ask them to keep track of measurements and lifestyle activities that could influence such values: all DQS participants reported recording their "numbers" on a written diary, or an Excel page or more frequently a dedicated App that they used on their mobile phone or computer. An illustrative example is that of Alessio, a 42-year-old man diagnosed with diabetes at the age of 13 who explained to me how he kept track and monitored of his self-management by "interacting" with a health mobile Application:

> These digital devices today… You tell them what you eat and they give you a number, and these systems where data are stores are visible to the… the diabetologist, you can also combine with the carbohydrates that you have introduced. (…) I keep track of the units [of insulin] that I inject and of the food that I eat. Usually... But I count them not with the four-pages paper

> diary that there was [in use] once, I have instead found an application (…) named My Fitness Pal and allows me to add meals and it does the carbohydrates counting. There is a database, already there, it is possible to expand it… And I add the food, and the weight of the food that I have introduced and it shows me not only the carbohydrates, but also all other components that… That there are [inside], and it tells me: "No, this product no, don't eat it, it's too... too greasy" (Alessio, 42 years old, T1D, employee, onset at 13 years)

As Appelboom and colleague (2014) observed, the promotion of quantified-self practices may allow ill people to be more engaged with their own health care by being able to self-monitor themselves, and this may empower them to take control of an unstable situation. Haraway (1985) asserted that contemporary, high-tech society shapes individuals that progressively become hybrids of human and machine, chimeras that break bodily boundaries and embody a technology that becomes an inextricable human extension. This is even more true for diabetic people, who need medical devices for survival. In fact, participants used such devices every minute of the day and night, some of them were attached to their bodies while others were transported separately, usually in a bag, but all of them were a prosthetic replacement of their pancreas and allowed them to survive. The majority of the "DQSs" reported using those devices as they were an integral part of their bodies. We can find an illustrative example of this in the words of Diego:

> After a while you get used to it, I mean, you forget that you have it attached [to your body]. Honestly. (…) Because after a while, when you get used to it, you forget about it, and it becomes part of your body. (Diego, 23 years old, T1D, confectioner, onset at 4 years)

Medical devices and self-tracking technologies are a type of prosumption, an "interrelated process of production and consumption" (Ritzer 2014: p. 3) where individuals contribute in generating, collecting and analysing data about their bodies and their behaviours. DQS's narratives describe their process of making sense of the data obtained in terms of goals to reach or those achieved, and in terms of lifestyle practices to be modified in order to accomplish such (numerical) objectives. This aspect highlights the *gamification* (Maturo & Setiffi 2016, Whitson 2013) dimension of diabetes self-management, which is particularly emphasized in DQS's narratives. According to Maturo and Moretti (2018: p. 1), the concept of "gamification" describes "the use of game elements in a non-game context" and in this specific case this has emerged as a useful strategy for strengthening people's motivation to engage in self-management. In fact, gamification practices have become very popular in the context of health and served as a tool for stimulating individuals to acquire healthy habits and change their lifestyles in order to reduce risk factors (Ibidem). The interactive use of the apps, downloaded on mobile phones and computers, encourage self-surveillance and body discipline practices through the incentive of goals to reach and competition among its users (Ibidem). In the context of the present research, competition does not concern the ability to exceed one's own body limits through sport as it is for the "athlete"; it is rather a numerical challenge that regards the ability to keep a glycaemic balance and to reach the best possible values of glycated haemoglobin or glycaemic level. It is a competition with other diabetic people – often enacted through the "showing off" of screenshots of the glycaemic results on the social media –, but also a competition with oneself, in a constant process self-improvement that often, as an unattainable reference, has the glycaemic values of non-diabetic people. Some examples:

> My glycated [haemoglobin] has lowered. I have always had quite a high glycated since when I began to measure it, such as 9, 11. Now I have 6. So, it is slightly higher of a non-diabetic person's. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

> You know, since when... Since when I have the insulin pump, I have 6.4, I am perfect. The [haemoglobin] glycated is all right, 6.2, it's perfect, very perfect. I am very satisfied. (Patrizio, 44 years, diabetes LADA, clerk, onset at 38 years)

> Because... [diabetes] is an opportunity to… certainty know oneself… grow up (…) And then it gives you the strength because it makes you face a new challenge… And it is useful not only in the medical context, but it makes you have an approach which is useful also in the professional context, because as I said before: what is diabetes? It's respect of the rules. And it is the same that happens at work. There are rules, you have objectives, from there you construct your strategy. So, there is someone that tries to limit the variables... and he follows rigorously the diet and injects always the same units of insulin... Then there is who instead wants… To explore... So he tries, makes a mistake, tries again… The important thing is always to reach the objective, which is, basically, the one number, the glycated, because if this number is all right, the damages are surely limited. So…it [diabetes] should be an occasion to learn to organized and determined. (Igor, 31 years old, T1D, shop assistant, onset at 28 years)

5.2.2 Quantifying the diabetic self/body: the "Quantified Patient" and the "Quantified Lay Expert"

The comparison of the stories collected has revealed similarities and differences in the diabetes-related practices narrated from "Diabetic Quantified Selves" participants. They have in common the narrative of a "quantified" self that tries to dominate bodily uncertainty through self-tracking and self-monitoring practices, but there are also differences concerning the meanings assigned to such practices, and in the different approaches to medical knowledge that informed their routines. The majority of this subsample – 11 out of 16 – could be described by the "Quantified Patient" sub-type, where a rigorous self-management was understood as an ability to comply with medical treatment, and medical knowledge was recognized in its authority and legitimacy. On the other hand, a minority of narratives – 5 out of 16 – could be illustrated by the "Quantified Lay Expert" subtype, where participants reported partially incorporating medical knowledge, but also questioning and "shaping" it around their personal experience, privileging individual expertise to the universal and abstract medical approach. In the following paragraphs I will delineate their typical features and explain them empirically.

5.2.2.1 Self-quantifying and adherence to treatment: the "Quantified Patient"

The narratives that can be categorized under this sub-type have in common an incorporation of medical knowledge that – unlike the other subtype – is not questioned in its legitimacy. It is possible to find an illustrative example in the following excerpts:

> I tend to... ask more to the experts. I have spoken to doctors, not only to him, also to other people, ... I mainly rely on medicine, [while] alternative... things, let's say... I see them as very dangerous. (...) So, I trust the doctors, yes. Mmm he's a person who gives me confidence, so... I tend to trust him. (Flavio, 41 years old, T1D, psychotherapist, onset at 36 years)

The "Quantified Patients" reported having autonomously searched for information about their condition, and they have done so mainly through reading scientific publications, as can be illustrated by the words of Damiano:

> Then I studied the subject a little, so... I was lucky I wasn't a child, when I got it, but I was already... let's say, in an age of reason, so I did some research and... I went to my GP, who was not exactly a friend, but I knew him well, and I had him give me some of his medicine books (he laughs) and I read them, [they were] a little pretentious, but still... useful enough. (Damiano, 58 years, T1D, manager, onset at 33 years)

Two participants, Silvio and Renato, reported blogging about their illness' experience, and especially in the case of Silvio this was done in collaboration with health care professionals, who recognized his personal "expertise":

> (…) **with the doctors, the diabetologist..**
> **Silvio**: Oh well...
> **Wife**: We're friends (she laughs)
> **Silvio**: (he laughs)
> **Wife**: We get there, hugs and kisses.
> **Silvio**: Yes, nurses, I mean, by now they have known me for a lifetime, then- then they always say that I am someone... who knows [this issue] almost like they do. (...) And then- the fact that I'm a computer specialist, a tech expert, I don't have trouble with the things, ... and the fact that I've always taken an interest, I wrote a book, I have a website, I have a blog, I mean… (Silvio, 51 years old, employee, onset at 35 years)

All 11 participants whose narratives can be described in the "Quantified Patient" reported being highly engaged in daily self-tracking practices and during the interview they offered a description of their self-management practices mainly in numerical terms, that were presented as a concise representation of their ability to be compliant to medical prescriptions. For this ideal type, the most important aspect of diabetes self-management was glycaemic monitoring: everybody but one participant reported using the continuous glucose sensor, and the only exception was Tommaso, a 53-year-old man who was diagnosed with diabetes at the age of 3 and, as a consequence of illness, was blind. He reported using the traditional glucose meter because it was more accessible and provided spoken display data. Overall, all participants motivated their choice of using the glucose sensor through the possibility of having higher control of their condition and symptoms. We can find an illustrative example in Flavio's words:

> I can monitor glycaemia in every moment of the day, and this is very useful (…) I can even measure it during psychotherapy sessions. (Flavio, 41 years old, psychotherapist, T1D, onset at 36 years)

All participants constantly monitored their glycaemic levels during the day and regularly downloaded those data on the computer. The collected data were then analysed through specific software or Applications that interpret them and aggregate them through statistics or graphs or other forms of data presentation. Those numeric results were then regularly shared with the GP or the diabetologist, and they were often showed to me during the interview, or used as a numeric reference that represented their ability to manage diabetes properly. Glycated haemoglobin in particular (namely, a value that shows the three-month average plasma glucose concentration) was the number that most of all was used as a mean to “show off” their competence. For example, when talking about his regular medical check-ups, Patrizio stated:

> And as a matter of fact, they told me (...): “Look, you’re... a model patient, because, ... you’re the only one here with the values you have.” (Patrizio, 44 years old, diabetes LADA, clerk, onset at 38 years)

Glycaemic monitoring values can be shared on-line with the diabetologist, but they can also be analysed and used by the user: this form of digitized self-tracking might be seen as a form of “dataveillance,” namely “the monitoring of citizens in the basis of their online data” (van Dijck 2014: p. 205). In fact, glucose meters and glycaemic sensors generate data through digitized self-tracking practices, and patients are invited to engage with this information in order to optimize and improve their self-management and their lives (Lupton 2016). This is a form of self-surveillance that the Quantified Patient uses for adapting his lifestyle (diet, physical activity, emotions…) in order to keep a glycaemic balance during the day. Many participants engaged in on-line forums dedicated to diabetes, and this virtual space allowed them to discuss with each others, or even to share their data through screenshots of their current glycaemic level and trend:[29] in this case, the self-surveillance became social surveillance, namely “observing other people’s data and sharing their own in social media platforms” (Marwick 2012; quoted in Lupton 2016: p. 102). For this subgroup, the exchange of information within

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[29] This information was not given to me during the interviews. Although I did not conduct a systematic analysis of on-line forums dedicated to diabetes, I was accepted as a virtual member of the most popular ones and I had the opportunity to see the numerous screenshots that have been regularly posted and commented by users.

online forum did not result in calling into question medical knowledge; on the contrary this virtual space served as a dissemination and reinforcement of medical management standards.

As for insulin delivery, a slight majority – 6 out of 11 – of participants used the insulin pump and the remaining reported using the insulin pens. All of them justified their choice by stating that (in both cases) this specific solution allowed them to be more in control. As Alessio said:

> Well, the diabetologist said to me (…) about the insulin pump... and I never tried it. And the reason why I never tried it it's because… I have learnt for thirty years with the injections and... changing with a system that I don't know, where often they have these glues that don't really work (…). My fear is that for some reason it comes off and you are outside... And it is not like having (administered) the long-acting insulin: the moment you don't have that micro-dose every 30 minutes, glycaemia will tend to rise. (…) I'm afraid I would not have full control of insulin delivery. (Alessio, 42 years, T1D, employee, onset at 13 years)

The experiences with medical devices, within this subgroup of participants, was overall positive and they were usually described with enthusiasm. One participant, Edoardo, reported that his wife "refused it" because she considered it as a real "intrusion into the couple," especially for the noise that it made during the night, when it signalled hypoglycaemias. As he recalled:

> My wife refused the insulin pump... She thought it was an intrusion in our couple. (...) She said: "You have to choose: me or it!" And I chose the insulin pump. (Edoardo, 53 years old, T1D, labourer, onset at 3 years)

He decided to keep it despite his wife's aversion, because, he said: "Well, for me the insulin pump meant... Meant and still means a better living, because I am monitored... Always monitored."

The majority of participants whose narratives can be explained from this sub-type reported using health Applications on their mobile phone in order to keep track and measure health parameters and control glycaemic trends and swings. We can find an example in the story of Patrizio, who used both the continuous glycaemic sensor and the insulin pump for self-managing diabetes' symptoms and who reported using "MySugr" App – that was one of the most popular Applications for diabetes management – and, he said: “It allows me to monitor everything.” It synchronized the data of the glucose sensor or insulin pump into the App, and provided an analysis of the data collected while proposing help in improving management practices.

The Quantified Patient’s narratives focused on the importance of conducting a “controlled” lifestyle in order to manage diabetes and prevent complications. As Liam observed:

> **If I say “diabetes”, what is the first thing that comes to mind?**
> Mh, (…) ... I think, ... for how I see it now, diabetes is… for me it’s being more controlled, compared to a normal person, eating right. (…) And not messing around, (…) you have to be careful with everything that surrounds you. (Liam, 24 years old, T1D, shop assistant, onset at 18 years)

A minority of participants reflected critically on the downsides of constant control such as the limited freedom that this entails – a criticism that instead influenced the “Free Spirit” ideal type’s narratives – but it nonetheless was considered from this group of participants an unavoidable effort to deal with, as Alessio recounted while describing his transition from the traditional glucose meter to the glucose sensor:

> And, instead, subsequently, through a continuous control of glycaemia, it became, how can I say, much more suffocating, or still, you have much more attention. Even if you don’t want it, you have it, because you have the sensor and therefore, for better or worse, you see the cell phone, you see a message and you, a diabetic, you know that glycaemia is the thing... a fundamental thing, so you monitor it and you always constantly keep it under control. (Alessio, 42 years, T1D, employee, onset at 13 years)

Silvio, in turn, highlighted how the constant control and self-surveillance were actually burdensome for him, and he eloquently compared self-management to an unpaid job:

> Since I read that there have been people who died for hypoglycaemia, well, (he laughs) you’re always on your toes, you don’t have... that night in which you sleep peacefully, no, you’re always... aside from the fact that you get up to urinate, because it’s normal. But... well, you don’t have that peace of mind of... I say, it’s a job, having diabetes is a job, they should pay us in... as if we had two jobs, because it’s a job. Constantly mmm... a continuous control. (Silvio, 51 years old, diabetes LADA, employee, onset at 35)

Self-monitoring and self-quantification did not only concern glycaemia measurements, but also food consumption. Overall, unlike the "Quantified Lay Experts," the majority (9 out of 11) narratives of the "Quantified Patients" did not report engaging in specific diets. The specificity of discourses around food consumption concerned the fact that they talked about food in terms of numbers. Numbers related to carbohydrates, to food weight (expressed in grams), numbers of the calculations that allowed them to estimate the amount of insulin units to inject in relation to the amount of carbohydrates that they would eat at each meal. This strategy is called "carbohydrate counting" and was used as the main "rule" for food consumption by 9 participants out of 11. An illustrative example is that of Patrizio, who reported having adopted a "free diet," and using "carb counting" strategy as the main rule for organizing food consumption. In the following excerpt it can be noted the constant reference to a "quantified" food:

> My breakfast, ... well (...) breakfast has always been a bit of a problem. Because I have a 1-to-5 ratio. It's a very low ratio.
> **Sorry, 1-to-5 ratio, can I ask you what does... it mean?**
> One... one unit of insulin, metabolizes only 5 carbohydrates. So in the morning I, I mean, my breakfast is... 20 carbohydrates, more or less, not more, if I eat a brioche, (...) ... while at midday, I have a higher ratio, 1-to-12, and in the evening, 1-to-7 again. So what do I do? I keep on about 20 in the morning, ... 50, on average eh, 50 and 20. (Patrizio, 44 years old, diabetes LADA, clerk, onset at 38 years)

Quantifying food is an onerous, time-consuming activity. Who does that, in the everyday life? Usually, according to the narratives collected, it's non-diabetic women (wives, mothers, etc.) that have the responsibility of preparing and organizing food consumption. For this subgroup of participants, in 9 out of 11 narratives the responsibility for meal preparation was assigned to participants' wives (7/9) or mothers (2/11) that have been "trained" to do it. For example, Patrizio's described how his mother – with whom he and his partner lived – cooked for him, while his partner disregarded this (gendered) chore:

> My mom, I'm telling you, she helps me, because well... I taught her more or less the carbohydrates counting. So, when I get back from work, ... mmm she has already counted, what, ... I mean, what I have to eat, ... she

> indicatively knows it, so she does the ratio, the proportions, there are no problems. Whereas my partner, mmm... if I ask her: “What shall I eat this evening?” she says: “Well, eat that.” ... And I tell her: “But that there, it’s proteins. I need to eat carbohydrates in the evening, because...” ... She doesn’t know, despite being a cook, ... in an old people’s home, she doesn’t know. (Patrizio, 44 years old, diabetes LADA, clerk, onset at 38 years)

An exception was Alessandro, who reported being “vegetarian” for ethical reasons and equally sharing household chores with his wife.

5.2.2.2 Constructing a “personalized” self-management: the “Quantified Lay Expert”

Unlike the other subtype, the 5 narratives that can be categorized under the “Quantified Lay Expert” ideal type have in common an incorporation of medical knowledge that is partially questioned in its actual efficacy and criticized in its application. Overall, it was contested the medical “paternalism,” namely the tendency of physicians to underestimate patients’ own agency and ability to understand diabetes’ symptoms and their consequences. As Lucio stated:

> My approach is to say: “All right. Ok. You are the professional. I mustn’t play by my rules. It’s clear that you have a formation, and a technique, ... that I don’t have and cannot have, and that I am not required to have. But I want to know what is happening here, what you’re prescribing me, because you are prescribing it to me, ... and I want to understand the procedure that takes you from point A to point B, ... and of why that was chosen.” (...) This is something that is kind of typical... unfortunately, of... I noticed, of Italian medical doctors. That (...) they tend to give diagnoses, or still, to... to approach the patient in a one-sided way. I mean, to say: “I know what’s good for you, now I’m telling you what you have to do.” ... And as a matter of fact, when I ask some questions, ... I notice that some doctors almost feel... almost opposed. Asking a question doesn’t mean opposing someone. I would simply like to understand the reason, and I can assure you I have the instruments to understand, (...) it’s something that... I can understand, and I want to understand. (Lucio, 28 years old, diabetes LADA, entrepreneur, onset at 36 years)

This subgroup of participants usually expressed the desire to better understand their condition, in order to engage in self-management practices in a more informed way. In this case, 4 out of 5 participants adopted a specific diet whose aim was to keep glycaemic balance during the day, avoiding glycaemic swings and limiting insulin intake. The “rules” that informed their food consumption were not proposed by diabetologists, but it was rather the result of their personal experimentation, their further readings and their information sharing mainly in on line forums. Instead, medical approach in regard to food consumption – namely, "healthy," not restrictive diet and "carb counting" – was usually criticised, as can be read in the words of Paolo:

> It seems like the objective of doctors – aside from earning – is that of making you feel normal, no? Well, instead, they should teach people to accept the fact that they're not normal, that they have a problem, and learn to accept it and face it in the best possible way. Not as if you don't have a problem: you do have that problem! And you will have other ones if you keep thinking you don't have them. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

The knowledge about diabetes that these participants derived from doctor's discourses, but also – just as the other subtype – from a personal interest to obtain information, which has brought them to look up "scientific" literature on the internet and to take up an "analytical approach" to the matter. For example, Lucio said:

> Well ok, I have a rather… analytical approach to the whole thing, I like to be informed, since it concerns me, so I went and read a lot of… a lot of information. (Lucio, 38 years, diabetes LADA, entrepreneur, onset at 36 years)

Medical knowledge was thus incorporated in terms of undergoing regular medical check-ups, using medical devices for self-monitoring and insulin delivery, and the incorporation of medical explanations of the disease. This subgroup of participants focused mainly on food composition and its effects on the body and on the glycaemic level. Paolo, for example, used the insulin pens and the glycaemic sensor and studied "empirically" the effects of the food on his body trough self-tracking and self-monitoring strategies. In his illustrative discourse, he began by criticizing medical approach to food consumption:

> Well, the method that physicians want you to follow, would be: breakfast, than after 2 or three hours a snack, then lunch, then after 2 or three hours a snack and than dinner. And may be a snack before going to sleep and every time you inject insulin. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

He then highlighted why this “schema” was considered as ineffective: because, in his opinion, eating without restrictions “makes you live under the constant effect of insulin, of glycaemic swings, of all this mess. (…) It is like a seesaw: you make it high and then you make it low. It’s a mess.” On the other hand, he developed a very “personalized” diet that, as he reported, together with a “personalization” of treatment allowed him to maintain a glycaemic balance, to reduce conspicuously the amount of insulin intake and to achieve a satisfying glycated haemoglobin value. In the next excerpt, it can be observed how he described his personalization of diet and treatment:

> When I wake up…[I eat] lettuce salad, always. Raw vegetables help making a barrier in the stomach and reduce carbohydrate absorption, so I eat them before and not after, because after it’s useless. (…) Then I measure glycaemia, and usually it is quite ok. So, I eat a bunch of salad, and then eat leftovers from last dinner that usually are pan-seared vegetables cooked somehow, with some legumes, together with 15 grams of bread. Then I have some nuts that usually are 30-40 grams... And I go to work. (…) I also inject some insulin, and I perform it twice, because –may be it is just a psychological thing- but I observed that it lowers insulin more slowly. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

Despite the fact that his diabetologist did not approve his “personalized” dietary regime, Paolo reported that:

> He likes the health outcomes: my glycated haemoglobin is lowered (..) from 9 to 6, just a little higher than a non-diabetic individual,” and his insulin need lowered “from 9 units of insulin, to 2. (Paolo, 32 years old, T1D, labourer, onset at 20 years)

A similar approach to diet was also described by Lucio, who said:

> [After the onset] I radically changed, because now I don’t eat.. almost any flour… refined flour, I try to avoid… when possible, all food with.. a glycaemic index… with a high glycaemic index. Straight after the onset, but… especially what… was trying to… trying to… limit the use of sugar, … of simple sugar, white sugar. (…) I have lost about twenty kilos, in the last… in the last two years, especially in the last year… It’s that significantly limiting… not many carbohydrates in general, but rather, those with a high glycaemic index, that might come from flour, … or from some refined grains, eaten in great quantity… I realize that… I have… very important benefits. (Lucio, 28 years old, diabetes LADA, entrepreneur, onset at 36 years)

In fact, control through a strict diet was, as a matter of fact, Lucio's main way to manage the illness:

> From a personal point of view, I believe that food is one of the main key… factors, obviously, I mean, how you eat, … is closely related [to] how you're managing your illness. (Lucio, 28 years old, diabetes LADA, entrepreneur, onset at 36 years)

An incorrect diet was, according to him, the cause of autoimmune illnesses like type 1 diabetes. In support of this hypothesis, he reported statistics relative to comparisons over time and between various countries, with a different incidence of autoimmune diabetes, depending on the different local food traditions. A "personalized" and rigorous diet was therefore the basis of his self-management and the constant research for wellbeing and experimentation brought him to try new foods. For example, he reported introducing in his diet the "American sweet potato" which, he said, "has 3 point 5 per cent of carbohydrates" as opposed to the "75, 80 per cent" of common potatoes: a numerical comparison of carbohydrates amount and glycaemic index values that informed most of his food choices.

All participants reported having adopted a "personalized" diet, which had some effects on diabetes self-management. As mentioned before, 4 participants out of 5 motivated their dietary habits highlighting its benefits on glycaemic levels. The only exception was Diego, a 23-year-old young man that was diagnosed with diabetes at 4, who described his "personalized" diet as consisting in eating "healthy," with a low amount of carbohydrates and sugars and high amount of proteins; he motivated this choice for diabetes management, but also for constructing a muscled body through body building. Despite the fact that traditional medical knowledge advises against this use for diabetic people because it overloads the kidneys, he reported disagreeing with it and proposed his personal alternative knowledge:

> Everyone says that proteins are bad for your kidneys, you mustn't take them, because you'll feel bad, the usual things, etcetera. So, considering first of all that proteins are also present in food, if I want to add a higher protein dose to my... to my day, ... you know more or less what the grams-per-kilo ratio you can handle is, without exaggerating... You drink a lot, you're purified, also in the sense that... your kidneys are purified. (Diego, 23 years old, T1D, confectioner, onset at 4 years)

The issue of “control” was crucial also for this subtype. As Diego explained:

> **If I say “diabetes”, what is the first thing that comes to mind?**
> (Long pause) Mm... (…) I think... (Long pause) Control? Maybe?
> **Ok, ... control... of what?**
> Of everything, in general... after all. It goes from the control of sugars, to behaviour- to the control of food, to the control... of the body, of sport, in general. Of life, yes, let’s put it this way. (Diego, 23 years old, T1D, confectioner, onset at 4 years)

Out of 5 participants, 3 of them reported taking care of food preparation and organization, while in the remaining 2 cases they said it was their wives’ responsibility. It is interesting how they motivate their involvement in cooking: Lucio reported that it was his responsibility because his wife “doesn’t know how to cook”; Paolo was considered from his partner – during the interview - a real “food expert” that cooked amazing meals with creativity and competence; finally, Raimondo reported being in charge of cooking because his wife had to work until late while he was retired and had more time. In sum, in this small subgroup the majority of men reported taking care of food consumption practices, but their discourses around this issue were far from the “mundane” and taken-for-granted involvement of women in food practices as recounted in the majority of the others narratives.

Overall, of the 5 participants, 3 of them reported using the glucose sensor for measuring glycaemia, 2 of them the glucose meter, 1 of them reported using the insulin pump, and 4 of them the insulin pens. Generally, this subgroup was different from the other one in so far as they had a positive approach towards medical devices, but unlike the “Quantified Patients” they did not show the same enthusiasm for glycaemic monitoring and numeric results were not described as representative of their ability to be compliant with medical treatment, but rather of the efficiency of their “personalized” self-management. They considered those devices as instruments for keeping diabetes’ symptoms under control and for experimenting food’s effects on their bodies. Also in this case, their bodies were often described as an hybridization of human and machine, and Diego’s account in this respect was particularly illustrative: he reported using a continuous glucose monitor which was "connected to the cell phone, and the phone rings when you reach certain limits," in such a way that he could constantly be under control. Also the insulin pump played a crucial role for his diabetes management, because it helped in "keeping glycaemic levels under control" and it was not perceived as an external medical device, but rather as an integral part of the self.

5.2.3 The "measure" of a man: diabetic men dealing with vulnerable, diabetic bodies

If compared to the other two ideal types, in these narratives men mentioned more often their "vulnerabilities," and their difficulty/impossibility to fulfil social expectations around dominant notions of masculinity. In many cases it was acknowledged that diabetes – and its health complications – somehow disrupted social expectations of bodily strength and reliability. For example, Liam illustrated this possibility within a typical scenario: that of a young, heterosexual couple, a context where expectations around the bodies are usually different and dichotomized, and where the presence of non-diabetic and "stronger" male others made him feel weaker:

> Mmm yes, at times I feel a little… weak. Maybe seeing other couples, for example, when… I had a partner, … maybe sometimes I wouldn't feel like doing something, an effort, of any kind, mmm it- it affected the whole thing. That's true. Yes. That's true. More than anything, it was a fear of mine to face, maybe, something, … in general, and maybe the… the other [male] guy did it without a problem, and I was maybe scared of the… of the reactions of glycaemia, that could have decreased, etcetera, etcetera, … and I have always said: "No, I don't feel like it." This cases make me uncomfortable. (Liam, 24 years old, T1D, shop assistant, onset at 18 years)

Or in the case of Leonardo, a well-known professional who run a private firm in a big town of Northern Italy, who acknowledged his "weakness" in a more indirect way: namely, by discursively constructing a virtual, non-diabetic self, that would comply even more with hegemonic ideals of masculinity and aggressiveness:

> Another thing I think is: "If I didn't have diabetes, maybe I would have been much more of an asshole."
> **What do you mean?**
> (Long pause) In not respecting others' weaknesses. In my relationship with

> others, I did hurt some people, and I ask myself: if I were even stronger, maybe I would have been.. (...) Yes, because in the end I am a person who, if I didn't have diabetes, I would have been less insecure, stronger in general, I wouldn't have lost a great number of livable and productive life hours (...) just like for the frequent diabetes medical appointments. A question I ask myself is: "How much does it cost to the 'business myself' to have diabetes?" (Leonardo, 52 years old, T1D, architect, onset at 4 years)

During the interview, participants used different strategies in order to dismantle the potential emasculation of those "vulnerabilities." One of the most common strategies to discursively distance themselves from the realm of the "sick" was the use of irony, as illustrated in the case of Renato, who recounted an episode about a meal he had together with other (male) friends who also suffered from other pathologies, which took place in the presence of a female viewer: the young waitress. In his words:

> There's a very funny story: I went to take a friend who was operated, unfortunately, because of throat cancer, to have a PET scan, together with another friend, who came with the both of us, and, in turn, he suffers from high blood pressure, and he takes medication, no? So we went, after the PET scan, we went to eat at a restaurant close by (…) there was the young lady who was taking… the… [order] and… when we were choosing, I took my insulin, (…), the other friend took his pills (he laughs) and the other one, he also took, I don't remember what, and… Since the young lady was looking at us in a strange way, we said: "Well… we think we'll make it to the end of the meal, but we can still pay before!" (Renato, 56 years old, T1D, entrepreneur, onset at 30 years)

Another distancing strategy used by participants while talking about their "fragilities," as Leonardo defined them, was that of trying to reverse – within the context of the interview – the asymmetry of power among interviewee and interviewer. As I have already mentioned in the methodological chapter, this became visible through the communicative licenses that some participants took towards me as a female researcher, and this was more common within the interviews categorized in this specific subtype. This strategy reminds Goffman's (1987, or. ed 1981; Ghigi & Sassatelli 2018: p. 81) analysis of footing changing during interactions, as a ritual way of constructing feminine or masculine identities. In this context this was visible, for example, when Leonardo inverted the interview rituals and asked me, while we were in the middle of the conversation about his retinopathy: “How old are you?” and, after my answer, when he commented: “Oh, you looked younger!”. Those change of subjects and flatteries would hardly have happened in the case of an old, male researcher conducting the interview.

Another discursive strategy that was typical of this subtype was the tendency of “explaining,” often in an expert, condescending and oversimplified way, the functioning of medical devices dedicated to diabetes, often through the “showing off” – regardless of their age or social background – of their ability to read graphs, curves, or analyse the collected data. An example, already mentioned in the second chapter, is that of Leonardo, who discursively opposed his ‘technological predisposition’ with a supposed numerical incompetence of an imaginary housewife/child or even the female (sociologist) interviewer, all intended as potential naïve listeners:

> You know, then for me it is not a big problem to correct a mistake on a vector, right? I just need to find the time to do it. But for a common housewife it would be [a problem]. The point is that this thing now eeh… in giving, it doesn’t only give you a result, like the glucometer, yet it gives you a curve, so it gives a trend (…) [These data] are downloadable on the computer and they can be analysed by any nerd as much as they want to. (…) Put simply, if I had to explain this to a child I would say: “Lots of not-accurate measurements are better than only 3 accurate measurements [in a day], because they give me the trend.” (Leonardo, 52 years old, T1D, architect, onset at 4 years)

As already mentioned in the previous paragraphs, gender dimension was relevant also in another crucial context of diabetes self-management: namely, food consumption. On the one hand, this dimension emerged when participants that followed a particularly strict diet confronted with social expectations around “male appetite,” as can be read in the case of Lucio:

> Many people might say: “But you’re eating less compared to before”, or who make... the typical little joke: “You eat like a lady!” diabetes LADA, Lucio, 28 years, entrepreneur, onset at 36 years)

When participants compared their food tastes with that of their partner/wives, it emerged the relevance of food consumption choices in relation to the constructions of social, gendered identities, and the organization of food consumption within family members was discursively used “in order to mark gender boundaries” (Sassatelli 2005: p. 173, my translation). For example, Damiano stated:

> [For dinner] I clearly eat what my wife has prepared me. She cooks healthy, not only for me, for my diabetes, but generally speaking she has a food culture of this kind.
> **So you and the rest of your family usually eat the same food or…**
> No, my son and me, we eat the same things. My wife eats different kind of things.
> **Such as..?**
> Because she is on a diet, and then she is a person that prefers eating integral food, eating biological food, she is vegetarian. She doesn’t eat meat. On the other hand, my son and I, we are less complicated (Laughing).
> **So you usually have meat..**
> We usually have meat, yes, exactly. Not often, we don’t really eat it often. I would say a couple times a week. Meat is fine, why not. Instead, my wife hasn’t touched it in five years. She touches it for cooking it to us! (Laughing) (Damiano, 58 years old, T1D, manager, onset at 33 years)

Food tastes have been used as a form of distinction, and in how meals were organized, prepared and cooked it usually emerged the reproduction of traditional gender relations. Another illustrative example is that of Leonardo:

> **Within your family, who’s in charge of organizing meals, buying the food, who decides what you eat?**
> My wife. Also because I’m away from home a lot of time, while she works at home, so…
> **Does she considers what you should eat [for diabetes management] or she freely…**
> She has her own theories… And we do have different tastes, I could say blood sausage and zucchini! (Laugh) (Leonardo, 52 years old, T1D, architect, onset at 4 years)

Overall, the narratives categorized under this ideal type mainly focused on the “pragmatic embodiment” (Watson 2000): unlike the “athlete” ideal type, participants here did not put particular emphasis on the presentational mode of construction which refers to a normative male embodiment, nor on the “experiential” embodiment, as in the case of the “free spirit” ideal type, but rather pragmatic embodiment, “a functional mode of construction categorized according to socially ordered and ordering male gender roles (‘father’, ‘husband’, ‘brother’, ‘uncle’, ‘grandfather’, ‘mate’, and ‘worker’)” (Ibidem: p. 119). On the one hand, DQS's narratives focused on participants' ability to fulfil the expectations of their habitus mainly in terms of being adequate worker "despite" diabetes. An illustrative example is that of Tommaso, a 53 years old man that was diagnosed with diabetes at the age of 3. As a consequence of diabetes, he is blind from the age of 20. When he said that he suddenly become blind for a "retinal bleeding," I asked him if he wanted to talk about this event, and he immediately switched subject and focussed the attention to the pragmatic embodiment, to his role of worker and his ability to work:

> It was quite tragic, I spent six months laying on the sofa and in the end I said that I had to move on, so we rolled up our sleeves and we went to do the course to go to work, and ok, all that followed, etcetera, etcetera. (...) I had to do the course in order to work afterwards, and from 1988 I work at the University of xxx (city in the North of Italy). So it has happened in 1985-1986, then in September-October 1986 I did one year of course for learning the job, and from '88 I began working at the University of xxx (city in the North of Italy), as an employee. And then I became a trade unionist... (Tommaso, 53 years, T1D, employee, onset at 3 years)

Another participant, Igor, gave an account of the importance of pragmatical embodiment for his sense of self by focussing especially in his praxis as a worker, which was described as an affirmation of masculinity and body appropriateness. In fact, in order to prove his "functional fitness," he did not "come out" as diabetic in the work context until he had "demonstrated" to the others that he was "social fit" (Ibidem: p. 119). In his words:

> I have always tried not to- not to take shelter behind my illness, I mean… in the beginning I didn't tell anyone. Then, little at the time, as I started being closer to my colleagues and with my superiors, I started opening up with them. But I wanted to prove… well, I think, looking back, more to myself than to others… that I was able to perform a job of that kind, even with diabetes. So… I never told anyone. I've always… pretended not to have it, managing it, and then… little at the time, I started saying it, when I had already proven it could be done… years…) And not because I was scared of losing the job… (Igor, 31 years old, T1D, shop assistant, onset at 28 years)

The importance of pragmatic embodiment emerged also indirectly: as a mode of embodiment that was put at risk from illness, as in the case of Liam, or as an ideal mode of embodiment that has been disrupted by visceral embodiment – namely, disease –, as in the case of Silvio:

> ...Mmm at times I think… that I could be different maybe when I'll have a family… in everyday life things that can happen to me, maybe… I now see my cousins, who are older than me, who… have had children, they get married, etcetera, maybe with children who… need their dad, and maybe in that moment I can go into hypo, and I can't be there in that case, … I don't know how I would feel. In that moment. (…) But… I'm afraid that in that case I can't… play the part of father, or… husband, for example, … we'll see. (…) It's a thought, for the future. (Liam, 24 years old, T1D, shop assistant, onset at 18 years)

> Silvio: I wasn't someone like this. (He laughs) I wasn't someone to pity, before. (…)
> **Interviewer: How were you before?**
> Silvio: Well, I worked, yes, I worked a lot, maybe too much, but I was always mmm I worked, worked, worked a lot, I mean. So basically I was always… busy. Now… the routine is what it is. … You have to reach- you have to reach a compromise with yourself. This is a little… (…) … Eh, it's tough. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

5.3 The athlete

> The iron-man is considered to be... the man of steel, indestructible, we are iron-men with diabetes, so... we are not heroes... we don't... don't want to go beyond our limits, ... but we want to provide tangible evidence that... it is possible... to explore our limits, and to fight... (…) to achieve our dreams. (Ivan, 51 years old, T1D, manager, onset at 27 years)

Erving Goffman (1963: p. 153) in his book *Stigma* outlined a set of "norms" and standards that characterized, in his opinion, the "ideal" American man: "A young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight and height and a recent record in sports." In his description, that reminds Connell's ideal type of hegemonic masculinity, he considered it important to acknowledge "sport" as an important feature in constructing a desirable model of masculinity. In reality, only few boys and even fewer men are actually able to achieve hegemonic ideals of physicality and commit to formal sport over time. Nevertheless, sport permeates male culture not only through its practice, but also through the discourses that revolve around its knowledge (Seymour 1998). In addition to being an important arena for masculinity construction, sport in general and physical activity in particular is crucial for diabetes self-management. In fact, together with insulin treatment, with healthy eating and with blood glucose monitoring, it is one of the pillars of diabetes self-management, because it is useful for controlling illness and for reducing the impact of its main symptoms.

The ideal type of the "athlete" follows doctors' recommendations to regularly engage in physical activity, but he goes far beyond their suggestion of going for a postprandial, quiet walk every day. He rather engages in endurance training through running, cycling and kayaking competitions or intensive and regular – on a daily basis – working out. Those activities are usually considered as "risky" for people with autoimmune diabetes, because they are physically demanding and might cause glycaemic imbalance. In the case of the "athlete," sport is narrated as a sort of counter-discourse that resists to medical suggestion for moderation and carefulness and relies on embodied experiences and on "diabetic athletes" as a subcultural world where sport practices are learned and shared with other individuals experiencing the same condition. The "Athlete" incorporates, resignifies and reappropriates a cultural capital that becomes subcultural and, then, within that specific subcultural context, it acquires value as symbolic capital and allows the subject to obtain a subcultural status. Sport, in this case, might be understood as a way for diabetic males to compensate their inability to enact the physical hegemonic ideals of masculinity, a "compensatory manhood act" (Schwalbe & Schroch 2009: p. 288) that involves refusing doctor's recommendations of "taking it easy," and, instead, preferring to engage in competitive, "risky" sport activities. Diabetes, as an intrusive chronic illness that requires constant body care practices, transgresses masculine expectations of corporeal self-sufficiency, toughness and healthiness. But, as mentioned above, diabetic men confront themselves with different and sometimes contrasting bodily expectations: on the one hand, they are expected to fulfil hegemonic ideal of masculinity deriving from their specific social contexts; on the other hand, they are explicitly asked to comply with a "docile diabetic body" deriving from the adherence to biomedical standards. In a way, "diabetic athletes" incorporate and comply with both social expectations. In fact, their way of "doing" diabetes through endurance and competitive sport is for the diabetic "athlete" an arena where he can enact a hypermasculine gender performance while maintaining the control of his condition.

The subculture of "diabetic athletes" might be considered as a real community of practices (Lave & Wenger 1991) where the "novice" diabetic man learns from experienced "members" how to practice sport while managing diabetes, and how to use endurance sport as an alternative therapeutic tool to control his condition. The subculture of "diabetic athletes" is mainly composed by diabetic *men*, and homosocial relations have a significant influence in gender construction of young men (Rinaldi 205: p. 448), as well as adult men, and in this case it contributes in producing a shared set of practices that shapes a certain form of "sporty," diabetic masculinity. The "creation of male-specific personal and social spaces, a true forge of 'pure masculinity,' has offered (and still offers) the opportunity to experiment, construct and strengthen homosocial bonds, also through the development of masculine codes, agonistic languages, competitions, violence and physical contact" (Rinaldi 2015a: p. 122). From being a peripheral member, he progressively becomes a full participant of the community and within the context of the interview he discursively constructs his full membership to such community through the discursive references to the "outsiders," those who cannot be included as full members of the community. In this case, the "athlete" mainly identifies as outsiders those diabetic individuals that have a sedentary lifestyle, those that are "passive" and that incorporate medical suggestions, such as the "Quantified Patient" ideal type or those that overeat, that drink alcohol, smoke and that do not discipline properly their bodies such as the "Free Spirit" ideal type.

5.3.1 "I will fight for it, I will achieve it, I will keep it": diabetic athletes engaging in individual sports

The majority of diabetic athletes of this sample – 13 out of 15 – engaged in individual sports. Such sports included competitive running, cycling, mountain climbing, boxing and triathlon races. "Domination" and "fight" were recurring terms that participants of this subgroup used for describing their illness experience, and sport was usually considered as a tool for fighting. Below, some illustrative examples:

> Diabetes is an ugly beast. Because it hits you constantly, trying to weaken your resistance.[30] I always say so. Eventually it knocks you down. If you are not smart enough to fight it back in a certain way, you don't realize it, but then, you collapse. (Massimo, 59 years old, T1D, retired, onset at 30 years)
>
> A motto I have come up with is: "I will fight for it, I will achieve it, I will keep it"[31] (…) so… to fight, absolutely to fight, fight, fight, fight, in order to achieve… but what is fundamental, especially for a chronic illness… is to achieve… to keep, to maintain, … so to never let your guard down, to achieve an outcome, and to never, ever, ever lose… sight of it. (Ivan, 51 years old, T1D, manager, onset at 27 years)

As mentioned in the previous paragraph, engagement in competitive sport is informed by rigorous norms of body normativity, and disabled/chronically ill bodies are often perceived to be weak and passive (Shapiro 1993). As a consequence, "people with less-normative bodies are vulnerable to being denied social recognition and validation" (Gerschick 2010: p. 372). This applies in every social context, but it is even more amplified in the context of sport, were physical prowess, resistance and body performance is at the core of the challenges. From the analysis of the empirical material it emerged that the choice to engage in individual – rather than collective – sports was in itself a coping strategy adopted by participants in order to deal with impression management (Goffman 1959) and limiting the risk of experiencing stigmatization. An illustrative example might be found in the experience of Martino, a 34-year-old man who was diagnosed with type 1 diabetes at the age of 8: in his narrative, the possibility of experiencing sport underperformance because of diabetes seemed to be more bearable if he competed outside of a team, only by himself. As he put it:

> I was ok at football (he laughs). [Then, once they started leaving me as a reserve all the time], I gave it up. I chose individual sports, ... because at least I was alone, competing. Also cycling, I go out by myself, I don't have anyone who forces me to go out, or not, just like with running.
> **So... somehow, doing team sports...?**

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[30] The original version was "ti colpisce ai fianchi", which in boxing jargon refers to the action of constantly hitting the hips of the opposing player in order to wear him down.
[31] The original version included a play on words: "Lotterò, l'otterrò, lo terrò."

> Eh, you are a little penalized by doing team sports, ... if you have diabetes. Because... it could be that your teammates see you... as the weak one of the group... and that's that. Instead, individual sports, it's you, you deal with yourself and that's it, most [diabetic people] I know engage in individual sports. Either running, walking, ... I know someone who does karate, someone who... who does mountain climbing... Who cycles, but most of [the people] I know do individual sports. Individual sports ... (...) it's you, your team doesn't have to rely on you, ... you can easily make it. If you make it, it's on you to win. If you lose, it's on you to lose. (Martino, 34 years, T1D, farmer, onset at 8 years)

In fact, individual sports allow having more control of the social dimensions of diabetic physicality: they allow managing social expectations around normative performances by reducing bodily accountability and keeping it in a more "private" dimension. This is possible because diabetes is, most of the times, an invisible disease. But in the context of sport it might become "visible" in many ways: through the examination for the medical certificate for competitive sport activity, through the hyper/hypoglycaemias that might occur during sport performances, or even through medical devices that are attached to the body such as the glucose sensor or the insulin pump. In contrast to team sports, individual sports allow deciding whether to train alone or with somebody else, and even in this case there is no obligation to share locker rooms with non-diabetic others or take part in collective meals, all social situations that, as we shall see in the next paragraph, would complicate information control (Goffman 1963). Furthermore, diabetes might become visible also directly, through the active disclosure of the diabetic athlete. In this subsample, all participants reported being "visible" – although with different nuances – into sport contexts. Visibility of illness was mainly associated with participants' membership in the subcultural world of diabetic athletes: in fact, despite competing as individuals, participants in this subsample reported being part of a real "community of practices" (Lave & Wenger 1991) composed by diabetic athletes that engaged in sport disciplines and shared their experiences and supported each other in order to improve sport performances and diabetes self-management. Participants in this subsample understood sport as a crucial instrument to manage diabetes. Diabetic athletes knew and incorporated medical knowledge, usually "shaping" a personal expertise through its incorporation and its experimentation in their everyday life. Among this subsample, a recurring issue was that diabetologists adopted a universalistic approach, which was perceived as abstract and far from practical experience, and that life with diabetes could only be really understood from people who experienced it in first person. As Massimo, a 59-year-old triathlete who was diagnosed with diabetes at the age of 30, remarked:

> [I]t's not only my opinion. I'm saying that us, us diabetics... mmm who do a certain kind of... of training, we confront one another, we communicate between each other, and we have the same ideas. It's the doctors who... sports doctors, diabetologists, that are completely… they live in a different world. (...) Only the diabetic understands the diabetic. Who isn't diabetic, I can guarantee that... they have a partial understanding of diabetes... but not living with it twenty-four hours a day for many years, in fact... they always have a limited understanding. (...) The truth that I have noticed for some time is that if you mmm, aside your... pharmacological treatment and your diet, you don't add physical activity, which has to be a bit intensive though, not moderated, because a moderated one is not useful at all, in fact you- in fact you don't... how can I say? ... You are doing... the... the... 60 per cent of what you should be doing. You see the problem?
> **Sure, sure.**
> But unfortunately the medical profession doesn't help us from this point of view. So... each one of us... has to, how can I say, we have to construct ourselves (he laughs) by ourselves. (Massimo, 59 years old, retired, onset at 30 years)

In these narratives, sport practices were a form of knowledge actively constructed by the subject, a lay expertise that could be (partially) counterposed to that of diabetologists and GPs. Such knowledge was composed by a set of specific technologies of the self that were learned and shared with other diabetic athletes and that had the main aim of keeping diabetes' symptoms under control and reducing insulin intake.

A first element of "resistance" to medical knowledge was engaging in endurance sports per se, because they were usually conceived as being too risky for subjects with autoimmune diabetes. An illustrative example is that of Ronaldo, a 46-year-old man that was diagnosed with diabetes at the age of 39: in his narrative, he reported having started sport practice as a real act of resistance to medical knowledge, a way of transforming a vulnerability into a challenge to overcome:

> No in fact the diabetologist, initially, had... even prohibited me from doing sports, saying: "Look, the diabetic's lifestyle has to be that of... staying still,

> immobile, breathing little, eating little, and whatnot." I gave him proof of the opposite. (Ronaldo, 46 years old, diabetes LADA, high school teacher, onset at 39 years)

Another example is provided by the experience of Gioele, a 39-year-old man who has had diabetes since the age of 12. At the moment of the onset, he was practicing football and the doctor had forbid him from continuing to practice sport, suggesting him to engage in "something calmer." But things went differently. After a period of time spent without practising any sport and after having become a little over weight, Gioele started running in order to lose weight, and he increased little by little the challenges and performance goals to reach, ending up firstly running in marathons, then even competing in national triathlons. When he began engaging in competitive running, Gioele reported having learnt – just as a novice – how to manage diabetes during endurance sports from a more "experienced" diabetic athlete, Ivan, who was described from him as a real "guru." Overall, associations and on-line communities dedicated to diabetic athletes were real "communities of practices" where "apprentices" gradually learnt from others' experiences and shared their own, in a network of mutual acknowledgement and support. As Gioele stated:

> Because it is important. (…) because you can talk with other people, and you listen to their point of view… Like I do with... my friend [Ivan]... who tells me: "Look, today I did this training here, I did this... I stopped the basal [insulin], I did this other thing, I did like this"... Maybe you try too, doing it, but it's not certain that it will go well for you... since we are all different. (He laughs) (Gioele, 39 years old, T1D, employee, onset at 12 years)

The "other people" Gioele was referring to in the quotation above were, according to the narratives collected, mainly males: in fact, sport is here described as enacted in a homosocial context (Ferrero Camoletto & Bertone 2017, Bird 1996; Lipman-Blumen 1976), where men engaged in a shared set of practices that were valued from other male athletes and were crucial in order to construct a successful (masculine) identity. In the next excerpt, Gioele recounted an episode were another diabetic (male) athlete helped him during a triathlon race:

> It happened to me two years ago, also this year... Two years ago at yyy (name of a Spanish city), (...) it was crazy, because... while I was in the sea, for the swimming part, three point eight kilometres of swimming, I started to feel, initially the insulin pump... vibrating, and that was fine, because I always start a little high, in glycaemia. Then it told me I was high, absolutely fine... The thing is that at a certain point it started vibrating and it wouldn't stop... Because we hadn't realised that there was a small crack in the battery area, and water had gone in it. And luckily my friend was out... there, watching the race, basically as soon as I was about to go out on the bike, I caught him, and... I took this one off, he gave me the other, I attached it, ... I continued with that one. (Gioele, 39 years old, T1D, employee, onset at 12 years)

Talking to and learning from other diabetic athletes allowed Gioele to become in turn an "expert member" of diabetic athletes subculture, and at the moment of the interview he participated in different activities of an association as a testimonial, in order to present himself as a model of "successful diabetic" and to show to early diagnosed boys that, despite diabetes, "you can do anything," as he stated.

Diabetic athletes that engaged in individual sports had in common a chronic condition, and shared the interest for a set of sport practices that had the main aim to manage it better. They did not constantly train together or see each other, they rather had kept in contact, and sometimes they met for marathons, or more often they communicated through social media and email. For the majority of them, knowing other people that where experiencing the same issues was described as crucial, as Ivan highlighted with a meaningful metaphor:

> [My nickname is the] "gladiator" (...) I like this mmm... not only... because of its meaning of... of being a fighter, one who never gives up. But, most of all, I always say... when the gladiator, in the movie, is in the arena, and the door is about to be opened... he says a very important thing: "Whatever may happen to us on the outside" so... whatever these chronic illnesses may bring up in the future, "the important thing is to be close to each other, ... to fight, side by side." (...) When one... of us, inevitably, experiences a moment... of self-doubt, or of decline, ... there is always someone else who can... support them. So the point is: never face this illness... alone, isolating yourself, ... and thinking that one is invincible, because if one manages to face it, ... he does it together with others. (Ivan, 51 years old, T1D, manager, onset at 27 years)

The majority of the participants that engaged in individual sports reported receiving support and social recognition not only from the peer group, but also from the non-diabetics athletes, who recognized their subcultural sport capital and expressed admiration for their greater efforts. In Martino's words:

> Yes, with those I do sports with, they know my problem, in fact, they admire me, because what they do, I can do it too, ...so sometimes they tell me: "You're great." They aren't diabetic.... But... they admire me because... I have the determination to do things. (Martino, 34 years, T1D, farmer, onset at 8 years)

In these narratives, non-diabetic sport mates have never been described as a source of stigmatization. They were rather a source of important support, and Martino recounted a significant episode:

> I was out with the usual [friend] I go out, I had to stop, and get off the bike because of a hypo, ... I measured it [glycaemia], I was at 45, ... and I didn't take it that well, mentally, because... in... 8 years that I've been doing sports, it never happened that I got off my bike. Getting off the bike, stopping, sitting on the ground, I was clearheaded, I was talking, I took my... carbogel, my sugar, ... but it was a defeat (...) Mmm having to give up after the first problem [that is, the illness]... I try not to surrender to the problem, ... I deviate here, there, I get over it. Instead, then I actually had to give up. Stop, sit down, stay sitting on the ground... for a quarter of an hour, twenty minutes (...) ... but for two, slash three days, the defeat was stuck in my head. ... I know- we were out on our bikes, ... we had 15 kilometres to get home, ... I got home with tears in my eyes... I was defeated. The only time in... all these years.
> **... And... how did your sport mates react?**
> (...) There was the guy who goes with me, ... he understood the problem, he knows the problem, he tried to take my mind off it.... "Yes, look here, look there," but by then I, my head was gone, (he laughs) it was gone, and the same in the evening, he called me again, also the day after, he called me... and for three days I didn't touch my bike. (...) Then I got back on it, ... but it remained... more than the scare... this defeat was.... A big defeat. (Martino, 34 years, T1D, farmer, onset at 8 years)

Mutual support and mutual recognition were crucial dimensions that informed participants' discourses around sport practices.

Another key theme that was often intertwined with social relations among diabetic athletes was that of competition. Overall, all participants that engaged in individual sports talked about different forms of competition. Bourdieu asserted that masculinity is produced and maintained not only with respect to femininities, but especially within homosocial contexts: "Male habitus is constructed and completed only in connection with the space reserved for men, the space in which the serious games of the competition are played among men" (Bourdieu 1997: p. 203). The "serious games of competition" were here described as a fuel that sustained participants' rigorous and hard training, or as the main driving force that made them try to always improve their sport performances. Competition, in participants' narratives, was declined in different dimensions. A first case was that of *self-competition*: in this regard, an illustrative case was that of Emanuele, a 43-year-old man that had been diagnosed with diabetes at the age of 16. At the moment of the interview, he worked as an employee and was a competitive runner. In addition to diabetes, Emanuele also had a paresis to one arm and one leg, caused by problems occurred during his birth. In his narrative, competitive running was highly valued for the personal meaning attached to it: the mere fact of participating in a running race was considered as an important achievement for him. He compared his personal story to that of "Forrest Gump," the protagonist of a movie directed in 1994 from Robert Zemeckis who, just as he did, managed to engage in sport despite physical difficulties and cultural obstacles. Emanuele's engagement in sport began after an informative event organised by an association dedicated to people with diabetes, where he – just as Gioele – met Ivan, and was by him introduced in the subcultural world of diabetic athletes. The day after they met, he run for the first time with Ivan, and despite some initial difficulties he began to exercise on his own every day. Self-competition began when a physiotherapist, specialised in working with diabetic people, told him that he would never be able to run because of his leg paralysis. At this point, competitive running became a real challenge for him, and his goal was to demonstrate – to the others, but especially to himself – that he could manage to step up to the podium despite diabetes, despite the paralysis, despite others' disbelief:

> A girl who studied to be... a physiotherapist and all, and preparation for [working with] diabetics (...), probably, knowing about this leg, not having seen me run, she told me: "No, no, don't worry about it, because I don't even know if you're able to run." I mean. Said by a stranger, as you could be, I look at you, I stare at you, I smile, and I go away... Said by someone you know, someone who loves you, ... can I say a bad word? I tell you to fuck off. I mean, ... and there I was absolutely furious. I mean, I said, I said: "Now... I'll show you." (Emanuele, 43 years old, T1D, clerk, onset at 16 years)

The importance of competition in individual sport was clearly affirmed by Martino, when he stated:

> Anyway, competing gives you the incentive to... to train, to... to participate- to do, well, it gives you the adrenalin rush, it gives you... it gives you many things, competition, ... (...) competition is good: I fight for something. (Martino, 34 years, T1D, farmer, onset at 8 years)

For Martino, competition had different dimensions: on the one hand, it was a way of testing himself and his strength, it was an objective to be achieved; but it also meant measuring his ability through the comparison with non-diabetic athletes. In his words:

> Let's say that, in the context of sports, diabetes teaches you many things. It teaches you that even if you have diabetes, you are strong just like to others... You can arrive... you can arrive among the first ones, you can arrive among the last, ... but still, ... you are in it like the others, you are... you're strong like the others. As I said: since I've been doing sports, I... I had many satisfactions... Because I saw people who don't have diabetes, ... struggling much more [difficulty], and arriving after me. It might be selfishness, but I say: "Geez, those people have nothing" so I... I say: "So if I didn't have diabetes, I would go much more." So despite having diabetes, I go faster than certain people of my age, yeah. (Martino, 34 years, T1D, farmer, onset at 8 years)

The narratives of the athletes that participated in this research were different from the case described by Connell (1990) in his paper about an Australian iron-man. All participants that engaged in individual sport had other jobs, and they did not – except in the case of Gioele – pursue a sport career. Competition with the non-diabetic others was often shifted at the level of the everyday life, by comparing their future situation with that of non-diabetic "sedentary" others where, in the future, the situation would be somehow "reversed": they would be "healthier," thanks to their constant discipline and hard training, while non-diabetic sedentary people would suffer the consequences of old age and unhealthy lifestyle. As Ivan affirmed:

> When you see, with your eyes, ...that you've obtained a condition of [physical] fitness... and wellbeing, and that, as the years go by, ... always less people, peers and even healthy [non-diabetics], whom I- we call "the sleeping healthies" precisely because they do not engage in physical

> exercise, ... and you see that ironically you are in a better shape, in spite of your chronic illnesses and... because I also... for a year now I've also had Crohn's disease, which is an autoimmune disease, this thing makes you... view... your future with more hope. So the expectations... the expectations grow, I... always say that... at the age of seventy, I will still want to... do the triathlon, and I will still have a better chance to step up... on the podium, because the competitive ones will be much less. (He laughs) (Ivan, 51 years old, T1D, manager, onset at 27 years)

A different dimension of self-management was highlighted from Ilario, who during his description of sporting performances reported enacting a sort of "passing" strategy: in fact, he reported not "showing off" his "diabetic performance," he rather focused on his ability to enact a normative, masculine and healthy bodily sport performance, without displaying diabetes' signs. In his words:

> I went for a gully on the Monte Bianco, [with] a person who... I mean, they knew it [the fact that he has diabetes] beforehand, I went to Norway, with the alpine guide, they knew, I mean... I still like to tell the truth, ... But at the end of the holiday, they told me: "Look, ... I didn't notice anything, I only noticed you like girls, and not... " (He laughs) (Ilario, 28 years old, T1D, shop assistant, onset at 5 years)

As for food consumption, individual sports allow greater freedom in organizing time and modalities of eating, and unlike collective sports there are not "social obligations" of sharing post-training or post-matches meals with teammates. All participants that could be assigned under this subgroup reported eating "healthy" and most of them reported engaging in a low-carb diet, where carbohydrates and desserts where eaten only "therapeutically," namely in order to avoid hypoglycaemia during or before sport performances. Overall, athletic men talked about food in terms of its benefits for sport performance, as can be read in Massimo's words:

> The diet of an athlete who does what I do, but also that of my son is very… different if compared to that of a… sedentary diabetic. So we almost eat all day long.
> **So... for example?**
> ...Eh, for example... for example, from... from six in the afternoon, until... almost midnight, all I do is eat. Because, moreover, I... often skip lunch (...) mmm having... this lunch gap, I end up being so hungry.. (...) I eat because... I have to eat because since I work out I have to eat. Because otherwise I

> have a fall... in... in performance. (Massimo, 59 years old, T1D, retired, onset at 30 years)

As for self-management strategies, the majority of participants reported using digital technologies, while a minority reported using traditional devices: 5 participants reported using insulin pens, 10 reported using the insulin pump, 1 reported using the glucose meter, and 14 reported using the glucose sensor. Overall, all of them motivated their choices (or their physicians', in the case of Ilario) in terms of what was more useful for sport activities. The majority of them preferred digital technologies because allowed them to monitor glycaemic levels and prevent hypoglycaemia during sport activities:

> For sports, so they [the insulin pump and glucose monitor]… help me a lot. Because it gives me much more information compared to only seeing the photograph every time [of the traditional glucose meter]. (Nicola, 23 years old, T1D, university student, onset at 13 years)

> Had it not been for this [the continuous glucose sensor], I would have never done it. Because with this you have the chance to have the monitor on your arm, managing to see at any... at any moment how I am with glycaemia... And I feel much safer. (Gioele, 39 years old, T1D, employee, onset at 12 years)

> I asked for it [the insulin pump], but (…) [the doctors] said: "No. Why should we modify something that is working just fine?" I mean, when they told me that there would be some problems concerning sport activity... So, I said: "Ok, it's fine, I will continue injecting." I mean, it's just 5 minutes... To give yourself an injection I think it requires me from 30 to 35 seconds... (Ilario, 28 years old, T1D, shop assistant, onset at 5 years)

5.3.2 "I'm a professional footballer": comparing two experiences of diabetic athletes engaging in collective sports

Compared to individual sports, collective sports usually entail different challenges for a person with a diabetic body, this mainly because both training and competitions take place in a context where there is proximity with other non-diabetic teammates. This specific situation arises a number of issues: if in the context of individual sports diabetes self-management can be contained into a private sphere, in collective sports the constant presence of an "outsider" non-diabetic audience makes it necessary to deal with non-diabetic “others” and their normative expectations, as well as with the possibility of experiencing illness-related stigma.

Overall, a minority of participants reported engaging in collective sport, only 2 out of 15: Filippo and Sebastiano. They both were football players, and their narratives reported similarities and differences. First of all, Filippo and Sebastiano’s experiences with football began in different ways: in the case of Filippo, a 34-year-old man who was diagnosed with diabetes at the age of 14, the initial occasion for playing had been offered by two “camps” dedicated to young diabetic people, in which international football tournaments were organised with teams exclusively composed of diabetic, insulin-dependent players. The context of a “camp” exclusively dedicated to diabetic athletes well illustrates the process of becoming a member of the subcultural world of diabetic sportsmen: in this case, Filippo participated as a young “novice” to the learning process that allowed him to develop expertise through the participation in a shared set of social practices. Through social interactions with more experienced members of the “community of practice” of diabetic athletes, Filippo learned how to manage diabetes while playing sport, as he said:

> **And have you ever participated to camps dedicated to diabetic people?**
> ...Yes, two times, always through the xxxx (hospital name) always... both dedicated to sport, to football. (...) They made selections on an Italian level, first at wwww (name of the city), and then I have been [selected] both times to represent Italy abroad, I have done several tournaments. It was a special experience, because changing from having a team like I have here, with non-diabetic guys... to play with all diabetic [people], ... it is a bit weird, honestly... [During those camps] they instructed you to measure the blood sugar before doing sports, during the intervals, and you obviously saw various situations... both me, that I took a therapy through insulin shots, - While others, through... the insulin pump, and I could see the management in various situations, both hyperglycaemia, hypoglycaemia, precisely... that I managed to perform the following year, because there, I was still not very experienced... in this regard. That was a great experience. A great experience, really.
> **And how did you feel with your diabetic teammates, if compared to... to the other team, where they were not?**
> Yes, a little more alike, but however I don’t feel that different in the team, here in my town, let's say... You feel a little more part... of the same pathology. (Filippo, 34 years old, T1D, nurse, onset at 14 years)

The other case is that of Sebastiano, a 33-year-old man that was recently diagnosed with diabetes, at the age of 31. At the beginning of the interview, Sebastiano defined himself as "an athlete" and, subsequently, as a "professional footballer." He reported playing football even before diabetes' onset, and when he received the diagnosis he had to stop physical activity for a short period of time. In this case, football was a sport dedicated to male homosocial interactions, and it involved an ambivalent combination of competition and complicity that informed men's social relations. When Sebastiano had experienced diabetes' onset, he reported having received great support from his teammates:

> With sports, after... a week, or ten days [after the onset], I already... started playing football again. I play football, I'm a professional footballer. So... after a week, 10 days, I grabbed the sport bag again, and everything, little by little, slowly, now I got back to being like before. Maybe even better. [My teammates] helped me a lot, because they encouraged me immediately to return, ... in fact, when it [diabetes' onset] happened to me in early October, ... in mid-October I had already come back, let's say, because they told me: "Come back, come back!". For the first training ten minutes, ... and then a quarter of an hour, then twenty minutes, gradually, trying to understand how it [my body] worked. Then I had a strange effect, when I do intense sport, at that moment it [glycaemia] goes up, it's normal, it goes up, it also arrived at peaks of 200. During intense efforts. And then, after that, it lowered after half an hour, an hour, ... but I have to say they helped me a lot, and ... thanks to them I returned... just as before, and maybe better. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

Both Sebastiano and Filippo reported training for 2-3 times a week, and both of them reported using sport as an instrument for better managing diabetes. In addition to football, Sebastiano reported also working out in the gym, because he thought that this would improve his illness self-management. As he stated:

> Two days a week, let's say, I go to the gym, ... or I do training, either I train, or I go to the gym... One day I train, ... other two I play football, another I go to the gym. (...) For example... (...) Saturday, which is a day off, ... I went out, ... I did... 7, 8 kilometres running... half an hour, ... and... as a matter of fact, the following day [glycaemia] was perfectly steady. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

As I mentioned at the beginning of the paragraph, engaging in a collective sport like football entails specific challenges for diabetic players, mainly because it implies impression management (Goffman 1959) with a non-diabetic, male audience. In this regard, Sebastiano and Filippo reported similarities and differences in how they managed the information of their condition within sport contexts. On the one hand, Filippo reported that he had always felt comfortable with respect to the visibility of his diabetes: in fact, during the interview he reported that everybody in his team had always knew about his condition, and that he kept the glucose sensor visible on his arm without any problem in front of his teammates. On the other hand, as a demonstration of the ambivalence of homosociality, he reported that despite the fact that his teammates had been very supportive in the initial period, he preferred nonetheless to administer his insulin injections in the toilet, in order to avoid the possibility of the stigma related to the transgression of bodily normativity in a context of high bodily competition. As he said: “You never know what people might think.” In fact, by disguising the most stigmatizing diabetes self-management performance – that of injecting - Filippo conveyed an image of his diabetic self that was more “tolerable” and normative, this way matching the non-diabetic expectations and avoiding illness-related stigma. Furthermore, he reported that recently another diabetic young man had joined his football team, and the opportunity came up to build a special relationship with him based on complicity and mutual support. As members of the same “diabetic footballers” community of practices, this had allowed them, for example, to exchange some sugar in moments of low glycaemia during football matches and to share information.

Sebastiano’s experience was quite different from that of Filippo. In his case, he reported injecting insulin in the locker room in front of the other teammates: as a matter of fact, this did not go unnoticed, and his teammates frequently taunt him because of the association of insulin injection with shooting-up. As he recounted:

> **And did it ever happened that… I don’t know, in the locker room, maybe someone saw your sensor, and they ask some questions?**
> Yes, yes, everyone, well but everyone knows... so... they asked me. Then they would also make fun of me, obviously joking, eh... They say: “You-you shoot up, you... you take drugs, you shoot up!” But ok, everyone jokes... But ok, it’s normal... that also happens. (...) I laugh about it too. A friend of ours always says: “Mmm if you make me angry, if you don’t... if you don’t pass me the ball, I’ll give you an injection of powdered sugar!” And ok, everyone jokes about it. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

As for glycaemia monitoring, Sebastiano recounted checking the glucose sensor in front of everybody, and during the matches he did it at the moment of intervals, "when the action stopped." Measuring glycaemia on the side-line and displaying the glucose sensor attached to his bicep captured the attention of the adversary cheering that, in turn, made jokes about his condition. Again, the dimension of competition and "punishment" for bodily transgressions and for failing to match non-diabetic audience's expectations, led to experiencing stigma. Jokes and insults about him transgressing bodily healthy normativity had the purpose of undermining his credibility as a football player, as a legitimate captain, as an adequate man. As he described the episode:

> An episode [that happened]... when we were in the field... [in] another football field, against another team. I stopped a moment, well they were... let's say, dying of envy, sorry if I say so, as they were losing the match, and some of the supporters of that team, I went towards the bench, I measured it [glycaemia] a moment... they say: "Look..." they say: "We're playing against paralytics." ... They said. (...) Because I was measuring it, yes. I don't know what they thought, but they used this term. (...)
> **And how did you react in that occasion?**
> ...Well, nothing, I had a laugh. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

Sebastiano's negative experience of complete disclosure and illness-related stigma, and Filippo's positive experience of a diabetes which was normalized through a combination of disclosure and passing strategies constituted, in a way, two most distant experiences: it is thus likely that the population of diabetic athletes engaging in collective sports might be positioned some way in the middle of this "continuum."

As far as food is concerned, both Filippo and Sebastiano reported not following a specific diet, yet they preferred adapting the amount of insulin to the quantity of carbohydrates contained in the consumed food. Compared to the athletes engaging in individual sport disciplines, they did not justify their food consumption through the reference to sport needs. They reported that everyday meals where usually organized by the grandmother in the case of Sebastiano and the mother, in the case of Filippo: in both cases, a woman. As Filippo stated:

> For lunch, obviously, you eat what there is, what my mom makes me, (he laughs)
> **Usually, what does your mom make for lunch? More or less... are there...**
> Well, it depends, let's say I adapt based on what there is to eat... If once we don't have pasta, I decrease... the units of insulin, if we have pasta... I increase them. (Filippo, 34 years old, T1D, nurse, onset at 14 years)

In order to maintain a glycaemic balance, Sebastiano reported organizing his meals differently with respect to his non-diabetic teammates:

> If tomorrow I had to [play a football match] at 10 p.m., I [would] come home at 7.30 p.m., and unlike the others, who don't eat and go to play at 10, if I play at 10 I eat at 7.30, I have a small dinner let's say, with insulin – some units less of insulin- and… after 2 hours, 2 hours and a half, I can play without problems. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

After football matches, dinners were an important opportunity to socialise with teammates, and in this case they reported eating just the same things as their teammates did, and compensating by increasing the dose of insulin to inject before or after the meal.

Unlike participants engaging in individual sports, neither Sebastiano nor Filippo talked directly about competition as the main incentive to play football. Implicitly, Sebastiano discursively constructed football as a prowess test, as a demonstration of his body ability despite diabetes and as an acknowledgment his condition did not affect his capacity to perform and display his strength. In his discourse, it rather reinforced it. During the interview I asked him how he felt about his performances during the football matches with respect to his non-diabetic teammates: on the one hand, he answered by acknowledging that they were more "performing," probably because of their younger age, but on the other hand this was somehow discursively counterbalanced by immediately answering by stating his position "of authority" within his team, that of captain:

> **With respect to your teammates, how do you feel about your performance on the field?**
> Well, fine. Very well actually, especially because I am the team captain! There are boys that are younger than me that physically perform better,

> but… let's say... they are 19, 20 years old, when I was their age I was more… But now I am 32, may be my performances are decreasing, but... I can hold my own. (Sebastiano, 33 years old, T1D, surveyor, onset at 31 years)

5.3.3 Sport, gender relations and diabetic bodies

The case of male diabetic athletes raises a number of question about how diabetic bodies may intersect with broader social processes. Overall, the analysis of the empirical material confirmed previous research on sport and male bodies (e.g. Messner 2005, Seymour 2003, White *et. al* 1995) according to which "sport" was considered as a critical vehicle for masculinity construction.

First of all, overall the totality of the "athlete" participants described sport as an occasion for social interaction with other (diabetic and non-diabetic) men. In fact, the majority of interviewees were "initiated" to sport by other diabetic male athletes, or, as in the case of Cristian, from his father. In Cristian's case, it appeared evident the gendered subdivision of care roles of his parents: he was diagnosed with diabetes at the age of 10, and while his mother took care of food preparation and medical treatment, physical activity was considered as a responsibility of his father. In fact, his father provided for his entrance in the world of sports, just as he had done in the past with his brothers (but not with his sister), this way confirming a gendered division of parenting care roles. In his words:

> The first day I got ill... when I found out... the first day of hospitalisation they told me: "Diabetes is treated like this, glycaemia (…) sugar level monitoring... insulin, ... diet, and sport. These are your four medicines." ... And when they said sport, they didn't mean going for a walk... They meant sport... And they insisted on this. So much that-... they also brainwashed my parents so much, ... that when we got back home, in xxxx (town name), they signed me up straight away, ... they made me try all kinds of sports, because I hadn't done any sport until that moment. That's it, and my dad made me try them all. (Cristian, 43 years old, T1D, manager, onset at 10 years)

Among all this subsample, nobody ever talked about women engaging in sport or doing training with them: they trained alone, with male friends or, in the case of Massimo, with his diabetic son. The most eloquent case in which the embedded gender dimension of sport was repeatedly affirmed during the interview was that of Ronaldo, a competitive cyclist that engaged in cycling only after diabetes' onset. During the interview he used an explicit double standard when talking about himself and his wife, with respect to sport: they both had an autoimmune disease that needed to be managed through medical treatment and physical activity. In his narrative – despite the fact that his wife had been a swimming champion – he reported that her daily physical "training" did not include physical and athletic prowess, like in his case, yet it included taking care of her elderly parents and doing the housework in a "big house:" this subdivision of roles and possibilities was taken-for-granted in his discourse, and this clearly emerged in the next excerpt, together with a stereotyped representation of "Southern women" depicted as lazy, sedentary an helpless:

> She is free to stuff her face with dessert, but I also have to say that since... she helps my in-laws, who are... 88 and 86 years old, so... she takes care of a three-story house, she... cleans it in the morning, she does it all, in fact it's like she burns all those sugars, it's like she is still doing a training of... at least 4 hours, 5 hours a day, she keeps doing it, and as a matter of fact, a few times when we went to the pool just to make her happy, she easily does 60, 80 laps without any problems, despite not being a... mid-level sportsperson anymore. Yes, all she has to do is clean the house, and she keeps trained. Yeah, this is a thing that I... often I tell to Southern women: "Look, if you clean up your house well, your glycaemia will decrease." Instead of lying on the sofa. (...) But just imagine that someone from the South [of Italy] starts doing sports, or let alone cleaning the house well, only to... try to treat their diabetes. (Ronaldo, 46 years old, diabetes LADA, high school teacher, onset at 39 years)

As Robertson (2003: p. 711) observed: "Sport represents an arena where masculinities can become unstable, evoking contradictory emotions for individual men." In fact, on the one hand men in this subsample reported expressing emotions and usually receiving – and giving – support with each other within the subculture of (diabetic) sport. But, on the other hand, their relationships were also informed by competition and by the possibility of being stigmatized in non-diabetic contexts.

In analysing these narratives and comparing them to other ideal types' experiences, it was evident that engaging in sport was highly associated to a specific class *habitus*: all participants where heterosexual and with a middle class background, and they had the economic capital that allowed them to dedicate time and resources in competitive sport.

Furthermore, the majority of them had the actual possibility to engage in competitive sport and follow a specific diet tailored around diabetes and sport training needs because they had a partner/wife/mother/mother-in law that took care of their food consumption practices. In this respect, there was a significant difference in how food consumption was managed into the private and into the public sphere. In the private sphere, food organization and management was usually organized by a female member of the family who respected "healthy" rules that were considered as appropriated for participants' construction of a normative, diabetic body.

With regards to the public sphere, food consumption was considered as a crucial context of (male) socialization. With respect to social expectations around masculinity and food, participants reported engaging in different strategies that can be described by two most different cases, that of Nicola and that of Martino, under the assumption that other participants adopted a variety of practices that could be positioned somewhere in between.

Nicola, a 23-year-old university student and competitive runner that had diabetes' onset at the age of 15, reported being aware of the fact that there were different social expectations regarding food consumption towards men, if compared to those towards women. As a matter of fact, he observed that usually men were expected to have a greater appetite then women. As he remarked:

> Since there is this stereotype, I have to eat more, I have to… I have to eat more, I have to… show that I won't collapse, yes. I think, I mean… Yes… It's kind of- it's kind of in your [nature] of men, this thing here. There is this thing, so, you do it. But the point is that, since you have diabetes, the… this thing here then has its consequences for which you also have to find some countermeasures, but… often, yes. There is this thing about the diabetic man, the non-diabetic, that… he has to prove that he is a little more. (Nicola, 23 years old, T1D, university student, onset at 15 years)

For this reason, for diabetic men it would be even harder to "pass" as non-diabetic, or to neutralize diabetes' symptoms. One possible solution was that adopter by Nicola, which consisted in injecting the regular dose of insulin before the meal, then eating the desired (unquantified) amount of food during the meal and afterwards adopting "countermeasures" – such as an insulin correction shot – immediately after the meal.

Also Martino reported being aware of gendered stereotypes that informed food consumption practices but he, unlike Nicola, decided not to modify his "healthy" food habits and instead to respect the rules of his dietary regimes. Since he was socially sanctioned through marginalization from his group of peers for "transgressing" gender normativity, he decided to keep food consumption practices in the private sphere and to avoid eating during social occasions:

> I have never loved going out... for dinner with friends, ... because they would always look at me a little weird, I went out [only] initially [after the onset]. But I ate my small ration, and that was it. On the other hand, they drink, eat, ... and that's already when they start to exclude you: "Well, you don't drink, and you don't eat much," they kind of exclude you from the group, (...) ... as long as you have to eat pizza it's ok, ... but when you start doing... abundant dinners, ... I have never liked it and somehow they judge you, because well... (...) you have a different lifestyle.
>
> **Could you for example, give me an example, like when you were... having dinner with friends, what did you do differently compared to others?**
>
> Well, dinner with friends, you go to dinner, I take my still water, as usual. They start... beer, and whatnot, liquor, yeah... (...) my dinner was... not eating excessively, with water, and that's it, my dinner was over. "Come on, take some dessert!" Well, ...I've never been, even before I [had] diabetes, ... a dessert guy... (Martino, 34 years, T1D, farmer, onset at 8 years)

5.4 The Free Spirit

> If I want to eat pizza, and everybody eats pizza, doesn't matter that I have diabetes: I eat pizza. (…) I mean, really, it is just as if a person wants to save money, and keeps saving, saving, saving... But in the end, what do you want to do? You want to die the richest of the cemetery? (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

The "Free Spirit" ideal type is a diabetic man that does not engage in hyper-compliance and numeric competition, such as the first ideal type that I have outlined at the beginning of the chapter; he does not even engage in endurance and competitive sport like the second ideal type described in the previous paragraph. In fact, the "Free Spirit" ideal type equates constant body self-surveillance and control with prohibition and denial, and he describes high-compliant diabetic people as wretched souls, obsessive individuals that live their bodies as sick bodies and that dedicate their whole life to diabetes management, this way forgetting to enjoy freedom and pleasure. The "Free Spirit" talks about his body as a tool for experiencing well-being, for feeling pleasurable emotions, for "feeling good" and having fun, for travelling and eating tasty meals. This ideal type encompasses those experiences where experiential embodiment dominates the narrative: according to Watson (2000: p. 119) experiential embodiment "is the primary site for the experience of emotions, in the sense of experiencing 'well-being'," a sensation that is perceived from bodily sensations."

In their research on type 2 diabetes management, Broom and Whittaker (2004: p. 2378) described something similar when they highlighted the theme of "miserable life of denial," where "[s]ocialising and enjoying oneself may be valued more highly than health, so people sometimes opt for doing 'the wrong thing'." The "Free Spirit" for example, recognises that the moment of the meal is a crucial social occasion "imbued with social meaning" (Ibidem) and a great opportunity for feeling pleasurable bodily sensations. On the other hand, food restriction would entail a substantial experiential and social loss.

If the "Diabetic Quantified Self" or the "Athlete" perceived digital devices as empowering instruments that were part of their own bodies and allowed them to better comply with treatment, or to elaborate an alternative knowledge around diabetes experience, in the case of the "Free Spirit" they are rather perceived as oppressive and foreign objects that impede their freedom, otherwise they are tolerated in so far as they allow to relegate diabetes "in the background" of their everyday life and allow them to dedicate themselves to other activities. Diabetes self-management is, for this ideal type, lowered to its minimum, less-impacting level. The "Free Spirit" does not attend on-line communities, nor specific associations dedicated to people with diabetes: his main reference is that of non-diabetic communities of practices, where he cultivates social relationships with whom he hangs out and enjoys himself: well-being and pleasurable sensations are valued more than fulfilling the "good citizen" ideal through a restrictive self-discipline.

5.4.1 “Life is something else”: the (un)doing of diabetes self-management

Overall, in the narratives collected under this ideal type diabetes was not described as an intrusive illness with a severe impact on participants’ everyday life. It was rather considered as a “nuisance,” a condition that needed some time to be managed, but that did not impinge completely participants’ identity. An illustrative example can be found in the words of Amedeo, a 50-year old man who was diagnosed with diabetes at the age of 30:

> I have to say that I never considered myself as sick, this maybe has always been my lifesaver. A nuisance, another thing to manage: like someone who is short-sighted wears glasses, someone who has diabetes takes insulin. But I never perceived it as a limit in my life, it never limited me in doing something, in... So I am always positive, I would say. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

On the same line, Giovanni, a 32-year-old man who was diagnosed with autoimmune diabetes at the age of 31, considered it a “condition”, rather than a chronic disease. Giovanni is may be the most extreme “Free Spirit” of this subsample, because he completely refused to engage in self-management practices (namely, he refused to inject insulin and he rarely monitored his glycaemia), because he followed the suggestion of what he defined as “psychosomatic medicine.” In his words:

> [It’s] a condition, I understand it as a situation to manage, now for me it has been the alarm bell that [indicated] to straighten my life, in the sense of focusing more on myself. (Giovanni, 32 years old, T1D, unemployed, onset at 31 years)

Unlike the case of the “Diabetic Quantified Self,” where self-monitoring and self-control practices were at the basis of the narratives, in this case participants eschew the possibility of constraining their lives in what they considered as a rigid and structured net of self-management practices. They rather kept self-surveillance – as well as medical treatment – at the minimum level. In this regard, Pasquale, a 47-year-old man that was diagnosed with diabetes at the age of 30, compared his “freer” self-management to a more “constrained” one, that of an acquaintance of his who had type 2 diabetes and managed to avoid drugs just by controlling food consumption. From Pasquale's perspective, this rigid approach to diabetes' self management could undermine the quality of one's life:

> He actually manages not to take the pill, because he cures [diabetes] through diet, he basically doesn't eat carbs. Or if he eats them, he just eats few of them. But what kind of a life is that?? I mean, for god's sake, he sure will live longer than me, but how? Because there is also the quality of life that is different, don't you think? I mean, I always say: "Life is something else."
> **Mmm so... the point is…**
> To live. (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

Another illustrative example is that of Massimiliano, a 40-years-old man who was diagnosed with diabetes when he was a child, at the age of 4. Massimiliano, who at the moment of the interview worked as a researcher, reported considering "excessive" to constantly measure and monitor bodily parameters, because he thought that this would impinge personal well-being as well as the quality of one's everyday life:

> For me, a constantly monitored life, even if it could be functional from the point of view of treatment... Then, from the psychological point of view... I think it is quite difficult. (…) Physicians usually suggest approaching illness in a certain way, but may be they (…) then only look to the number at the end of the exam, you know? Not all of them, not all of them. But they should consider the possibility that... an extra point of glycated [haemoglobin], after all, it's not that important as the influence that it has in one's disposition, and in growing with that pathology. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Massimiliano compared the way illness was approached when he was a child to the way today's diabetic children are monitored: he observed that, if on the one hand contemporary use of digital technologies allows for better results in terms of blood tests and overall illness management, on the other hand he noted that also the downsides of constant monitoring should be considered, which he compared to a real "slavery":

> Today that… there is more… control, there are many possibilities, but on the other hand dealing with disease is very… oppressive, from a practical… point of view. Because you know, kids today have to constantly monitor themselves already at the age of 2, 3 years… If [glycaemia] goes up to 200: "Oh, something must be done!" While I remember that… except if it was 400 my parents never... All in all: "You run, you don't eat the snack" You see? In this respect I was lucky, I haven't had great complications so far. But

> if I see the way I was treated at the very beginning, and compared to the contemporary situation… This is a disaster, ok? (…) They sure are stronger from a therapeutic and medical point of view but it is more difficult to deal with it from a psychological point of view, especially for children, to deal with this thing, because they are forced to constantly being enslaved from therapy, you know? (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

From his point of view, it is crucial to "reach a compromise" and find a "not too oppressive" way of managing diabetes, and in his case this contemplated also allowing himself alternating periods of a particularly low adherence to treatment:

> I did the bare minimum, then… I wouldn't care, I wouldn't care at all. Ok, … every now and then, you have these wonderful moments, … of complete leisure, and they're also good for you. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

For many participants, reducing control did not necessarily mean avoiding it: it rather entailed a different approach to illness and to its daily management. For example, a common practice was that of relying on "physical sensations" in order to "estimate" glycaemic levels – and more than anything hypoglycaemia – instead of measuring it constantly with medical devices. As Amedeo put it:

> Now, if it [hypoglycaemia] happens during the day I feel it before, you know? I mean, I start feeling discomfort, you feel dizzy, and you feel that you don't think straight (…) it's a sensation that you know well, I already know what it is: so I eat everything obviously, because you have munchies and you want something sweet. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

Pietro, a 27-year-old man who was diagnosed with type 1 diabetes at the age of 16, talking about an episode of hypoglycaemia, recounted:

> [Once] I lost the ground beneath me… I was scared, at the beginning I didn't know what it was. Now I know it, and when I feel this way, I know what it is. (...) Weakness, sweating too much, great anxiety that you have because the brain turns to mush… But then it's pretty cool, because you can eat... sweets, you have munchies, you are incredibly hungry: I opened the fridge and ate everything: I had a sandwich, then an ice cream, then a yoghurt, then a pasta, I mean... I was really hungry. (…) Now, I really don't like it, because I have bad vision when I have a hypo. It's like looking at a cubist painting, you struggle and confuse the object (…) everything is confused in

> your eyes, and you are confused, and people talk to you but you cannot answer.
>
> **And when this happens, what do you do?**
>
> I get pissed off, because I really don't like it. (…) Honestly, me, in the last months, I didn't even measure glycaemia. I'm not saying that I do well, because I know, that I am wrong. (…) It's 6-7 months, (…) because there are a lot of things that you have to do in life. (…) I cannot always think about it obsessively, otherwise if I spend all days thinking about it, I freak out. (Laughing) (Pietro, 27 years old, T1D, musician, onset at 16 years)

This group of narratives differentiate from the other ideal types also because participants described themselves in an "unquantified" way: they measured glycaemia infrequently or even not at all, and the avoidance of this constant self-surveillance was considered from them as a prerequisite that improved their psychological well-being. As Giovanni stated:

> I see other people that set themselves as a goal to have glycaemia always at 90. And if it goes at 120: "Shit!" and they become paranoid. This doesn't happen to me, so... I think that this approach… Of not being paranoid, I mean, it makes things easier. (Giovanni, 32 years old, T1D, unemployed, onset at 31 years)

Avoiding measuring glycaemia was also used as a strategy in order to avoid social stigma, as Elio, a 29-year-old man who was diagnosed with diabetes at the age of 24, recalled:

> When you are in a group... I mean, as long as you are only with two friends, is ok. When you are in a group, with people that you don't know very well, this is more difficult. It is very much more difficult. When I go dancing, you don't feel like measuring, then you have to go to the bathroom, you have to inject insulin, you have to count… Or when you go out for eating dinner with people that may be you don't know, having to go to the bathroom (…) it's not easy. You are at some friends' house, especially when there are people that you know the least. Because there are people that don't understand, that see... and that then don't feel like asking... (Elio, 29 years old, T1D, shop assistant, onset at 24 years)

Another context where all participants reported being almost "unquantified" was that of food consumption, where – unlike the other ideal types – none of them engaged in a rigorous "carbohydrate counting." As Giovanni said:

> I should... They always told me that I should do the carbohydrate counting. And it is something that I… In fact, the doctor knows: “You are not good at it!” Because counting bothers me… (…) I know that carbohydrate counting is important, because I am old enough to understand it, but it is something that I don’t… If I had to do it... I don’t know, it is something that (he laughs) I can do it for one day, two days, but the third day I already begin feeling awful, I mean. (Manuel, 28 years old, T1D, employee, onset at 16 years)

Overall, the majority of interviewees reported “estimating” the amount of carbohydrates contained in the food they ate without using dedicated App nor memorizing numerical properties for each food consumed:

> I don’t do the carbohydrates counting in a precise manner, even if I attended a course with a nutritionist, actually I ballpark it. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

In the same line of thought, Matteo, a 58-year-old man who was diagnosed with diabetes at the age of 5, stated:

> You know, because there is no point in doing the math… I see how much pasta I have on the plate, and I adapt... Without... Because carbohydrate counting is... It is a little bit complicated, come on. The approach is changed, now this is the first thing that they teach you: the carbohydrate counting. I know how it works, it is not that complicated, but I use something in between. (Matteo, 58 years old, T1D, retired, onset at 5 years)

Matteo is the only participant in this subgroup that reported participating to the activities proposed by a local association dedicated to diabetic people. But he did so in a very different way if compared to the other two ideal types: for example, he recounted an episode that is particularly illustrative of his approach to illness. When the association proposed a course for learning the “carbohydrate counting” method, he said: “No one understood anything.” And to a man who, in that occasion, reported struggling with hyperglycaemia, he proposed a non-medical solution, in line with his approach: namely, drinking beer. In his words:

> Now the [medical] approach is carbohydrate counting. (…) I like attending courses [organized by the association] because it is so funny! I’ll tell you a story (laughing): a friend of mine, once, he arrived at the course, you know, and he said that he wanted to lower glycaemic levels after dinner by running, riding a bike. (Laughing) And he went, he went running after dinner: before he had 250 [of glycaemia] and after 300. “You got it all wrong… Come with me!” [I said]. One time, two times, and the third evening: “But where do you

> want to go?" [He asked]. "We go to drink a beer" [he replied]. (Laughing) /"What? We go and drink a beer?"/ (With a surprised tone) (Laughing) We went and drank a beer, then he went back home… Oh, for god's sake, then he began to drink beer! (Laughing) (Matteo, 58 years old, T1D, retired, onset at 5 years)

Overall, with the exception of Matteo, participants in this subgroup reported not participating in associations' activities. One of the main reasons why they did not attend was, as Amedeo and Massimiliano observed, because this could become a form of segregation:

> I have never been someone that goes to those associations, because on the one hand they provide support, but on the other they ghettoize too much (…) closing oneself in this… it is like constructing a ghetto, don't you think? (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

> I have never done this [going to an association] because if I'd start putting myself into this, diabetes would have become an… everyday thing. It would become a form of "segregation," in quotes. And this fact... It's not that I hate this, or that I don't want to do it. But I never found it stimulating to be part of these things here, you know, mmm... I have had some friends, I continued with those friends. Then, if they had diabetes or not, I didn't really care. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

In order to reinforce their position as "Free Spirits", participants discursively distanced themselves from another "type" of diabetic experience: that of the hyper-monitored, hyper-compliant, or sporty diabetic person. For example, Pietro compared his approach to an extremely opposite one: that of middle-class women whom he had encountered at a meeting dedicated to diabetic people. As opposed to him, in his opinion they had unnecessarily turned their lives upside down because of diabetes, a condition that they managed with a sort of numerical obsession. In his words:

> But then the… Problem is that (…) your illness becomes your life… And not the other way around. Because the other way around, it would have an excessively philosophical taste (he laughs). But your illness kind of becomes your life, …because you have to really be… if you wanted to be perfect, (…) and to be… excessively controlled, and not to have any problem… (...) These forty-, fifty-year-old ladies, these little ladies who live around here [he lives in a little rural town], who care a lot… only think about themselves, no, …and about their own family, in their own house, …they fall into depression, when they get diabetes. They fall into depression, and (…) for

> example… [they] call an ambulance for hypoglycaemia, after you've had diabetes for twenty years, it's pure madness, …and there's also… I have heard it told like this… I think… I mean, it's a basic anxious thought, no, to think about… I maybe underestimate certain things too much, but they… instead, they really see them, these ladies… (…) I mean, I couldn't care less if after you've done 300 metres on foot, on a Saturday morning, with your poodle, …you measured your blood sugar before leaving home, [and] it was 74, you came back, it was higher. "But why??" [they ask themselves]… Well, there can be a thousand factors... Instead, the questions they ask are those: "Ah but I went for a walk, like you told me" (…) "but when I came back my [glycaemia] was higher than the one…" it's an obsession for this numerical value.
> **… And you don't have the obsession for this value?**
> I eeh … honestly, in the past months, …I haven't even measured my blood sugar levels. (Pietro, 27 years old, T1D, musician, onset at 16 years)

In the same vein, Massimiliano talked about different approaches to diabetes by referring to those diabetic people obsessively concerned with glycaemia measurements, who constantly monitor it and that always weight their food, this way dedicating much time of their lives to diabetes self-management:

> Because I've heard some incredible things, (he laughs) they say: "Ah, 95 point 6 grams of pasta." It's pasta! (He laughs) There's something that's complete madness which is (he laughs) the half a teaspoon of... of sugar in your coffee, which, all you have to do is get up, get your ass off the chair, sorry if I'm telling you, but the half a teaspoon is gone: you take two breaths, and it's vanished... (He laughs) (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Another dimension of "otherness" was that of sport engagement. In this subsample, no one participated in sport or engaged in regular physical activity. For example, despite the fact the diabetologist advised Matteo to engage in physical activity in order to better manage his diabetes, he reported that he "has always been klutz with sport," but that this was not due to his chronic condition, it was rather his general attitude towards physical activity. Using irony, he stated: "I consider every other possibility in order to avoid physical activity. Anything. Absolutely anything. So, I've even bought a motorbike," and with his motorbike he also used to go to the mountains without the need to walk nor to "struggle." On the same line, the "others" diabetics were described from Matteo as the athletes, that "at 5 a.m. go up to the top of the mountain, running," those diabetics that are active, slim and fit. This kind of engagement in sport was considered, for him, “excessive”: he would rather, as he said, “run after the hypoglycaemias.”

5.4.2 Accounts of freedom and constraint in using digital technologies for diabetes self-management

Overall, the majority of participants whose narratives could be described by this ideal type reported using traditional medical devices, while a minority of them reported using most recent digital devices: with regard to glycaemia measurements, 5 of them used the glucose meter and 3 of them reported using the glucose sensor; as regards to insulin delivery, 5 of them reported using the insulin pens while 3 of them chose to use the insulin pump. Despite the fact that participants made different choices in terms of self-management strategies, all of them justified those strategies by referring to the higher level of freedom and psychophysical well-being that this entailed in their everyday life.

For example, Pietro reported having tried to use the insulin pump, but he then had opted for the insulin pens because he considered that the pump was too much time-consuming and he considered it a “foreign” object to his body that could have a negative impact on his well-being:

> **What is the reason that led you to chose... to have... to use [insulin] pens?**
> Because [the insulin pump] is a pain in the arse, mainly because it comes off [by itself]. And this gets on my nerves, because may be I put it on with great attention, I try to stay on track, and then this thing comes off. And then I should pack it up in the middle of my belly, and there is all a work you have to do (…) And, by the way, it is always a thing, that you have attached there. If you put a tape, then you have to shower, and then this thing comes off, and you had just filled it [with insulin], you have to fill it again… (…) Because if you begin to have problems with this thing that you should change every three days, then it comes off every two, or in one day. In the meanwhile you have the other [the sensor] on your arm, that needs to stay there for two weeks, then it comes off... You lose track. This drove me crazy... (Pietro, 27 years old, T1D, musician, onset at 16 years)

Massimiliano, who reflected on the possible “downsides” of digital technologies by comparing his experience to that of contemporary hyper-monitored diabetic children, gave a similar account:

> From the point of view - I try to think - to see today's children... that have the insulin pump, that have the glucose sensor, that are… very much in contact with this thing [illness]... And I… used to spend entire weeks were I hardly injected insulin sometimes… I mean, let's say the truth... (He laughs) Sometimes I think… it is possible that this could cause in someone some difficulty, not only in dealing with diabetes in itself, but mainly in dealing with life outside diabetes. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

One of the difficulties that he envisioned was the possibility of perceiving medical devices as an extraneous object attached to the body, a "ball and chain," a sensation that could be lived as a constant reminder of the disease and could influence the quality of life experienced. For this reason, he decided to use glucose sensor every once in the while and to avoid the insulin pump. In his words:

> I tried to use the insulin pump, but I can't.
> **For what reason, does it bother you?**
> It is psychologically impossible for me to have one more thing… (…) I don't want to say that the worse therapy is the best, absolutely, but it is important to look for a compromise within a therapeutic situation where there is less oppression. Honestly, feeling it attached to me, from the psychological point view, this is (…) oppressive. If it can be positive for someone not to inject insulin, conversely for others… to constantly have a machine attached, it could be felt as a real slavery. You know? It is, actually it is. (…) But if you are adult, it sure can give you more tranquillity in therapy, unlike the insulin... [that you inject] 4 or 5 times a day (…). So [the insulin pump] allows you to avoid some daily injection, that I don't know if it is worse if compared to having a needle inserted [into your body] 24 hour a day for 3 days. I would never do that. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

According to Massimiliano, on the one hand the fact of having an object attached to the body – the sensor of the insulin pump – could improve adherence to treatment, precisely because it constantly reminds to the person that he has got an illness to manage. On the other hand, an excessive self-surveillance, in his opinion, could have a negative impact on the person's psychological wellbeing. In his words:

> I think it's often, ... the fact that... seeing it, continuously, and having it always [attached] on yourself, this, in quotes, this makes you more aware of what you have to do... From the therapeutic point of view, if compared to... mmm to that of... injections per se, you see... I repeat, I'm not a doctor, but... but... from a psychological point of view... I noticed that too, it's more the

> impact of having a thing, or the sensor: obviously, you've always it attacked to you, and so you're constantly going to measure. Don't you think? When you use the glucose meter, beyond the fact that you... prick your fingers, however, ... even with the glucose meter, you could do it continuously, almost. Every half hour, every hour, but you don't do it... no, because... you focus to do anything else, and instead in that case there, you're constantly instigated mmm... and induced, to measurement... Ok? (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Giovanni, in turn, represented diabetes as an opportunity to change his life, to break free from any form of constraint and to concentrate on his own psychophysical "well-being." As Frank stated: "Illness takes away parts of your life, but in doing so it gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years" (Frank 1990: p. 1). This, in his narrative, was understood as feeling physically and mentally well, and it entailed quitting his job in order to avoid stress. This approach also entailed not injecting insulin and measuring glycaemia only occasionally. Among this sample, Giovanni was the only participant who completely refused medical treatment. In his words:

> I measure it, but not usually. And now I don't have the need to bring the glucose meter with me, and always measure it the two hours after. No. I've never... I do not. I do it every now and then, when I want to. However, as I said before, to keep me under control, in short, at least I verify that from one day to the next it doesn't rise to 300. But I'm calm, I mean, for me... also... also another thing that... changes, no, I mean... if I see the glucose meter that measures 140, 150, it [glycaemia] is not within the limits, the blood sugar, but it is not even high. But... I don't care, I mean, I'm not going to say: "Fuck, I have to be under 110, because otherwise.." And then correct [with insulin], and so on. (Giovanni, 32 years old, T1D, unemployed, onset at 31 years)

On the other hand, 3 participants reported feeling freer and less under control through the use of digital medical devices. For example, Amedeo at the moment of the interview was using the continuous glucose sensor for measuring glycaemia and the insulin pump for insulin administration. As I mentioned before, he did not engage in a rigorous and "numerical-oriented" management, but digital devices for him served to feel less constrained during the day, to monitor quickly the situation without the need of stopping his activities for injecting insulin or pricking his finger and measuring glycaemia. In his words:

> So I have clients here, I manage real estate in London, I go back and forth. This means that there are days that maybe I stay at home all day and work from home at the computer. And there are days when I'm out all day on foot or by bike and I go out with a client at the restaurant or eat a salad on the fly and... This added to the fact that today I'm cycling or like yesterday I was at home all day, so the physical activity, eating at the restaurant rather than... And mmm there are variables that obviously complicate the self-management. (...) And let's say that today with this [the insulin pump] I manage to correct not so much what I eat, but to keep the basal [insulin] and to manage it in a certain way. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

In the same line, Vito, a 30-year-old man who was diagnosed with diabetes at the age of 23, in his narrative put more emphasis on the many activities that he managed to engage in, such as parting and travelling for fun, and he described his self-management as kept to a minimum level, in order not to let it intrude his experiential embodiment. With this approach, he found the insulin pump to be the best solution for insulin administration, because it allowed him to feel "freer" and not to constantly thinking about bringing with him and using insulin pens several times a day. In his words:

> I like to travel, to go around, I mean, I don't really like comfort. For example, now I'm going to do a surfing course, but at the Canary Islands. Which are four hours away... (...) the thing that bothers me is... having my mind on something. Like thinking about all those things, how to get organised, where to keep the insulin, that's why I don't mind this [the insulin pump]. Because in the end I, even if I don't think about it, once I measure it, I tell it what it has to do, [and] it does it. (...) But say you go alone, you go... on an trip organised by people you don't even know, ... it would be a little more... but, it's not something for which I say: "I won't make it because I have diabetes." (Vito, 30 years old, T1D, employee, onset at 23 years)

Another participant, Elio, during the interview often referred to the importance of his experiential embodiment, especially his interest for partying and travelling. As a way of demonstrating his ability to contain diabetes difficulties and to limit its intrusion into his life, he reported travelling often and also on his own: "I travel very often, next week I'll go back to Amsterdam for three days, I went to Copenhagen for three days in February, and... I like to travel, I also do it by myself." Despite the difficulties, he still managed to go out and party with his friends or go to concerts – albeit not as much as he wanted to -, and, in those occasions, he brought with him a “shoulder bag” with a “kit” for managing his condition. In the meantime, not letting diabetes intrude into his (social) life, sometimes, also meant mismanaging its symptoms, and avoiding both measurements and therapy:

> Sometimes, I think that you’re so focused when... I mean, you’re still with friends, you’re still detached [from illness], ... That thinking about it, having to deal with it, it takes you back to that conception of reality that you would rather forget for a moment. So it would be oppressive, and so you put it aside. (Elio, 29 years, T1D, shop assistant, onset at 24 years)

On the other hand, managing illness during social occasions not only brings illness into the picture, but it also may lead to experiencing stigma. This the case, for example, of Pasquale:

> In the morning, when I see that [inside the insulin pump] there are 20 units, [I know] it is not enough for all day, so I bring my cartridge and my insulin in the office. When it plays, maybe [my colleagues] now know it, it plays “for Elise” (laughs), it’s set up like that. So, I fill it there, even on the desk, ... and someone just: “Eh, go to the bathroom!” But I mean, it’s not that I’m shooting up, eh, I mean.. It’s nothing... “But do you have to perform this here?” [And I]: “You go to hell!” (Pasquale, 47 years old, employee, Diabetes LADA, onset at 30 years)

5.4.3 The unquantifyied food: on taking pleasure and managing illness

Overall, participant in this subgroup did not report engaging in restrictive diets and, compared to the “DQS” ideal type, they usually did not talk about food in a “quantified” way. In this case, food was not selected and meticulously partitioned along the day in order to pursue the ideal of a normative, sporty body, an in the case of the “Athlete.” Instead, discourses around food were usually associated with the dimension of pleasure in eating: in fact, enjoying the meals was the main reason that explained food consumption practices. In this respect, it emerged mainly two types of discourses that marked the distance from the rigid disciplinary regimes. On the one hand, in narratives of participants with a middle-high cultural capital they revolved around the “quality” of food, and on the claim of transgressing rigid diet regimes in order to eat at restaurant, as in the case of Massimiliano or Amedeo. For example, Amedeo reported eating often at restaurants and enjoying happy hours at night with his friends, while when he ate at home on his own he reported cooking for himself “healthier,” but still tasty meals, such as “eggplant parmigiana, but with grilled – and not fried – eggplants.” In his words:

> I am someone who likes to eat. I like to eat well, I like to cook, although... if I go out mmm if I go to a restaurant where the food is good or whatnot, I don’t hold back, in the sense that lunch out or dinner out, I mean, what I don’t... I am not the one that doesn’t eat dessert or what is, absolutely. Then at home, I try to be stricter. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

Dealing with diabetes’ self-management makes it more difficult to enjoy freely the meals: diabetic individuals, in fact, before eating they should know the exact quantity of carbohydrates contained in the food they will consume, in order to inject a proportional quantity of insulin. In this respect, a strategy adopted in order to appreciate the food without restrictions was that of injecting insulin after the meal, instead of before, without engaging in a rigorous carbohydrate counting, but rather “estimating” the amount of carbohydrates they ate. For example, Amedeo stated:

> If I am at lunch or dinner outside, once or twice a week, I do it, and I do not do the carbohydrate counting… I order the food I want, at the restaurant I always have insulin afterwards. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

The second type of discourses, that seemed to describe more the experience of young, party-loving diabetic men, revolved around the pleasure of eating a free “quantity” of food and drinking alcoholic beverages regardless of diabetes restrictions. An illustrative case is that of Manuel, a 28-year-old man who was diagnosed with diabetes at the age of 16. During the interview he reported that his food consumption practices were not informed by strict rules. He rather ate the food that made him “feel good,” because he considered the food as a source of psychological well-being: “If I drink coffee, I might eat… the time I eat, I don’t know, pastry… a dessert. A piece of chocolate, I like it a lot, … it’s also good for your mood.” In his narrative, he often highlighted his ability to eat large amounts of food – and this complies with social expectations around male bodies to display “great appetites” – to the point of being called by others the “Terminator.” In order to enjoy his meals without the "constriction" of carbohydrate counting and constant self-control, he reported injecting a fixed amount of insulin every meal:

> Desserts, ... it's not true that you can't eat them. For example, I have breakfast with cappuccino and brioches (...) and if there's pastry, I'll eat it. (...) For example, ... let's say, Saturday at lunch, ... I ate two sandwiches, with mortadella, so they were... I counted, it was two buns, which are standardised, because they always have the same shape, more or less, so the level of... carbohydrates is standardised, and so, the insulin I took as a consequence. While in the evening, we went... we had an informative banquet with the association, so there was barbeque.... (…) ... I ate- I ate- I had to start eating the grilled meat, then someone didn't eat the pasta, I ate the pasta, then I ate the grilled meat, calamari, chips. (He laughs) So, potatoes, calamari, pasta. So I basically ate for two. (...) Because... I mean, when something is left [to eat], ... I mean, they call me Terminator. (He laughs) (Manuel, 28 years old, T1D, employee, onset at 16 years)

Another case is that of Giovanni, who reported engaging in a "healthy" diet in order to "feel well" and in order to avoid insulin injections. In his discourse, he counterposed his past situation, in which he was stressed because of his occupation, when he ate "junk food" and injected insulin, to the present situation, in which he felt "good" because he quit his job and he was able to cook for himself the food he wanted to eat:

> For me [diabetes it's] like having seized the opportunity, ... to really do what I wanted to do before. That is: changing diet, starting to... kind of understand myself, what I want more, how to treat myself better. And... this illness placed me in front of the choice, so... either you overindulge, you use the insulin, you eat... junk food like before, no, all these things, ... or you start to... settle a little. (...) Since last October, I've been at home, I quit my job, voluntarily, because I didn't- the environment- it was ten years I had been in that environment, in that workplace (...) my objective when I quit was to wake up in the morning, open the window, look outside and say: "Oh, what a wonderful day, what can I do today?"... And I got there. (...) it's as if I had created this situation in which I have removed all those... stress-inducing factors, ... which always kind of busted my balls before, ... and now I'm probably regenerating, maybe also due to the fact that I can... eat like I want. (Giovanni, 32 years old, T1D, unemployed, onset at 31 years)

With the aim of eating what actually made him feel good, he also used to eat at restaurants:

> But when I go out, ... with friends, for lunch, to the restaurant, etcetera, I couldn't care less, for once, about eating something that will increase my

> glycaemia a little! (...) I mean, I've never eaten forcing myself to things that disgusted me, just to... think about diabetes (Giovanni, 32 years old, T1D, unemployed, onset at 31 years).

And, in those social occasions, he reported not limiting his food consumption, nor engaging in self-management practices, because this would "ruin the moment":

> If I go outside, first course, second course... Bread, wine, alcohol, I don't... No problem. Especially because it a time for enjoyment, when you go out with friends. So I don't spend time in thinking to something that could would ruin the moment. (Giovanni, 32 years old, T1D, unemployed, onset at 31 years).

Eating with other people in social occasions without following a strict diet often entailed arousing the curiosity of non-diabetic people, as well as confronting with stereotypes around this condition. One common stereotype that informs lay people's knowledge around diabetes is that this condition would be caused by overindulgence with food in general, and with desserts in particular. At the basis of this "victim blaming" (Crawford 1977: p. 663) approach there is the assumption that health is a personal responsibility and that the individual is "essentially independent of his or her surroundings, unconstrained by social events and processes" (Ibidem: p. 677). As already mentioned before, type 1 diabetes is an autoimmune disease, whose onset often occurs during childhood and seems not to be caused by "unhealthy" lifestyle habits. Elio gave an account of this occurrence within past social interactions:

> There are those people... because, for someone who has no experience of diabetes, on himself or with a close relative, he obviously doesn't know what this means... And... Because in my opinion people know little about it [autoimmune diabetes], maybe in recent years there is more prevention, there is more advertising, but one does not know it, so they think you're diabetic because you ate a lot of sweets and candies when you were a child. (Elio, 29 years, T1D, shop assistant, onset at 24 years)

As a consequence, the second most common stereotype, reported in the majority of the interviews, concerned the surprise in seeing diabetic people eating desserts, which were usually thought to be rigorously "forbidden" for diabetic people. In order to neutralize the stigma derived from illness' disclosure, usually participants engaged in explanations and clarifications strategies. In their words:

> Last Sunday I was having lunch in London with two of my clients, and this lady, she was one who did not know... And we ate ice cream. "Eh, you cannot eat ice cream!" I said: "Yes, look, trust me (laughter) I can eat ice cream, I have to manage it, (...) but I can eat ice cream." By the way, ice cream is not even the most complicated dessert, but it's a classic, they look at you as if to say: "No, but it is impossible that…" This is a bit of ignorance... (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

> Sometimes it pisses me off, can I use the term pissed off? (Laughs)
> **Yes, sure.**
> The people that… Because there is unfortunately... there are the people who do not understand anything, I mean, you go outside: "Eh, but you cannot eat the cake!" "But who- who told you that I cannot eat the cake?!?" ...I mean... "I eat the dessert! For you, ... your pancreas works by itself, while I have this here [the insulin pump], I throw a little extra insulin, but I eat the dessert, it's not that I don't eat it." (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

5.4.4 "They call me Terminator": embodied masculinities and diabetes management

Overall, participants categorized in this subgroup presented themselves by discursively distancing from the hyper-compliance, hyper-monitoring or hyper-discipline that characterized the other two ideal types. This discursive strategies lead to two critical considerations about the intersection of the "Free Spirit" with masculinity construction. The first one is that the construction of a "freer" and often "non-compliant" self, as well as the symmetrical discursive opposition of self-construction through the reference to the most different "obsessive" and hyper-disciplined "others" are, in the majority of cases, gendered constructions. The fact of rejecting the restrictive disciplinary regime prescribed by the diabetologist and at the same time adopting a hedonistic lifestyle, corresponds to a specific way of constructing hegemonic masculinity, that of laddish masculinity, typical of a working class context. With the exception of two participants, all "Free Spirit" narratives have been produced by participants with a lower cultural capital.

Let's take, as an illustrative example, a quotation that has already been mentioned before: that of Pietro, a young musician who reported conducting an unregulated, eventful life, where self-management was reduced to sporadic insulin injections and where the "others" where discursively identified in *middle class*, number-obsessed diabetic *women* who constantly monitored their bodily parameters:

> But then the… Problem is that (…) your illness becomes your life… And not the other way around. Because the other way around, it would have an excessively philosophical taste (he laughs). But your illness kind of becomes your life, …because you have to really be… if you wanted to be perfect, (…) and to be… excessively controlled, and not to have any problem… (...) These forty-, fifty-year-old ladies, these little ladies who live around here [he lives in a little rural town], who care a lot… only think about themselves, no, …and about their own family, in their own house, …they fall into depression, when they get diabetes. They fall into depression, and (…) for example… [they] call an ambulance for hypoglycaemia, after you've had diabetes for twenty years, it's pure madness, …and there's also… I have heard it told like this… I think… I mean, it's a basic anxious thought, no, to think about… I maybe underestimate certain things too much, but they… instead, they really see them, these ladies… (…) I mean, I couldn't care less if after you've done 300 metres on foot, on a Saturday morning, with your poodle, …you measured your blood sugar before leaving home, [and] it was 74, you came back, it was higher. "But why??" [they ask themselves]… Well, there can be a thousand factors.. Instead, the questions they ask are those: "Ah but I went for a walk, like you told me" (…) "but when I came back my [glycaemia] was higher than the one…" it's an obsession for this numerical value.
> **… And you don't have the obsession for this value?**
> I eeh … honestly, in the past months, …I haven't even measured my blood sugar levels. (Pietro, 27 years old, T1D, musician, onset at 16 years)

In this case, associating the "obsession for numerical values" to a female figure implicitly entailed an emasculating factor of self-care, which was discursively counterposed with the statement of his "independence" from diabetes and from self-management related practices. With different nuances and emphasis, the construction of the self as "free" from diabetes – indeed, as far as this could be realistically possible – characterized all the narratives grouped under this ideal type. As mentioned before, this entailed a less compliant approach to monitoring and treatment practices, and also the tendency to prioritise the pleasure in eating – through the description of binge eating/drinking and the selection of "tasty" food – to the respect of a rigid "healthy" diet that complies with medical suggestions. These discursive strategies in the presentation of the diabetic self can be interpreted as a manhood act (Schrock & Schwalbe 2009). As Courtenay (2000: p. 11) stated: "Each embodied health practice that a man demonstrates simultaneously reinforces and reproduces gender (and gender as difference). Unhealthy behaviours often serve as cultural signifiers of "true" masculinity." On this issue, it is illustrative another excerpt that I already mentioned before and that

I propose again in a shorter version, that of Manuel, a young man that described an episode in which he over-indulged with food and where his (masculine) identity was recognized from the others by a nickname they gave him, "Terminator," which clearly echoed the homonymous movie directed in 1984 by James Cameron where the protagonist was a cyborg assassin:

> Desserts, ... it's not true that you can't eat them. For example, I have breakfast with cappuccino and brioches (...) and if there's pastry, I'll eat it. (...) For example, ... let's say, Saturday (...) in the evening, we went... we had an informative banquet with the association, so there was barbeque.... (…) ... I ate- I ate- I had to start eating the grilled meat, then someone didn't eat the pasta, I ate the pasta, then I ate the grilled meat, calamari, chips. (He laughs) So, potatoes, calamari, pasta. So I basically ate for two. (...) Because... I mean, when something is left [to eat], ... I mean, they call me Terminator. (He laughs) (Manuel, 28 years old, T1D, employee, onset at 16 years)

On the same line, Pasquale gave a similar account, where he seemed aware of the possible health complications that this practices could cause, but he weighted pro and cons, and finally chose pleasure in eating over restriction:

> ...I do not know, for example I am someone that maybe... I organize work dinners, you know, in the sense, work dinners in the sense that everyone pays what they eat, (he laughs) but among friends, you know, and so someone who knows me, but does not know me as well as I know others, because then to the group there is always someone who knows you less, you know, and maybe knows that you have diabetes, you know, and goes: "Pasquale, are you crazy to drink all this Prosecco? ... But you have diabetes!!" "Yes, I understand, ... but it's an evening, ... please, I mean, the doctor with me, I don't want him." (...) Today I have no complications, ... maybe in 10 years I will say: "What an idiot!" Sorry. I use just... I speak...
>
> **Sure, sure**
>
> My language eh, ... and I say this because maybe they might amputate a foot to me- now, just to say, you now - but at a certain point I will say: "Yes, but ... I enjoyed it!" (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

Another participant, Vito, had explicitly talked about the gendered dimension of diabetes self-management and he identified in diet the set of practices that, more than others, marked the difference among the genders:

> **And with regard to the... management of diabetes, in your opinion ... between men and women, ... is there someone who has more rigour, or more resistance?**
> (Long pause) Well, women are seen as being more law-abiding... so... maybe they have less trouble following certain settings...
> **(long pause) In any field in particular? ... Or in general?**
> No, maybe in the diet... or eating.
> **(long pause) So, let's say... you feel less law-abiding to your diet,**
> Yes, yes, yes..
> **(Long pause) And why do you think that is? I mean, why for example do you choose... to... break the rules every now and then?**
> Eh, because I like it. / I like to eat. / (laughing) Yes, but I mean... I don't know how to define it. Well not because I want to kill myself, but if I see… If I like red meat, I eat it. (...). Then I like alcohol, wine, ... but, ...of course, always- of course, it's not that I eat red meat every day. (long pause) But if I see something I like, it's not that I refrain. I mean: I eat it. (Vito, 30 years, T1D, employee, onset at 23 years)

On the other hand, unlike the other ideal types, in this case the majority of participants – 7 out of 9 – reported organizing food consumption on their own. In this subsample, 3 out of 9 participants reported being single, 2 of them reported being in a non-cohabiting relationship, 1 of them was a widower, 2 reported being single and living with their parents and 1 reported being married and living with his wife. With the exception of Manuel and Elio – respectively 28 and 29 years old – who lived with their parents, all the other participants reported organizing food consumption practices on their own. A minority of participants – 2 out of 9 – reported engaging in cooking practices with enthusiasm and described themselves as excellent cooks. In so doing, they enacted a masculinity performance that was distant from the everyday, mundane cooking: it was rather the demonstration of a combination of skills and creativity. For example, Pasquale recounted:

> **And usually, who cooks at home?**
> …Mmm many times I do, and fewer times my wife does, (he laughs) yes, but I'm very good in the kitchen!
> **You like cooking…**
> Yes, yes, yes, yes. I cook, things like that, I prefer... the first courses. In the sense that... a little bit elaborate, I mean, I do not like to make the sauce with the meat, the "Bolognese" is it called? I mean... I'm someone... maybe because I'm often outside for work, and maybe I stop at the restaurant, I eat a particular dish, (...) and mmm so I copy the recipes, you know, maybe I go to restaurants "Oh man, they made that dish..!"...Then maybe I take the picture [of the dish] to remember, then I create eh, maybe I'd add something... (Pasquale, 47 years, employee, Diabetes LADA, onset at 30 years)

Lastly, a consideration about the situatedness of masculinity performances within the larger social structure. As Connell (1995: p. 78) stated: "[T]here are specific gender relations of dominance and subordination between groups of men." If, on the one hand, diabetes may challenge traditional ideals of masculinity in terms of bodily strength or healthiness, on the other hand two participants – Amedeo and Elio – described an identity trait that was perceived as far more challenging for the way they perceived themselves as men: homosexuality. Being homosexual was in fact described as highly impacting on the construction of a masculine self, much more than a chronic disease. In the words of Amedeo:

> **Do you think that... having diabetes has somehow changed the perception you had of yourself [as a man], before and after? (...)**
> Good question, but... I'll go back to what I said before, because I think this question is more tied to the matter of homosexuality, rather than that of diabetes. In the sense that being a homosexual, yes, it certainly gives me more the perception of vulnerability (...) and diabetes doesn't, in the sense that it hasn't moved me much from this thing, [exactly] because before there was a much bigger one to manage. Clearly, I mean, probably for someone who isn't a homosexual, eh, this instead becomes the important change, for me no... no, no, I really live it as an extra pain in the neck, to add to the fact that I have to wear contact lenses or brush my teeth. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

When talking about the impact of diabetes on the way he perceived himself as a man, Elio acknowledged that experiencing disease could have an emasculating effect within social interactions. Since he self-identified as "gay," in his opinion the coming out as "diabetic" did not affect very much his masculinity performance, because he was already far away from enacting a "macho" ideal of masculinity. In the following excerpt it can be noted how he discursively positioned different subordinate masculinities (diabetic and homosexual ones) within a power hierarchy, where homosexual masculinity laid at the bottom:

> The man has to perform the strong man, the one that, if he cries, he cries in secret, he doesn't display it, he has to be strong, what is... but in general, even a non-diabetic, when he has a problem, especially if he has an illness, he tends to hide it, not to talk about it, ... Derived from... old generational concepts, and... so yes, especially what is negative, what has to do with illness, you try not to... not to keep it. Most of all, it's true, ... the male, ...

> can suffer of this... weakness, let's say. And... weakness that you have to prove, because it's not a weakness per se. It's that you have to prove you have this weakness. And this is what, in my opinion, can be...
> **What do you mean, by weakness?**
> Eh, the fact that diabetes, which [is] something that constrains you, which... you're – it's bad [to say], it's not true – but the term is "you're inferior to others." ...Proving it, ...saying in front of a table of 10 people that you are physically inferior to others because you have a deficiency, ... for a man who wants to be... a macho man, and that's not my case, eh! Surely... in fact, the more someone sees himself as an alpha male, the more they suffer because of this thing... Not me. Aside from the fact that I'm gay, so I live in a completely different world. (...) So... the matter of masculinity, ... is there. And it's true and it's important. It's never concerned me because... (he laughs) I'm not manly. I don't have a manly body... (Elio, 29 years, T1D, shop assistant, onset at 24 years)

5.5 Conclusions

This chapter offered an analysis of the relationship between men, masculinity(ies), embodiment and health by studying men's accounts of diabetes self-management. I began this chapter by talking about "health" and "health society," and I then briefly examined literature about gender with the main aim of bringing these two issues together and problematize masculinity in relation to chronic illness. Overall, normative assumptions of health as a moral identity, and of masculinity as a situated ideal configuration of practices, influenced the way participants "did" diabetes, as well as the way they narrated their illness experiences within the context of the interview. Since an "ill" body is by definition at odds with the hegemonic ideal of masculinity and illness self-management practices (e.g. self-care, food organization and cooking...) are traditionally considered as feminizing, there is the possibility that diabetic men try to resignify such practices in order to renegotiate their masculine (and diabetic) identity.

From the analysis of empirical material it emerged that, overall, the high majority of participant was highly engaged – although in different ways and with different meanings – in self-care and self-management practices, and this findings contrast with the pathologizing thesis that masculinity is bad for men's health (see Harrison 1978). Conversely, this analysis embraces Robertson's (2007) call for producing more critical analyses about men's identities and lifestyle practices in relation to health (and illness).

The analysis of the 40 narratives collected shows that the experience of illness intertwines with masculinity construction and performance in complex ways. All the stories examined here had in common the necessity to deal with a body that required a certain amount of time and care in order to manage diabetes symptoms such as hypoglycaemia, hyperglycaemia and, in some cases, diabetes-related health complications. All participants embodied social expectations around the "healthy citizen," with whom they often complied, other time they discursively distanced themselves from it or even resisted actively to its moral obligations. However, all of them reported being aware of the medical imperative to govern properly illness by managing in certain ways their bodies and exert a certain degree of self-surveillance on their lives and selves. The "Quantified Patient" is indeed the most compliant of all ideal types, and describes those narratives that incorporated biomedical knowledge and complied "passively" with its recommendations and, just as the Quantified Lay Expert, adopted the discursive practice of describing his illness experience – from food to symptoms, from failures to achievements – through numerical references. The Quantified Lay Expert, on the other hand, although using a quantified vocabulary in order to describe his illness experience, incorporated medical knowledge by "shaping" it around his personal experience, this way constructing a "bottom-up" expertise that was deemed as more accurate than the more "abstract" one proposed by doctors. These two ideal types have something else in common, in addition to the description of a quantified-self: namely, the reproduction of traditional gender relations in care roles. In fact, in the majority of cases DQS's participants used food consumption practices as a form of "gender distinction." A similar result emerged from the analysis of the Athletes' narratives: diabetic athletes had the real opportunity to dedicate much time and resources of their day to training and competitions because there was an – almost invisible, in their narratives – female member of the family (wife/partner/mother, etc.) who took care of household chores and food consumption organization. It is then clear that also within a "marginalized" diabetic masculinity, there are still some niches of gender privilege, some social spaces that take for granted women's dedication and care role and that exclude them from participating in privileged, male homosocial spaces such as sport (in this regard, the example of Ronaldo mentioned above is particularly illustrative).

In this regard, a different narrative seems to be provided by the "Free Spirit" ideal type. In that subsample, men reported privileging "pleasure" in eating and avoiding strict self-management rules. Furthermore, the majority of them reported being in charge of cooking and preparing food on their own, but it was rather a matter of circumstances: out of 9 people, 3 of them were single, 2 were in a non-cohabiting relationship, 1 of them was widower and his wife used to cook for him when she was alive, 2 of them lived with their parents and only one of them was living with his wife and reported taking care of cooking practices more often than his wife did, and in describing his cooking performances he proposed a "spectacularized" description of his cooking approach, that was very different from the high majority of accounts that men gave of the mundane, everyday cooking practices enacted by their wives/partner/etc.

In conclusion, diabetes is a severe chronic condition that influences the enactment of a normative hegemonic masculinity and offers, through the adoption of "feminizing" self-care practices, the opportunity to renegotiate gender performances in the direction of a "hybrid" and alternative form. From the analysis proposed in this chapter it emerged that diabetic men often incorporate illness in a series of embodied self-management practices that "hybridize" their masculine performances, but at the level of gender relations it seemed that hegemonic gender expectations still informed participants' stories and lives.

Chapter VI

Men, masculinities and sexualities in the context of autoimmune diabetes

6.1 Introduction

In the first empirical chapter I sought to explore the impact of diabetes in the context of men's everyday life, while the second empirical chapter has been dedicated to explore how masculinity construction intersected and interacted with illness management practices. The present chapter investigates further the construction of masculinity(ies) in relation to illness by focusing on an arena of practices which is deemed as crucial for masculinity construction and which is often influenced by diabetes: namely, sexuality.

Diabetes, among all chronic diseases, is the one where men's sexuality has been explored more extensively (Schover 1988). The first written mention of the link between diabetes mellitus and sexual problems goes back to the writings of physician Avicenna, who lived in medieval Persia and wrote about a "collapse of sexual function" detected in people with "sweet urines" (Köhler & McVary 2016: p. 178). After that, this association has been observed by Scottish surgeon John Rollo in 1789 who researched diabetic men who experienced erectile difficulties (Ibidem) and the first contemporary study that explored diabetic men's "sexual function" was the one conducted by Rubin and Babbot (1958) in which it was found that the 55% of their sample reported experiencing the so called "erectile dysfunction" (from now on, ED). More recently, studies on diabetes and sexuality have continued to focus, over time, mainly on *male* sexual health and on the incidence of ED, which is estimated to occur from 35 to 90% of the cases across all age groups (McCabe 2016, Stein *et al.*1985). According to this literature, ED in the diabetic population occurs 10-15 years earlier if compared to the non-diabetic population, and it is associated with a reduced quality of life and with depressive symptoms (Kizilay 2017, De Berardis 2002). More generally, the majority of research on this issue has been carried out by medical professionals and has mainly focused on pathophysiologic processes in men's sexuality (e.g. Schofling *et al.* 1963, Bacon *et al.* 2002). The contemporary Italian situation has been described by Fedele and colleagues (1998, 2000, 2001), as well as by De Berardis and colleagues (2002) and, more recently, by Corona and colleagues (2013, 2014, 2016) who confirmed the international data on the incidence of ED in diabetic men's population.

Overall, few research studies distinguished among autoimmune diabetes – the onset of which occurs during childhood or adolescence and involves insulin injections for survival – and type 2 diabetes, the onset of which usually occurs during adulthood, it has not an autoimmune origin, and usually does not need insulin for survival. This chapter focuses on the narratives of men with insulin-dependent diabetes and on their discourses around sexuality. Diabetic men usually have their sexual functioning checked at regular (usually every 6 months) medical examinations, where the diabetologist asks a series of questions in order to monitor patients' overall health. The *Standard Italiani per la Cura del Diabete Mellito*[32] (2016) is the national document intended to provide clinicians and healthcare professionals with the main standards for diabetes care. According to this document, Erectile Dysfunction is included in the diabetes-related health complications and it is described – drawing on the DSM-5'S definition (American Psychiatric Association 2013) – as "The recurrent or recurring inability for a man to obtain and/or maintain the erection until the end of sexual intercourse" (Ibidem: p. 209, my translation). Where the given definition of "penile erection" is "a complex neurovascular event that requires the interaction of four systems: 1) central nervous system; 2) peripheral nervous system; 3) endocrine system; 4) smooth muscles of the penile arteries and trabeculae" (Ibidem: p. 209, my translation). The specific sexual health standards legitimized by medical knowledge in the context of diabetes "quantify" the "healthiness" of male

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[32] Namely, "Italian standards of medical care in diabetes mellitus." The original document has been retrieved from: http://www.standarditaliani.it/skin/www.standarditaliani.it/pdf/STANDARD_2016_June20.pdf Last seen 20/10/2018.

sexuality relying on initial anamnesis and on a numerical "measurement" which is calculated through the use of the International Index of Erectile Function[33] (Rosen *et al.* 1997; Rosen *et al.* 1999) and, if necessary, with further medical examinations (e.g. free testosterone levels, prolactin, etc.). Overall, the way in which male sexual functioning is assessed does not differ from that of the general male population, the only difference is that diabetic men undergo such check-ups as a routine practice, while for the rest of the population this only happens when they visit male sexual health specialists. The envisaged medical solution for the occurrence of ED, in turn, does not differ from that prescribed to non-diabtic men and it entails "use of phosphodiesterase type 5 (PDE-5) inhibitor drugs (sildenafil, vardenafil, tadalafil, avanafil) by taking into account the pharmacokinetic characteristics and in particular their duration of action" (Ibidem: p. 208, my translation). In addition, in order to maintain a "healthy male sexuality" it is advised to conduct a healthy lifestyle and reduce obesity. At the end of the paragraph dedicated to ED complication, in the document it is specified: "With regard to therapy, it should be noted that medical treatment does not modify the underlying disease or the natural history of disease and that of the complication but it can improve patients' quality of life" (Ibidem: p. 208, my translation).

At this point, since diabetic men are necessarily embedded into a medical framework which conveys a specific ideal of healthy/pathological male sexuality, it is interesting to find answers to the following questions: what are the implications of such biomedical model of male sexual health? How do the definitions it entails influence personal experiences and sexual practices of diabetic men?

First of all, diabetes might, over time, cause "organic" complications – such as endocrine, microvascular, and neurologic problems – that could have an impact on men's sexuality in terms of sexual desire and quality of erection. But it should be noted that medical approach gives a supposedly "objective" and universal definition of sexual health standards that does not take into account subjective understandings nor the social and relational context in which sexuality is experienced.

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[33] For a critical analysis of the International Index of Erectile Function see Salis (2016).

With a critical approach, Tiefer (2016) observed that the abovementioned definition of "Erectile Dysfunction" is itself arbitrary and socially constructed, just as any other definition. In fact, back in the nineties the concept of "ED" had replaced another one, that of "impotence," with the main aim of changing the focus from a more psychological to an organic aetiology of sexual difficulties, that would, in their intention, reduce the social stigma attached to such definition. While this definitional change has been useful for that purpose, one of its "unintended consequences" has been the broad expansion of the medical domain into the sphere of sexuality, which has effectively undergone a progressive medicalization process (Ibidem, Maturo & Conrad 2009, Conrad 2007). In fact, different factors, such as the recent emphasis on the importance of a life-long sexual activity, the growing interest of the media for sexual topics, the needs of what was in the '80s the emerging field of specialty medicine and new medical technology, together with social expectations on male sexuality, interacted with each other and lead to a process of medicalization of male sexuality (Tiefer 1986, Ferrero Camoletto & Bertone 2016).

The very term "dysfunction" implies a pathologization – regardless of the many possible causes – of the absent or imperfect erection performance during sexual activity. This is described as a "disastrous affliction in the male – an abnormality, a failure to stand up and be counted as a "real" man. It constitutes an "illness" peculiar to the male body (Potts 2015: p. 90). Such "illness" can be treated with specifics drugs, the EEMs (namely, Erectile Enhancement Medications), that do not "cure" the problem yet are supposed to "improve patients' quality of life" – as the Standards of Medical Care in Diabetes asserted – in so far as they promise a sexual performance that fulfils the standards of a healthy, hegemonic male sexuality. As Potts (2015: p. 90) stated: "This construction posits that the healthy erect penis desires only the vagina, and healthy sex is equated with the successful implementation of heterosexual intercourse." This model clearly entails a specific notion of "masculinity," assuming that a "healthy" male sexuality involves an adequate erection in terms of duration and rigidity; a "healthy" desire to penetrate (a vagina); the primary interest in performing (heterosexual) intercourse; the tendency to neglect autoeroticism and to relegate other sexual practices as "foreplay"; and the occurrence of erectile dysfunction as an inevitable health complication of diabetes, with the consequent need to constantly scrutinize one's own sexual performance in order to detect potential abnormalities in time and to treat them adequately.

Although organic factors are a common occurrence in diabetic men's sexual performances, they might not be the only cause of sexual difficulties and it is useful to explore Tiefer's (1986) critique of the biomedical model because it gives a multidimensional perspective through which we can look at the specific case of diabetic men's sexuality. As mentioned above, the medical approach to sexuality – whether it entails diabetic bodies or not – is a recent phenomenon that has been determined by the assertion that the psychogenic cause of sexual difficulties had been overestimated through time at the expenses of the organic dimension, which instead was considered as much more common and significant than previously estimated (Ibidem). In this regard, a crucial criticism that has been addressed by Tiefer is that organic and psychogenic causes are often considered as mutually exclusive phenomena (Ibidem), while according to empirical research it is actually difficult to distinguish one from the other, and there is often a combination of factors that informs men's experiences. In the context of diabetes, the mainstream biomedical approach to male sexual health mainly considers organic factors (such as neuropathy and vascular disease as a chronic complication of diabetes) as predictive of ED. Official standards for diabetes care do not even mention the possibility of experiencing sexual difficulties as a result of a psychogenic cause. However, a recent study (Maiorino *et al.* 2017) conducted on men with type 1 diabetes highlighted that the prevalence of ED was higher in the diabetic population if compared to the non-diabetic population, but also that the main role in the pathogenesis of the ED was to be attributed to psychological factors caused by the impact of a chronic condition into one's life, rather than relying only to organic causes. The present research confirms those finding because usually participants – even those who received a diagnosis of erectile dysfunction caused by diabetes-related complications – attributed their sexual difficulties to a combination of psychological and organic factors.

Perelman (1984, quoted in Tiefer 1986) pointed out that the psychogenic component is present "in any potency problem, regardless of the degree of organicity" (Ibidem: p. 590) and posited that physical sexual function is characterized by a psychosomatic complexity that could have the "ability to successfully compensate for its own deficits" (Ibidem: p. 590). Instead, the medical response to a (diabetic) patient who experiences sexual difficulties does not consider the psychological dimension of the situation, nor opens to the possibility of a subjective definition of "problem." There is no possibility for diabetic men to refer to psycho-sexological services for free: the only option – at least for the most disadvantaged sections of the population who cannot afford private health services – is that of a medical support and medical treatment, and this could, in my opinion, have an influence on the way men understand and signify their own sexuality and masculinity. An andrologist whom I have interviewed as a medical expert who at the time of the interview worked in a public hospital highlighted the importance of a more psychological dimension in treating erectile difficulties, but she also underlined the impossibility for medical specialists (urologists and andrologists in particular) who work in a public structure to take into account such issues within a medical setting:

> We usually have 15 minutes. So we obviously focus on the andrological part, then... however, we don't have psycho-sexological support services that I think would be essential. There is no psycho-sexological service covered by the ASL [the Italian national health system]. If they have to, I mean, if they decide to go... they have to pay for it by themselves. Let's say that the psychological sphere is not even contemplated.
> **OK, so usually... what is contemplated within the health services is...**
> The classic, yes, andrological approach. Hormones... We administer hormones, eventually we have them perform more detailed tests, but... We prescribe the pill and that's that. (Andrologist 1)

Another andrologist, in turn, confirmed the above-mentioned statement of Perelman (1984) about the interconnection of psychogenic and organic factors by reporting that, in her experience, even in the case of organic complications of diabetes, sexual activity is always the result of both an anatomical and psychological dimension. In her words:

> Let’s consider that the 70% it’s in the head. The 30% are vessels and nerves. (Andrologist 2)

Another medical specialist of sexual health – an urologist – whom I have interviewed with the role of expert, reported that, in his clinical experience, diabetic men were “some of the most difficult patients” because they usually had erectile difficulties as a result of a combination of psychological and organic factors:

> Diabetes is one of the causes of impotence due to the fact that in the diabetic individual there is a generalised arterial disease that also causes problems within the penis arteries, so there no longer is a sufficient blood supply. And then psychological mechanisms arise, because the problem is significant, if I have to say, in men when they can’t get an erection -because an erection is both a vascular, nervous and, let’s say, also a psychological involvement- often the man who cannot get an erection seeks a sexual encounter not only because of sexual desire... Yet, to see whether it works or not. I mean, the sexual intercourse is related to a desire, to a physical desire and to a desire with the partner. On the other hand, those who have these impotence problems, even if they don’t have this desire, they do it to see whether they get an erection or not. In diabetic people, the majority are problems -impotence is mostly psychogenic- it’s mostly psychogenic. (Urologist)

From this excerpt we can find an example of how the medical model could have an impact on diabetic men’s sexuality: sexual performance might be understood from diabetic “patients” not much as a spontaneous, relational experience, but rather as a “litmus test” that gives a measure of the onset or progress of a potential – and expected – health complication. Although the abovementioned urologist recognized that diabetic men often experience erectile difficulties as a combination of organic and psychogenic factors, he – just as the Standards of care in diabetes recommend – then offered a purely medical solution, composed by several “steps” of therapeutic intervention which were deemed to be effective regardless of the causes of erectile problems:

> With a single pill, now thanks to these new drugs, Vardenafil, (...) these are drugs that have the ability to increase vasodilation (...) in the diabetic individual. (...) But they have to -I tell everyone who has an impotence or whatnot- they have to follow a treatment plan, you also have to be very, very motivated, you see? You have to be motivated. Initially, in a diabetic individual, you give him a medicine that gives him vasodilation. If it works, that it gives him vasodilation, because you have to keep in mind that he has

> diabetes, aside from the vascular matter and also from a neuropathic one. You know what neuropathic means? It's a problem that also affects the nervous system. And this also has an effect. So the problem, that is, the erection of the diabetic person is a neuro-vascular matter. Of course, it's one single thing, so you start with the medicine, the vasodilator one, in the diabetic person, if it gives him enough vasodilation for an erection, but if there is also a nervous component, I mean, you widen the arteries, and the medicine doesn't work. Within the psychogenic matter, also the medicine works. The patient takes the medicine, he sees he gets an erection, so maybe it helps him to [psychologically] unblock. (Urologist)

If the pharmacological solution does not work, he reported following the subsequent passages:

> And this is a medical approach, if the medical approach doesn't work, usually at that point you go on with physical methods. And this is where the difficulty lies; when you don't go to the pill, yet need something more. Usually the individual raises the white flag. If you're not more than motivated, they raise the white flag. What are the methods to intervene? You start... basically, it's called FIC [*Farmaco Infusione Cavernosa*, a drug for cavernous infusion], which are intra-cavernous injections of prostaglandin. An insulin needle, you inject it in the penis before intercourse. (...) [This works] in any moment: the intra-cavernous injection has nothing to do with desire, because you directly inject this drug that causes dilation. (...) But many reject it because diabetic individuals are scared of injections. Then there are other methods, which are called the vacuum [device], which is a thing, how can I explain? You place the penis in a sort of box which aspirates... which creates a vacuum, it draws the blood to the corpus cavernosum and you then place a lace at the base of the penis, to avoid an outflow, so one gets an erection, finishes intercourse, and then naturally... (...). Then, if it doesn't work you go on to placing prosthesis. (...) But you have to be highly motivated. (Urologist)

Which are the possible allures of a "medicalized sexuality"? First of all, framing male sexual problems with a biomedical approach allows men to shift the responsibility of their "failures" from a personal responsibility to an uncontrollable, external, physiological malfunction. As Tiefer (1986: p. 594) stated: "[M]en view physical explanations for their problems as less stigmatizing and are better able to maintain their sense of masculinity and self-esteem." In fact, as Talcott Parsons (1951) pointed out, the "sick role" that results from an organic diagnosis is characterized by an absolution of the sufferer from any personal responsibility for his/her own condition, and this is less detrimental to men's self-esteem and allows them avoid psychological treatment or self-disclosure with the partner, which are considered as more threatening and embarrassing (Tiefer

1986). This could be even more alluring in the context of diabetes, where the responsibility of its onset and consequences are very often attributed to the individual and his unhealthy lifestyle. Finally, the medical treatment for sexual problems promises to overcome all kind of performance concerns: from performance anxiety to depression, from low libido to organic impotence. As Tiefer (Ibidem: p. 592) stated: "Technology seems to offer a simple and permanent solution to the problem of lost or threatened confidence." Although in this sentence she was talking about penile implants, this also can apply to other medical solutions. In the context of diabetes, just as the more general medical context in relation to male sexuality, physicians tend to prescribe pharmacological treatment because it is considered to be effective with a low incidence of adverse effects: EEMs are considered as the "magic bullet treatment" (Marshall 2002: p. 133) that do not cure ED, but that "adjust" male sexual underperformance to a mechanical and standardized model of efficiency (Ferrero Camoletto & Bertone 2016).

This problem-solution approach rests upon the assumption that men should always be "ready" for sex and should always be highly performant, and in the context of diabetes this seems to be a matter of concern only for men: in fact, despite the fact that diabetes might have an organic impact also on women's bodies and influence how they experience sexuality, this is rarely taken into account and the document of the Italian standards of medical care in diabetes does not even mention the possibility of assessing sexual function in diabetic women. An exception to this trend is provided by the work of Maiorino and Esposito (2018) who acknowledged the occurrence of "sexual dysfunction in women" (Ibidem: p. 3) as a diabetes consequence (both in type 1 and type 2 diabetes). They observe that, despite the fact that there has been empirical evidence of this problem since three decades, there are no guidelines for treating sexual dysfunction in diabetic women. In the light of this, they proposed to use the same diagnostic strategies existing for non-diabetic women, which entails the use of the Female Sexual Function Index (FSFI) (Isidori *et al.* 2010) and pharmacological treatment. This method of assessment is a confirmation of the dichotomous gender ideal that is promoted by the biomedical model of sexuality: it does not take into consideration the social and relational context in which sexuality takes place, it rather conveys the ideal image of a woman that always needs to be aroused, lubricated and "ready" for (hetero)sexual intercourse. Whenever the respondent fails to meet the numerical score required by the definition of "healthy sexuality" implied by the FSFI, the authors suggest prescribing Flibanserin, a drug that promises to treat "female hypoactive sexual desire disorder" (Ibidem: p. 3).

Thus, the overall model of sexuality that emerges from medical knowledge in the context of diabetes care seems to be highly influenced by a heteronormative, phallocentric, and hegemonic construction of male (and female) sexuality, which reproduces a dichotomous and complementary notion of masculinity and femininity. As Plummer (2005: p. 179) observed, "ours is a phallocentric culture," and the penis is not only the source of male's erotic pleasure, it is also a crucial symbol of male power. As Blanck (2012) stated: "In a very real way, the hard penis is heterosexual sexual activity. In virtually every era, in virtually every culture we know, to be a sexually active male is to penetrate with the penis, and to be a sexually active female is to be penetrated by one. Not for nothing are lesbians sometimes raped by those who think it will convert them to a 'correct' heterosexual appreciation for the penetrating penis" (Ibidem).

On the other hand, the absent or imperfect erection is itself fraught with meaning: the penis is "weak, soft (or semi-soft), less active; it has no stamina, no control. It cannot perform 'like a man'" (Potts 2002: p. 142; quoted in Plummer 2005). On the other hand, in a "real man" the penis "functions" regardless of the relational contexts, of subjective preferences and feelings, and regardless of diabetes. Otherwise, the penis – as well as the masculinity that it represents – is considered as dys-functional, something that needs to be fixed. "Healthy male sexuality," whether it is related to diabetes or not, is socially constructed. Normal and normative models of sexuality are constructed around the reduction of sexuality to heterosexual practices and intercourse, and everyone who does not want to – or cannot – fulfil such ideal becomes "dysfunctional," because s/he contravenes standards of normalcy and appropriateness. The advent of Viagra and its successors in the 1980s' reinforced such hegemonic model of sexuality and it has progressively extended the imperative of pursuing a "healthy sexuality" and maintaining a normative performance even with a “sick body,” this way neutralising the multiple effects of disease on the body/self and erasing the insecurities associated with its performance. Diabetic men are inevitably embedded in a cultural context where the hegemonic model of masculinity informs media representations, social interactions and sexuality practices. Their bodies are shaped, just as everybody else’s, from medical knowledge, embodied feelings, impression management and from the complex interrelation of a multiplicity of social dimensions such as institutions, culture and interaction (Ghigi & Sassatelli 2018). From this perspective, the diabetologist and medical professionals specialized in male sexual health function as real “guardians” of male sexuality standards, and the incorporation of such understandings of sexuality might lead to specific self-surveillance practices in this specific field in addition to the others that have been extensively analysed in the previous chapter and that concern the everyday life. Medicine has a great role in regulating and defining sexuality (Foucault 1979) for diabetic people and for the overall population: medical knowledge draws boundaries of what it is to be considered as “normal” and what, instead, should be defined as “pathological,” and those discourses become naturalized and incorporated as a form of moral imperative to be individually and collectively enacted. Foucault, in his crucial first volume devoted to the History of Sexuality (1976), reflected on the social construction of sexuality, and he rejected the “repressive hypothesis” according to which Western society suppressed sexuality from the 17th century as a result of capitalism and burgeons society. He rather illuminated the productive nature of the sexuality dispositive that – through power relations – does not repress individual sexual expression, it rather creates the conditions in which sexuality can exists through the development of numerous mechanisms of control, regulation and economy (Ibidem). In the context of men with diabetes, narrating one’s own sexuality to medical professionals becomes a potential device for narrating and constructing the self, as well as for improving self-knowledge under a medical gaze: being defined as sexually “impotent” or “healthy” has inevitably a great impact on the (re)production of masculinity(ies) and on definition of the self.

This chapter follows Bertone and Ferrero Camoletto's (2011) invitation to "bring male masculinity into the picture," under the assumption that sexuality is an arena of practices that can provide for useful information about masculinity (and gender) construction and its changes over time. International literature on the intersection of masculinity construction, sexuality and illness has focused on the construction of masculinity in the context of prostate cancer (Oliffe *et al.* 2009, Oliffe & Thorne 2007, Oliffe 2005, Gray *et al.* 2002, Chapple *et al*. 2002), in the context of testicular cancer (Gordon 1995), in the context of multiple sclerosis (Rissman 2003), while other empirical work has focussed on gender, sexuality and disability (i.e. Arfini 2011, Shakespeare 1999, Seymour 1998). Little qualitative work has been done so far on the intersection of masculinity construction and sexuality in the context of diabetes (i.e. Kolling 2012, Lemone 1993)

Overall, the Italian literature that focussed on gender and sexuality had mainly taken into account femininity and dissident sexualities (Bertone & Ferrero Camoletto 2011), while a paucity of studies dedicated attention to the intersection of sexuality and masculinity construction through everyday sexual practices (i.e. Bertone & Ferrero Camoletto 2011, Bertone 2010, Bertone & Ferrero Camoletto 2009, Ferrero Camoletto & Bertone 2010). To my knowledge, to date there is no Italian empirical study that explores the intersection of masculinity construction, sexuality and chronic illness.

Therefore, this chapter offers insights into how men dealing with a chronic disease – autoimmune diabetes – experienced sexuality and its changes in relation to illness and how this intersects with the complex process of masculinity construction. Interviewing men about their sexuality has not been an easy task. If, on the one hand, they gave articulated account of everyday life practices in relation to diabetes self-management, on the other hand this did not happen in relation to sexuality issues. Many participants reported not having talked about their sexual problems with anyone before, and this was sometimes reflected on the lack of self-reflexive accounts: they usually tended to give short answers and I often perceived some embarrassment in their words, as a sign that sexuality is still considered something that should be kept into the private sphere, or at most it should be disclosed within a medical setting. However, the empirical material collected gave interesting insights about diabetic men's sexuality, and in this chapter I have organized such findings in an attempt to highlight the complexity of men's experiences. I have thus focused on the emerging representations of male sexuality models, on the impact of diabetes on such representations and on the multiple responses of participants to the challenges posed by illness. I then focused on the variety of explanations that participants gave to their sexual difficulties, from the psychological ones to the organic ones, to the combination of the two and to explanations of sexual difficulties understood as part of the life cycle. The complexity of men's experience of sexuality is then analysed with respect to the multiple strategies adopted in order to deal with sexual problems, that include but is not limited to biomedical approach.

6.2 Hegemonic sexuality and the threat of illness in diabetic men's accounts

The most recent survey on sexual behaviour and attitudes on the Italian population (Barbagli, Dalla Zuanna, Garelli 2010) found important changes, but also the persistence of tradition in how people experience and understand sexuality. On the one hand, sexuality is intended as a privileged context for realizing the self even outside predefined roles and scripts; on the other hand, sexuality practices are inevitably influenced by the cultural context in which they take place, and this affects the way men and women relate to each other (Bertone 2010). According to national data, in Italy 65% of the women and 58% of the men believe that men's sexuality is more about physical pleasure, while women's is more about feelings. This different understanding is not only reported in order to describe different forms of desire among genders: it is also used to judge through different standards male and female sexual behaviours. Thus a “double standard” emerges that gives different values to sexual practices depending on the gender of who enacts them: in fact, for women sexuality is associated to the context of the couple and to a romantic entanglement, while the association of males' sexuality to physical pleasure seems to legitimize the possibility of sexual experimentation outside of the couple, separating male sexuality from emotional investment (Ibidem). Overall, it seems that there is still a broad consensus around the supposed stronger sexual need and desire in men if compared to women: in fact, 66% of the Italian population – regardless of gender, age and social class – endorses the stereotype of the "hydraulic" conception of male sexual health, which is intended as governed by a natural instinct that exert pressure and find release into orgasm; this vision is informed by a biological approach to male sexuality, which is perceived as fixed, unchanged and common for all males regardless of their social context (Bertone 2010, Bertone & Ferrero Camoletto 2011).

Concerning the object under analysis in this research, we could think that a chronic condition such as diabetes could create the context for renegotiating the hegemonic ideal of male sexuality in the light of the many life-threatening situations (glycaemic swings, ketoacidosis, coma, etc.) that challenge the hegemonic ideal of physical strength and sexual potency. On the other hand, a cognitive dissonance could occur in so far as diabetic men experience a "changed" body that does not fulfil social expectations around sexual performances, and in this regard medical normative gaze could reinforce the hegemonic model of male sexuality with its offer of medical solutions.

6.2.1 "She saw me as a weak, ill person": experiencing diabetes-related stigma in the context of sexuality

In her research on people with type 2 diabetes in Brazil, Marie Kolling (2012) observed that, when she went to visit a diabetes association she found out that, out of 70 members, only three of them were males. When the researcher asked to the secretary for an explanation, the latter replied: "Let me tell you a secret. Men with diabetes become impotent. Everybody knows that and therefore they don't like to show that they have diabetes because it is a big blow to them to lose their potency. Potency means everything. Without it they are no men!" (Ibidem: p. 92). The risk that diabetes could undermine men's "potency" is something that emerged also in this research. This could be found, for example, in the more general assumption of an inevitable weakening of the diabetic body and its consequent being at odds with hegemonic ideals of potency and power, as Leonardo well illustrated in the following excerpt:

What are the diabetes stereotypes you happened to face?

> Well, of inability, I mean, of no potency in general, “No, no, so you’re diabetic, you can’t do that, what do you expect a diabetic to do…” Then clearly maybe we, because of our generation or cultural heritage, I don’t even know if that’s the right word, but we’d say: “The fuck are you saying? I could even be an astronaut!” (Leonardo, 52 years old, T1D, architect, onset at 4 years)

More in particular, overall participants acknowledged that sexual problems were stereotypically associated with diabetes and that, as will be further addressed in paragraph n. 6.3, disclosing about their chronic condition could entail confronting with the idea that diabetic men are “impotent,” as exemplified in the words of Renato:

> ...On the perception of myself, as a... [male] figure, from this point of view there was, at the beginning [after the onset], I’m telling you, the idea [that] diabetics would become impotent, there was this thing on... from a sexual point of view, (...) there was this image. (Renato, 56 years old, T1D, entrepreneur, onset at 30 years)

As Tiefer (1986: p. 581) stated: “It is no surprise, then, that any difficulty in getting the penis to do what it ‘ought’ can become a source of profound humiliation and despair, both in terms of immediate self-esteem and the destruction of one’s masculine reputation, which is assumed will follow.” The impact on the self of failing to meet the normative performance requirements is recounted in a particularly eloquent way by Leonardo, who stated:

> For a man, it can be tough, honestly.
> **What?**
> Any symptom of impotence. Eh, it’s a form...
> **And what effect can this have, in your opinion?**
> …Eh, well, one of insecurity, of loss of self-confidence, no? (Leonardo, 52 years old, T1D, architect, onset at 4 years)

Hegemonic male sexuality entails a healthy body. Diabetes, in some of its manifestations, may become visible to others and may challenge sexual performance in so far as, for example, glycaemic swings occur and the person inevitably experiences a (more or less) temporary malaise, weakness and erectile difficulties. This is what has happened, for example, to Martino, a 34-year-old man who was diagnosed with diabetes at the age of 8. He reported experiencing hypoglycaemia while he was having sex with his ex-partner. He reported feeling weak, and he decided to stop the sexual activity in order to eat something and make his blood glucose levels rise. After restoring his glycaemic balance, while it would have been fine for him to continue what they had interrupted because of his low glycaemic levels, on the contrary his partner did not get over the "failure" of Martino's body to fulfil the potent and healthy masculine ideal. In that period he was experiencing trouble with glycaemic swings and insulin therapy, and this had an impact on his sexual performances. According to his narrative, his partner perceived his unpredictable and uncontrollable display of an "ill" body as an "obstacle" and for this reason she decided to break up with him. In his words:

> You hope that when you're in that situation, hypoglycaemia will never occur. (...) Not always do people understand... It always depends on the person... from person to person. There's the one who understands, ... and another who doesn't understand at all.
> **Mm-mm (long pause) And... do you remember any episode, if you want to tell me...**
> ...Episodes... it happened once that... she knew my problem, and... I had to... [stop and tell her]... "I'm in hypo, I have to eat"... And then she didn't want to continue. Because she looked at me... she looked at me as a weak person, an ill person, who couldn't do that thing in that moment. I was fine after that, I could have easily... But she was a little... with her head... And we talked about it, ...it didn't go on for much longer. Because that was a problem for her. So... yeah. I said (he laughs) life goes on, that's it. (Martino, 34 years old, T1D, farmer, onset at 8 years)

Both the eventuality of "erectile dysfunction" and illness as emasculation factors were also mentioned by Pietro, a 27-year-old man who was diagnosed with type 1 diabetes at the age of 16. In his words:

> In men, ... it happens because... many can actually have emasculation problems. Because you're weaker, ... because there is this thing, it is there, of erectile dysfunction. On which obviously we only joke, because ... still you have to be a little bit of a moron, no? ... And so maybe the people who... this thing can happen, added to the fact that it is an illness after all… (Pietro, 27 years old, T1D, musician, onset at 16 years)

6.2.2 "The man is a beast": the persistence of the hegemonic male sexuality model despite diabetes

Overall, in the majority of cases participants' narratives were informed by the dominance of a traditional conception of sexuality, where social expectations around men's and women's sexual performances were mainly dichotomized around the belief that men's sexual desire is natural and stronger than women's, thus confirming the recent survey on a national sample (Barbagli, Dalla Zuanna, Garelli, 2010). This was detectable, for example, from the discursive construction of a hyper-sexualized self that, through the reference of an "excessive" voracious male sexuality, dismantled the potential stigmatization of (actual or virtual) impotence. This is the case, for example, of Pietro, who even reported "hoping" to experience erectile dysfunction in order to put a physical limit to his "excessive" sexual appetite:

> I've never had the problem of erectile dysfunction. Because it never... it never happened to me, I don't know. But not even... ever... slightly. Quite the contrary. It's more the opposite, so every now and then I wish... (He laughs) I actually wish I had it. Yes, because I'm not sixteen anymore, I'm 27. So at a certain age: "Try to calm down!" (...) I mean. ... Too much voraciousness. But that's always been a problem. It causes problems in life. (Pietro, 27 years old, T1D, musician, onset at 16 years)

In another point of the interview, he again presented a hyper-sexualized self that did not engage in physical activity in order to manage diabetes – in line with the "Free Spirit" ideal type described in the previous chapter –, but rather frequently engaged in sexual activity, under the implicit assumption that this would benefit his diabetes management:

> Well I used to cycle a lot, cycling and mountain. A lot... And now for various reasons, I do... I just can't cycle anymore (...) ... A lot of sex. Loads of sex. Doing just that. It's enough. The best sport ever. (He laughs) (Pietro, 27 years old, T1D, musician, onset at 16 years)

The social expectation of male sexual voraciousness has also been acknowledged by another participant, Nicola, who expressed better than others the different impact of cultural and social expectations on sexuality practices for men and women, and on the way these are naturalized and incorporated to the point of not being able to distinguish self-expectations from that of the others, which are both, clearly, mediated by cultural contexts:

> Eh, well they're connected- I think the two things are connected.
> **What do you mean?**

> Yes, I mean, I... it's sort of a belief of mine, I mean the fact that... Table and bed, well, they're similar. (He laughs) So (...) ... They have four legs, they're flat, (he laughs) /first of all, / (laughing) And you do what you like on them. You do- you do what you like on them. (...) I mean, the- the common thing is the matter of hunger. I mean, I have to show that I am hungry. So... (long pause) Yes. To show you'd be able to... in quotes, "eat" the other person. Yes, that's it... It's a good analogy. Ah, I dunno, I mean (long pause) I mean... I- well. (Long pause) Neither on eating, or on sex I feel particular expectations by others, that I should show I eat a lot, that I last a lot. But, ... I am the one who wants to show- I mean, that... that if- that ... that I feel like, ... wanting to... show that I am, like, flawless, maybe. It can be something like that. And... (long pause) yes. I mean, it's not- it's not that... I feel- I feel the other who... I mean, for how they relate to me, what they say, how they look at me, like that, ... they expect that I eat a lot, OK. But... in- I mean, no- I don't know, but it's because it's difficult to distinguish the others from yourself. Because maybe I feel it, but probably somehow, there, what the heck, it's difficult to distinguish others from you, because well, a little- you are the one projecting yourself on others. (Nicola, 23 years old, T1D, university student, onset at 13 years)

A short and effective example of how the hegemonic model of male sexuality emerged in terms of sexual double standards can be illustrated through the words of Leonardo, in which the uncontrollable male sexual desire is considered "bestial," clearly stronger and more present, if compared to that of women:

> **What is the biggest difference that... comes to mind?**
> (Long pause) Well, increased desire... Increased frequency... less focus on quality, maybe? But, eh, here we're going into... I mean... you kind of end up mentioning the classical joke, no? Man is a beast, no? (Leonardo, 52 years old, T1D, architect, onset at 4 years)

Predictably, the pressure of enacting an appropriate model of male sexuality was stronger in the case of single participants, or in the case of the first sexual encounters with their actual partner. For example, Pietro recounted talking with a friend of his about the high performance expectations that characterize the "first times" with a new person: it was not about feeling pleasure, but rather on being enough "performant." This well illustrates how an activity such as sexuality, were instinct, impulse and desire are thought to guide the experience, is actually imbued with cultural and social meanings. In Pietro's words:

> **You talked before about the... emasculating potential [of diabetes]. I mean, often there is... this expectation of... performance..**

> Oh well, but that’s because... that’s because, there, it’s the first- it’s the first- it’s the first times that you have to make or not- a friend of mine told me the other day, he cracked me up... The first times, you must always make a good impression. So you must always enact this performance, where... where- actually something that... that- that normally, for your own pleasure, you would never do. Because you make such a great effort... But the first impression must be good. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Also Massimiliano, a 40-year-old man who was diagnosed with diabetes at the age of 4, referred to social expectations that inform first sexual encounters. He observed that the “superhero” sexual performance was something expected regardless of the presence/absence of an ill body, and this mostly happened during the first sexual encounters, while within a stable relationship an intimacy script would prevail. Intimacy, he claimed, was important mostly for women, who – according to the abovementioned double standard – were thought to experience sexuality not much as a physical experience, but rather with a more “emotional” involvement. In Massimiliano’s words:

> But on the other hand, from a... practical... point of view, ... certainly facing, ... a new relation, a new partner, is a... relatively- but this, ... not only for... for this kind of pathology, but, ... also for normal people, no? Facing, or thinking of being a superhero, (he laughs) who does his tricks, and vice versa, ... women, girls, have ... the same kind of, in the first... in the first moments, when you’re peaceful together. In the sense that you’re together. After, surely, ... after a few times, ... you get to know each other more, ... and, you reach an intimacy that... is needed to be... peaceful and happy, which... is the first important thing... Not only, for us, ... but, ... even more often for... for girls, no? For women, who... live it even more emotionally, yes, generally. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Paolo, a 32-year-old man who was diagnosed with type 1 diabetes at the age of 20, developed further the dichotomous vision of sexuality and of sexual expectation around men’s performance: again, what prevails is the ideal of sexuality as an arena of practices where men display strength and potency, as a proxy for representing an appropriate masculine self. In Paolo’s words:

> **Paolo**: (…) So, yes, anyway one of the first things that I thought: “[Since] I have diabetes, I will never be able to pick up a girl, hold her in my arms and run through a field”, I mean, things that one... The fact of always projecting on an exaggerated situation that will never happen and thinking that you

> can't do it, so you're no longer who you used to be, but that you've never been that person…
> **Partner**: but maybe also because, especially men…
> **Paolo**: In men, sex is a physical prowess. Sex, in men, for men…
> **Partner**: culturally
> **Paolo**: ...it's physical strength, it's proving strength to the woman.
> **Partner**: yes, culturally! (Paolo, 32 years old, T1D, labourer, onset at 20 years)

In the majority of cases, successful hegemonic masculinity in sexual context was highly related to the capacity of achieving and maintaining a satisfying erection throughout the duration of sexual intercourse. The penis – and above all its performances – is overall conceived as it was an external and independent part of male sexual corporeality; it is, as Potts (2001: p. 145) noted, "a synecdoche for the male body" over which the man seems to have only partial control and upon which his sense of self seems to depend. In this regard, an illustrative example is that of Ronaldo, a 46-year-old man who was diagnosed with diabetes LADA at the age of 39. At the moment of the interview, Ronaldo reported having received a diagnosis of ED and using EEMs in order to cope with erection difficulties. While probably attempting to discursively counterbalance the emasculation potential of his impotence, he began the interview by describing a hyper-sexualized self, characterised by his ability to successfully fulfil the hegemonic ideal of male sexuality in terms of an objectification of women ("all women were the same to me"), of his ability to "serve" and satisfy no less than 3 women per day and, thus, his ability to guarantee successful sexual performances that seemed to be separated from the (inexistent) relational context. In his words:

> ... So at that time I had a life that was... let's say, not normal. And basically... I had a very intense sexual life... you know. And basically the... I realised it [the onset of diabetes], because I changed partners often, I even had two or three partners a day, and I realised that... at a certain point I won't able to perform. (...)
> **This in the sense of... problems of... erection, or...?**
> Exactly. And basically I realised that... I had this erectile dysfunction... Yes. (...) ... Well, but statistically not even 10 per cent of diabetics... notices it, because in fact then others have different symptoms... And nothing. Well basically since... we couldn't understand... the cause, also because for the kind of life I lead at the time, ...all women were the same to me, still I was popular and so... I had to serve them. And as a consequence it came up like this, you say: "But why?" I went to the doctor's and the GP made me notice

> I have a family history of diabetes... (Ronaldo, 46 years, high school teacher, onset at 39 years)

Sexual performance was considered crucial for Ronaldo, and he mainly talked about his experience of sexuality in terms of his ability to attain a specific number of erections per day and comparing it to the performances "before diabetes." After diabetes' onset he reported being unable to maintain this "excessive" sexual standards and this marked the most important turning point of his illness – and biographical – trajectory. In fact, his inability to perform a hegemonic sexuality made him shift from an "oversexed" and "non-normal" sexuality, as he defined it, to a "normal" – namely, monogamous and "normally sexed" – sexuality within a stable relationship. But this did not mean that he abandoned the predatory script model in favour of the intimacy script one. He maintained a hegemonic male sexuality in so far as he never spoke about sexuality in relational terms, and also discourses around his wife tended to objectify her (for example, he said that he decided to "take" only one partner, as it was a matter under his exclusive control). In the next excerpt, a concise illustration of how his perceived inability to perform a successful masculinity made him opt for a "respectable" sexuality script. As he said:

> The fact of having understood that... I can disappoint, from the point of view of sexuality, then pushed me to take only one partner. (...) Well, [from before, now] there's one difference. In the sense that at 39 years of age... I could even have three partners a day, ... now, as a married man, it's only my wife. (Ronaldo, 46 years old, diabetes LADA, high school teacher, onset at 39 years)

Another example of the centrality of erection performance in Ronaldo's account concerned his definition of a "normal" sexual life. In fact, after engaging in sport activities and undergoing medical treatment he reported managing to overcome his erection difficulties. His "normal" sexual life was then quantified in "four erections per day," in this way he demonstrated that he had incorporated the cultural imperative of being always performant, as well as the medical definition of male sexuality that focused on the quality and quantity of erections. In his words:

> I mean, I tell you, look, thanks to cycling I've now managed to have a... normal sexual life, as if that... that unfortunate incident a few years ago had never happened.
> **May I ask you what you mean, what is "normal" for you?**
> ... Well, I manage to have at least 4 full erections a day. (Ronaldo, 46 years old, diabetes LADA, high school teacher, onset at 39 years)

The reduction of the male sexual body to the penis and the focus on its performance as a proxy for general sexuality satisfaction was often also attributed to their partner, as if sexuality was not a product of a mainly relational dimension, and as if one could be individually satisfied without considering the satisfaction of their partner during sex. Therefore, sexuality seems to be conceived as more individualised, as a performance governed by specific rules that, if transgressed, would compromise one's own satisfaction and that of the partner. A particularly eloquent case is that of Francesco, a 51-year-old man who was diagnosed with diabetes at the age of 3. At the time of the interview, Francesco reported having experienced erectile difficulties for several years and having undergone a medicalized treatment in order to solve them (that is, in the first place drugs, then injections, and at the time of the interview he was considering the possibility to proceed with a penile implant). The interesting aspect of his account, which highlights the pervasiveness of the hegemonic male sexuality model, is that in his narrative he kept separate the dimension of pleasure – which he reported experiencing without any difficulty by achieving orgasms – and that of performance. What prevailed in his sexual account was the incorporation of a negative judgement of his performance, assigned to him by his partner and "confirmed" and medicalized by doctors. His sexuality – just as his masculinity – was considered inadequate because of orgasms achieved "too fast" and because of an inability of his to fulfil a fundamental dimension of the construction of masculinity: the control of one's own penis, and therefore, the control of one's own body. In his words:

> It's not a, I dunno- a situation that is... fully satisfactory, yes. So...
> **OK. And can I ask you whether it is something... that is more related to performance, or to pleasure?**

> ... More... related to performance. However, from the other's side, more than mine...
> **What do you mean?**
> I mean that... I can... finish. But let's say that the duration is limited, and... and the ability to manage myself... that is also... limited. (Francesco, 51 years old, T1D, employee, onset at 3 years)

Sexual performance has been often described, from participants categorized in the previous chapter under the "athletes" ideal type, through sport metaphors. In the case of Francesco, fulfilling the hegemonic ideal of male sexuality was considered – despite his medicalized attempts to achieve it – beyond his actual physical possibilities, and he compared his sexual performance to that of sport: as a competitive runner, he compared this situation of non-fulfilment to that of him playing against professional players of basketball, a sport that he was not familiar with. As he said:

> **Are they different compared... to the expectations your partner has about you?**
> ... Yes- yes. I mean, surely there's a difference in expectations, surely the-the problem is that I am not able to ... live up to these expectations.
> **... Your expectations?**
> The other's expectations.
> **The other's.**
> Yes. No but, it's not that ... I mean, unfortunately let's say that in life there are things that go beyond one's own abilities, (he laughs) ... if you ask me to... play basketball, against... basketball players, I can't... I can't do it, ...
> **OK, so how do you react to this?**
> This is one of the things you have to keep… in your… life, unfortunately… you have to do… let's say you can- you can do everything possible, to … to solve them, but more than what's possible, you can't do the impossible. (Francesco, 51 years old, T1D, employee, onset at 3 years)

Despite the fact that he stated that his performance was satisfying for him because he could achieve an orgasm, he reported having undergone medical treatment in order to fulfil his partner's expectations, that would not only help achieve her own personal satisfaction, but this would also hold his constant feeling of inadequacy that, in turn, affected even more his sexual performances:

> Let's say that it's frustrating, this thing. And... so... it's a situation that... yes, one would like to... I mean, the idea was also, if possible, to perform an implant surgery... but it's something that... let's say it might solve my mental problem, more than everything else. (Francesco, 51 years old, T1D, employee, onset at 3 years)

A final, brief observation regarding the importance assigned by participants to male sexual performance is that, according to their perception, their partner expected them to be "always ready" and to be able to engage in sexual activity without interferences due to their illness. When this happened – often due to glycaemic swings – in many cases the female (or male, in the case of the gay participant) partner seemed not to accept diabetes as a legitimate justification, they rather attributed the responsibility to the fact that they were not enough sexually attracted to them. In the following except I propose an illustrative example through the words of Nicola:

> **And... as for hypoglycaemia, ... you told me, has it happened to you?**
> ... Eh, that's it, you necessarily have to stop there, (...) there and then, and... the feelings are the same, I mean. Then the other feelings are the same. (...)
> **... OK. ... And... your... girlfriend, how...**
> Eh, how does she react? The first times she thought I that... I wasn't attracted to her. But, I mean, I had ... because- I mean, I had measured it [glycaemia], she was also there, I mean. So: "You saw that I was low" ... but, I mean, it was as if she thought I had gone into hypoglycaemia, ... if... wait, because, despite the hypoglycaemia, it was because I was not attracted- I was not attracted to her enough. (Nicola, 23 years old, T1D, university student, onset at 13 years)

6.2.3 "I don't have a particularly good erection, but I'm happy with my sex life": renegotiating sexuality because of diabetes

A minority of participants who experienced sexual difficulties did not adopt a predatory conception of male sexual health in their discourses: they rather talked about their sexuality in terms of the concreteness of life's experience, with the possibility of an interference of illness in its enactment, but this not in terms of a non-fulfilment of specific sexual performance standards, but rather in terms of a changed experience of one's sexuality. This could be interpreted as an act of resistance to medical knowledge, even if participants did not give explicitly such an interpretation. Furthermore, there is also the possibility – albeit remote – that it is in fact doctors who promote a different and more subjective image of male sexual health, as illustrated by the following excerpt of an interview conducted with an andrologist:

> I think everyone finds his own wellbeing, there is no standard... What I always say is: "How is intercourse for you, is what you have satisfying?" It's

> subjective, I can’t say that... it has to be like this. Because there are no rules, I have people coming to me and they tell me: “Look, I don’t have a very valid erection, but I’m happy with my intercourse, I am satisfied, because maybe I do other things...” So I think it’s very subjective, there is no standard definition of sexual health. Or rather, there is one in books, so there is the definition of erection and everything, but I don’t think it’s something that should be standardised, no. (Andrologist2)

For example, Vito, a 30-year-old man who was diagnosed with type 1 diabetes at the age of 23, reported experiencing an “imperfect” sexual performance in the last few years. But he did not refer to his sexuality in terms of quantity and quality of his erections, or fulfilment of cultural hegemonic standards. Despite the fact that he acknowledged that usually men are described as “animals” within sexuality context, he mentioned the relational dimension of sexuality and the possibility to focus more – when diabetes interferes into sexual performance – on “quality”, rather than “quantity.” In his words:

> Well, I could also decide to... (he laughs) focus on quality... no, come one, now it’s not nice to say, (...) I mean ... also that- I mean, in the sense that, one must also realise that. I mean ... we’re not animals. Also the person you have... by your side, maybe... especially if she will become the one- ... the person with whom you want to spend your life with, shit... I mean, usually it’s us who are more... animal, from a sexual point of view... (Vito, 30 years, T1D, employee, onset at 23 years)

Adopting a model of intimacy seems to occur, within the participants’ narratives, particularly within a committed relationship, where re-negotiating a sexuality which is changed by the impact of illness becomes a less stigmatising process and it is rather considered part of the dynamic relationship of the couple. For example, Pietro himself, who had emphasised the importance of a certain kind of bodily performance during sexual activities with a new partner, clearly shifted argumentation when talking about doing sex within a stable relationship. Although in his narrative a predatory vision of male sexuality prevailed, at the same time he introduced a relational dimension in the possibility to face underperformance by talking about it with his partner and expecting from her a “smart” understanding:

> So in that case [first sexual encounter] I can understand. In a committed relationship, I don't understand it. Whether it is a man, or a woman, or... anything else, because... sex, after all ... is also intelligence, so it's not that... I mean... sex for the sake of it is one thing. Sex... with a person you love, and who... I mean. It's nicer if there is intelligence, aside from, no? ...So a person whom I think is intelligent, these are things that she can understand, sure. (Pietro, 27 years old, T1D, musician, onset at 16 years)

The fact that within the same narrative it is possible to find different discourses around male sexuality gives a measure of the complexity of people experiences and meanings of male sexuality that may change according to different social contexts and dimensions.

In the national survey mentioned at the beginning of this paragraph, a minority of participants was found to describe the possibility of more "symmetrical" relationships, where women and men were believed to have the same sexual desires (Barbagli, Dalla Zuanna, Garelli 2010). In this sample, a minority of participants mentioned the relevance, for a "successful sexuality," of their partners' sexual satisfaction not (only) in terms of their ability to attain and maintain a perfect erection, but rather in terms of the occurrence – or not – of their partner's orgasm. For example, Vito stated:

> Because... the man, once he... did... once he / achieves an orgasm / (laughing) one night, ... I mean, he no longer has any problem... I mean, if you want the woman to- I mean, if you want to... satisfy the woman more and more -now it seems like I'm Rocco [-Siffredi, an Italian porn actor] but to let you understand, (...) Maybe if... I feel that she doesn't... doesn't always achieve an orgasm, I ask myself that... And because of this, ... I talk to my friends as well. (Vito, 30 years old, T1D, employee, onset at 23 years)

The fact of experiencing diabetes might have an impact on the way men define their sexuality and on the importance assigned to penetrative, hegemonic sex. In few cases, participants described the context of the stable couple as an occasion to construct a deep intimacy, based on reciprocity and on the possibility of experimenting sexuality changes over time and across those life events that influence sexual desire, and/or physical performances, such as in the case of illness in general and diabetes in particular. An illustrative example is that of Lucio, a 38 year-old man who was diagnosed at the age of 36. Lucio reported having experienced, since his diabetes onset, a significant change in sexual desire.

In his narrative, he did not talk about feeling inadequate about his masculinity performance, he rather normalized sexual difficulties and incorporated them as a change that might occur in someone's life but that does not need to be "fixed" and that is not negatively judged. He rather reported talking of this with his wife, who in turn experienced illness in the past and who in turn talked with him about the changes of her own sexual desire as a result of the impact of her illness. In his words:

> I talked about it... yes, I talked about it to her. I have to say that with her... we always talk about it in a way... I mean, about the whole thing, in a rather... spontaneous way, I have always talked to her about it, she has always talked to me about it, so we have always dealt with it in this way. She also had, some time ago, an... illness, for which she had to have- and from which she has recovered, and this thing, the treatment was really tough, so she also told me. (...) But also because- not... not because with each other, I mean, in a not exclusively sexual relation, so in a relationship that is also affective, it's obvious that... differently, a lack of desire, a lack of sexual... activity can be mistaken as a symptom of lack of interest – also emotive – at least, I see it like this. I have always seen it like this, and [in the past] when the relationship was about to end, it was ending, generally one of the reasons why [it was ending] was that... I didn't feel this desire, from an exclusively physical point of view, and which was therefore a symptom of lack of emotional desire. (Lucio, 38 years old, diabetes LADA, entrepreneur, onset at 36 years)

6.3 Experiencing sexual difficulties

> Sexual virility – the ability to fulfil the conjugal duty, the ability to procreate, sexual power, potency – is everywhere a requirement of the male role, and, thus, "impotence" is everywhere a matter of concern. (Tiefer 1986: p. 579)

Overall, 30 out of 40 participants reported having experienced some sort of sexual difficulty. The majority of the participants referred to erectile difficulties, while a minority talked about a loss of libido and a more generic underperformance; two of them reported experiencing, in addition to erectile difficulty, also premature ejaculation. 27 participants out of 30 attributed, through different type of explanations, the responsibility of sexual problems to diabetes: among them, 15 talked about the impact of glycaemic swings on their sexual performance, 7 of them reported experiencing sexual difficulties as a diabetes-related organic complication and 5 of them reported experiencing anticipatory anxiety and performance anxiety related to the possibility of diabetes' symptoms occurring during sexual activity; 4 out of 30 attributed the responsibly to aging; overall, only two of them explicitly mentioned also the relational context as relevant for explaining their erectile difficulties.

The hegemonic model of male sexuality imposes impossible standards of performance, for diabetic as well as non-diabetic men. Diabetes, then, further complicates things, because of the unpredictability of its symptoms, because of the visibility and intrusiveness of its medical devices, because of the possibility of experiencing organic complications. Overall, the problems that diabetic men might face in the context of sexuality mainly concern, just as non-diabetic men, the difficulty in fulfilling the expectations around the hegemonic ideal of male sexuality in terms of physical performance and masculinity construction. As Plummer stated, "the penis (physical) and the phallus (symbolic): both can bring problems" (Plummer 2005: p. 180). The inability to attain an erection at the proper time and place, an erection that lasts long enough and that performs as it "should" perform, has in fact an impact on the perception and on the entire definition of the self as a "man." In this research, men explained their sexual difficulties in many ways. Usually, their narratives were dominated by an organic or psychological explanation, but at the same time the majority narratives included, to some extent, a psychological dimension, although it was not always predominant in their discourses.

As mentioned in the introduction, one of the criticisms that Tiefer (1986) posed to the biomedical model was that of counterposing "organic and psychogenic causes of impotence as mutually exclusive phenomena" (Ibidem: p. 589). In this paragraph I will consider them separately for illustrative purposes, because they often imply different discursive strategies and they had often different implications at the level of practices, under the assumption that boundaries are inevitably blurred when talking of sexuality and sexual difficulties, and that the reason why an explanation prevailed over the other in discourses should be put in perspective by acknowledging that all empirical material has been constructed in a specific context, that of the interview with a female interviewer, and thus discourses could be “biased” from social desirability and from the desire to “save face” and to construct a “successful” masculinity during this specific interaction.

6.3.1 “Psychological” explanations

As already mentioned in the introduction, Tiefer (1986) observed that one of the main causes of impotence in men is the so called “performance anxiety” which may “generate a self-perpetuating cycle that undermines a man’s confidence about the future even if he recovers from individual episodes” (Ibidem: p. 591). In this specific subsample, only two participants explicitly referred to the well-known “performance anxiety,” that happened when “emotions” got in the way (this regardless of diabetes). As in the case of Alessandro, who said:

> The difficulties are... psychological. (He laughs) / When it happens / (he laughs) because I was too nervous (he laughs) (...) the usual anxiety, performance anxiety. (Alessandro, 46 years old, T1D, employee, onset at 3 years)

On the other hand, the majority of participants reported experiencing another form of concern that preceded sexual activity and involved their chronic condition: anticipatory anxiety. That is: they knew that sex – just like all physical activities – could provoke glycaemic swings and interfere with their sexual performance and sexual desire; they also acknowledged that their bodies were somehow “changed” after diabetes’ onset – for those who had the onset at an adult age – and that they could not be “always ready” for engaging in a certain physical effort that sexual activity could entail. This is well expressed in the words of Paolo, when he stated:

> Anyway, I think that in that case the biggest problem is the anticipation of the problem... It’s kind of the mechanism of fear in general: one anticipates too much and becomes stressed... you create the problem you still don’t have. So, yes, anyway one of the first things that I thought was: “[Since] I have diabetes, I will never be able to pick up a girl, hold her in my arms and run through a field,” I mean, things that I... The fact of always projecting on an exaggerated situation that will never happen and thinking that you can’t do it, so you’re no longer who you used to be... (Paolo, 32 years old, T1D, labourer, onset at 20 years)

Since diabetic individuals are necessarily embedded in a medicalized framework, and since they – as I mentioned in the introduction – regularly undergo medical examinations where their sexual functioning is checked, all participants reported being aware of the possibility of experiencing ED as a possible diabetes complication, and often this entailed conceiving ED as a real "sword of Damocles," an ever-present threat to their health and to their masculinity.

For example, a young interviewee, Diego, stated:

> Eh, it [ED] will occur, fuck! I hope this will arrive as late as possible. (Diego, 23 years old, T1D, confectioner, onset at 4 years)

ED as a "sword of Damocles" seemed to have an impact on how they understood sexual difficulties, even when they knew that there could be other "explanations." For example, Enzo, a 40-year-old man who was diagnosed with diabetes at the age of 15, reported having experienced hypoglycaemia during sexual activity (a very common occurrence, as it will be explained soon), an event that compromised his sexual desire and physical performance, and that he interpreted as a possible beginning of diabetes-related organic complication. In his words:

> Then when you have hypoglycaemia, I mean, nothing works anymore. You're unwell, so you don't... You go into complete paranoia. It happened to me once, not because of the act, I was already low. Already before, yes, [I was] low. Clearly it was an episode of hypoglycaemia, but not due to sex, I mean. (...) If you're a person who's honest to yourself, I mean, you know. Then after 25 years, I, pff, I mean, you know it, so... If it doesn't work, it doesn't work... It's clear that if there isn't a certain degree of intimacy you tend to get depressed, clearly, because you think that it will never work again, you think that it's a secondary effect, I mean, how do you say it? Hm… yes, OK, a secondary effect of diabetes.
> **A complication?**
> Yes, a complication, eh, thank you. Yes, you think that it's a complication and that you're becoming impotent. It's normal. It's the first thing that comes into mind, because you say... I mean, I had a similar episode in the past. I went into total paranoia! Completely! Because I've had every exam in the world, hormones and everything, I went to the diabetologist, I talked... (...) So, yes, but you tend to think about it. I think of complications immediately, as soon as I have the slightest pain... (Enzo, 40 years old, T1D, researcher, onset at 15 years)

Another example of anticipatory anxiety associated to the fact of being aware of the possibility to experience ED and erectile difficulties as a result of fearing this eventuality was that of Igor, a 31-year-old who had diabetes onset at the age of 28. As he recounted:

> So we tried for a few months to... have children, but with no luck, and... from there, a lethal mix, in the sense that... you can have children, and you don't... I have diabetes... a mental block starts to form, let's say, in this way. But, also then, I mean, I wasn't in a desperate situation, I mean... I was... aware of the situation and... of my abilities and of what I could do and how I could react... so I reacted, I thought: "It's a mental block, there is nothing physical," also because the onset had... happened not long before, so, I mean, it wasn't actually physically possible that... already... it could have repercussions. So... well, we overcame that period, we then had a little girl... (Igor, 31 years old, T1D, shop assistant, onset at 28 years)

A similar experience is that of Ivan, a 51-year-old man who, just as Igor, experienced erectile problems in correspondence with the period in which he and his wife were trying to have a baby. According to his reconstruction, his erectile difficulties occurred as the result of the fear of experiencing them, just as a self-fulfilling prophecy. In contrast to Igor's narrative, Ivan used a medicalized terminology to talk about his erectile difficulties: he used "erectile dysfunction" as a definition and reported immediately recurring to medical support for checking his actual sexual functioning:

> So... I'll tell you... bluntly, bluntly, bluntly. When at the beginning, we tried for children, they didn't arrive... So it had been ... 9 years since the onset. The thing had gone off, ... my- my fear, that the problem was me... Once all the tests had been done, ... and established that, ... I was OK, immediately, ... I was free of this thing, ... because... the... the erectile dysfunction, ... maybe ... that wasn't systematic, but it might have happened, it was related to that fear. Saying: "Eh, OK, but still ... I can't have them, because... it's a complication." (Ivan, 51 years old, T1D, manager, onset at 27 years)

Massimiliano, in turn, observed that the fact itself of being aware of the possibility of experiencing ED as a diabetes-related complication could act as a self-fulfilling prophecy and "provoke" it, in line with the Thomas theorem which states that "if men define situations as real, they are real in their consequences," regardless of the actual validity of its premises. This seemed to happen also for erectile difficulties in diabetic men, as Massimiliano recounted:

> This thing, obviously, ... happens, ... to everyone, I mean, it doesn't happen only to people with diabetes. Certainly people with diabetes have... a... from a mental point of view, ... the difficulty, to maintain a little more it under control. Because, ... they attribute a lot, ... of what is their state, ... to the pathological condition itself, which can be there. OK? ... And this, ... we know it, it's not only the doctor who knows it. ...No? And this creates ... no?

> An interpretation of ours, which... "Ah, I won't make it" so, ... "Ah, I could have problems, ah, now I'm over 40," "40 years old, and I will surely have them [problems]," (he laughs) And all these things. Especially if you have it when you're very young, you can also have... If you've always lived with this thing, no? And... all things considered, yes. I- I don't know what would be... honestly, the best approach for these kind of things. Because, ... if you talked about this, ... there would be... you'd trigger even more, ... the possibility that, ... in some of the people, ... you trigger this thing (...) And because, ... if someone has never had problems, it's obvious that ... they trigger this thing, and they say: "Ah yes, so..." Because... there will surely be someone who... will say: "Yes. I have huge problems." Because there are... honestly. No? ... Both those with diabetes and those without have them. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Difficulties in attaining an "adequate" erection might be understood as the result of personal "insecurities," something that diabetic men have in common with non-diabetic men, to whom (as will be further explored in next paragraph) they often ask for confirmation in order to exclude diabetes' complications:

> Unfortunately, tied to what we were talking about before, ... when, let's say, you enter an intimate relationship, then... the... psychological aspects... They are very important. So, (...). There has been, obviously, ... sometimes, ... when, ... let's say, ... my, in quotes, insecurities, or... my way of, ... of... sensitivity, I don't know what it is, it happens that, sometimes, ... all things considered, ... there can be a few failures [the original term was "*défaillance"*]. But all things considered, ... even talking ... to people, ... who are not diabetics, these things... happen. (He laughs) (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Simone, a 53-year-old man who was diagnosed with diabetes at the age of 9, reported experiencing erectile difficulties that he understood as the result of both organic, "mechanical" erectile problems as a complication of diabetes and a psychological cause, namely the lack of desire caused by stress. In his words it can be found the persistence of a hegemonic model of male sexuality, where men should always be desiring and performant, regardless of the context:

> It depends on the time. It's also a matter- it's also a mental matter, obviously. Certain days you feel, ... there is no desire, because I have the- ... either the day was tough, or ... the brain... it is- is a real bastard in these things. Because it goes on to affect in a ... negative way, so despite... there is a will to do, ... weirdly the brain, and consequently also the body, don't collaborate (Simone, 53 years, T1D, touristic guide, onset at 9 years)

Finally, psychological explanations might intersect with organic explanation in an inextricable way. For example, an organic basis such as glycaemic swings may cause anxiety or depression, as Massimiliano recounted, and this might be an example of the complexity of how sexual difficulties might be understood simultaneously in different ways from who experience them:

> The aspects related to... let's say, to sexual relation- I mean, to sexual relations of men, are surely, I think ... with a normal control... normal, or medium, of treatment: obviously with a... disastrous control, ... it's clear that the possibility that this [underperformance] occurs, also from a... psychological point of view, it is very high. Because. Because... it creates a series of ... alterations in one's state of anxiety, of depression, related to... If you (...) have few hypoglycaemias, ... and... few hyperglycaemias, then, ... the mood swings are relatively less overwhelming. Less strong, less frequent. If on the other hand, ... you have ... a disastrous control, I mean, many hypo- hypoglycaemias, or even worse, many hyperglycaemias, ... these have, not only a practical effect from a self-control point of view, ... but... they have a huge effect... in time, with what... the state- your state of anxiety, of... depression, of... insecurity, and these, are the most... overwhelming and strongest aspects, also, as you can imagine, in... in couple problems. OK? (...) Certainly this... aspect that, ... has affected me, ... in a few moments, (...) and is certainly... a... a ... really delicate thing. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Another example of the complex relation among organic and psychological dimensions was provided by Francesco, who posited that the medical approach and intervention on his sexual health actually compromised further the situation, because of its psychological impact: the need of planning ahead sexual activity and respecting the duration of time envisaged by EEMs administration, together with the fact of being diagnosed with a "dysfunctional" penis could have an impact, in his opinion, on his self-esteem and, in turn, on his sexual performances. As Francesco put it:

> Yes, yes... well, I think that diabetes has to do with it... to the same degree, I'm not saying 50%, but it has to do with it the same degree, compared to the psychological aspect, and the psychological aspect has to do with it. On two... two levels. One level, ... is the fact that... you are not fully... confident in yourself. Another level, ... which maybe is more or less the same, is that you didn't have- didn't have the chance to- to experience it calmly. Because somehow, the fact of having to... use a drug, so having to stick by certain times, ... [the interviewee's phone rings, the conversation is interrupted]
> **So, you were telling me...**
> Yes, in the same way, the psychological aspect has to do with it, ... which removes the faith in yourself, let's say, ... which- the confidence in... in something you're used to do. Let's put it this way. The physical aspect, ... which... surely has had an impact somehow ... on- on you. Which however,

> they told me, the andrologist I went to see, is not ... normal- I mean, it's not normal, but it's... a frequent thing, which still doesn't have an impact... But, I don't know. (...) Then an aspect that maybe is also related to... I mean, I have also had some tests done, ... and there was a physical aspect, ... a structural one, because from the test I had done, it emerged... I had an only *corpus cavernosum*, instead of two. The point is that decreasing the faith in... yourself, you end up... it all adds up (Francesco, 51 years old, T1D, employee, onset at 3 years)

6.3.2 "Organic" explanations

> How do you explain to someone who hasn't promised in-sickness-and-in-health that, hey, sometimes I'm too sick for sex? Or, better yet, how do you explain that the act of sex itself, in all its acrobatic glory, will drive you low and leave you weak and stranded? That, despite how hard I try, there will be times when I have to stop you, like the cruellest of teases, so that I can go down some sugar?"(Karmel, in an on-line blog)[34]

When talking about diabetes and sexuality, the majority of research focused on the occurrence, experience and possible aetiology of erectile dysfunction. The empirical material collected for this research highlighted another "organic explanation," that occurred in the majority of cases: namely, the impact of glycaemic swing on sexual desire and sexual performance. As it will be soon explained further, sex can provoke low blood sugar levels, and, if not treated in time, this could render diabetic men even unconscious. For this reason, it clearly poses a challenge for diabetic men to fulfil hegemonic expectations around their sexual performance. The second "organic explanation" is the more obvious reference to "erectile dysfunction" as a possible complication of the disease.

Overall, the discursive strategy of exclusively attributing to organic factors – whether this involves glycaemia or neuropathy – the responsibility for sexual "failures" can guarantee a sort of exemption from personal responsibility because it refers to mechanisms on which men cannot exert control. Especially in the case of erectile dysfunction, there is also an incorporation of an interpretive register derived from a medical framework, which refers to biology and pathology and, in turn, relieves men from personal responsibility for their sexual problems. Aside from the "mechanical" problem of erective difficulties, both glycaemic swings and ED are used to justify an even more stigmatizing occurrence in male bodies:

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[34] Retrieved from: https://asweetlife.org/diabetes-and-sex-when-hypoglycemia-gets-in-the-way/ Last seen 22/10/2018.

the lack of desire. The body of a man, conceived as a desiring machine that should be “always ready” and “always desiring,” is in the majority of cases justified by participants in its “sexual failures” through a biologizing explanation, that does not account for other personal or relational factors that are entailed and that enacts a sort of separation of men’s will from their bodies’ actual possibilities. This, in turn, allow men to distance themselves from the potential stigma which is associated with transgressions from the hegemonic model of male sexuality, because the responsibility is attributed to an external and uncontrollable factor.

6.3.2.1 “You can’t get it hard if you’re in hypo”: narratives of glycaemic swings and sexuality

Just like every physical exercise and strong emotion, sexual activity might alter glycaemic levels and cause hyper or hypoglycaemia. In both cases, diabetic individuals usually feel more tired and lethargic, and in men glycaemic swings might cause the inability to attain and maintain an erection as well as difficulties in ejaculation. In order to avoid glycaemic swings, it is usually advised to leave the insulin pump attached to the body (in order to continue insulin administration and avoid hyperglycaemia), and to eat some food before sex or immediately after, in order to raise glycaemic levels and compensate for the glucose which has been burned. According to participants, this “preparation” rarely happens, mainly because sexuality is conceived as something difficult to plan in advance. Overall, participants reported that the possibility of experiencing hypoglycaemia during sex was, as Manuel stated: “Part of the routine,” something they needed to come to terms with.

In this regard it is illustrative the case of Pietro, who recounted an episode in which his partner was seducing him and he wanted to have sex with her, but he could not attain an erection because of a hypoglycaemic episode. Facing his girlfriend disappointment, he then reported eating a large amount of ice cream in order to let the glucose level increase and physically “perform” as he was expected to:

> Sometimes. Sometimes- ... it can happen that maybe... you go into hypo before, or during, eh... (...) Said bluntly, very bluntly, ... you can't get it hard if you're in hypo. You just can't. I mean, physically- I mean, you're unwell, ... but you tell the other, if you're feeling like- Physically. The moment when you're not in hypo, ... you'll prove yourself, and everything will be all right, if... it's quite simple really. (...) The ane- the anecdote? Because this... this will make you laugh. But. She had bought a whole... one of those outfits that are really... Plus it was a time, no? ... When we were always arguing, so... this outfit came out, I concluded the evening well, breaking a glass scale. A... glass scale, one of those she had in her house. As soon as I got back home. Broken into pieces. Good start. It was supposed to be a romantic dinner, ...drinking, eh, smoking, taking out this incredible outfit, no? ...By which I was exaggeratedly attracted, ... the problem is that... while she was showing off with her outfit on, I felt I was going into hypo, no? So I had this bowl of ice cream, ... so while she was doing… With the ice cream, I, [he mimes the act of eating ice cream] there eating it, and all, so...
> **... And then?**
> Eh, then I couldn't get it hard. (He laughs) Because I was unwell. I was in hypo, I was horny, and in hypo. I just couldn't, ... and she... she... says: "But you're not hard," I tell her: "Honey, ... I'm in hypo, it's two hours that I'm eating ice cream, give me a moment," she goes: "For fuck sakes," I go: "Look, I can hardly look at you," I tell her: "When I finish eating this ice cream, it's over!" And as a matter of fact, then... then let's say that... in the sense that, after a while it all went well, no? Because the male tends to... to exaggerate things. But, actually, then... things go well. (Pietro, 27 years old, T1D, musician, onset at 16 years)

Another participant, Nicola, on the same line reported that when hypoglycaemia occurred for him it has been difficult to continue sexual activity, because it has been necessary to stop and balance glycaemic levels. But unlike Pietro, Nicola reported having difficulty in continuing sexual activity afterwards:

> **Some interviewees talked to me about... having had sexual difficulties... related to diabetes. Has it happened to you?**
> ... Sometimes- I mean, rarely, but with hypoglycaemia yes. I mean, it's a pain in the ass because... everything goes limp. (...) ... And yes, you have to stop there, [because] you feel unwell. But... yes. OK... (long pause) yes, so yes, the feelings are the same, I mean. (long pause) And yes, then [when it happens] you stop and you adjust it [glycaemia], you have to. And then you don't... however, you struggle to start again, so the feeling of... I mean, the body is still... recovering. (Nicola, 23 years old, university student, onset at 13 years)

When hypoglycaemia occurred, some participants recounted talking about it with their partners, others reported avoiding sexual activity because they "felt" that hypoglycaemia might occur and they did not want to disclose their condition to the occasional partner. As Paolo said:

> Going into hypoglycaemia happened to me... (...) It happened to me (...) to avoid. With her, [he indicates his girlfriend] to tell her. It happened that I looked for excuses, you know, to delay it a moment, taking time also in stupid ways.
> **Such as**?
> Eh, I don't know, like that, continuing to chat, rather than shifting the attention on something else. (...) And often ruining everything! (Paolo, 32 years old, T1D, labourer, onset at 20 years)

Since the ability to control the erection lies at the centre of male hegemonic sexual model, hypoglycaemia and the consequent inability to get an erection might be particularly frustrating for men. Instead of "eating ice cream" and continuing after the rise of glycaemic level as in the case of Pietro's account, in many cases this has been experienced as a frustrating event, a failure that undermined the self-esteem and compromised the mood of the moment:

> It happened. I'm going to be honest with you. Yes... Yes, yes, yes. That happened. Hypoglycaemia happened. And... we stopped immediately, just talking like this, ... and she made me comfortable, I had really felt uncomfortable. (He laughs) Because then as a matter of fact- I... my mood changed and... I closed myself in and I didn't want to talk, in that moment. She understood the situation... Also because I... had realised, I felt unwell, and I told her immediately... (Liam, 24 years old, T1D, shop assistant, onset at 18 years)

In other cases, the decision not to continue sexual activity after the hypoglycaemic episode was attributed to the partner, as in the case of Edoardo, who stated:

> Let's say that I have had a few difficulties, because maybe during intercourse I went into hypoglycaemia, so... I had, I had problems... yes, maybe that's true... I had problems during the hypoglycaemic episode, yes.
> **Do you want to tell me what happened?**
> Well, in the sense that... I had this hypoglycaemic crisis, and... basically I had to stop... because I didn't have the strength to go on. And my wife was a little surprised, but... in quotes, this is part of the game. (...) We stopped. I had to take some sugar... and then it all ended there because then... my wife didn't really take it well, she was kind of scared it would happen again, so... we stopped... we gave up on going on with the thing. (Edoardo, 53 years old, T1D, labourer, onset at 3)

Despite the fact that almost all participants, when talking about sexual activity, referred to the coital imperative (McPhillips 2001) of sexuality, one participant recounted experiencing hypoglycaemia during masturbation:

> **Some interviewees told me that diabetes can also lead to sexual difficulties. Has it happened to you?**
> ... Well. During sexual intercourse, no. During masturbation, yes, because, for example, if you're in hypoglycaemia, ... you can't achieve orgasm. (Elio, 29 years, T1D, shop assistant, onset at 24 years)

As mentioned before, also hyperglycaemia can influence sexuality experience. An illustrative example is that of Alessio, a 42-year-old man who was diagnosed with diabetes at the age of 13. When talking about sexuality, he referred to a "respectable" script of sexuality: he described himself as married, monogamous and "faithful" to his wife. He reported that hyperglycaemia, more than hypoglycaemia, interfered with his sexual desire, and when blood sugar levels were high he would not even notice the presence of a "beautiful girl," something that seemed to be otherwise expected. This did not go unnoticed from his male colleagues, who soon began to joke about this "inattention." As Ferrero Camoletto observed: "Social and linguistic practices through which such use of humour is expressed might be diversified, but they usually are forms of interaction highly ritualized, that follow a well-known script which is shared in homosocial male contexts: verbal challenges with ritual insults (for example, reciprocal insulting of one's own mothers); mockery and derisions (for example, about sexual attributes or erotic skills); wordplays, ambiguous talking, double meaning talking; (…). In all those practices, sexual issues emerge as the main reference" (Ferrero Camoletto 2013: p. 5, my translation). Humour and irony, in turn, are mechanisms that play a key role in masculinity construction and in the definition of boundaries and hierarchies. From a quick look at the majority of interview excerpts mentioned above it is immediately evident the frequently recurrence of the "he laughs" transcription. Ferrero Camoletto (Ibidem) interestingly observed that laughing *with* someone when talking about sex, and in this case with the interviewer, could be interpreted as a search for complicity with the interviewer, a way of finding reassurance and confirm of the adequacy of the (heterosexual) masculinity that was performed during interaction. In many cases, just as in

Ferrero Camoletto's research, participants laughed and somehow expected the interviewer to do the same, as a demonstration of a shared conception of heterosexual masculinity (Ibidem).

In the case of Alessio, the failing to fulfil the hegemonic "manhood act" of expressing physical appreciation to "beautiful women" while he was walking with his colleagues resulted in ritual mocking by them, who made humour through the reference to his supposed hyperglycaemia – and thus his illness - that in a way could justify his failure in fulfilling typical homosocial mechanisms of collective heterosexual masculinity construction. In his words:

> **According to research, diabetes often leads to having sexual difficulties. Has it ever happened to you?**
> Well, it absolutely happens, yes, based on your glycaemia condition. I mean, hypoglycaemia, the... actually, more because of hyperglycaemia and... what really changes in [sexual] desire, I mean... Depending on how your glycaemia is, your desire... changes, so I... OK, I laugh and joke about it, I am serious nonetheless, I've never been unfaithful to my partner, but something that I say also with her...me, when I see a good-looking girl, I say: "Oh, look, I've fallen in love!" because the eye sees... it's a game that... I've always done, no? (...) And I realise that also in that case, glycaemia... my colleagues, we are all men, you go to the shopping mall, you see the girls, there, he goes: "You're not seeing them now, your glycaemia is probably high, you haven't noticed them," and: "No, no, I was thinking" ... As a matter of fact (...) the state of your glycaemia absolutely has an effect on desire. I realise, even only on... on the stupid joke: "Today I've fallen in love," because I see people I find beautiful or I don't notice them and... it's often related to my glycaemia, which might be rapidly increasing (Alessio, 42 years old, T1D, employee, onset at 13 years)

6.3.2.2 "It's like a faulty machine": sexual difficulties as a diabetes complication

As mentioned above, overall participants were aware of the possibility of experiencing "ED" as a diabetes-related complication. Even those participants who reported not experiencing sexual difficulties somehow distanced themselves from that possibility, as did Flavio, in a self-ironical comment:

> Because unfortunately it's something that... 60, 70 per cent of men... has these kind of problems. Those are high data... Then they say diabetes actually... I mean, I have seen that... it can cause problems... over time, but I dunno, I fortunately don't have these problems. For now... "All good for now," as the guy who was felling off a skyscraper said. (He laughs) (Flavio, 41 years old, T1D, psychotherapist, onset at 36 years)

An illustrative example of "organic explanations" was provided by the narrative of Silvio, a 51-year-old man who was diagnosed with diabetes at the age of 35. When I asked him if he ever experienced sexual difficulties, he immediately answered positively, and he associated his sexual problems to neuropathy, a complication of diabetes that may cause damage to the erectile tissues that would complicate or make impossible to attain and maintain an erection. In Silvio's words, his inability to achieve erections was the symbol a degenerative disease which was altering his body: he did not talk about sexual difficulties in relational terms (nor did his wife, that was present during the interview), he talked about his "dysfunctional" penis by using the mechanical language incorporated by medical knowledge, just as if this part of his body could work independently from the rest of the body/self and from the relational context. Since when he could not get erections, he reported trying all medical solutions that the doctor suggested him. Considering the high effort he put into trying to restore erections and the degree of discouragement with which he talked about this issue, it was clear that sexuality for him was a key arena for his sense of self. As he put it:

> **According to research... often diabetes can lead to experience sexual problems. Have you...?**
> Yes... yes, there are also those. Eh, there are indeed. (He laughs) They're there, they're there. It's pointless to tell you they're not.
> **Since... when?**
> Eh... since some time. Five or six years ago. As a matter of fact, I always say: "We're lucky we managed to have a son." It was a little borderline, more or less, as a matter of fact we did then have difficulties having children. And it was borderline because then immediately after he was born, then everything broke out... despite having had the tests done, in that area, there were no problems... But yes, yes, [diabetes] leads to problems. But- ... it brings problems all around, there is no... nothing for which it doesn't bring problems... (...) These are things that happen to you because you're unlucky.
> **OK, ... and did your ... your GP propose some…**
> Yes, but although, I think everyone is a little in the dark... Because yes, they know... it's due to diabetes, in particular they know it is due to neuropathy. Because not having anymore... control... yes, of the peripheral system... also that part is affected. (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

A similar story, but with a different epilogue, was that of Leonardo. Just as Silvio, he defined his erectile difficulties with a medical and mechanistic vocabulary, and at the time of the interview he reported using EEMs in order to improve his ability to get and maintain erections. Another commonality with Silvio was that he also considered ED as a symbol of the progression of the disease on his body, and for this reason he reported, in the past, "ignoring" erectile difficulties, because this allowed him, in a way, to ignore – as much as this was possible – the presence of diabetes into his life and body. As he recounted:

> In fact [difficulties in the sexual area] was... one of the struggles in which, let's say, I felt myself getting older was... was this.
> **So what are the, I mean, what did you perceive as different over the years?**
> Mmm… just as the textbook ones, I don't know how to say, the... (long pause) Yes, after turning 30, it would happen that I wouldn't get an erection unsuspectedly, let's say... (...) It happened more like: "Let's try again next time," let's say, and then maybe I would make up for a bit of it, but still not, now I don't know if there is a measuring system, but (he laughs) with let's say... less...intensity. (...) Considering that it's something that one usually cares about, but I had remained in that limbo of... "Diabetes is not there", no? So, I dunno, I also kept... [its consequences] (Leonardo, 52 years old, T1D, architect, onset at 4 years)

Since when he began to adhere to treatment for self-managing his diabetes, Leonardo reported also taking care – in a medicalized way – of his sexual difficulties, and he reported "restoring" his erections with the help of specific medication, even though he seemed to be partially critical towards their actual functioning (see paragraph 6.4).

The association of erectile difficulties with diabetes was an explanation that derived from medical knowledge: participants incorporated the definition given by doctors and used it in order to talk about their sexual experience. A particularly illustrative account was that of Raimondo, a 57 years-old man who was diagnosed with diabetes LADA at the age of 37. When he begun to experience sexual difficulties he first reported interpreting them as the result of aging. But after talking with his diabetologist he seemed to accept a medical explanation of his sexual changes. With regard to the response to such problems, he reported following doctor's advice: although the diabetologist suggested him to take medications, the cardiologist advised against them because of their possible side effects, and he did not take them. Raimondo used a revealing and classical metaphor, in order to describe his diabetic body and his "dysfunctional" penis: he compared it to an old car with a broken windshield. In this mechanistic vision, the medications potentially could (although not in his case) "fix" the "faulty machine/body." Also Gough (2007) in his work on men and food consumption found that men used to talk of their bodies by comparing them to a machine. In Raimondo's words:

> **According to research, diabetes can often lead to experience sexual difficulties. Has it ever happened to you?**
> ... Yes, yes, unfortunately I have to say so. (...) I talked about it with my diabetologist. He told me: "Eh, unfortunately... it's one of the complications of diabetes. You've already had... complications on a cardiovascular level, so on a circulatory level... this is not looking too good. In the sense that the illness, ... despite being controlled, it always- it always progresses." So, yes. (...)
> **When did you notice? Since... a long time? Or is it a recent thing?**
> ...No, mmm I noticed about, I don't know, six years ago. So. But, ... I would connect it all to a life cycle. You're born, you grow up, you grow old, and you die. So... I mean, then in the end, ... I mean, I realised, I say: "Well, a car that arrives at 100,000 kilometres, at least... a windscreen wiper that doesn't work, a blinker that doesn't work, will be there," I mean. I can't arrive... halfway through my old age, ... and everything is working, I mean. I mean, I have made the comparison to... with the car. (...) They proposed drugs, those in... in use, on the market, but I never used any. Because... the cardiologist advised against them. (Raimondo, 57 years, diabetes LADA, retired military, onset at 37 years)

Finally, some men reported a combination of explanations: for example, Simone, a 53-year-old man who was diagnosed with diabetes at the age of 9, reported experiencing a loss of desire and erectile difficulties, and recounted taking EEMs in order to deal with them. As an explanation, he reported a combination of "aging" and "complication" understandings, with a prevalence of illness as an explanation and medicine as a main interpretative framework:

> **According to research, often diabetes can also lead to experiencing sexual difficulties. Has this ever happened to you?**
> Yes, these have, absolutely, yes. That's true... It happens at times. I have to be honest, it happens at times. I am 53 years old, so I am also at a certain age, that's also... that's also... it all depends on me though, ... there is a decrease... there is a decrease in desire, at a certain point, ... that is not related to... to bad relationships, or this or that, it's brought about by that thing. I would say... that [sexual problems] are much more tied to diabetes than to age, yes. There is a bit of- there is a correla- correlation between the two, but still, the main thing is diabetes, yes. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

6.3.3 “My approach to sexual life is changing”: the aging explanations

A minority of participants interpreted their sexual difficulties as a result of aging. The “aging” explanation, which seems to be mainly derived from a personal interpretation, may serve as a discursive strategy that, on the one hand, absolves men of the responsibility to their “sexual failures” or loss of sexual desire. On the other hand, the “aging” explanation may also serve as strategy to distance oneself from the realm of illness and its possible effects on the body. “Aging” is an “internal,” physiological mechanism that influences their experience of sexuality, but it is at the same time an uncontrollable factor that affects diabetic as well as non-diabetic male bodies. Ferrero Camoletto (2019, forthcoming), in her analysis on the social representations of men’s sexual health problems in expert medical discourses observed that contemporary discourses on aging and sexuality are simultaneously influenced by two cultural phenomena: the cultural imperative of “positive aging” and the advent of sexuopharmaceuticals such as Viagra and its competitors. This intertwining of occurrences lead to a shift from the “sexually retired” narrative – where age was associated to a physiological decline – and the “progressive” narrative – where decreased erectile function was interpreted as an opportunity to understand sexuality as less connected with penetration – to the new “sexy oldie” narrative, which responds to the imperative of a forever functional sexual activity.

In this research, diminished erectile function was understood as a part of a life cycle mainly in two ways. In the first case, there was a direct reference to a life course sexual script (Simon & Gagnon 2003)[35] that entailed a shift from the sexuality typical of a young age, centred on performance and on “quantity,” to another one typical od adult age and mature masculinity, where men where expected to focus more on respectable or intimate sexuality (see Ferrero Camoletto 2019, forthcoming; Bertone & Ferrero Camoletto, 2009).

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[35] Simon and Gagnon (1973; 2003) elaborated a scripting perspective on sexual conduct which conceived sexuality as the result of a learning process, just as it is for all other human behaviours. Scripts, they observed, “are involved in learning the meaning of internal states, organizing the sequences of specifically sexual acts, decoding novel situations, setting the limits on sexual responses, and linking meanings from nonsexual aspects of life to specifically sexual experience” (Simon & Gagnon 1973, p. 13).

An example of the first case in Amedeo, a 50-year-old man who was diagnosed with diabetes at the age of 30. He talked about how his erectile difficulties were for him the sign of a more general change in his approach to sexuality. His description of his "youth" sexuality entailed a clear separation of his sexual functioning from the sphere of relations and even that of sexual desire: he could "function" in every situation, regardless of his actual involvement. This vision clearly drew on the conception of men's sexual desire as something innate and biological, which could be separated from the overall context. But this approach to sexuality changed over time. In fact he reported that, while in the past he used to be able to attain and maintain an erection even if he did not feel sexual desire towards the person he was having sex with, he observed that this did not happen anymore, because, as he said, "it doesn't work." He reported that occasional sex was a common practice in the "gay world" he frequented, and that in such circumstances the fact of "not being… particularly involved from the person, nor from the situation" did not constitute a limit when he was younger, but it did at the moment of the interview. He did not associate his erectile difficulties to diabetes: he rather understood them as a changed sexuality due to a more "mature" approach. In sum, he described his "past" sexuality with a higher separation of his body (and his ability to perform sex) from his sexual desire and emotional involvement, while the current self was described as more "integrated" and, perhaps, more "respectable" according to social expectations about sexuality in adult age:

> I turned 50 two months ago and I am thinking about the fact that my approach to sexual life is changing, compared to when I was 20 or thirty, without a doubt.
> **In what way?**
> It's changing because... I realise, oh well, you are well aware that... the homosexual world... The dynamics... are a little different, not a lot, but a little bit, in the sense that there definitely is more promiscuity, -there was, now I see that even in the heterosexual world, the... chats and apps also exist there so, [between] Tinder and Grindr, there is not such a big difference- but let's say that historically, and actually because of an anthropological reason, men, (...) the dynamics are different, [for us it is] much easier to meet up, have quick sex. And with regard to this, I am aware that, 10 years ago, twenty years ago, it was all simpler, no? Now... it's a little more complicated, because... I don't think it's a physical matter, in the sense that difficulties, to be more technical, of erection, are not given by a physical

> problem, because it can happen that the following day I have no problem at all, it's much more of a matter of the mind. I mean, if I am with a person that I don't like, it doesn't work. So it's nothing but a complication or a difficulty, because you say: "Well, who cares," in the sense that... "Why do you have to do it anyway even if you don't like it?" Eh, yes... it was easier before. Now... it's a further, let's say, difficulty, so you say: "OK." (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

This changed approach to sexuality was described to be mainly the result of several years of psychotherapy:

> [These] years of analysis helped me, irrational, you say: "OK", there is a part of me that still gets caught into panic and what it does happen form and... and another part which instead puts things back in their place, rationally, as an adult, parent who says: "OK, that's fine, you don't like this person, why do you still have to have sex with him?" Or still, eh, I'll turn the page, absolutely, absolutely, now I've met a person in London, whom I am seeing, and on the other hand, there is also surely an interest, on my part, no? It's a person I like, whom I gladly see, but not to sleep with him. So, years ago, maybe I would have gone for the ride, and it might have even been fine, and in fact in that situation there wasn't even performance anxiety, because you say: "I don't care at all," so... Now, I really can't do it... I mean, I can't even put my hands on him. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

Also Edoardo interpreted his sexual changes – he talked about loss of desire and erectile difficulties – as a sign of the time passing and body changing. But Edoardo is an example of the second way of explaining the impact "aging" on sexuality, namely in a more inevitable and biological way, as part of the life cycle, as a "sexual retirement" (Ferrero Camoletto 2019, forthcoming). His diabetologist warned him about the possibility of experiencing erectile dysfunction as a complication of diabetes, but he did not understand his situation in such terms, this way distancing from medicalized understanding of sexual difficulties. In his words:

> Let's say that the older you grow, the less desire there is, in the sense that... (...) of course, compared to twenty years ago, it's a different thing. In the sense that twenty years ago, there was enthusiasm, more desire, and also more wanting a family and there was also more time... Then obviously the years go by, and as a consequence... even though desire is still there at times, it's not completely dead, luckily. (...) Maybe the desire is still there sometimes, and then it is gone in that very moment, but I don't know how to define it, a... a dysfunction. (...) I am aware, of course [of ED as a possible complication of diabetes]. We are both aware of it, but let's say that by now

> we're – I say "we're," but I speak for myself – at an age when... it's not that I have to act like a young man, and I don't want to be a young man. I'm fifty-three years old and I want to be a fifty-three-year-old. Also because I wouldn't cope with a twenty-years-younger girl. (...) As a matter of fact, if I had to go out with someone who is ten years younger than me, I couldn't do it. (Edoardo, 53 years old, T1D, labourer, onset at 3 years)

On the same line, Damiano mentioned also the long-term coupledom as a possible implication, when he stated:

> **According to research, diabetes can often lead to experience sexual difficulties. Has it ever happened to you?**
> ... Difficulties?
> **Sexual.**
> ... Well, let's say that the... the... yes, desire has decreased a little, over the years. It's not that it's a sexual difficulty. (...) I think that there could also be other factors. In the sense that... it's also the age, probably it's slightly different, I mean, clearly, also the couple relationship, of course... (Damiano, 58 years old, T1D, manager, onset at 33 years)

6.4 Dealing with diabetes-related sexual difficulties

Empirical material showed that there are many ways of dealing with sexual difficulties. In this paragraph I will focus on, first of all, the discourses around *talking* about sexual difficulties with others. Sexuality is central for masculinity construction not only in its practical experience, but also in its "narrative" form: talking about sexuality means talking about oneself and presenting and constructing a certain kind of masculinity. I then analysed participants' narratives in order to explore how they talked about dealing with sexual difficulties, and this entailed a multiplicity of strategies, from an uncritical incorporation of medical knowledge to the search for alternatives, considering that those were not mutually exclusive categories.

6.4.1 (The difficulty of) talking about sex and diabetes

Overall, participants reported not talking much about their sexual difficulties with other people. For example, Leonardo, who was diagnosed with ED and used to take medications, despite the fact that he was using EEMs since many years, and despite the fact that he reported also seeing a psychologist for many years, he stated: "This is the first time that I talk about this with someone, you know?". One of the main fears that participant expressed about the possibility of talking about sex problems with others was that of being taunted, or that of having to deal with other men's competition, that would discourage disclosure and encourage a "bluffing" strategy in order to construct a successful imagine of the masculine self. Francesco recounted, as an example, his experience with diabetic (males) friends: if, on the one hand, he found it easy to talk with them about managing glycaemia during sport activity, on the other hand he reported that they did not share information about their sexual difficulties with each other. A place where instead he thought it was possible to look for information without being afraid of being judged was Internet. As he put it:

> **So I wanted to ask you: is it something you talk about, maybe with other diabetic men with whom you're in touch? Or...**
> No, no. But in fact the idea... which is more or less wrong, but I think that there is some truth to it, that men are not really willing to talk about it, especially to other men... And especially... when you don't see a solution... you look for one, ... on an anonymous tab, on the internet, eh (he laughs). Then I don't know, with regard to suggestions about how to manage glycaemia with physical activity, about this maybe we can talk with each other. On this matter, ... it seems more difficult to have a discussion... because... first of all you have to be clear in what you're saying. I mean... to make someone believe something, ... it doesn't take much time, and then... I mean, telling half of the truth, it doesn't take much time, and at this point, who believes your half-truth, when they arrive exactly where you are, ... they say: "Oh, but he- for him it's like that, for me it isn't," Eh, in fact it's "for him it isn't, for me it isn't neither," (he laughs) so... it risks being a further source of frustration... (Francesco, 51 years old, T1D, employee, onset at 3 years)

Despite the fact that, as it has been highlighted in the previous chapter, the majority of interviewees was embedded in a variety of different diabetic "communities of practices" where they received support and shared information, none of the interviewees reported talking about sexual difficulties with other diabetic male friends. In the majority of the interviews it was reported, instead, the practice of talking about this issues with other male friends, usually non-diabetic men of their same age.

Another context where men talked about their sexuality was that of the diabetologist's office, and they reported a range of different experiences. Vito, for example, recounted that during each routine medical examination the diabetologist made him answer to a set of standard questions concerning his sexual health and probably, according to his description, it was the short version of the International Index of Erectile Dysfunction. Despite the fact that over the last years he was experiencing some erectile difficulties, he had the sensation that he was not authorized to talk about this with him, nor to ask questions concerning sexuality issues, this mainly because his “final score” achieved at the end of the questionnaire was “under 18,” as he said. Since he did not exceed the numerical boundary that officially separated the “normal” from the “pathological” sexuality and it was “objectively” categorized as “normal,” he felt that the doctor would say that there was nothing to worry about, nor to talk about. For this reason, he preferred to talk about sexual issues with his (non-diabetic, male) peers, and this could be seen as an alternative solution to the medical framework:

> Also because, ... when... you do... the day-hospital, once... once a year you have all your screenings done, and there are also those questions... Yes, in the end (...) I... talked to some of my friends, instead of them [the doctors]. Because you have to know that... well, (...) their argument is basically that if you have... dysfunction problems, they have you treated by someone. But otherwise, if you ask them a question that is a little more specific, a little more technical... [In the questionnaire] there are questions, that actually make you say... OK ... For example, it says, OK, if you never have sex, if you never have ere[ctions].. To be treated by someone, you have to- basically you never have to have an orgasm, ... it often happens that you have dysfunctions... But otherwise, I don’t know how much they can help you. But if you talk and compare yourself to people of your own age, (...) ... but it’s things more than anything to... I mean, to understand if happens- I mean, if it’s normal, or if... it only happens to you. Do you know what I’m saying?
> (...) So, to my diabetologist, I can’t- I mean, in the sense that... It’s those questions, they are very specific. (...) Because of that, if you compare yourself to who you have... who you have around you, if you see that it’s... that things changed for them too… (Vito, 30 years, T1D, employee, onset at 23 years)

Overall, participants reported difficulty in talking about sexual health within the medical context. As regards the GPs, they were usually considered doctors to which ask only for medical prescriptions, but nothing more than that. For everything else, participants usually reported referring to medical specialists. For example, Francesco, who reported experiencing “erectile difficulties” and who at the moment of the interview was using EEMs, said:

> But then... in the end... let’s say that aside the prescription of medicine, the indication [given by the GP] was to see a specialist, (...) let’s say that he didn’t give me any solutions ... (Francesco, 51 years old, T1D, employee, onset at 3 years)

Diabetologists, on the other hand, were usually considered to have little time to dedicate to patients, and even if “sexual health” was one of the areas under examination, Vito’s excerpt well illustrates how medical approach did not leave much space for exploring the complexity of male sexual experience, because it was framed into a standardized and supposedly “objective” impersonal assessment.

Another reason why they did not talk about sexual difficulties with doctors was because it was considered a sensitive topic and the impersonal approach of health care professionals would make them feel uncomfortable. For example, Lucio, who reported experiencing erectile difficulties over the past few years, recounted that he did not talk about this with his GP or diabetologist:

> **And... and is it something you’d talked to your diabetologist about?**
> No. I have to say that my diabetologist, since she is quite... she is three years younger than me, so this was because of a prejudice of mine... (...) Then, she is probably very... she is very... she is very formal in her approach to things, she is very... on certain things also almost, I wouldn’t want to say scholastic, academic, but still rather... rigid... I don’t automatically feel like talking of certain things. (...) In other words, never... never faced the matter with her.
> **And with your GP?**
> ... Worse than ever.
> **(She laughs) How come?**
> A... seventy-year-old woman, almost seventy, not because she is a woman, I mean, I’ve had a time in which I had... I had cysts on my testicles. And the endocrinologist was a... was a woman, ... (...) I don’t know if anyone has ever told you how these tests are done, but one of the things they do, is... basically they squeeze a lot so that... the skin is pulled a lot, that the testicle pushes against the skin, and you can see, whether there is a cyst, so that you can... let’s say, see it through the layer of skin. (...) So... it’s not a problem of woman or non-woman, (...) the fact is that she is even more uptight, you can’t talk to her through email, you need to book an appointment on the phone, and every time I explain what she has to do, ... she writes extremely slowly on her computer, to print out the prescriptions, I really just want to say: “Look, ... forget all the other things I have to talk to you about, I’ll talk to someone else, in another occasion, because... otherwise we won’t be getting back home from here.” (Lucio, 38 years, diabetes LADA, entrepreneur, onset at 36 years)

On the other hand, few participants reported recurring to the diabetologist when anxiety about the possibility of experiencing erectile dysfunction as a diabetes complication rendered it unbearable. In the next excerpt, Massimiliano recounted an illustrative episode in this regard: a few days before the interview he directly phoned, for the first time in his life, to his diabetologist because of an emergency. His life was not at risk, but probably his masculine self was: in fact, he experienced erectile difficulties while having sex with a new partner, and he was afraid that diabetes' complications could be the cause. On the one hand, his diabetologist gave him a "medical" support:

> It happened that some time ago, ... I met, ... someone, ... in that moment I considered, ... as rather important. And, ... maybe at the beginning, ... I had a few [sexual] difficulties, no? (...) In that moment, ... when a few weeks had gone by, yes, ... and I started to ... to really feel this thing, no? In the sense that... I knew that, it was something, ... mental. And... maybe that was the first and only time that... I phoned my diabetologist... directly, who is also diabetic... And... and he gave me... obviously, the point of view both of a doctor, and of a [diabetic] person (he laughs). As a doctor he told me: "Oh well, Massimiliano, come on, tomorrow you come over, ... and I'll do the... the thing," no? ... and because it was something, ... that I needed to solve... soon, and this creates (he laughs) / even more anxiety, / (laughing) (...) "Come here, I'll give you a quick referral form, ... we'll have some tests done, if there's anything, we'll see it." A typical test you do, no? (...) ... It's... measurements that more or less are done... on... on electrical conductivity, ... from the lower belly, ... more or less, to the rest of the body, and in particular to the brain. (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

On the other hand, the diabetologist, who in turn was a diabetic man, gave him the opportunity to "talk about sex" within a homosocial context among men sharing the same condition and this had, in a way, a "curative" effect for both his sexual problems and his wounded masculinity. After that he managed to "successfully" have intercourse with his new partner, his restored sense of masculine self and his sexual prowess had been then celebrated, in a way, with his diabetologist, who switched his relational position with him from health professional to that of diabetic man, member of the same "community":

> The previous example, that I phone him at... at ten pm, I mean, it's not that I always do it, I never do it, I've never done it, but... (...) also the fact of... of... having the chance to call him, ... to me, in that moment, it was important, ... it didn't... in that moment, solve anything, (he laughs) no? But it allowed me, it allowed me to... to... let off some steam, talk about something that... I couldn't keep in, because... I was scared that... this would actually... take

> over more. (...) I don't know if it was a Thursday, something like that, I would have had to go to work on Friday, or (he laughs) no? Friday then something happened at work, I didn't go, I told him: "Look, ... Marco, I'll come on Monday." "OK, that's fine... Don't worry. Maybe at the end of... of my appointments, you can come, we'll do..." ... And ... and that- that weekend, ... the thing, went really well, in the sense that I overcame by myself (he laughs) the problem that (he laughs) I mean, so OK. So nothing, I went there, I brought some beer, (he laughs) and we drank together. (He laughs) (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

Another context where participants reported talking of their sexual difficulties was that of the relationship with their partner. In this case, three different situations emerged from the analysis: the one occurring within a long-term, stable heterosexual/homosexual relationship; the one occurring with a new partner; and, thirdly, the one occurring within an occasional sexual encounter. All participants engaged in a long-term heterosexual relationship reported "talking" about sexual problems with their wives/partner, albeit it has not been possible to explore further this dimension during the interviews because they gave short or generic answers and tended to change the subject of conversation, perhaps for the general imperative of taking sexual health as a personal responsibility. As for situations involving new partners, in this case clearly performance expectations were usually perceived to be higher and the degree of confidence lower. One case is that of Massimiliano: as it can be read in the above-mentioned interview excerpt, he did not talk with his new partner about sexual difficulties, he rather preferred to talk with his diabetologist and keep diabetes contained in the private/medical sphere.

Another case was that of Vito, who recounted an episode in which he experienced hypoglycaemia during the night after having sex with a woman he met few days before, and in this case he talked to her in order to explain his urgent need to eat sugar after sex for compensating low blood glucose. Finally, Amedeo reported experiencing erectile difficulties for several years, and he recounted his experience within a same sex relationship. In this respect, he compared his situation with that of heterosexual men, and he had the perception that gender roles were crucial in sexual context: in fact, he posited that gay men had, in his opinion, higher performance standards and expectation around sexual activity if compared to that of heterosexual women towards their male partners', and in his opinion gay men were also less “understanding” then women when sexual problems occurred during sex. In his own words:

> **When, as a matter of fact, it happened that you had difficulties... with erections, then did you talk about it or not?**
> Well no, in the sense that it it’s a relationship that’s not all that important, you don’t. In the sense that, in a relationship that is more... I mean, a relationship that maybe lasts a month or two, yes, you talk about it, / I mean, only last year, yes / (talking low) the other person is always wound up, but also like I do, after all: “It’s my fault, he doesn’t like me enough, he doesn’t like me anymore, he’s already tired of me,” and this is obviously the first thing you think when it happens to the other person. Or that the other person thinks when it happens... it happens to me. But the difficulty in talking, this certainly exists. I think that in a heterosexual relationship, sometimes I think about it, I mean, a woman is definitely more understanding or more... They find a different balance in this situation. With two men, absolutely. I mean, like it is much easier, in these cases it is much more difficult because (he snaps his fingers) you need to be ready, and highly performant, always and regardless of the situation. With a woman, I think that she would forgive you a little more, because there is another series of... For us, no, we forgive much less. And it’s the same for me, I am probably just this way. In the sense that, in a certain situation of promiscuity... eh, either it works or it doesn’t. It’s not that you act all understanding: “Bye bye!” (...) But I think that it’s more of a problem, that these things are more of a personal problem, in the sense that one has to... manage to, with himself, to talk about this things, to admit... so you then manage to talk about it with others... and I don’t think this progress is happening, compared to the past. (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

6.4.2 Responding to sexual difficulties: from the naturalization and incorporation of medical knowledge to alternative strategies

After the advent of Viagra in 1998 and his successors, the visibility of problems connected to male sexual health has significantly increased, mainly through the advertising of such pills and, in Italy, through social campaigns, journal articles, and web sites that addressed these issues (Ferrero Camoletto & Bertone 2012). International literature defined this as the “Viagra phenomenon,” namely “a peculiar case of a construction of masculinity through medicalized practices” (Ibidem: p. 437), where sexual problems are “fixed” through medical solutions: this happens not only in the case of middle-aged, chronically ill men, where sexual function are often a health complication of disease, but also for all other men that are more generally unsatisfied with their sexual performances. For this reason, we can talk about this phenomenon as the expansion of medicalization of life (Conrad 2007) into the context of male sexual health. As it has been explained in the introductory paragraph, medical solutions to sexual male problems has an impact on the way they construct their masculinities and on the way they understand their sexuality. The advent of Viagra, in fact, promised to fix sexual problems regardless of their causes: whether they were psychological or organic, the pills guaranteed to allow the men to regain complete control of their bodies and penises and restore the symbol of their power. In this paragraph I will take into account participants' experiences and attitudes towards the use of EEMs and the experiences of who, instead, found "alternative" solutions to their sexual problems.

6.4.2.1 "You will take Viagra": Erectile Enhancement Medications and their ambivalence

Overall, 5 participants reported using drugs for restoring their erectile performances, and in all cases this was the result of medical advice. Among them, 4 were experiencing health complications (neuropathy and retinopathy) associated with the progression of disease.

Many participants referred to the possibility of taking drugs for restoring their sexual functioning as a sort of expected step of their diabetic career, or, more in general, an expected step in their life course as men. As Pizzolati (2016) observed, we have in fact witnessed to the construction of a new concept, "male menopause" (or manopause), that describes the condition of men experiencing body changes (such as loss of energy, of virility, of potency, of fertility, etc.) and to the medicalization of such condition(s). In this perspective, the representation of successful aging entails that to physiological problems related to aging, medical knowledge proposes a pharmacological solution, under the imperative of "sex for life" (Katz & Marshall 2003). This can be found in the illustrative words of Massimiliano:

> [The diabetologist] said: "Maybe when you will be sixty… When you will be sixty you will take Viagra e get over it anyway. Just as the other do." (He laughs) (Massimiliano, 40 years old, T1D, researcher, onset at 4 years)

In some cases, participants considered themselves as more "justified" to take drugs if compared to non-diabetic men, because they had diabetes. In fact, according to the literature, diabetic men seem to be more likely to have filled a prescription of PDE-5 inhibitors from their doctors (Eardley *et al.* 2007). We can find an illustrative example in the words of Renato, who said:

> About that, I could be even more justified, from a certain point of view. (…) [If I'd experience erectile difficulties] I would choose the most effective [solution] probably. (Renato, 56 years old, T1D, entrepreneur, onset at 30 years)

Overall, participants seemed to incorporate medical definition of the "problem" in terms of "pathology" and many of them who did not report suffering from erectile difficulties affirmed that, in such circumstances, they would probably use EEMs, just as they use medicaments for every other illness. For example, Alessandro stated:

> **In case you experienced that [erectile difficulties], you think that…**
> (...) I believe that, after all, the drug, ... or any drug, serves to solve a problem, no? So, if I'm sick, I tend to... I use it... If I have a fever, I take Tachipirina [paracetamol]. (He laughs) (Alessandro, 46 years old, T1D, employee, onset at 3 years)

Tiefer (1986: p. 594) talked about penile prostheses, but the same discourse can be applied to EEMs, as she stated: "[P]ermanent mechanical solutions to sexual performance worries are seen as a gift from heaven in erasing, with one simple operation, a source of anxiety dating from adolescence about failing as a man." Three out of five participants that were using drugs for improving sexual functioning reported being overall satisfied of the outcomes, because "it works" as Leonardo said, and made him feel more confident not only in the context of sexuality, but also with respect of the overall impact of diabetes on his body and on his life. In a way, Leonardo – who reported using Cialis - described this result as a way of being able to take more control on diabetes and to fight complications. In his words:

> **Have you ever though about taking specific drugs for this [for erectile difficulties]?**
> Yes. Well, at some point I talked about it with my GP and he told me: “Try this pill!”
> **Ok. And how was your experience with pills?**
> Well, it works. And about this, this was part of my [thought] “everything is declining,” but actually I had some improvements. (Leonardo, 52 years old, T1D, architect, onset at 4 years)

As mentioned before, Amedeo experienced erectile problems, but he signified them as the result of a changed and more “mature” approach to sexuality. He observed that, in his opinion, problems in attaining erections would have a greater psychological impact on heterosexual men, who for this reason could be more likely to use drugs at an early stage of the problem in order to restore their wounded masculinity. Although he was not critical against drugs, he reported not taking them. In his words:

> I understand that, for a man, it [erectile difficulties] is actually really… The apotheosis of... For a man in a general… I mean, for the alpha heterosexual male it is the most difficult hurdle he can face. For a homosexual person like me, who still had to find a balance between a whole set of other variables, this thing here [erection problems], you know… (Amedeo, 50 years old, T1D, realtor, onset at 30 years)

On the other hand, some participants also talked about the “downsides” of drugs. Leonardo and Francesco, for example, observed that the obligation to confine sexuality into a specific time of execution and planning rendered it less pleasurable and instinctive, and more “calculated,” and this lead them to avoid (temporarily) the use of drugs. In Leonardo’s words:

> It happens to me... here it happens... to have sexual activity in a very very extemporaneous way. So… This thing, clearly the drugs are not designed for this. Some more, some less, but they have a... That’s something that: “Tonight I’ll do it, so…” (...) This is something that doesn’t belong to me. And so mmm it happens... [that] so many of those poor pills have (he laughs) have not been really used, I don’t know how to say it, many other times I simply did it without them. (Leonardo, 52 years old, T1D, architect, onset at 4 years)

In Francesco's case, as I already mentioned before, he reported that the need to respect the half-life of drugs caused him anxiety and made it more difficult to "experiment" sexuality without feeling pressure. In his words:

> Yes, yes... well, I think that diabetes has to do with it... to the same degree, I'm not saying 50%, but it has to do with it the same degree, compared to the psychological aspect, and the psychological aspect has to do with it. On two... two levels. One level, ... is the fact that... you are not fully... confident in yourself. Another level, ... which maybe is more or less the same, is that you didn't have- didn't have the chance to- to experience it calmly. Because somehow, the fact of having to... use a drug, so having to stick by certain times (…) (Francesco, 51 years old, T1D, employee, onset at 3 years)

Francesco reported a similar problem also in the case of penile injections:

> But in the end, the injections are similar to the drugs, and in fact they are quite traumatic. (He laughs) Let's say. I tried them in the initial phase, ... and I do not like to… (he laughs) also because, let's say, that then it is not a situation in which one would... operate on (he laughs) command. And so I... I don't know. Or you do the injection every night, regardless [of what could happen] and then, who knows? (He laughs) but not... (he laughs) or [you can] give an appointment for… it's not... I mean… (Francesco, 51 years old, T1D, employee, onset at 3 years)

Another negative impact of EEMs was, according to participants, that of his possible side-effects. In fact, despite the fact that they are often advertised as free from possible consequences, they actually might have side effects, such as headache, nausea, facial flushing, hot flushes, dizziness, blurred vision and a blue tinge that might colour men's vision. Silvio, for example, reported that they made him "feel sick." Despite that, he reported trying all the possibilities in order to find the one that would not give him problems:

> **Did the doctor suggest you to use drugs for this?**
> Yes, he made me use them. They make me sick.
> **Can I ask which ones did you try?**
> The traditionals, all of them. Look, I tried them all. If you look… all of them, all of them. From the [penile] injections, to the pills, but they make me sick, because they lower the blood pressure... (Silvio, 51 years old, diabetes LADA, employee, onset at 35 years)

Another participant, Simone, who used Viagra "when needed," reported in turn having experienced some adverse effect of the drugs:

> **Have you ever considered using drugs for this?**
> ... Yes Yes Yes. The blue pill, classic... Only that one eh, I did not try anything else... It worked, but... it gave me side-effects, which I did not like so much. (...) There was fun eh, for heaven's sake, I'm not arguing. But... eh, I suffered... it's my personal experience eh, maybe others don't. But I seemed to have tachycardia, and (...) everything was tinged with a weird blue, ... and then I was prone to headaches... a certain number of hours after the administration [of the pill]. (Simone, 53 years, T1D, touristic guide, onset at 9 years)

The fear of the possible side-effects was also the reason why other participants decided not to try drugs. For example, Raimondo reported following the advice of the cardiologist and did not take such pills (even if his GP suggested him to) in order to avoid other possible problems. He said: "[Drugs] fix one thing and break other 40 things]."

Another downside of drugs was that, despite the promise of immediate "results" in terms of performance, in some cases they seemed actually to require more time in order to improve sexual function. As in the abovementioned case of Silvio, some of them might have some side-effects and thus participants needed a period of experimentation and changes, in order to find the one who did not give them collateral problems. In the case of Francesco, for example, who used discontinuously drugs, the results in terms of quality of erection were not satisfying enough –at least for his partner- and took him a long time of attempts, changes, adjustments and readjustments and this constant treatment meant, for him, continually facing his "failure" to being able to achieve the promised and desired sexual performance. This could have a psychological impact and contribute, in turn, to "worsen" his underperformance and to provoke a possible dropout. In his words:

> In the end, let's say, beyond the prescription of drugs, the indication [of my GP] was to go see the specialist, and the specialist beyond experiments with various drugs, various... substitutes, let's say, he has not given me any solution...
> **What kind of drug did he give you?**
> (...) Cialis, Viagra, with various dosages, in different ways. Let's say it's fifteen years... that I try various solutions; let's say there's no solution. Let's say, at the beginning the solution was... a period of... a therapy of a certain type, which would have to solve the problem... However... always pharmacological [solution]... And instead the problem has not been solved.

> Let’s say, the problem is there, and it’s not even a matter of... management of blood sugar levels. Because obviously after [islet] transplantation, the blood sugar levels have been perfect for a while, then [they are] fine even now, ... and it’s not ... a solution that has solved the basic. (…)
> **And, how was your experience with drugs?**
> ... The experience with drugs had an impact more on me than on her [the partner]. Let’s say, because at that point, it should be that... drugs should be... as well as a routine, ... would be a path that one should undertake, accepting to suffer... a stress of dissatisfaction every time, especially on her part, ... and... that is a path that, all in all, (laughs) I don’t know how much it is worth to follow.
> **That is, you say that before you get a result, you need…**
> Getting a result, because... from my point of view, ... it is not just a physical matter, it’s also a mental matter. To overcome my mental problem, ... a physical result would be needed, which should be repeated and prolonged over time. And that in any case it would not be... gratifying for her. So it’s as if to get the result, it takes a year, ... you train for a marathon, you give a goal to a year, ... but... from here to a year, ... something in between you want to achieve, and instead here, ... there are not results in between... and what you get from a year’s distance, its not even sure it’s... the result. So, why should I face this path so... difficult, improbable, and frustrating, ... if then in the end there is no guarantee of... (Francesco, 51 years old, T1D, employee, onset at 3 years)

6.4.2.2 Considering alternatives: from physical activity to food supplements

In many cases, participants talked about a variety of strategies in order to deal with sexual problems. Although I did not find a complete correspondence, there was a partial correlation between being a sportsman (in the previous chapter I identified the “athlete” ideal type) and dealing with/prevent sexual problems through sport activities. An illustrative example of this approach was Ronaldo. Despite the fact that he also reported taking Tadalafil, the dominant discursive strategy that he used for describing how he dealt with erectile problems was that of using sport. Instead, pharmacological treatment was explained as “preventive” for blood clot on his scrotum, which was a non-required justification that could perhaps serve for distancing from erectile dysfunction as a (emasculating) pathology and for reinforcing his argument of engaging in sport as a form of lay expertise. As he recounted:

> **Did [the GP] propose a drug therapy for erection problems, or he did not?**
> ...Yes, he proposed it to me. And I use it, I take Tadalafil, but only one pill every two weeks. The smallest dose. It’s 5 milligrams, but the doctor told me: “You don’t need it. Take it only for one reason: as a form of

> prevention. (...) Do it only to thin the blood. A pill every two weeks that doesn't serve for sexual issues". He told me: "I cannot give you the specific one… Because, let's say that you feel like doing some cycling competition, those drugs are all labelled as doping. (...) So, (...) do it only for the reason that this prevents the formation of blood clots, especially in the scrotum, because in any case... [when you cycle] the scrotum is on the seat, even if you wear protection, however you have a compression, under the scrotum. [It is] a drug that lasts 36 hours, I take it every 15 days, in these 15 days if I have sexual intercourse with my wife, ... I last anyway. (...) because if you're athletically trained to physical effort for three hours and a half, ... still, you're not on a bicycle, you're on a mattress, you have to last three hours and a half. Because you're training your heart to resist to physical effort. (...)
> **Ok…. What about the difficulties with erections: did they continue or not?**
> ...All problems disappeared, thanks to sport. Medicine is useful, it helps. You cannot say that you do not take the pill. (...) But if you do not burn what you eat, it is obvious that practically everything remains as a residue in the body (…) the complications are then associated to that. Because eating too many carbohydrates... sooner or later you'll have damage related to diabetes. Instead, practicing a normal sport, not necessarily a competitive one, but doing it periodically, it helps, it helps a lot, and this is the best solution. That is: you don't have to eliminate the pill. But, surely, the choice of sport let you avoid much more strong drugs. (Ronaldo, 46 years old, high school teacher, onset at 39)

In the same line, Ivan reported having "cured" what he defined in medical terms as "erectile dysfunction" only through sport and food supplement. The dimension of lay expertise, in this case, was even more clear and enriched in details of his alternative knowledge. In his words:

> I'm telling you... that... (...) once I've started physical activity, things went, ... not great, but... even better. I'm telling you, even better.
> **So you found you got better also in this area?**
> But absolutely, absolutely, because... Valeria, [name of the interviewer], what I always say: [the penis] is a muscle, ... if your vascularity, ... and its- your cardiac circulation is powered up by regular physical activity, eh, all muscles are affected- and obviously the consequence... is optimal. (...) The only thing... zinc. Zinc. Because zinc, ... it's the... I mean... as it is good for mobility, and... to the strength of sperm cells, so zinc, liver, or pills. Zinc. (Ivan, 51 years old, manager, onset at 27 years)

Another case was that of Ilario, who reported to "get prepared" for sexual activity just as he did with sport activity: namely, by eating something before in order to avoid the risk of hypoglycaemia. But the problem was not for him only the risk of hypoglycaemia, but also that of hyperglycaemia, that would cause frequent urination and undermine his erectile function. Balancing glycaemic levels was thus a delicate operation that would allow him to engage in sexual activity. In his words:

> Sexual problems, yes, sometimes (...) tied to the glycaemia being too high. In the sense that, going often to the toilet, ... obviously my body was used to... urinating, and not to facing a... sexual matter. (...) Over time, let's say I learnt to manage myself, in the sense that... Always... from a diuretic point of view, ... (...)
> **... And hypoglycaemias? Many people tell me that often it happens...**
> ...Absolutely not. In the sense that... I mean, in the sense that when... I feel that... my glycaemia is quickly decreasing, maybe I have the foresight of... surely, eating something, or even only drinking a... some sweetened tea, restores [the glycaemia level]... And then the same thing... of doing physical exercise, in quotes. In the sense that, it's a physical effort made by your body, so... more or less intense, but... it's not as intense as a race (he laughs) that can be... mountaineering, cross country, a 30-chilometre marathon, I mean... (Ilario, 28 years old, T1D, shop assistant, onset at 5 years)

Another way of dealing with (and preventing, in other cases) sexual problems was that of glycaemic control. This approach envisages different cases. For example, Patrizio, who in the previous chapter has been classified under the "lay patient" ideal type, reported being able to prevent ED, and diabetes complications in general, through a proper glycaemic control. In a way, the absence of ED was for him a proof of his ability to control glycaemia and diabetes through a rigorous adherence to medical prescriptions. Stating that he did not experience any problems was, in a way, a certificate of him being a "successful lay patient." In his words:

> **According to research, diabetes often... can lead to experiencing sexual difficulties. Did this... happened to you?**
> Look, ... No. It did not happen to me. I had been looking for information, ... and I had [this] fear. Reading on the internet, - but I don't mean looking in Dr. Google, because so many people now use Dr. Google, and talk shit... you cannot imagine- ...I rather looked for... scientific documents, where they said that yes, ... [ED occurs] for those who are decompensated, for cardio-vascular problems, etc., etc., maybe for those who also have other therapies, such as beta-blockers, that stuff, ... they can cause problems of dysfunction, etc. etc. Fortunately, I do not have such problems. I can have other kind of problems, with my partner. However, no. No, [I am] honest, I don't have it. (...) My diabetologist had told me, he told me: "If the glycaemia is good, ... if the [haemoglobin] glycates is good and everything, ... complications no, that is, it is difficult that there occur. It is sufficient that... If one has exaggerated [high] and prolonged [hyper]glycaemia, ... yes, complications

> sooner or later will occurr. (Patrizio, 44 years, diabetes LADA, clerk, onset at 38 years)

Another way of balancing glycaemic levels was that proposed by Pietro who, in line with his "free spirit" (see previous chapter) approach, reported eating – when possible – some food before having sex. As he said:

> Oh well, look, since it's all anonymous [in the interview] – I got a text [from my partner, who said]: "Tonight sushi and sex".
> **Wow**
> And I can't say anything other than... sushi makes you high [in glycaemia]. (...) No, in the sense that you can really live easy. (Pietro, 27 years old, T1D, musician, onset at 16 years)

6.5 Conclusion

This chapter has investigated the experiences of diabetic men within the context of sexuality, an arena of practices that is often threatened by illness on a multiplicity of levels. I have highlighted in the introductory paragraph that diabetic men are inevitably embedded into a medicalized context, because in order to survive they need to regularly see the doctor for adjusting insulin dosages and checking the possible progress of the disease on their bodies. Usually, every six months diabetic men undergo medical examinations where, among other things, also their sexuality is assessed. I posited that the patient-doctor relationship was an important context not only for incorporating a specific knowledge around self-surveillance and self-monitoring practices apt to deal with and control diabetes' symptoms into the everyday life, but it also could have an impact on the way diabetic men understood and signified their sexuality and on the way they shaped and constructed their masculinities.

Overall, the majority of participant seemed to incorporate a hegemonic model of male sexuality, according to which male's sexuality is characterized by impulse, biological needs of sexual satisfaction, ability to control their bodies and the expectation of being always ready, performant and desiring. This ideal derived from the cultural patriarchal context in which men of this sample lived, and it was probably reinforced by the specific conception of male sexual health conveyed by medical knowledge, where a "healthy" sexuality corresponded with patients' ability to engage in (heterosexual) intercourse, their capacity to have successful erections regardless of the context, of their personal preferences, and of their relations. In these cases, discourses around sexuality entailed the reference to the ability of fulfilling hegemonic ideals of physicality and performances, with particular emphasis on the quantity and quality of erections, and on the impact of their inability of fulfilling such ideals on their self-esteem.

Despite this, a minority of participants seemed not to adopt a predatory conception of male sexuality, and they rather described sexual changes in terms of being a part of their life experience, where performance was important, but at the same time underperformance would not compromise their sense of (masculine) self: in this case, the effects of illness on the body where incorporated into an ever-changing and relational experience of sexuality.

Diabetes had an impact on participants' sexuality in many ways. First of all, many participants reported suffering (or being afraid of such possibility) for the stigma deriving from the common stereotype of the "impotent diabetic." This could have influenced also the disclosure of sexual problems with others, especially with other diabetic males, and this could also have influenced their disclosure –and the omissions- in the context of the interview.

An interesting finding was that, despite being embedded into a medicalized context, participants usually described their sexual difficulties with a combination of explanations, which could not be reduced to a fixed separation from psychogenic and organic factors. Such aspects seemed to be usually inextricably combined with each other and other factors, and together those explanations influenced men's lives in a complex mutable way, which changed through time and through different type of relations.

Literature on diabetes and sexuality usually focuses on the occurrence and on the aetiology of DE, and on its influence on psychological health. The empirical material collected here suggested that identifying diabetes-related sexual problems only with ED does not do justice to the complexity of actual lived experience: in fact, among the organic factors that more than others affected participants sexuality, it emerged also the possibility of experiencing glycaemic swings, and this is an aspect that gives numerous insights on the overall expectations of bodily performance and male body normativity that informs this specific arena of practices.

Overall, despite the fact that according to the literature diabetic men seem to be more likely than others to receive a prescription of EEMs, just a minority of participants reported using them in order to restore their unsatisfactory sexual performance, and the experience with such drugs was described with its (actual or potential) benefits, but also through a series of downsides that may undermine all the promises of immediate gratification and efficiency that pharmaceutical companies assure in the media advertisements and social campaigns that they promote. On the other hand, numerous alternative strategies where adopted by participants in order to prevent or deal with sexual problems, and this was not necessarily described as in contraposition with medical framework: with respect to the previous chapter, where self-management practices where used as a clear sign of distinction, in this case the analyses revealed that participants' experiences where more complex and transversal to socio-demographic dimensions and to the subgroups identified in previous chapters.

Chapter VII

Conclusions and implications

7.1 Diabetes as a complex experience: research aims and main findings

There has been a growing interest in the study of masculinity and its intersection with health and illness, and this work aimed to further expand this knowledge by focusing on men's accounts of autoimmune diabetes. More specifically, I explored the impact of chronic illness in men's everyday life, I analysed illness narratives in order to investigate the multiple ways of "doing diabetes" and how these intersected with the "doing" of masculinities and, finally, I examined diabetic men's accounts of sexuality and intimacy practices.

As it has already been stressed throughout this dissertation, the starting point for many researches dedicated to men's health has been men's general disadvantage in health compared with women, a trend that has usually been explained with their engagement in unhealthy and risky practices in order to demonstrate masculinity: as a result, hegemonic – and in particular white, traditional, middle-class – masculinity has been blamed for men's ill health. Men's self-destructive and risky behaviour has thus been described as a direct consequence of the same gender order that victimized women, although to a different extent (Rosenfeld & Faircloth 2006). On the other hand, critical perspectives on the study of men, masculinities and health/illness underlined the risk of over-simplification of such interpretations and stressed the importance of considering the larger socioeconomic, political, and gender structures that informs men's beliefs and behaviours (Rosenfeld & Faircloth 2016, Gough & Robertson 2009).

This concluding chapter shall recapitulate the main empirical findings emerged from the analysis of the 40 narratives of young and adult men with autoimmune diabetes that have been collected. Throughout the chapter I shall highlight how empirical findings relate to previous research on this issue and state the contribution of this work to the existing literature; after that, on the basis of the empirical findings I shall suggest some possible practical implications for health care professionals working with diabetic men; lastly, I shall discuss research limitations and point towards possible areas to be addressed by future research.

7.1.1 The impact of autoimmune diabetes on men's everyday lives

Through a biographical approach, the empirical findings described into the first empirical chapter gave an overview of the complex impact of illness on participants' everyday life. The analysis has highlighted a typical way in which participants narrated their diabetes stories, and this implied going through a series of sequential stages: the very beginning of the "diabetic careers" was represented by the first stage of the onset, when participants remembered the unknown ill feelings that suddenly affected their bodies, which marked an initial change in how they approached their corporeality. Many researches focused on adult-onset diseases, while autoimmune diabetes has the specificity of emerging both during childhood / young adulthood and during adulthood (although rare), and this offered the opportunity to explore the many ways of living with and signify chronic illness at different points in life.

Retrospectively, the *incipit* of the diabetic trajectory was described in different ways depending mainly on the age at the moment of the onset. In the case of childhood-onset participants, they usually described themselves as mute bodies whose experiences had been recounted by their parents: predictably, they remembered experiencing a bodily change to whom they did not give any form of interpretation. The older were the participants at the moment of the onset, the more they clearly recalled early diabetes signs on their bodies and their first interpretations of this altered body condition. Usually, participants described initial diabetes signs (increased thirst, excessive urination, etc.) through a vocabulary borrowed from medical knowledge, – for example, talking about "symptoms," "polyuria," "polydipsia" or "Erectile Dysfunction" – this suggesting their progressive incorporation of a medical perspective and its basic grammar as a lens from which to read their personal experiences. In this first stage, the gendered dimension of illness experience emerged especially in the narratives of participants who had a childhood-onset of the disease, who reported that it was usually their mothers who took care of them from this very first stage and who were more emotionally involved if compared to the fathers.

The prolonged unwell feelings and the failure to resolve them led participants to search for medical assistance. Despite the fact that all interviewees at some point sought help for their health problems, an interesting finding was that, in the case of adult-onset participants, many of them tended to discursively distance themselves from the realm of the "sick" by pointing out that they waited quite a long time before they went to the doctor, and some referred that before diabetes onset not only they were unfamiliar with blood tests or medical examinations, but they also described themselves as overall 'healthy' and not particularly prone to engaging with medical assistance. This discursive strategy used in the reconstruction of their illness story is consistent with Robertson's findings (2009) that point to complex ways in which men understand and narrate health issues. This could be interpreted as a discursive way to distance themselves from the feminizing sphere of health and self-care: a "manhood act" (Schrock & Schwalbe 2009) that solves retrospectively the "don't care and should care" dilemma (Robertson 2009) in which ill men might find themselves, with on the one hand the pressure to fulfil social expectations around dominant ideals of masculinity and, on the other hand, the recognition of the moral conception of health and its disciplining power to comply with standards of good citizenships.

The subsequent common stage entailed the diagnosis process with all its ambivalences: in fact, giving a name to an unknown situation served as a cognitive tool to legitimize a new bodily condition and it was crucial in order to find a solution to manage and control its destabilizing effects. On the other hand, the diagnosis implied a life-long sentence: without any known reasons, their immune system was progressively destroying all their pancreatic cells that produced insulin and there was no way of stopping this process. As a consequence, in order to survive they would have had to replace the pancreatic function with multiple insulin injections every day, for the rest of their life. For the majority of participant, the process of diagnosis has been quite straightforward, while a small minority of them where at first misdiagnosed and their path towards an understanding of symptoms has been more complicated. The diagnosis has been usually followed by a period of hospitalization, where participants have been, in a way, “initiated” to their “diabetic careers.” The challenges related to diabetes self-management and to its impact on the self and on the everyday life continued especially after leaving the hospital, and multiplied when participants returned in the social contexts that they attended before diabetes’ onset, where often “healthiness” and body normativity were both taken for granted.

According to participants’ accounts, the impact of diabetes – of its chronicity over time, together with the intrusiveness of its symptoms into the everyday life, the allotted time for self-care and the uncertainty of the even more precarious future – required then, in a third stage, the difficult but necessary time of coming to terms with this condition. In fact, the body has a crucial role in both the construction of the self and in social interactions: our body appearance, functioning and reliability mediate our experience into the world and affect our possibilities to function as social beings. Experiencing alternative corporealities means relearn, renegotiate and remaking new ways of being and shaping a (male) body.

As underlined in chapter n. 2, sociological attention on chronic illness has been dominated by the conceptual framework inaugurated by Bury (1982), who claimed that the everyday experience of chronic illness entailed a severe disruption in the lives of who experienced it, regardless of possible mitigating factors. This approach also informed other researches on autoimmune diabetes: Rajaram (1997), for example, explored the experiences of insulin-dependent diabetic individuals, claiming that “the experience of a chronic illness disrupts a person’s sense of self” (Ibidem: p. 282). As it has been shown, although living with autoimmune diabetes necessarily implies a high degree of uncertainty, change and loss of control, according to the empirical material collected the concept of “biographical disruption” (Bury 1982) might not be able to describe the complexity of diabetes trajectories. In fact, in this regard I have explored common patterns in the discursive ways in which illness narratives where constructed, and only a minority of them could be described in terms of “biographical disruption,” while the majority of them has been organized in different ways that I have labelled with the terms “fluctuation” and “continuity.”

Such findings are in line with Carricaburu & Peirret (1995), Williams’ (2005) and Faircloth and colleagues’ (2004) critical approach to chronic illness, whose aim was to further Bury’s (1982) paramount concept of “biographical disruption” and to avoid treating concepts such as this one as “mechanistic truisms” (Faircloth *et al*. 2004: p. 245). In fact, often the effects of diabetes are normalized and the everyday life “continues its on-going flow of events, actions, reactions and self-preservation of identity” (Ibidem: p. 245). Overall, the analysis of empirical material highlighted that in the case of diabetes the disruptiveness of the disease seemed to depend mainly on the age at the moment of the onset, on the severity of the disease and especially on the social context in which participants were living: in this respect, social class background was indeed relevant, but the job strain model developed by Karasek and colleagues (1981) proved to explain with higher accuracy the influence of environmental characteristics on diabetic men’s everyday life because it allowed to take into account the environmental conditions that shaped participants experiences.

As it has been illustrated in chapter n. 4, a minority of participant constructed their illness narrative according to Bury’s (1982) definition of biographical disruption. But unlike this original conceptualization, the disruptiveness in those cases was not considered as a single event located at the beginning of the illness trajectory: it was rather described as a process that persisted over time and affected irremediably their everyday routine, shaped their present and disrupted their plans for the future. Another similarity with Bury’s groundbreaking work was that in this research all the narratives that could be categorized under the “biographical disruption” ideal type involved participants who had adult-onset diabetes, and this might have complicated their ability to adjust and to come to terms with their new bodily condition. Another point of similarity was that who described his biography as disrupted by illness tended to represent diabetes as a burden and to make reference to a past (and healthy) self and a past (and healthy) life that could not be recovered, as well as to a present which was tainted by the pervasiveness of illness, by its relative stigma, by the body constraints it caused and by the repercussions it had on their (male) identity, which was often perceived as far from dominant ideals of masculinity.

Another dimension which was also found as relevant in determining the degree of disruptiveness was that of the positioning in the Job Stain Model (Karasek *et al.* 1981): in fact, a physically/psychologically demanding job where the decision latitude was low increased the risk of experiencing illness as a disruptive experience. The diabetic men who have been interviewed not by chance focused on occupational context: in fact, in line with other researches on gender and illness (i.e. Rissman 1990, Broom & Lenagh-Maguire 2010, Kolling 2012), this specific social context was considered as crucial for participants' embodied sense of (masculine) self.

As it has been pointed out, social class was found as a relevant dimension in explaining the ways in which participants talked about the "costs" of living with a chronic condition and the potential consequences of its disclosure. In fact, the lower were the cultural and economic capitals of participants, the higher was the possibility of incurring in the (potentially) disrupting effects of diabetes, both in the present and in the future.

As it has been mentioned before, an interesting and unexpected result of the present research was that the majority of narratives could not be described by the "biographical disruption" framework. In fact, nineteen out of forty narratives have been structured as a "biographical fluctuation" and the remaining sixteen as a "biographical continuity." With regard to the first, the terminology clearly echoes Faircloth and colleagues' (2004) concept of "biographical flow," with which it shares the representation of illness as being part of an on-going and ever-changing life, and it also draw from Sanderson and colleagues (2011) concept of "fluctuating normality," which entails patterns of uncontrolled disease activity and crisis with intermittent stability of the everyday life. In this case, it has been observed that participants usually organized the reconstruction of their illness stories around specific turning points that served as narrative anchors and mainly involved some "expected transitions" (Bonica & Cardano 2008: p. 20; my translation) such as (a) the transition to adult age; (b) the beginning of a stable relationship; (c) the beginning of working life. At the same time, the "unexpected transitions" (Ibidem: p. 21; my translation) that were mainly mentioned concerned (a) the emergence of more or less severe health complications related to diabetes; (b) changing from more 'traditional' self-monitoring tools, such as insulin pens and glucometer, to medical devices such as the insulin pump and the continuous blood glucose sensor.

Usually, the narratives classified in this type described the transition to adult age as a delicate life stage in which participants recalled feeling high pressure to conform to the (male) peer group norms, and during those years in which they gained more autonomy from their parents this usually resulted in a period of mismanagement of their condition, that was explained as a way to ideally "bracket" illness and construct an adequate masculine identity.

According to participants' narratives, the beginning of a stable relationship and marriage constitute a substantial change in terms of adherence to treatment, stability of the routine and well-being. In this regard, from the analysis of empirical material it emerged that women played a crucial role in providing care and support for their partners, usually confirming a traditional embodiment of gender expectations.

As already mentioned before, occupational context emerged as crucial in the narratives of diabetic men here analysed. In some cases, participants reported not being employed because of their condition, while an inclusive and understanding work environment seemed to be associated with a higher adherence to treatment. In many cases, the same individual experienced different situations in different periods of his biographical trajectory and through these fluctuating narratives it was even more evident the crucial role played by job conditions in shaping illness experiences.

With regard to unexpected transitions, diabetes-related health complications (for example ketoacidosis, coma, nephropathy, retinopathy etc.) emerged as a significant event that, in these cases, disrupted participant biographical careers. The experience of invasive health problems has never been a neutral element in the life of participants: these occurrences were perceived as a reminder of the degenerative nature of illness, of the vulnerability of the body and of the fragility of life. In fact, after an initial period of crisis the fear of loosing their sight, kidney function or even of dying usually stimulated a greater adherence to treatment and in some cases this allowed them to change their lifestyle and improve significantly their well-being and everyday life.

A second "unexpected transition" concerned the adoption of medical devices for diabetes care. In those cases in which this change was described as relevant, modern digital technologies supplanted more traditional devices and usually stimulated patient engagement in self-care. In fact, insulin pens (or, even more, insulin syringes) and the traditional glucose meter were in some cases perceived as a constant reminder of illness, and this may have discouraged the adherence to treatment, especially in the presence of other people. In some cases, such objects have also been perceived as "gendered," or better as "gendering" their users, and this seemed to have an impact on participants' overall adherence to treatment. On the other hand, self-monitoring practices enacted through the use of digital technologies have the advantage of stimulating men's technical expertise and appearing not only less stigmatizing to an outside eye, but they also may have attached a positive value because of their resemblance to the latest generation of mobile phones.

The diabetic body is not a separated entity, unconnected with the mind and with the circumstances of life: it is actively constructed and shaped by biographical events and by the social contexts in which people flow. As it has been stressed, these stories show that diabetes trajectories are influenced by the variability of illness, by the vulnerabilities of the bodies, by the concrete – cognitive and material – possibilities of taking care of oneself and by the opportunity to access medical technologies. This findings are aligned with the work of Charmaz (1997: p. 198) who observed that – in the context of chronic conditions – narratives are often reconstructed as illness chronologies punctuated by events that divide periods of "crisis and quiescence, flare-ups and remissions, rigid regimens and convalescence."

Another relevant finding of this research concerned the third and last "narrative form" that emerged from the analysis of the empirical material, which according to its characteristics was named "biographical continuity." Illness stories that have been categorized under this type were in line with Williams' (2005) further elaboration and criticism of Bury's (1982) concept of chronic illness as a biographical disruption: in fact, in this case participants did not describe their biographical trajectory as irreparably disrupted, but they rather represented illness as a "normality" and as an integral dimension of their embodied sense of self (Ibidem). Out of sixteen, eight narratives belonged to participants who had a childhood-onset of diabetes. In fact, one of the main criticisms discussed by Williams (2005) with respect to the dominant perspective on chronic illness was that it entailed an adult-centered model of illness, which hardly described the situation of individuals who experience illness from a young age. Illness accounts that could be categorized in this narrative type had in common the recurrent use of discursive strategies that minimized the disruptiveness of diabetes upon their everyday life. Diabetes was often discursively reduced to a routinized set of practices of self-management, and in these cases diabetes-related complications were in fact mild or absent. Also in this case, work emerged as a crucial context and all 16 respondents reported having high control of daily time scheduling freedom: for them, this meant being able to accommodate time and tasks depending on illness needs and organize their routine autonomously.

7.1.2 The (un)doing of diabetes self-management

The second empirical chapter had the main aim to explore how men "did" diabetes and what meanings they assigned to self-discipline and self-surveillance practices that composed illness management. More particularly, I was interested in studying how specific illness-related technologies of the self (Foucault 1988) were intertwined with the construction of masculinities and how the combination of these two dimensions produced distinctive types of "diabetic masculinities" enacted during the context of the interview.

As we have seen, a first relevant result that emerged from the analysis was that, overall, the majority of participants reported being engaged – although in different ways and with different meanings – in self-care and self-management practices, and these first findings contributed to challenge the pathologizing thesis that masculinity would be bad for men's health (see Harrison 1978). Furthermore, they are also in line with previous qualitative research that questioned this oversimplifying assumption and that supported the hypothesis that men engage differently in health-related practices depending on social circumstances (e.g. Robertson 2007, O'Brien *et al.* 2005, McVittie & Willock 2006).

And it was by focussing on how diabetic men described to a female interviewer how they disciplined and controlled their bodies that emerged their multiple ways of unravelling from the double bind of masculinity construction and illness management. As it has been explained in detail in chapter n. 2, this dissertation draw from a social constructionist perspective that intended masculinity as performative, as a dramaturgical task, as a configuration of practices that are accomplished in social interaction and that are indissolubly embedded in historical situated social structures (West & Zimmerman 1987; Connell 1987, 1995, 2000; Bourdieu 1988). Starting from this premise, men never stop learning "how to signify a masculine self in situationally appropriate ways" (Schwalbe & Schrock 2009: p. 283) and, for diabetic men in particular, dealing with a chronic disease also meant relearning how to use their bodies and how to present themselves within social interactions in such a way that their membership in the "male" gender group was confirmed. In this perspective, this research has sought to explore how diabetic men compensate for their inability to fully enact the hegemonic ideal of a healthy, strong and reliable masculine corporeality through specific and compensatory "manhood acts" (Ibidem), namely discursive strategies that were enacted within the context of the interview. The forty diabetic men's accounts analysed in Chapter n. 5 were thus ordered into three ideal types that identified three different modes of understanding, self-disciplining and monitoring diabetic male bodies: the "Diabetic Quantified Self," the "Athlete," and the "Free Spirit."

As it has been illustrated, the *Diabetic Quantified Self* (DQS) was characterized by a data-centric discursive representation of the self, where diabetes experience has been narrated with a particular emphasis on self-surveillance, self-discipline and self-tracking practices and on participants' ability to achieve specific (mainly numeric) goals. The majority of participants whose narratives could be described under this ideal type reported being enthusiastic about wearing digital medical devices, and the way they talked about such technologies being an integral part of their bodies reminded on some level Donna Haraway's (1987: p. 291) concept of "cyborg," a "hybrid of machine and organism" that challenges the cultural frontiers that divide organism from machine. Cyborgs break bodily boundaries between human and non-human and the embodiment of digital technologies become for these diabetic men much more than just an "artificial pancreas" used for survival: they become a sort of human extension, an integral part of the self.

In the case of diabetes, self-managing and self-monitoring practices have changed significantly over time. Some of the oldest participants still remembered the glass syringe that their parents used when they were young in order to inject them the daily doses of insulin: it was larger than the modern ones, it needed to be boiled and sterilized each time and it was stored in a small metal case used also for the sterilisation process. Similarly, different forms of glycaemia measurement evolved through time: in some interviews it has been recalled that, once, glucose monitoring was run only in laboratory, and home blood glucose monitoring devices have been introduced only in the 1980s and at the very beginning they were very expensive and bulky. Moreover, in the recent past, blood glucose levels and food habits were recorded on paper diaries, while contemporary insulin-dependent diabetes self-management includes innovative digital technologies that are able to provide with immediate availability a constant and updated monitoring of glycaemic trends, which are recorded by specific apps and can be downloaded at any time. Whirls, on the one hand, self-tracking practices have a long tradition in diabetes self-management, on the other hand contemporary ways of measuring, monitoring and recording medical data through digital technologies have offered new means of understanding and knowing oneself and one's own body functioning. As Sassatelli (in Neresini 2016) observed, in consumer capitalism digital technologies may constitute the contemporary evolution of "discipline" as a specific form of power (*sensu* Foucault) that creates the subject and its subjectification through the constant application of disciplinary techniques. As she observed: "Today, digital technologies, notably self-monitoring apps, represent perhaps a third wave in such long term process, with portable devices installing disciplinary technologies directly onto the individual body, and with embodied subjects all the more vigilant and willing to submit what were once perceived as personal, and even sacred, provinces of themselves (…) to self-monitoring quantification."

Moreover, the same condition and the same medical devices might result in different approaches and meanings. In fact, among those who described themselves through biometric data and highly engaged in self-tracking practices it has been possible to distinguish different ways of understanding such numerical achievements and disciplining strategies. More specifically, the DQS ideal type could be further subdivided into two subtypes.

The first subtype was the *Quantified Patient*, who mainly understood his body parameters in terms of adherence to treatment and represented the majority of this subsample; in this case, participants talked about diabetes self-management and their personal goals through an explanatory model grounded in medical understanding, to which they were fully compliant. They did not question the legitimacy and efficacy of medical standards of care but rather presented their (numerical) medical results as the demonstration of their ability to comply with doctors' prescriptions. On the other hand, the *Quantified Lay Expert* ideal type in turn incorporated biomedical knowledge, but unlike the other subtype this was combined with personal experience. Participants who could be described by this subtype reported personally searching for further information about their condition and its treatment as well as engaging in a series of "experiments" on their own bodies in order to refine, improve and fine-tune the more abstract and universalistic expertise offered by diabetologists and physicians. Food was discursively dissected into its main components (i.e. carbohydrates, proteins etc.) and quantified in terms of weight, number of carbohydrates and their impact on glycaemia. The "competition" in this case revolved on their ability of developing a "personal combination" of diet regimes and insulin treatment that would maintain a stable glycaemic level during the day while using the smaller amount of insulin units as possible. The ability to be in control was often reinforced by putting emphasis on what Watson (2000) defined as "pragmatic embodiment," and in particular on participants' capacity to fulfil the expectations of their *habitus* mainly in terms of being an adequate worker "despite" diabetes. Although these two subtypes presented some differences between them, they had in common the enactment of a specific “diabetic masculinity,” which was characterized by an emphasis on their ability to discipline their bodies properly, to be rational, competent and self-reliant. Thus, numerical achievements such as the glycated haemoglobin level or the glycaemic trend served as a discursive strategy to, in a way, satisfy the middle-class masculine ideal of being always able to exert proper control on their (male) bodies and selves. In a situation of high bodily and emotional uncertainty, self-surveillance and self-care practices were in fact signified as a (re)appropriaton of their body, which often were at the mercy of their symptoms. A second signifier of manhood that emerged from the narratives was that of “competition”: in this context, this did not concern the ability to exceed one’s own body limits through sport, as emerged in the case of the Athlete. It was rather a numerical challenge that regarded participants’ ability to reach the best possible value of glycated haemoglobin or glycaemic level: a competition with oneself, in a process of constant self-improving; but also a competition with other diabetic individuals, which is often enacted through the sharing of screenshots regarding the glycemic trends on the social media and on-line communities; a competition that, after all, has been structured through the discursive opposition with the most different “others,” that have been represented by those diabetic people who mismanage illness such as the “Free Spirit” ideal type.

As emerged from the analysis, a second ideal type was represented by the *Athlete*, which described a diabetic man who went far beyond the doctors’ suggestion to go for quiet postprandial walks in order to better manage glycaemic swings: participant classified as “Athletes” rather reported engaging in competitive sports and endurance training through, for example, running, cycling and kayaking. Within the interview, participants proposed this as a counter-discourse that resisted to medical suggestion for moderation and relied on the embodied experiences of the “diabetic athletes,” a subculture that could be considered as a real “community of practices” (Lave & Wenger 1991). Participants whose narratives could be described by this ideal type incorporated, resignified and reappropriated a cultural capital that become subcultural and then, within that specific subcultural context, acquired value as symbolic capital and allowed the subject to obtain a subcultural status. According to the narratives collected, as we have seen, the other members of this specific "community of practices" were reported to be mainly males: in fact, sport was here described as enacted in a homosocial context (Ferrero Camoletto & Bertone 2017, Bird 1996; Lipman-Blumen 1976), where men engaged in a shared set of practices that were valued from other male athletes and were crucial in order to construct a successful (masculine) identity. Based on the assumption that chronically ill bodies are often perceived to be weak and passive (Shapiro 1993), endurance sport might be understood as one of the many ways for diabetic men to compensate their inability to fully enact the hegemonic ideal of masculinity and to counterbalance the stigma attached to their condition.

The majority of diabetic athletes of this sample engaged in *individual sports*. Such sports included competitive running, cycling, mountain climbing, boxing and triathlon races. From the analysis of the empirical material it emerged that the choice to engage in individual – rather than collective – sports was in itself a coping strategy adopted by participants in order to deal with impression management (Goffman 1959) and to limit the risk of experiencing stigmatization among non-diabetic others. In this subsample, participants understood sport as a crucial instrument to manage diabetes: they "tailored" self-management through a combination of incorporated medical knowledge and personal expertise derived from learned subcultural practices and personal experimentation.

Only 2 participants engaged in a *collective sport*, namely football, and their narratives reported similarities and differences. As we have seen, compared to individual disciplines, collective sports usually entail different challenges for a person with a diabetic body, this mainly because both training and competitions take place in a context where there is proximity with other non-diabetic (male) teammates and thus interactions are informed with normative expectations of corporeality. In this context, it emerged clearly the ambivalence of homosociality: if, on the one hand, participating in team activities with other male teammates has been a substantial source of support and recognition, on the other hand the context of high bodily competition and normativity produced the increased probability of experiencing illness-related stigma, and this has meant in one case resorting to the invisibilization of self-management practices and in the other case the visibility of medical devices attached to the body made one participant experience stigma. These two narratives provided, in a way, two most distant experiences: it is thus likely that other diabetic athletes engaging in collective sports might be positioned some way between those two polarized experiences.

Overall, the analysis of the empirical material confirmed previous research on sport and male bodies (e.g. Messner 2005, Seymour 2003, White *et. a*l 1995) according to which "sport" was considered as a critical vehicle for masculinity construction. First of all, overall the totality of the "athlete" participants described sport as an occasion for social interaction with other (diabetic and non-diabetic) men. Among all this subsample, nobody ever talked about women engaging in sport or doing training with them: they trained alone, with male friends or, in the case of one participant, with his diabetic son. In analysing these narratives and comparing them to the other ideal types, it was evident that engaging in sport was highly associated to a specific class *habitus*: all participants where heterosexual and with a middle class background, and they had the economic capital that allowed them to dedicate time and resources in competitive sport. Within this ideal type, participants mainly focused on a normative embodiment (Watson 2000), which – as it has been explained in chapter n. 2 – entailed a description of how an idealized body shape may have been achieved and maintained through the incorporation of self-discipline and self-surveillance practices.

Finally, an interesting result concerned the third and last ideal type, labelled as *Free Spirit*, which encompassed a minority of narratives and described the experiences of participants who represented their bodies as an instrument for experiencing pleasurable sensations and freedom from constraints. As it has been highlighted, this often entailed a lower adherence to (or even refusal of) medical treatment. The "Free Spirit" ideal type equated constant body self-surveillance and control with prohibition and denial, and described high-compliant diabetic people as wretched souls, obsessive individuals that live their bodies as sick bodies and that waste their whole life managing diabetes and disciplining their selves, this way forgetting to enjoy freedom and pleasure. Unlike the other two ideal types, the majority of participants in this subgroup reported privileging unquantified, free diet regimes and they discursively distanced themselves from the hyper-monitoring or hyper-discipline typical of the other two ideal types. As noted, the fact of describing oneself as rejecting the restrictive disciplinary regime prescribed by the diabetologist and at the same time adopting a hedonistic lifestyle, could be understood as a specific manhood act (Schrock & Schwalbe 2009) that corresponds to a specific way of constructing hegemonic masculinity: that of laddish masculinity, typical of a working class context. With the exception of two participants, all "Free Spirit" narratives have been produced by participants with a lower cultural capital, and in the other two cases this could also be interpreted as a way of distancing themselves from the "feminizing" effect of self-care practices. This group of narratives differentiate from the other ideal types also because participants described themselves in an "unquantified" way: they measured glycaemia infrequently or even not at all, and the avoidance of this constant self-surveillance was considered from participants as a prerequisite that improved their psychological well-being. With reference to Watson (2000) male body schema, participants whose narratives could be described by this ideal type mainly emphasized their experiential embodiment, namely a presentation of their body as the primary site for experiencing emotion and physicality.

Overall, the analysis of the empirical material explored the relationship between men, masculinity(ies), embodiment and health by studying men's accounts of diabetes self-management. It emerged that men might "do" diabetes in multiple ways and that illness-related self-care practices become an arena for (re)negotiating specific forms of "diabetic masculinity." In sum, the three ideal types identified in this analysis highlighted that gender and health are inextricably intertwined and that the (un)doing of diabetes as component of a discursive presentation of a "masculine self" is inevitably the result of embodied dispositions and structured positions within a plurality of social stratifications and hierarchies.

Despite the fact that, as it has been explained in chapter n. 2, recent researches on masculinities have pointed to less hierarchical and more inclusive masculinities (see Anderson 2010), this dissertation's findings rely on previous work on masculinity. In fact, participants' narratives clearly highlighted the influence of hegemonic notions of masculinity in the way they presented themselves, engaged in care activities and shaped their diabetic bodies: therefore, an interesting result was that experiencing an intrusive chronic condition did not necessarily imply the enactment of a marginal masculinity. In fact, it has been observed the persistence of elements attributable to hegemonic ideals of masculinity together with and appropriation of practices that apparently seem counter-hegemonic (such as self-care and self-monitoring practices, or dieting) but that actually have been presented with a renegotiated meaning that pointed to the ever-changing – and at times contradictory – nature of hegemonic masculinity.

7.1.3 Doing sex, doing gender

Among all chronic diseases, diabetes is the one where men's sexuality has been explored more extensively (Schover 1988). In fact, epidemiological studies on diabetic men highlight that "Erectile Dysfunction" is estimated to occur as a complication in 35 to 90% of cases across all age groups (McCabe 2016, Stein *et al*. 1985). For this reason, diabetic men have their sexual health periodically scrutinized, along with other body parameters, within routine check-ups. Since diabetic men need to incorporate medical knowledge in order to survive and since the idea of "healthy" and "pathological" sexuality it entails conveys a specific normative ideal of masculinity, the last empirical chapter investigated further the interrelation between gender and health by analysing diabetic men's discourses around sexuality and their experiences of sexual difficulties, with particular attention to the implication of biomedical model of male sexuality. As Foucault (1979) highlighted, medicine has a great role in regulating and defining sexuality: medical knowledge draws boundaries of what is to be considered "healthy" and what, instead, should be classified as "pathological," and such categories are performative and normative in so far as they produce the actual conditions in which sexuality may – or may not – exist.

As we have seen, the analysis of empirical material highlighted that, overall, in the majority of cases participants' narratives were informed by the prevalence of a traditional conception of sexuality, where social expectations around men's and women's sexual performances were mainly dichotomized around the belief that men's sexual desire has biological origins, it is naturally stronger than women's, and it is more about physical pleasure, while women's sexuality would be more centred on feelings. These findings are in line with a recent survey on a national sample (Barbagli, Dalla Zuanna, Garelli, 2010). On the one hand, the majority of participants experienced some kind of sexual problem and almost all of them acknowledged the risk of being stigmatized both for the association between diabetes and impotence and for inhabiting a "sick" body. On the other hand, they used some discursive strategies as compensatory manhood acts (Schrock & Schwalbe 2009) in order to defuse the threat of impotence on the presentation of the self within the context of the interview, for example by accentuating their sexual appetite and prowess.

Such (hetero)normative approach has been also observed in the Italian standards of medical care (Standard Italiani per la Cura del Diabete Mellito 2016) that inform medical practice, where ED is taken into account as a possible complication of diabetes. The majority of participants seemed to have incorporated meanings and terminology typical of the dominant model of male sexual health and, in fact, they talked about their sexuality mainly in terms of duration, quality and quantity of their erections, just as they also attributed great importance to intercourse performances with no or little regard to the relational or emotional context. These findings are consistent with a previous qualitative study (Kolling 2012) on diabetic men's experiences of sexual difficulties.

However, we have seen that a minority of participants gave different accounts of sexual experiences and difficulties: in fact they did not refer to the pathologizing concept of erectile dysfunction, nor they have mostly focused on the imperative of sexual performance. They rather had a more "symmetrical" perspective on sexual relations and this was also consistent with the findings of the abovementioned national survey (Barbagli, Dalla Zuanna, Garelli 2010). In this case, diabetic men signified their sexual changes as being part of life experiences. The possible effects of illness on their bodies and on their sexual performances have been in this case incorporated into an ever-changing and relational experience of sexuality, probably facilitated by the fact of being in the context of a stable relationship.

Overall, the majority of participants reported having experienced some sort of sexual difficulty. 27 participants out of 30 attributed some degree of responsibility of sexual problems to diabetes: among them, 15 talked about the impact of glycaemic swings on their sexual performances, 7 of them reported experiencing sexual difficulties as a diabetes-related organic complication and 5 of them reported experiencing anticipatory anxiety related to the possibility of suffering diabetes' symptoms during sexual activity. Therefore, with respect to the existing literature on these issues, this explorative study was relevant because it allowed expanding the area of analysis beyond the dominant issue of erectile dysfunction, and by giving voice to diabetic men it explored the complexity of meanings and experiences related to sexuality experience.

An interesting finding was that, despite being embedded into a medicalized context, participants usually described their sexual difficulties with a combination of explanations that could not be reduced to a fixed separation from psychogenic and organic factors. Consistent with Tiefer's (1986) reflections, such aspects seemed to be usually inextricably combined with each other and to other factors, and together those explanations seemed to affect men's lives in a complex and mutable way, which changed through time and through different types of relations. As it has been highlighted in chapter n. 6, critical literature (i.e. Perelman 1984, Tiefer 1986) on the medicalization of male sexual health has stressed the importance of considering the psychogenic causes that often inform men's experiences and that are usually underestimated by biomedical approach. Although I was not qualified to distinguish between organic and psychogenic causes, I was able, as a sociologist, to study the discourses that have been produced by participants around their sexual difficulties. It emerged that usually the narratives were dominated by an *organic* or *psychological* explanation, but at the same time the majority of narratives included, to some extent, a psychological explanation. For example, the analysis showed that in many cases men had erectile difficulties because of "anticipatory anxiety": they knew that sexual activity – just as all physical activity – could provoke hypoglycaemia and this, in turn, could cause underperformance. Moreover, the pervasiveness of public discourses on the medicalization of men's health, together with the medicalized framework in which diabetic men were necessarily embedded, led many participant to conceive ED as a real "sword of Damocles," an ever-present threat to their health and to their masculinity. As a result, in some cases participants experienced erectile difficulties as a self-fulfilling prophecy, and it was not unusual that they recurred to a medical solution.

At the moment of my fieldwork, the official Italian standards for diabetes care only mentioned organic causes of ED and proposed medical and surgical treatments regardless of the possible aetiologies. The combination of dominant ideals of male sexuality and the understanding of sexuality as a health indicator might contribute in shaping the ways in which men signify their sexual difficulties, and this is an aspect that should be taken into account within clinical practice.

Scientific literature on diabetes and sexuality usually focused on the occurrence and on the aetiology of erectile dysfunction, and on its impact on psychological health. The narratives here analyzed seem to point to a more complex understanding of sexual problems. It emerged, for example, that among the "organic explanations" participants gave particular relevance to the possibility of experiencing glycaemic swings – and hypoglycaemia in particular – during sexual activity. In fact, low blood glucose level emerged as a crucial factor in causing the inability to attain and maintain an erection and also in causing the lack of desire. The second "organic explanation" concerned the more common occurrence of ED as a health complication related to illness, which was often associated with other complications such as neuropathy. In this regard, Tiefer (1986) critique of biomedical model has been particularly valuable to better understand the possible reasons for explaining the success of the medicalization of male sexuality: for example, framing sexual problems with a biomedical approach may allow men to shift the responsibility of their "sexual failures" from a personal level to an external, uncontrollable, physiological malfunction and this way they may avoid the stigmatization attached to impotence.

Few participants attributed their change in sexual desire or erectile performance to aging, therefore explaining in terms of a physiological change their inability to fulfil hegemonic ideal of sexual prowess at any age, a perspective that somehow associated potency with a young age and an older age with a physiological decline. This type of explanation could also serve as a discursive strategy that absolved men of their responsibility for their underperformances, and it reminded in some respects the explanation of “hormonal imbalance” that is attributed to women’s loss of sexual desire: it is, in fact, a combination of organic and psychological causes that in both cases ascribes to an uncontrollable factor the responsibility for not adhering to an expected behaviour.

Despite the fact that according to the literature diabetic men seem to be more likely than others to receive a prescription of erectile enhancement medications, despite the fact that taking drugs for restoring sexual function was usually considered as an expected step that would occur at a point in the future in order to “fix” physiological decline in sexual function, and despite the fact that, as a recent research study (Ferrero Camoletto & Bertone 2012) has highlighted, in Italy there have been a series of social campaigns on male sexual health that promoted a medicalization of male sexual health, just a minority of participants reported using EEMs. Participants who reported using them described their experience both in terms of benefits and downsides and depicted a picture that was far from the simplistic one promised by pharmaceutical companies in the media advertising. One of the main concerns that emerged was the possibility of experiencing drugs’ side effects, among the others headache, facial flushing, dizziness, blurred vision etcetera. Another “downside” of EEMs was the necessity to “plan” sexual activity and to keep to the time allowed from medications’ half-lives, a specificity that interfered with the spontaneity of sexual interactions. On the other hand, a variety of alternatives where adopted by participants in order to prevent or deal with sexual difficulties, and this was not described as in contraposition with medical knowledge: unlike self-management practices, that as it has been shown in chapter n. 5 have been used as a sign of distinction, in this case the analysis has revealed that participants’ experiences where more complex and transversal to socio-demographic dimensions.

7.2 Limitations of the study and future directions

This work has its limitations. I should stress that it has been primarily concerned with one chronic illness, autoimmune diabetes. While, on the one hand, this does not allow me to extend the predictability of the findings to chronic illnesses more in general, on the other hand it has allowed me to access to the complexity of experiences within the same pathology, which is usually considered in a monodimensional way. However, further research focusing on masculinities and illness could design a comparison between illnesses with different degree of intrusiveness in the everyday life and on masculinity: for example, by comparing diabetes experiences with that of asthma, as some researchers have already done (e.g. Williams 2000); or with multiple sclerosis, an illness whose intersection with masculinity has already been studied by Riessman (2003); or with, for example, with depression, an invisible problem which is often considered as potentially emasculating because it is associated to an uncontrollable expression of emotions (see, for example, Emslie *et al.* 2005).

Another possible limitation of this study is the use of only one research technique. Although in-depth interviews have been crucial for accessing men's experiences of illness and for exploring the particular performance of masculinity enacted in this particular interaction, further research could also explore this issue on an individual and a collective level of analysis. Since masculinity is mainly constructed through interactions, further research could further explore the intersection of masculinity and illness through participant observation and focus groups as main research techniques. In the first case, the researcher would be able to observe a "live performance" of their subjects of analysis in their original environment (the context of an association, for example) and this could give rich data in terms of how they interacted with each other and on the role of care of their partners. The group interactions of focus groups, on the other hand, could also be a precious source of information and allow studying interactive processes of co-construction among (male) participants and collective production of meanings in a homosocial contexts.

It would also be interesting, for further research, to increase the heterogeneity of the sample through a stratification based also on other intersectional dimensions such as ethnic origins, that would surely have an impact both on the way participants "do" diabetes and the way they "do" masculinities. Furthermore, the research design that guided this work focused on the central phases of life of participants – youth and adulthood – because of their supposed relevance with respect to higher social expectations that surrounds male body normativity both in the case of illness and that of masculinity. It would be nonetheless interesting to explore the phases of adolescence, where male identity is in construction, and also older age, where somehow illness could be an “expected” life experience and thus have a different impact on men’s everyday life.

7.3 Recommendations

Notwithstanding the abovementioned research limitations, the analysis of empirical material suggests significant possible implications for clinical practice.

First of all, to autoimmune diabetes participants did not assign a universal meaning: they rather reported living with this condition in many different and complex ways. Heterogeneity in the way of understanding, representing and dealing with diabetes has had a significant impact on participants’ compliance to treatment and on the probability of experiencing diabetes-related complications. Practitioners should consider the subjective experience of diabetic patients in order to better plan long-term treatment around individuals’ actual limitations and possibilities.

An important consideration that can be drawn from this empirical research is that the monolithic conception of “male health disadvantage” that informs the majority of theoretical and empirical work on this issue does not take into account the complexity of diabetes experiences. This is due to two main reasons, which may provide significant implications for clinical practice with chronically ill, male patients. First of all: as this thesis clearly demonstrated, complying with social expectations around masculinity does not necessarily exclude compliance to treatment, and can simultaneously perform traditional forms of masculinity and engage in self-management practices. Therefore, clinicians “should not assume that men have an irresponsible attitude toward their health” as Robertson (2007: p. 149) observed. Despite the relevance of statistics that highlight men’s poorer health if compared to women, it is nonetheless crucial to distinguish among different groups of men (for example, distinguishing by age, ethnicity, social class, sexual orientation etc.) and to acknowledge the individual experience (Gough 2006). It is also crucial to consider the actual possibility – in terms of economic and social capital – of the diabetic individual to engage in, for example, healthy eating or physical activity, which could be undermined in the cases where poverty, unemployment or other factors impose significant obstacles.

Furthermore, despite the general support of the literature around the hypothesis that men do not talk about their health, from this thesis it emerged that actually men talk about health and illness-related issues, even though at the beginning they could find it difficult and could need some time to get used to it. A possible recommendation for clinicians, based on my personal experience within the context of the interviews, is thus to create a “safe environment” where men could feel at ease and disclose about their illness experience and concerns without the rush of the limited time dedicated to routine check-ups, nor the pressure to conform to a moral standard of health.

Another consideration is that, overall, traditional gender relations emerged when talking about the role of care: in line with Favretto’s (*et al.* 2007) research, both in the case of diabetic children and young boys, it was considered the mother’s responsibility to assist them during the hospitalization period and administered their treatment afterwards. Also in the case of diabetic adults, where this was mainly found in the context of organizing and taking care of food consumption practices, a task that was described as a taken-for-granted responsibility of women. When we talk of “gender inequalities” in health, this is also an – almost invisible – dimension that should be considered. Men might be compliant, but who do they “owe” it to? Otherwise they might be overly non-compliant, but who will take care of them when complications arise? A possible recommendation to practitioners, then, could be to consider the “hidden side” of the story, the often invisible and taken-for-granted role of care provided by women. In concrete terms, this could mean to develop best practices, for example, for including fathers during the assistance of diabetic children in the first period after diagnosis. A participant, when talking about his hospitalization period, recounted that there were only mothers assisting other diabetic children in the hospital, and that health professionals taught them how to cook for their children by using recipes adapted to a diabetic diet. Implicitly, this reinforces traditional gender roles and contributes to women’s subordination to men. This also means, in clinical practice, to promote diabetic men’s independence and teach them (and not to their non-diabetic wives) how to cook recipes suitable for diabetic people.

A third consideration concerns diabetic men’s sexual health. As I explained above, an innovative finding of this research was that men who reported experiencing diabetes-related sexual difficulties attributed their problems not only to organic factors, as the majority of literature only considers. They also believed that psychological factors could have had an impact, regardless of the presence of diabetes-related organic complications. Therefore, a possible recommendation to clinicians would be to provide also psycho-sexological support, which could help in dealing with sexual difficulties without reinforcing the hegemonic imperative of being “always ready” and “always performant” regardless of personal preferences or the relational context. Also, from the research it has also emerged that the majority of participants had incorporated traditional representations of sexuality, and medical knowledge may have contributed in such direction. A further recommendation would then be to consider subjective and relational experiences of sexuality, rather than limiting its assessment on biological and mechanical features that rely on a hegemonic ideal of male sexual health. Such approach might represent a limitation for men’s possibilities or interests in sexual practices that in some cases could be not limited to heterosexual intercourse and the centrality of erectile performance.

In this doctoral work I sought to “problematize ‘masculinity’ and ‘health’” as suggested by Robertson (2007: p. 157), under the assumption that gender, as a social structure, informs social practices and influences in many significant ways how diabetic men understand and “do” health and illness. For this reason, I claim that gender should be taken into account both in sociological research on health and illness, and in clinical practice, with the objective of expanding our knowledge on this issue and of improving men’s (and women’s) experience of health and illness.

Appendix A: Leaflet

UNIVERSITÀ DEGLI STUDI DI TORINO

SOMET
Sociology and Methodology of Social Research

UNIVERSITÀ DEGLI STUDI DI MILANO

Uomini e diabete: una ricerca sociologica sulle esperienze di chi convive con una malattia cronica

Siete invitati a prendere parte a uno **studio** sulle esperienze di chi convive con una malattia cronica, il diabete.

La ricercatrice è Valeria Quaglia, una dottoranda in Sociologia e Metodologia della Ricerca Sociale presso l'Università degli Studi di Milano e l'Università degli Studi di Torino (SOMET-NASP).
Sono invitati a partecipare alla ricerca uomini con una diagnosi di diabete, di età compresa tra i 20 e i 60 anni.

La partecipazione consisterà in un'intervista singola che potrà durare da una a due ore; le interviste potranno avere luogo presso l'Università degli Studi di Milano, presso la vostra abitazione o attraverso Skype, a seconda delle vostre preferenze.

Gli argomenti dell'intervista riguarderanno le **esperienze e la gestione del diabete nella vita di tutti i giorni**, le domande saranno aperte e si potrà, nel caso, decidere liberamente di non rispondere.

Le informazioni raccolte verranno utilizzate a scopo scientifico nel rispetto delle normative vigenti in materia di protezione e valorizzazione della proprietà intellettuale e in materia di privacy (L. 196/2003). I dati verranno usati in forma anonima attraverso l'utilizzo di pseudonimi e modificando ogni informazione identificante che potrebbe rendere l'intervistato riconoscibile.

Per partecipare alla ricerca o avere maggiori informazioni rivolgersi a:

Valeria Quaglia
Ph.D Candidate in Sociology and Methodology of Social Research
Università degli Studi di Milano, Università degli Studi di Torino
Email: valeria.quaglia@unimi.it Telefono: 3495985300

(English translation of the Italian Leaflet)

UNIVERSITÀ DEGLI STUDI DI TORINO

SOMET
Sociology and Methodology of Social Research

UNIVERSITÀ DEGLI STUDI DI MILANO

Men and diabetes:
a sociological study on the experience of who lives with a chronic illness

You are invited to take part in a **study** on the experience of who lives with a chronic illness, diabetes.

The researcher is Valeria Quaglia, a PhD student in Sociology and Methodology of Social Research at the Università degli Studi di Milano and the Università degli Studi di Torino (SOMET-NASP). **Men aged between 20 and 60, with a diagnosis in diabetes are invited to participate in the research project.**

Participation will consist in one interview that can last from 1 up to two hours; interviews can take place at the Università degli Studi di Milano, at your residence, or through Skype, depending on your preferences.

The topics of the interview will concern the experience and management of diabetes in everyday life, the questions will be open and you will be able to, eventually, freely decide not to answer.

The information gathered will be used for sole scientific purposes, in accordance to the policies of protection and valorisation of intellectual property and on the matter of privacy (L. 196/2003). The data will be used anonymously, through the use of pseudonyms and changing any identifying information that could make the interviewee recognisable.

To take part in the study or for more information please contact:

Valeria Quaglia
Ph.D Candidate in Sociology and Methodology of Social Research
Università degli Studi di Milano, Università degli Studi di Torino Email:
valeria.quaglia@unimi.it Telephone: 3495985300

Appendix B: Recruitment Invitation Poster

UNIVERSITÀ DEGLI STUDI DI TORINO

UNIVERSITÀ DEGLI STUDI DI MILANO

HAI IL DIABETE?
FAI SENTIRE LA TUA VOCE!

Se sei un uomo di età compresa tra i 20 e i 60 anni e hai una diagnosi di diabete hai la possibilità di partecipare attivamente a una ricerca sociologica.

Lo scopo della ricerca in corso è di **contribuire allo studio di questa malattia cronica in Italia**, dando voce a chi ne fa esperienza in prima persona.

La partecipazione consiste in un'**intervista** che dura circa un'ora, le domande sono aperte e si può rispondere liberamente.

Le informazioni raccolte verranno utilizzate in forma anonima a scopo scientifico nel rispetto delle normative vigenti in materia di protezione della privacy (L. 196/2003).

Per partecipare o per avere informazioni contattare:

Valeria Quaglia, Università di Milano, Università di Torino
Email: **valeria.quaglia@unimi.it** Telefono: **3495985300**
Facebook: **Ricerca sul diabete**

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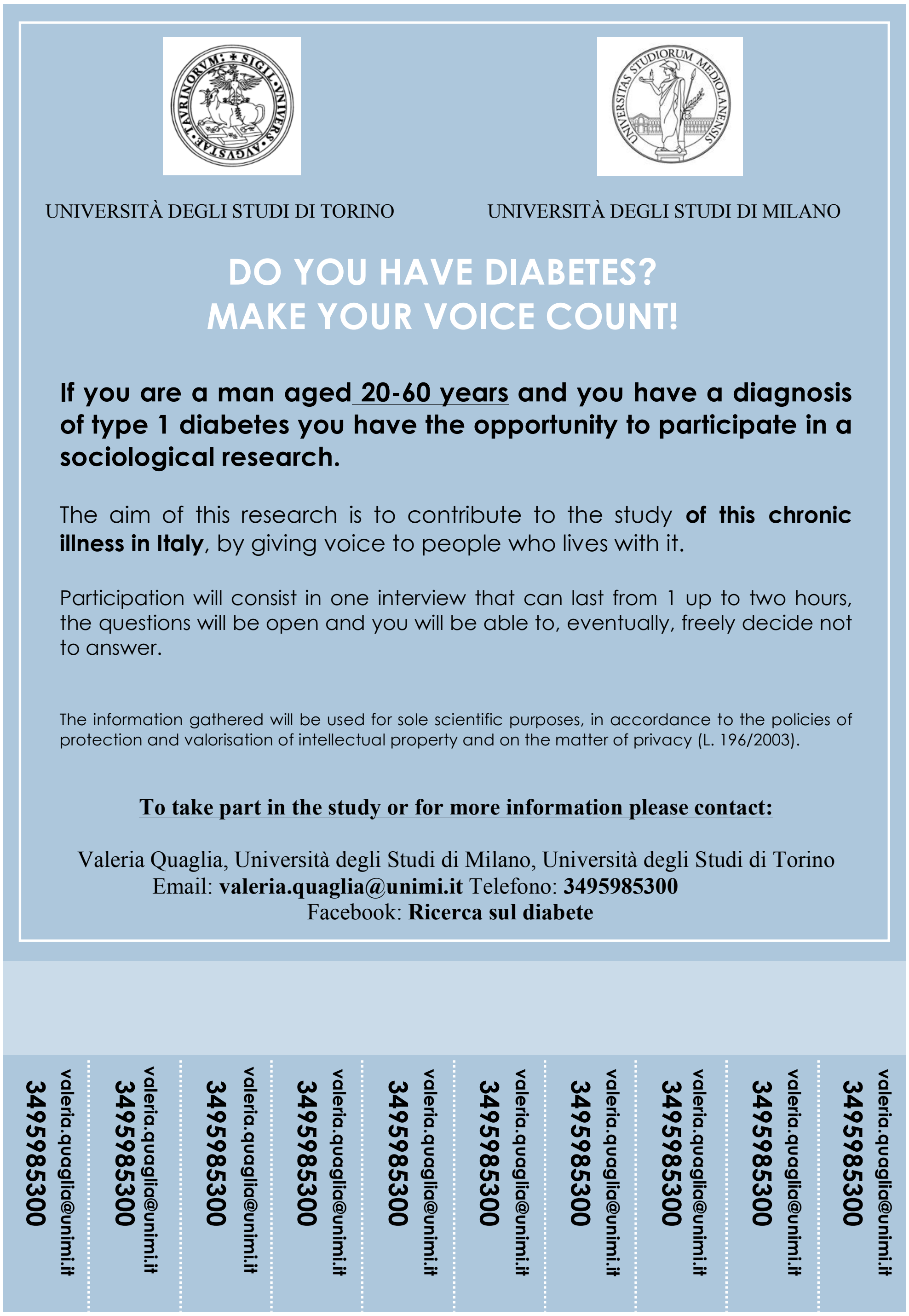
(English translation of recruitment invitation poster)



UNIVERSITÀ DEGLI STUDI DI TORINO

UNIVERSITÀ DEGLI STUDI DI MILANO

DO YOU HAVE DIABETES?
MAKE YOUR VOICE COUNT!

If you are a man aged 20-60 years and you have a diagnosis of type 1 diabetes you have the opportunity to participate in a sociological research.

The aim of this research is to contribute to the study **of this chronic illness in Italy**, by giving voice to people who lives with it.

Participation will consist in one interview that can last from 1 up to two hours, the questions will be open and you will be able to, eventually, freely decide not to answer.

The information gathered will be used for sole scientific purposes, in accordance to the policies of protection and valorisation of intellectual property and on the matter of privacy (L. 196/2003).

To take part in the study or for more information please contact:

Valeria Quaglia, Università degli Studi di Milano, Università degli Studi di Torino
Email: **valeria.quaglia@unimi.it** Telefono: **3495985300**
Facebook: **Ricerca sul diabete**

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Appendix C: Facebook Banner Advertising

UNIVERSITÀ DEGLI STUDI DI TORINO

nasp NETWORK FOR THE ADVANCEMENT OF SOCIAL AND POLITICAL STUDIES

UNIVERSITÀ DEGLI STUDI DI MILANO

SOMET Sociology and Methodology of Social Research

HAI IL DIABETE?

FAI SENTIRE LA TUA VOCE!

È attualmente in corso una ricerca che ha l'obiettivo di **contribuire allo studio del diabete in Italia**, dando voce e ascoltando le esperienze di chi ne fa un'esperienza più diretta. Puoi **partecipare alla ricerca**:

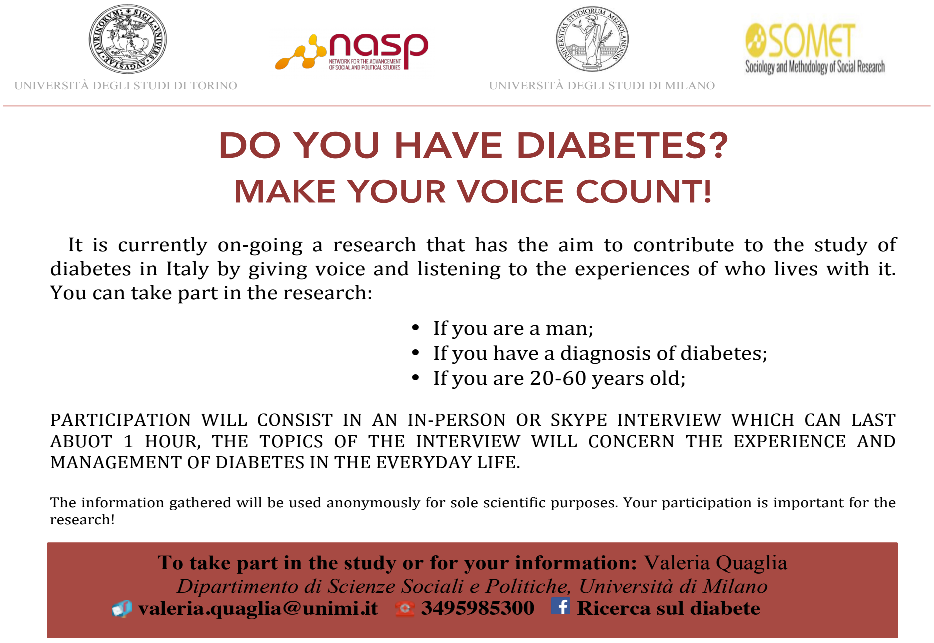
- Se sei un **uomo**;
- Se hai una diagnosi di **diabete**;
- Se hai tra i **20 e i 60 anni**;

LA PARTECIPAZIONE CONSISTE IN UN'**INTERVISTA** (DI PERSONA O ATTRAVERSO VIDEOCHIAMATA) CHE DURA CIRCA UN'ORA. GLI ARGOMENTI DELL'INTERVISTA RIGUARDERANNO L'**ESPERIENZA CON IL DIABETE NELLA VITA DI TUTTI I GIORNI.**

Le informazioni raccolte saranno trattate in **forma anonima** e verranno utilizzate unicamente a **scopo scientifico**. La tua partecipazione è un **contributo** fondamentale per la **ricerca**!

Per partecipare o per info: Valeria Quaglia
Dipartimento di Scienze Sociali e Politiche, Università di Milano
✉ **valeria.quaglia@unimi.it** ☎ **3495985300** f **Ricerca sul diabete**

(English translation of Facebook banner ad)



UNIVERSITÀ DEGLI STUDI DI TORINO

nasp NETWORK FOR THE ADVANCEMENT OF SOCIAL AND POLITICAL STUDIES

UNIVERSITÀ DEGLI STUDI DI MILANO

SOMET Sociology and Methodology of Social Research

DO YOU HAVE DIABETES?

MAKE YOUR VOICE COUNT!

It is currently on-going a research that has the aim to contribute to the study of diabetes in Italy by giving voice and listening to the experiences of who lives with it. You can take part in the research:

- If you are a man;
- If you have a diagnosis of diabetes;
- If you are 20-60 years old;

PARTICIPATION WILL CONSIST IN AN IN-PERSON OR SKYPE INTERVIEW WHICH CAN LAST ABUOT 1 HOUR, THE TOPICS OF THE INTERVIEW WILL CONCERN THE EXPERIENCE AND MANAGEMENT OF DIABETES IN THE EVERYDAY LIFE.

The information gathered will be used anonymously for sole scientific purposes. Your participation is important for the research!

To take part in the study or for your information: Valeria Quaglia
Dipartimento di Scienze Sociali e Politiche, Università di Milano
✉ **valeria.quaglia@unimi.it** ☎ **3495985300** f **Ricerca sul diabete**

Appendix D: Consent form

UNIVERSITA' DEGLI STUDI DI TORINO

SOMET
Sociology and Methodology of Social Research

UNIVERSITA' DEGLI STUDI DI MILANO

MODULO PER IL CONSENSO INFORMATO

PER L'INTERVISTATA/O

Il sottoscritta/o ____________________ ______________________
Nome Cognome

Nata/o a __________________ il ________________

AUTORIZZA
la registrazione audio dell'intervista condotta dalla Dott.ssa Valeria Quaglia e il successivo utilizzo della stessa a soli fini scientifici, nell'ambito di un progetto di ricerca che esplora le esperienze di persone che convivono con malattie croniche. La registrazione audio e l'utilizzo sono da considerarsi effettuate in forma del tutto gratuita.

Letto e approvato,

Data __________________________ **Firma _____________________________**

PER L'INTERVISTATORE

Io sottoscritta, Valeria Quaglia, dichiaro che la/il sig.ra/sig. ___________________________________ ha spontaneamente firmato il modulo di consenso informato per la registrazione audio e l'utilizzo della stessa a soli scopi scientifici, nel rispetto delle normative vigenti in materia di protezione e valorizzazione della proprietà intellettuale e in materia di privacy (L. 196/2003).

Data _________________________

Dott.ssa Valeria Quaglia
Ph.D Candidate in Sociology
and Methodology of Social Research
Università degli Studi di Milano,
Università degli Studi di Torino

(English translation of the consent form)

SOMET
Sociology and Methodology of Social Research

UNIVERSITÀ' DEGLI STUDI DI TORINO

UNIVERSITA' DEGLI STUDI DI MILANO

CONSENT FORM

FOR THE INTERVIEWEE

The undersigned, Name: ____________________ Surname: ____________________

Born in: ____________________ DOB: ____________________

AUTHORISES

the audio registration of the interview led by Dr. Valeria Quaglia and the subsequent use of it for solely scientific purposes, within the scope of a research project that explores the experience of people who live with chronic diseases. The audio registration and its use are free of charge. The gathered data will be treated anonymously and will be solely used for scientific purposes.

Read and approved,

Date ____________________ **Signature: ____________________**

FOR THE INTERVIEWER

The undersigned, Valeria Quaglia, declares that Mr/Mrs/Miss _______________________________ spontaneously signed the present consent form for the audio registration and the use of it for sole scientific purposes, in accordance to the policies of protection and valorisation of intellectual property and on the matter of privacy (L. 196/2003).

Date ____________________

Dott.ssa Valeria Quaglia
Ph.D Candidate in Sociology
and Methodology of Social Research
Università degli Studi di Milano,
Università degli Studi di Torino

Appendix E: Notation table for transcription[36]

Symbols and rules	**Examples**	**Description**
Questions & answers	**Do you think that people that don’t have diabetes understand what it is like to have it?** I don’t think so. They don’t understand it, in my experience.	The font of questions is bold, while that of the answers is normal in order to distinguish the interviewee from the interviewer.
Direct speech and polyphony	But, let’s say, people my age, they say: “But you don’t look sick, this is not true.”	When the interviewee reports direct speech (it could be the discourse of somebody else of its own in the past, or hypothetical situations).
Names	And the context is that of xxxxxxx, (city name in the North of Italy)… at the beginning of the ‘80s	In order to guarantee participants’ privacy, city names have been omitted and people’s names have been changes
Capital letters	NO WAY! Really? You don’t look it at all	Words written with capital letters transcribe parts of the discourse that have been pronounced with a particularly high tone of voice.
/ text / (whispering)	/It is better than anything else/ (whispering)	It indicates the parts of the discourse that are pronounced in a certain way (in this case, whispering)
Short pause	the heart is fine, ... the arteries are fine, ... all the rest is fine.	Ellipsis indicates a short pause (more or less 3 seconds)
Long pause	I don’t know. (Long pause) I think diabetes is a complex illness.	When the pause exceeds 3 seconds, it is expressed with “(long pause).”
[Text]	from the moment this object came out [he lifts his shirt and points to a tiny round object, attached on his belly]	Comments of the researcher

---

[36] Adapted from *Notazione Atb per la trascrizione delle interviste discorsive* (Cardano 2011; p. 301)

Appendix F: Interview guide

Durante l' intervista le farò domande di vario tipo, a cui può naturalmente decidere di rispondere o di non rispondere; tutte le informazioni saranno utilizzate in forma anonima e a solo scopo scientifico.

Vorrei che mi raccontasse la sua storia con il diabete, cominciando da dove vuole..

ESORDIO

A che età le è stato diagnosticato il diabete?

Come ha scoperto di avere il diabete?

Quale pensa sia il motivo che l'ha portata a farne esperienza?

Aveva altri problemi di salute prima della diagnosi?

DIAGNOSI

Come ha saputo di avere il diabete?

Come ha reagito alla notizia di avere il diabete?

Cosa significa per lei "diabete"? Cosa significa per lei "malattia", e cosa significa per lei invece "essere in salute"?

È stato ricoverato dopo la diagnosi?

Mi vuole raccontare un po' di questo periodo?

ADJUSTMENT

Come è cambiata, se è cambiata, la sua vita dopo la diagnosi?

(Se ha ricevuto la diagnosi da bambino) **Come è stato per lei avere il diabete durante l'infanzia?**

Come lo gestiva a casa e a scuola?

I compagni di classe lo sapevano?

(Se sì) Come si comportavano nei suoi confronti?

Il periodo dell'adolescenza spesso può essere più complicato, com'è stata la sua esperienza col diabete in quella fase della vita?

Pensa che avere il diabete abbia influenzato la sua percezione di se stesso come "uomo" durante l'adolescenza, se paragonato ai suoi coetanei? Può aver influenzato l'immagine

che gli altri avevano di lei come “uomo”? E da adulto?

Dove ha cercato/ avuto la maggior parte delle informazioni riguardanti il diabete?

(IN)STABILITA’

Il suo approccio alla malattia è cambiato nel corso della sua vita?
Ci sono stati momenti da quando le è stato diagnosticato in cui ha avuto maggiori difficoltà nella gestione quotidiana del diabete? Come mai?

Gestire il diabete può essere spesso un compito oneroso e impegnativo; lei ha mai deciso di non fare terapia insulinica? (se sì) In quali occasioni? Le è mai successo di non misurarsi la glicemia? (Se sì) in quali occasioni?

Si trova bene oggi con il piano terapeutico che le ha proposto il suo medico? Lo segue ogni giorno o fa qualche eccezione ogni tanto?

GESTIONE DEL DIABETE NELLA VITA DI TUTTI I GIORNI

Come gestisce il diabete nella vita di tutti i giorni? (Piano terapeutico: eventuali farmaci assunti, regime alimentare, esercizio fisico, autocontrollo glicemico)

In che modo la sua routine quotidiana è diversa da un ragazzo/uomo della tua età che non ha il diabete?

*****SELF-MANAGEMENT*****

Di solito quando esce di casa porta con sé qualcosa per gestire il diabete?

Tiene nota delle misurazioni di glicemia? Pensa che sia importante tenerne traccia?

Trova semplice o difficile gestire il diabete ogni giorno?

Ha mai avuto episodi di ipoglicemia/iperglicemia?

Se sì: Come li gestisce? Cosa fa per prevenirli? Si accorge quando li ha? Cosa Sente?

Le sembra di più che sia lei a controllare il diabete o che sia il diabete a controllare la sua vita?

Vuole provare a descrivermi il suo giorno tipico rispetto al diabete e alla sua gestione? Si sveglia di mattina..

*****ALIMENTAZIONE*****

Come organizza di solito i suoi pasti?
Quali sono gli alimenti che mangia di solito?
Quali sono i cibi che cerca di evitare?
Chi si occupa di solito di organizzare i pasti?

Di comprare il cibo? Di cucinarlo?

C’è differenza tra i giorni della settimana ed il weekend?

Ci sono occasioni in cui dover controllare l’alimentazione la mette a disagio?
Secondo lei, in generale, ci si aspetta che gli uomini mangino in modo diverso rispetto alle donne?

Pensiamo a una situazione ipotetica, in cui si trova a cena con altri amici, anche loro uomini, magari a vedere insieme la partita. Il menù è pizza, carne alla brace, patatine e dolce. Tutti mangiano porzioni molto abbondanti e bevono diverse birre ognuno. Lei come pensa che si comporterebbe?

*****SPORT*****

Lei pratica qualche tipo di sport?

Se sì:

-Da quanto tempo?

-Il fatto di avere il diabete ha inciso sulla sua pratica sportiva?

-Come gestisce il diabete durante l’attività sportiva?

-Quanto conta per lei, nella pratica sportiva, la competizione?

*****SOCIAL RELATIONS*****

Ha una relazione? C’è differenza tra prima e dopo l’incontro con la sua/il suo partner nella gestione del diabete?

Il diabete ha avuto qualche tipo di influenza sulla sua vita di coppia in generale?

Ricorda episodi specifici in cui è stato trattato in modo diverso dagli altri in quanto diabetico?

Da chi pensa di aver ricevuto maggiore supporto nelle diverse fasi della sua vita?

Frequenta qualche associazione o qualche community virtuale dedicata alle persone diabetiche?

Pensa che, più in generale, chi non ha il diabete si renda conto di cosa significhi?

Nel caso di molte patologie si formano dei gruppi di auto-mutuo aiuto tra pazienti che possono essere di grande supporto per le persone. Lei ha mai partecipato a un qualche gruppo con altre persone diabetiche? (Se no: sarebbe interessato a una tale esperienza? Che caratteristiche dovrebbe avere?)

ILLNESS DISCLOSURE AND STIGMA

Preferisce avere privacy quando controlla i livelli di glicemia e fa terapia (o cambia il set del microinfusore)?

A casa lo fa con altri familiari presenti o preferisce non essere in compagnia in quel momento?

Come gestisce il diabete sul luogo di lavoro/all'università? (Autocontrollo glicemia, alimentazione, assunzione farmaci..)

I suoi amici/colleghi/parenti sanno che lei ha il diabete? Di solito in quali occasioni le capita di dirlo ad altri?

Le è capitato di andare al mare con il microinfusore? Dove lo posiziona?

COMPLICANZE

Parliamo ora delle complicanze: le è capitato di avere altri problemi di salute legati al diabete?

(Se sì)

Di che tipo?

È cambiato qualcosa per lei dopo la scoperta dalla/delle complicanza/complicanze?

DIFFICOLTA' SESSUALI

Secondo le ricerche spesso il diabete può portare ad avere difficoltà sessuali, le è mai capitato?

Se sì:

-Che tipo di cambiamenti? A cosa li attribuisce?

-Cosa succede solitamente quando ha questo tipo di difficoltà?

- Il suo diabetologo/medico di riferimento le aveva anticipato la possibilità di avere difficoltà sessuali a causa del diabete? Le capita di confrontarsi con lui/lei su questo tema?

- Ha mai ricevuto una diagnosi specifica rispetto alle sue difficoltà sessuali?

- Le è mai capitato di usare farmaci o pensare di usare farmaci più specifici per la cura delle difficoltà sessuali? (Se sì: quali erano le sue aspettative prima di prenderli? Sono state soddisfatte? Ha mai considerato alternative ai farmaci per curare le difficoltà sessuali?)

- Le capita di parlare con la/il sua/o partner delle sue difficoltà sessuali?

- Le è mai capitato di parlare delle sue difficoltà sessuali con qualcuno al di fuori della coppia? (un amico, un confidente, ecc.)

Che importanza ha, secondo lei, la performance sessuale per sentirsi ed essere riconosciuti come “veri uomini”? **Come gestisce il microinfusore durante i rapporti sessuali? Pensa che farebbe diversamente se fosse la prima volta con una/o sconosciuta/o?** **Le è successo di avere problemi di ipoglicemia durante i rapporti sessuali?** **(Se sì) come l’ha gestita?** **Lei ora mi hai parlato della sua esperienza col diabete. Pensa che gli altre persone diabetiche la vivano più o meno come lei o pensa invece che ci siano molti modi diversi di vivere il diabete?**
Se lei dovesse dare dei consigli ad un ragazzo a cui è stato appena diagnosticato il diabete su come gestire questa condizione, cosa gli consiglierebbe?
Ci sono degli aspetti sul diabete che non le ho chiesto e di cui vorrebbe parlarne?

(English translation of the interview guide)

During this interview, I will ask you different kinds of questions, to which you can obviously decide to answer or not; all information will be used anonymously and exclusively for scientific purposes.
I would like you to talk to me about your story with diabetes, starting from wherever you want...
ONSET
At what age were you diagnosed with diabetes? **How did you find out you had diabetes?** **What do you think might be the reason that caused it?** **Did you have other health problems before the diagnosis?**
DIAGNOSIS
How did you find out you had diabetes? **How did you react to the news of having diabetes?** **What does "diabetes" mean to you? What does "illness" mean to you, and what does "being healthy" mean to you?** Were you hospitalised after the diagnosis? Could you tell me about this time?
ADJUSTMENT
How did your life change, after the diagnosis? (If diagnosed as a child) **How was it for you, to have diabetes during your childhood?** How did you manage it at home and at school? Did your classmates know? (If so) How did they behave towards you? **Adolescence can often be more complicated, how was your experience with diabetes in that period?** **Do you think that having diabetes affected the perception of yourself as a "man" during adolescence, compared to your peers? And as an adult?** Where did you seek/find most of the information concerning diabetes?

(IN)STABILITY

Did your approach to the illness change throughout your life?
After you had been diagnosed, were there moments in which you had greater difficulties in managing everyday life with diabetes? Why?

Managing diabetes can often be a burdensome and demanding task; did you ever decide not to follow your insulin treatment? (If so) In what occasions? Did it ever happen that you did not measure your glycaemia? (If so) In what occasions?

Now are you happy with the treatment programme proposed by your doctor? Do you follow it everyday or do you make an exception now and then?

MANAGING DIABETES IN EVERYDAY LIFE

How do you manage diabetes in your everyday life? (Treatment plan: possible medicine taken, diet, physical exercise, glycaemia self-control)

In what way is your routine different from that of a man/young man of your age who does not have diabetes?

SELF-MANAGEMENT

Usually, when you go out, do you bring something with you to manage your diabetes?

Do you keep note of your glycaemia measurements? Do you think it is important to keep track of it?

Do you find it easy or difficult to manage diabetes everyday?

Have you ever had hypoglycaemia/hyperglycaemia episodes?

If so: How do you manage them? What do you do to prevent them? Do you realise when they occur? What do you feel?

Do you think you are the one controlling diabetes more or that diabetes is the one controlling your life?

Could you describe your daily routine with regard to diabetes and its management? You wake up in the morning...

DIET

How do you usually organise your meals?
What kind of food do you usually eat?
What food do you try to avoid?
Who buys the food, usually? Who cooks it?

Is there a difference between the weekdays and the weekend?

Are there any instances when eating makes you feel uncomfortable?

Do you think that, generally, men are expected to eat differently compared to women?

Let's imagine a hypothetical situation, in which you're having dinner with some friends, also men, maybe to watch a football match. The menu includes pizza, grilled meat, chips and dessert. Everyone is eating a lot and they are all drinking several pints of beer each. How do you think you would behave?

*****SPORT*****

Do you play any kind of sport?

If so:

-When did you start?

Did having diabetes affect your sports practice?

-How do you manage diabetes during sports activities?

-How much does competing mean to you in sports?

*****SOCIAL RELATIONS*****

Are you in a relationship? Is there any difference in the management of diabetes between before you had met your partner and after?

Has diabetes had any kind of influence on your life as a couple, in general?

Do you remember any specific episodes in which you were treated differently because of your diabetes?

From who do you think you have received the most support in your different life stages?

Do you attend any association meeting or virtual community dedicated to diabetic people?

Do you think that, in general, who does not have diabetes understands what it means?

For many pathologies, self-help groups are formed by patients who can be of great help to people. Have you ever taken part in a group with other diabetic people? (If not: Would you be interested in such an experience? What characteristics should it have?)

ILLNESS DISCLOSURE AND STIGMA

Do you prefer privacy when you check your glycaemia levels and you take your medication (or change the insulin pump set)?

At home, do you do it in presence of other family members or do you prefer to be alone in that moment?

How do you manage diabetes on the workplace/at university? (Glycaemia monitoring, food, medication...)

Do your friends/colleagues/relatives know that you have diabetes? Usually in what occasions does it happen to you to tell others?

Have you ever been to the sea with the insulin pump? Where do you leave it?

DIABETES-RELATED COMPLICATIONS

Let’s talk about complications: have you ever had other health problems related to diabetes?

(If so)

What type of complication?

Has something changed for you after discovering you had diabetes-related complication?

SEXUAL PROBLEMS

According to research, diabetes can often lead to sexual problems – have you ever had any?

If so:

- What kind of changes? To what do you attribute them?

- Usually, what happens when you have these kinds of problems?

- Did your diabetologist/GP mention the chance of having sexual problems related to diabetes? Do you ever discuss this matter with him/her?

- Have you ever been given a specific diagnosis for your sexual problems?

- Have you ever used or thought of using more specific drugs to treat your sexual problems? (If so: what were your expectations before taking them? Were these expectations met? Have you ever considered alternative methods to treat your sexual problems?

- Do you ever talk to your partner about your sexual problems?

- Have you ever talked about your sexual problems with someone outside the couple? (a friend, a go-to person, etc.)

- In your opinion, what importance does sexual importance have in feeling and being recognised as “true men”?

How do you manage your insulin pump during sexual relations? Do you think you would do this differently if it were the first time with somebody new?

Have you ever had hypoglycaemia problems during sexual relations? **(If so) how did you handle them?** **You have talked to me about your experience with diabetes. Do you think other diabetic people experience it more or less in the same way as you do or do you think that there are many different ways to experience diabetes?**
If you had to give some advice to a young man who has just been diagnosed with diabetes about how to manage this condition, what would you advise?
Are there any aspects of diabetes I have not asked you about and you would like to discuss?

Appendix G: Socio-demographic questionnaire

UNIVERSITÀ DEGLI STUDI DI TORINO   SOMET Sociology and Methodology of Social Research   UNIVERSITÀ DEGLI STUDI DI MILANO

QUESTIONARIO SOCIO-DEMOGRAFICO

I dati raccolti con il presente questionario saranno **trattati in forma anonima** e verranno utilizzati, nel rispetto delle normative vigenti in materia di protezione e valorizzazione della proprietà intellettuale e in materia di privacy (L. 196/2003), all'interno di una ricerca sociologica sulle esperienze delle persone che convivono con malattie croniche, condotta dalla Dott.ssa Valeria Quaglia, dottoranda in *Sociology and Methodology of Social Research* presso l'Università degli Studi di Milano e l'Università degli Studi di Torino.

Grazie per la cortese partecipazione.

Anno di nascita : ____________________

Luogo di nascita: ____________________

Stato civile: ☐ Sposato ☐ Convivente ☐ In una relazione senza convivenza
☐ Single ☐ Divorziato ☐ Vedovo ☐ Altro (specificare:_______________)

Figli: ☐ No ☐ Si: Quanti? ________

Tipologia zona di residenza: ☐ Città (più di 100 mila abitanti) ☐ Cittadina (tra 10mila e 50mila abitanti) ☐ Paese (meno di 10mila abitanti)

Ultimo titolo di studio ottenuto: ☐ Licenza Elementare; ☐ Media inferiore; ☐ Media superiore;
☐ Laurea; ☐ Post-laurea.

Professione:
☐ Impiegato; ☐ Operaio; ☐ Dirigente; ☐ Commerciante;
☐ Artigiano; ☐ Libero professionista; ☐ Imprenditore; ☐ Insegnante;
☐ Pensionato (indicare ultima professione svolta__________________);
☐ Studente;
☐ Disoccupato (indicare ultima professione svolta__________________);
☐ Altro (specificare:____________________________).

Diagnosi attuale:
____
____
____
____
____

Età al momento della diagnosi: ____________

Piano terapeutico attuale (Eventuali farmaci assunti, regime alimentare, esercizi fisici specifici...):

Altre patologie al momento della diagnosi:

Altre patologie successive alla diagnosi:

Complicanze legate al diabete (ovvero: tipo di complicanza, quando è comparsa..)

A quale tipo di specialisti ha fatto riferimento per la gestione del diabete? (Ad esempio: diabetologo, medico di famiglia, nefrologo, urologo, psicologo..):

(English translation of the socio-demographic questionnaire)

UNIVERSITÀ DEGLI STUDI DI TORINO

Sociology and Methodology of Social Research

UNIVERSITÀ DEGLI STUDI DI MILANO

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

The data gathered through the present questionnaire will be **treated anonymously** and will be used, in accordance to the policies of protection and valorization of intellectual property and on the matter of privacy (L. 196/2003), within a sociological research project about the experience of people living with chronic diseases, conducted by Dr. Valeria Quaglia, PhD student in *Sociology and Methodology of Social* Research at the Università degli Studi di Milano e l'Università degli Studi di Torino.

Thank you for your participation.

Date of birth _: ______________________

Place of birth: ______________________

Marital status: ☐ Married ☐ Cohabiting ☐ In a relationship without cohabitation
☐ Single ☐ Divorced ☐ Widowed ☐ Other (please specify:_________________)

Children: ☐ No ☐ Yes: How many? ________

Area of residence: ☐ City (more than 100,000 inhabitants) ☐ Small City (10,000-50,000 inhabitants) ☐ Town (less than 10,000 inhabitants)

Highest qualification: ☐ Elementary school; ☐ Middle school; ☐ High school; ☐ Degree; ☐ PG degree.

Occupation:
☐ Employee; ☐ Labourer; ☐ Director; ☐ Salesman;
☐ Artisan; ☐ Private practice; ☐ Entrepreneur; ☐ Teacher;
☐ Pensioner (please indicate your previous job: ____________________);
☐ Student;
☐ Unemployed (please indicate your previous job: ____________________);
☐ Other (please specify:________________________________).

Current diagnosis:
____
____
____
____
____

Age at the time of the diagnosis: _____________

Current treatment plan (Medication, diet, specific physical exercise...):

Other pathologies at the time of the diagnosis:

Other pathologies after the diagnosis:

Complications related to diabetes (type of complication, when it emerged...)

What type of professionals did you refer to, to manage diabetes? (For example: diabetologist, GP, nephrologist, urologist, psychologist..):

Appendix H: Online article on this research

Uomini con diabete: ricercatrice in Sociologia raccoglie interviste[37]

Il diabete non è certo un tema da affrontare solo da un punto di vista strettamente medico. Scienze Sociali e Medicina possono collaborare verso un comune obiettivo: comprendere l'esperienza di chi convive con patologie croniche, e impegnarsi ad analizzarne gli specifici bisogni. Un impegno concreto in questo senso è dato dalla ricerca di Valeria Quaglia, una giovane dottoranda in Sociologia e Metodologia della Ricerca Sociale all'Università degli Studi di Milano e all'Università degli Studi di Torino. Una ricerca per cui **è richiesta la preziosa partecipazione di un campione di uomini con diabete, di età compresa tra i 20 e i 55 anni.**

Gli uomini con diabete di tipo 1 e 2 che rientrano nella fascia d'età indicata potranno partecipare a una **serie di interviste a scopo scientifico** centrate sull'impatto della patologia sul vissuto. Si tratterà di un'**intervista singola, anonima, che potrà svolgersi all'Università degli Studi di Milano, nell'abitazione del paziente, o anche attraverso Skype.**

Gli argomenti dell'intervista riguarderanno la **gestione del diabete** nella vita di tutti i giorni. A spiegare i motivi dell'importanza di un'analisi scientifica del tema sono innanzitutto i dati.

"Secondo la rilevazione dell'Istituto Nazionale di Statistica (Istat) del 2015 – spiega la Dr.ssa Quaglia – il diabete si qualifica come una delle condizioni croniche più diffuse in Italia, che coinvolge il 5,4% della popolazione italiana. Vale a dire: circa 3 milioni di persone. Sia secondo i dati delle ricerche italiane, sia secondo i dati internazionali, il numero di persone con il diabete è in costante aumento. Si tratta quindi di una condizione cronica vissuta da un numero sempre più elevato di persone, che quindi richiede l'**attenzione della ricerca scientifica su diversi fronti: prevenzione, cura, ma anche gestione della malattia nella vita di tutti i giorni**".

Quali sono gli obiettivi? La gestione quotidiana della patologia è appunto il focus della ricerca. "Partiamo da una definizione di malattia – specifica la ricercatrice – che comprende un insieme complesso di condizioni biologiche e sociali, organiche e culturali". È quindi fondamentale un **approccio interdisciplinare**, in grado di analizzare l'intreccio di fattori che rende l'impatto del diabete una "biological disruption". Ovvero un "punto di discontinuità" nel percorso di vita delle persone, capace di segnare un "prima" e un "dopo" la diagnosi. Il fatto che il campione interessato sia di soli uomini con diabete, risponde al fatto che la ricerca si inserisce nei cosiddetti *Men's Health Studies.* Ovvero studi dedicati alla specificità dell'esperienza maschile di malattia, e ai complessi modi in cui gli uomini vivono e costruiscono le loro identità in rapporto ad essa.

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[37] The original article, written by Aura Tiralongo, can be found at: http://www.diabete.net/uomini-con-diabete-ricerca-in-sociologia/news/attualita/42491/ last viewed on 23/09/2018.

Le informazioni saranno raccolte in forma anonima, e verranno utilizzate per contribuire alla conoscenza e allo studio del diabete a partire dalla voce di chi ne fa un'esperienza più diretta. **È invitato a partecipare sia chi con il diabete convive da più tempo, come in molti casi di diabete di tipo 1, sia chi ha avuto l'esordio in età più adulta, come in molti casi di diabete di tipo 2**.

Tutti gli uomini interessati a **partecipare alla ricerca**, o desiderosi di avere maggiori informazioni, possono rivolgersi a:

Valeria Quaglia – Ph.D. Candidate in Sociology and Methodology of Social Research
Università degli Studi di Milano, Università degli Studi di Torino
Email: valeria.quaglia@unimi.it

(English translation of the online article on this research)

Men with diabetes: Researcher conducts interviews

Diabetes is certainly not a matter to face only from a strictly medical point of view. Social Sciences and Medicine can collaborate towards a common objective: to understand the experience of who lives with chronic illness and to seek to analyse their specific needs. A practical commitment on the matter is provided by researcher Valeria Quaglia, a young PhD student in Sociology and Methodology of Social research at the Università degli Studi di Milano and Università degli Studi di Torino. A study which **requires the valuable participation of a sample of men with diabetes, aged between 20 and 55.**

Men with type 1 or type 2 diabetes who are within the indicated age range will be able to participate in **a series of interviews with scientific intent**, focused on the impact of the pathology on what is experienced. This will involve **a single, anonymous interview, which can take place at the Università degli Studi di Milano, at your residence, or through Skype, depending on your preferences.** The topics of the interview will concern the **management of diabetes** in everyday life. Above all, statistics show the importance of a scientific analysis on the matter: "According to reports from the National Statistics Institute (Istituto Nazionale di Statistica, Istat) in 2015 – as Dr. Quaglia points out – diabetes qualifies as one of the chronic conditions that are the most common in Italy, which affects 5.4% of the Italian population. That is to say, about 3 million people. According both to the data of Italian research, and to international statistics, the number of people with diabetes is constantly increasing. It is therefore the case of a chronic condition that is experienced by an increasing number of people, which consequently requires **the attention of scientific research on different aspects: prevention, treatment, but also illness management in everyday life**".

What are the objectives? As previously mentioned, everyday management of the illness is the main focus of the study. "We stem from a definition of illness – the researcher specifies – which includes a complex ensemble of social and biological, organic and cultural conditions". Therefore, an **interdisciplinary**

approach is fundamental, which is able to analyse the entanglement of factors that make the impact of diabetes become a "biological disruption." That is to say, a "discontinuity" in people's life, which allows for the marking of a time "before" and "after" the diagnosis. The fact that the sample considered is that of only men with diabetes is due to the fact that the study is part of the so-called *Men's Health Studies*. That is to say, studies focused specifically on the male experience of illness, and on the complex ways in which men live and build their identity in relation to it.

The information will be gathered anonymously, and it will be used to contribute to the knowledge and the study of diabetes, starting from the account of who experiences it directly. **The researcher is seeking both people who have lived with diabetes for a long time, as in many cases of type 1 diabetes, and those who have had their onset at a later age, as in many cases of type 2 diabetes**.

Anyone who is interested in **participating in the study**, or who wants to receive more information can contact:

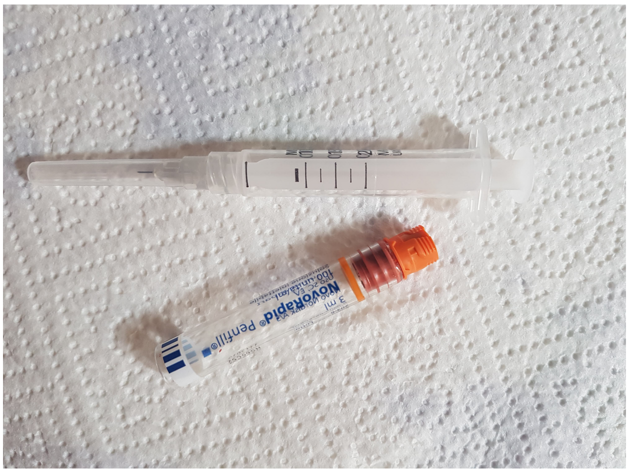
Valeria Quaglia – Ph.D. Candidate in Sociology and Methodology of Social Research
Università degli Studi di Milano, Università degli Studi di Torino
Email: valeria.quaglia@unimi.it

Appendix I: Illustrative Images

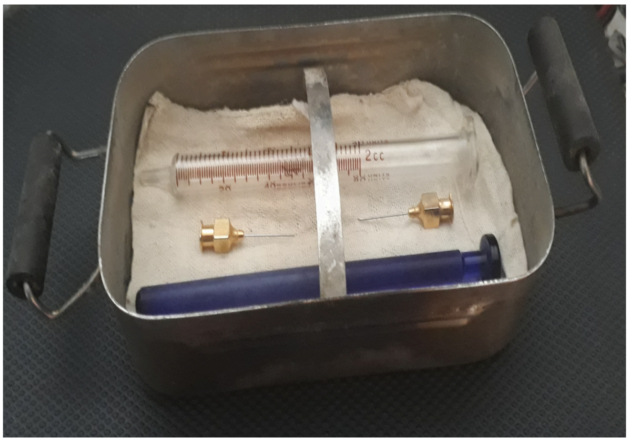
Picture (a): Tubeless continuous glucose monitor and insulin pump.

Picture (b): Diabetes "kit". From the left: mobile phone with glycaemic trend, which is connected with the continuous glucose monitor; "Glucosprint," a food supplement containing glucose, to use in the event of hypoglycaemia; "Personal diabetes manager," it is a handheld that manages the administration of insulin of the insulin pump; sugar packets.

Picture (c): Traditional glucose meter, blood glucose test strips, insulin pen.



Picture (d): Traditional disposable syringe for insulin injections



Picture (e): Glass syringe (no longer used for contemporary diabetes self-management)

Appendix L: Sociodemographic characteristics of participants

Pseudonyms	Age	Sexual orientation	Marital status	Level of Education	Occupation	Diagnosis	Age at the onset
Alberto	43	Heterosexual	Married	Degree	Employee	T1D	28
Alessandro	46	Heterosexual	Married	High School	Employee	T1D	3
Alessio	42	Heterosexual	Cohabiting relationship	High School	Employee	T1D	13
Amedeo	50	Homosexual	Single	High School	Contractor	T1D	30
Cristian	43	Heterosexual	Married	High School	Manager	T1D	10
Damiano	58	Heterosexual	Married	High School	Manager	T1D	33
Diego	23	Heterosexual	Single	High School	Confectioner	T1D	4
Edoardo	53	Heterosexual	Married	High School	Labourer	T1D	3
Elio	29	Homosexual	Single	High School	Shop assistant	T1D	24
Emanuele	43	Heterosexual	Non-cohabiting relationship	High School	Employee	T1D	16
Enzo	40	Heterosexual	Married	Ph.D.	Physics researcher	T1D	15
Filippo	34	Heterosexual	Single	Degree	Nurse	T1D	14
Flavio	41	Heterosexual	Married	Degree	Psychoterapist	D. Lada	36
Francesco	51	Heterosexual	Cohabiting relationship	High School	Employee	T1D	3
Gioele	39	Heterosexual	Cohabiting relationship	Degree	Employee	T1D	12
Giovanni	32	Heterosexual	Single	High School	Unemployed	T1D	31
Igor	31	Heterosexual	Married	High School	Shop assistant	T1D	28
Ilario	28	Heterosexual	Cohabiting relationship	High School	Shop assistant	T1D	5
Ivan	52	Heterosexual	Married	High School	Manager	T1D	52
Leonardo	52	Heterosexual	Married	Degree	Architect	T1D	4
Liam	24	Heterosexual	Cohabiting relationship	High School	Shop assistant	T1D	18
Lucio	38	Heterosexual	Cohabiting relationship	High School	Entrepreneur	D. Lada	38
Manuel	28	Heterosexual	Single	High School	Employee	T1D	16
Martino	34	Heterosexual	Single	Middle school	Farmer	T1D	8
Massimiliano	40	Heterosexual	Multiple relationships	Ph.D.	Chemistry researcher	T1D	4
Massimo	59	Heterosexual	Married	High School	Retired (ex employee)	T1D	30
Matteo	58	Heterosexual	Widowed	High School	Retired (ex labourer)	T1D	5
Nicola	23	Heterosexual	Non-cohabiting relationship	Degree	University student	T1D	13
Paolo	33	Heterosexual	Non-cohabiting relationship	High School	Labourer	T1D	20
Pasquale	47	Heterosexual	Married	Degree	Architect	D. Lada	30
Patrizio	44	Heterosexual	Cohabiting relationship	Degree	Employee	D. Lada	38
Pietro	27	Heterosexual	Non-cohabiting relationship	Degree	Musician	T1D	16
Raimondo	57	Heterosexual	Married	High School	Retired (ex military)	D. Lada	37
Renato	56	Heterosexual	Married	High School	Entrepreneur	T1D	37
Ronaldo	46	Heterosexual	Married	Degree	High school teacher	D. Lada	39
Sebastiano	33	Heterosexual	Cohabiting relationship	High School	Surveyor	T1D	31
Silvio	50	Heterosexual	Married	High School	Employee	D. Lada	35
Simone	53	Heterosexual	Married	High School	Touristic guide	T1D	9
Tommaso	53	Heterosexual	Single	High School	Employee	T1D	3
Vito	30	Heterosexual	Single	High School	Shop assistant	T1D	23

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