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ECOLOGIES OF CARE

Invisible work and knowledge in diabetes care

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Le cicatrici
in fondo
son poco e tanto
di quell'alterno sgomento,
che di pari forza
e slancio
ti ricordan chi sei

e quando cambia il vento

Marti Bas, *Farsi DiVersi*, *RaccontiInVersi*, Edizioni Inaudite, 2018

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“To light a candle is to cast a shadow”

Ursula Le Guin, *A Wizard of Earthsea*

INTRODUCTION

Anselm Strauss, a landmark figure for any scholar engaging with chronic illness and sociology in general, died in September 1996 at the age of 80. Susan Leigh Star, one of the pioneers of Science and Technology Studies, was Strauss' student and friend. At the time of his death, they were writing an article together that has been fundamental for this research and for the discipline in general: "Layers of Silence, Arenas of Voice: The Ecology of Visible and Invisible Work" (Star and Strauss 1999). Both Strauss and Star have been very interested in looking at invisibility, at that which is left un-noticed and un-seen, and its consequences. Strauss left us paramount concepts such as "trajectory" or patients' "chronic illness work", a labour that must be performed in the background in order to cope with chronic illness. In the 70s and 80s, the trajectories of chronic illnesses viewed through the lens of work, family and the patient's own body were almost completely unstudied; Star has been working her whole career to render visible the violence behind standards and protocols, but she has also pointed out the spaces in which resilient and synergic interdependent relationships are negotiated through "boundary objects", creating new possibilities and new "ecologies". When they first met in the late 70s, Star was a young student interested in radical feminist works who had just moved to San Francisco. These were the years of invisible work coming to the surface from different disciplines and social movements. In the acknowledgements she wrote for him, Star vividly describe the exact moment they met and the way that, over time, he became a sounding board for her thinking and her struggles, a role that he continued to play until the very end of his life. I like to think about this article they wrote together, critically examining the consequences of invisible work, as an object that speaks for their relationship as well: an invisible thread that lasted more than twenty years, made of endless conversations at the office, in the car, with Susan Leigh Star driving since Strauss was chronically ill, or at Strauss' home together with his wife, who was always welcoming towards his community of scholars. I like to think about the story of their collaboration and friendship as a story of care.

Care is everywhere. It is the invisible thread that binds people together or pushes them further apart; care causes people to argue about what it is good and bad, about what would be good to do but is actually not possible. Care is what makes people feel safe and loved, or abandoned, abused, and neglected. Because care is invisible but pervasive, it is not easy to define or locate it. When I first encountered chronic illness, I felt that different worlds of care were melting and creating new challenges: the good care forged within relationships through negotiation, communicating feelings and all the daily activity involved in making *good* care requires formatting. In the context of chronic illness, clinical care bursts violently onto the stage. It brings new codes of behaviour to learn: what good patients are expected to do, how they should interact and what they should pay attention to, what they need to change in daily life. Further, clinical care brings new actors that demand space: pills, different types of professionals, and other people with the same illness, but also different objects, a different perception of time, space, and the body. From that moment on care needs to adjust again as it had so many times before, adapting to what makes the individual feel good as a person who is cared for and as a caring person. If this is true of chronic illness, it is even more true of diabetes. Diabetes disrupts almost every aspect of daily life, from the morning's breakfast to the night's sleep. It permeates all the daily practices that people do with others, such as eating, going out, having lunch at work, going to the bathroom to inject insulin when at the restaurant, checking glucose levels before going for a run, and alerting friends and colleagues in case of hypoglycaemia. These are only few examples of the daily aspects of living with diabetes, examples which show how the person with diabetes holds the responsibility for care in their hands. Diabetic patients are asked to change their diet and nutrition, to engage in sport and physical exercise, to correctly follow the assigned treatment, to learn how to measure and count. All in order to keep their sugar levels balanced, never too high or too low, they are asked to respect medical check-ups, diagnostic programs, supplies of drugs and therapeutic aids, record the biometric parameters as assigned by the diabetes team. In the case of diabetes, this is considered the best care possible. The first time I encountered diabetes and came face to face with diabetes care, I had the impression that it was very complicated. The pressure on patients is very high, not only in terms of clinical care but in terms of other significant forces as well. Diabetes still sails on bulky metaphors: it is still the illness of the greedy, the glutton, the overly-emotional person. The pressure to do good care is not easy to locate, with diabetes. All the aspects of care as well as the power relations that care puts in place must be constantly scanned and fixed: how should I take care of my sugar levels? Is this too much control? Or too little control? Who takes care of food, who *needs* to take care of food; and if I change my daily actions, am I still the same person?

Invisible care has always been relegated to the private domain. In academia, care has received little scholarly attention and even then, only after the 1950s, in the wake of feminist works, disability studies, and the sociology and anthropology of medicine. The feminist care ethics tradition was the first to provide a set of definitions of care that influenced later sociological, philosophical and political literature. The studies and debates generated in the last decades of the last century have pointed out that care can be analysed in terms of its materiality. Care is not innocent; it is constructed on the basis of hierarchies in which the autonomous, independent subject sits at the top and the dependent, passive subject at the bottom. Within this hierarchy, the intersection of gender, race and class determine the social position of the people involved in caring relationships. Conflicts and tensions around care reveal the power relations through which care is maintained, transformed, and adjusted. Questions such as who constitutes an object of care and who does not, who has the power to care and how should care be administered, are highly relevant in this field. The feminist tradition of care ethics has contributed to untangling these questions with the notion of *interdependency*. This concept has the advantage of giving shape to all the relationships that care sustains and, in so doing, disrupting the hierarchical construction of care by pointing out how care, in its different forms and on a daily basis, moves back and forth among the people who give and receive care. Feminist ethics has also pointed out that care has ethical and moral dimensions which have to do with the way we want to interact with, and relate to, others. How we define and imagine care therefore has important moral and political implications. The work of Hochschild has furthermore revealed the role of the emotion management of care in both family life and working life. The close link between emotion management and the situated ethics of care can be highlighted using care practices. The value of this early feminist work on care is of paramount importance for this research, as for the sociology of health and illness more broadly.

The aim of the first three theoretical chapters is to reconstruct the concepts and definitions of "care" and "care practices", from the first feminist care ethics literature to relational materialist approaches, with the purpose of situating care practices at the intersection of family, gender and medical practices. The concept of care practices, it is argued, can be used to look at the way care is *done* in different contexts. It allows us to approach care as a relational practice. Sociological investigations into care must take into account these complexities while focusing on care as practice or, in other words, on the way we *do* care as practice, the way we do care for each other. Applying the concept of practice brings with it several advantages. First of all, care practices are an extraordinary portal onto relationships, whether they be family, kin, friendships, or relatedness. Care practices are intertwined with family and gender practices in many ways, with care expressing family values, affect and feelings. Care is also a fundamental mechanism of display (for actions which are self-explanatory). The literature concerning food, eating practices and body care has grounded care as an effective display mechanism of family life. It is important to note that, for the purposes of this analysis, family is understood in broad terms, not only the family unit but also friends, both kinship-based and beyond, to include more general relatedness. The sociological literature has already highlighted the fact that care weaves relationships of support and commitment. The concept of practices itself has the advantage of paying attention to both socio-material practices, and the ethics and moral landscapes associated with attachment, love and well-being in daily care. How people *do* care tells us a lot about how people want care in relationships, how they position themselves within a hierarchy of care and how they reconstruct it on a daily basis. In other worlds, how emotion management operates in situated contexts of care. Finally, using the concept of care practices has the advantages of exploring care in multiple spaces, from the domestic to the clinic, and of including materials as active agents and participants in practice. We need to include care and cure. To do so, the literature on chronic illness is of paramount importance in this research in that it enormously enriches the sociological literature on care.

This intersection of the literature on care with the body of literature on health and illness give rise to a concept of care that can be applied to multiple spaces. Observing care practices in multiple spaces has the potential to reveal how family, care, gender and medical practices intersect in daily life. The literature on care has shown the hidden work of care and the power relations embedded in care; chronic illness literature has also uncovered the different types of (invisible) work that people dealing with a chronic disease have to carry out every day in order to maintain and construct their identity, life and social relationships. Chronic illness practices therefore have a multi-stranded connection with care and family practices, and a concept of care that includes these contributions can be used to look at the work of people with chronic illness in multiple contexts. Alongside the debates on care, the literature on chronic illness has drawn attention to the experiences of people who are "cared for"/ "patients", thereby overturning the image of the patient as passive and dependent. Instead, as these studies show, chronic illness work encompasses a series of activities, both emotional and physical, that consume the daily life of the patient; the people being cared for, for their part, actively construct and transform their surroundings. It is care work as chronic illness work, in other words. There are similarities between the concept of care and chronic illness work: an analysis of care practices in different contexts must pay attention to the power relations embedded in care by looking at the way care circulates between people (interdependency) complete with its ethical and emotional components.

One of the most urgent issues in the sociology of health has been the question of the disease/illness divide. This debate has cut across all of the medical sociological and anthropological literature in the last few decades, trying to grapple with the limits of knowledge for the sociology of health and its relationship with medicine. For a long time, while the realm of illness was an arena for exploring the patient's experience, biomedicine, the realm of disease, was cut off from sociological investigation. Constructionist approaches challenged this dichotomy by pointing out that both illness and disease are socially constructed. The third chapter illustrates how the concept of medical practices has emerged from an overcoming of the illness/disease dichotomy, giving rise to an approach, grounded on relational materialities, that looks at the relationships between situated practices in which biomedicine, biographies and other worlds interact, or, as Mol would say, the "logics embedded in practices". When care is analysed in practice, the tensions linked to complexities, power relations, embodied situated knowledge, ethical and affective dimensions rise to the surface. Through "praxiography", relational materialist approaches are interested in the way people *do* care in multiple places. Care practices inform both family and medical practices in situated interactions with different agents: humans, materials, emotions, the senses and the environment. Since socio-materialist accounts of practice treat practices as containing embedded empirical ethics and address both material and discursive relations, to explore practices is to explore situated care ethics, the production of relations in which humans, objects and technologies alike are the effects or "achievements" of these practices. Sociology of health and STS are a shared space in which socio-material approaches and practice theories give visibility to care, to how it circulates and produce knowledge, conflicts and relationships.

The fourth chapter explores a specific chronic illness: diabetes. In the first part of the chapter, I explore how diabetes has been described in the last few decades as a "lifestyle disease" and "non-communicable disease" that must be tackled with preventive medicine. Diabetes is an interesting case and one that is garnering increasing attention. The transformation of the disease itself has taken place over the course of only one century, completely transforming humans' coexistence with the illness. Diabetes went from a deadly disease to a lifestyle disease that can be managed and adapted. Since most of the daily care must be carried out by patients themselves, the care work and chronic illness work of patients and their relational arena become central. Indeed, diabetes care has a profound relational dimension. Diabetes can be contextualized through its current biomedical classifications, WHO description and broader sociological readings of risk, preventive medicine and lifestyle. Furthermore, recent scholarly attention to (lay) expert knowledge, especially due to the employment of certain kinds of patients in diabetes care, have shown the complex intertwinement of emotional, care and chronic illness work associated with patients as citizens and consumers. I therefore argue that all of these dimensions of care need to be considered when looking at situated care practices. While sociological approaches on risk have pointed out that biomedicine narratives and practices on risk and prevention have become pervasive in orienting current practices of subjectification, a focus on patient knowledge grounded in care practices, materialities and relationships bring to light the complexities of care, highlighting instances of daily negotiation, resistance and knowledge production.

In order to explore care practices within diabetes care in multiple spaces, I decided to follow the emblematic case study described in chapter four: the case of the Emilia-Romagna Region, in Italy.

In chapter six, I explore the process of becoming a competent citizen and how “citizenship” constitutes the framework outlining an ideal model of patient-citizen that patients are asked to follow. At the same time, however, it also offers a framework for mobilization as well as the circulation and production of knowledge which, as the data shows, goes beyond the purely experiential to also affect scientific production.

In chapter seven, care practices are brought into view. Practices such as eating, physical activity and therapy (treatment), the three pillars of diabetes care that involve a diverse range of people, objects, apparatuses and environments, are explored in their relational dimensions. Because care only exists within relationships, tensions and conflicts emerge around biomedical concepts as lifestyle and self-care that render relationships invisible. The ethnographic material points out that intersections of gender, illness and class have a cumulative effect in producing care, emotion and chronic illness work. In this chapter, different types of work are also explored as they appear in both individual stories and the findings of ethnographic participant-observation of collective practices of eating and walking. In this context, collective practices are a space for producing, and tinkering with, identities and knowledge that can circulate and be used to make *good* care.

In last chapter I analyse training and educational practices as practices of collaboration carried out in multiple spaces by expert patients and some professionals. These collaborative practices show how patient knowledge exists only through relationships, created and circulating in vast ecologies through nodes, shared practices, and objects. Patient knowledge does not consist in a discrete body of knowledge and neither is it merely experiential in nature. Rather, it includes translation, orientation and relationship-making practices. This knowledge is directed towards the search for *good* care and the making of *good* care, not as a normative style but in situated contexts. The knowledge embedded in expert patients in this situated context does not exist by itself; it is sustained through relationships and the uses people make of it vary according to the situated context. Care therefore plays a paramount role in producing science and knowledge. In order to highlight the role of care and its capacity to foster communities of practice, in the conclusion I have employed the metaphor of “ecologies of care”.

CHAPTER 1– CARE PRACTICES

FROM INVISIBLE TO VISIBLE CARE WORLDS

Care became a key concept in sociology after the appropriation, by feminist scholars and activists, of issues such as housework, women employment and domestic violence. Ann Oakley opened "the sociology of housework" (1979) with an attack on the treatment of women in sociology, who, like ghosts, shadows and stereotyped characters, were invisible in methodological work in sociology, but over represented in sociology of the family, portrayed reflecting other people's theories about them, instead of their own experiences. In the same years, feminist ethics of care's authors in particular have initiated a debate on care, by pointing out that care is not confined in the realm of the private but invests the whole society (Gilligan 1982, Tronto 1993). Care has material characteristics, as work, and from them there is the need to start, bringing them into surface, with a process of de-naturalization of care. According to these authors, care needs to become visible, constructions of care need to emerge in order to reveal multiple oppressions in society. The aim was to place care from hidden to central in social, economic and political life.

The studies that follow in this section contributed to a further conceptualization of care, enriched by different and sometimes opposing positions which highlighted the complexities and power relations within care relationships. They showed that care is constructed according to axes of gender, class, ability and race. The construction of care only emerges after questioning the "naturality" of care and its connection with love and family. Care has dimensions of power that confine care work in hierarchies according to which care work may grant visibility, values, recognition. These contributions highlighted the interdependent and relational character of care and the embodied and situated ethics of care. An analytical concept of care needs to account for these issues and dimensions in order to look at care as a practice. The concept of *care practice* has helped to look at dynamics of care work and care in action.

CARE AS AFFECTION OR CARE AS WORK?

From the 1980s the attention has been directed to the extending of the boundaries of concepts of care, by redefining what care is and what counts as care work, the social status of care giver and care receiver (Thomas 1993).The 80s have been a very dense decade for a denaturalization of the concept of care by problematizing the different positionalities of the caring positions, the consequences of its material and emotional components. These works attempted to conceptualize care by defining it either as love and affection (Graham 1983, Gilligan 1982), "tending" to others (Parker 1981) or care as "work".

Graham's work played an important role in powering up the feminist thinking of care in these years. In "Caring: a labour of Love" (1983) she identified care with the gendered identity of the carer, associating care with the "private places where intimate relationships with women are found" (p. 16). According to Graham, care is a practical activity with a love component. If, on one hand, Graham contributed to highlight the gendered character of care as daily reproduction work and its links with love and home, nonetheless her approach has been largely criticized for reproducing a concept of care that naturalized it as gendered, raced and classed. If on one hand feminism started the discussion with the emerging of care from the private to the public, some feminist authors reproduced the binarism which confines care into the essentialist realm of the female/nature/private as opposite of masculine/rational and public. The debate generated from Graham's work brought into light the fact that within the family and familial care relations may be abusive and not loving (Land and Rose 1985), and that the attention to only gendered aspects of care invisibilises classed and raced components, reproducing care relationships as predominantly white (Collins 1986; hooks 1981; Davis 1971), a condition of invisibility that Collins has vividly described:

> As Scott points out, "from reading the literature, one might easily develop the impression that Black women have never played any role in this society" (1982: 85). Where white males may take it as perfectly normal to generalize findings from studies of white males to other groups, Black women are more likely to see such a practice as problematic, as an anomaly. Similarly, when white feminists produce generalizations about "women", Black feminists routinely ask "which women do you mean?" In the same way that Rollins (1985) felt invisible in her employer's kitchen, Afro-American female scholars are repeatedly struck by their own invisibility, both as full human subjects included in sociological facts and observations, and as practitioners in the discipline itself. It should come as no surprise that much of Black feminist thought aims to counter this invisibility by presenting sociological analyses of Black women as fully human subjects. (Collins 1986, 528).

Joan Tronto (1993) contributed enormously to systematize and conceptualize previous feminist works on care, by problematizing its invisibility and fragmentation due to its confinement on the emotional private:

> Our understanding of how care is fragmented in several significant ways. In the first place the work of care is fragmented, caring processes are incompletely integrated, and differing kinds of care are assigned different weight in society. In the second place, care is described and discussed as if it were only about trivial concerns. Care conjures an association with the private, the emotional, and the needy; thus a concern about care is a sign of weakness. Both the devaluation of care as work, and the location of care within trivial, private and emotional states, make understanding the broader social, moral and political ramifications of care difficult. (1993: 112)

Ungerson also criticized this idea of care portrayed by feminist authors like Graham. The notion of care as distinctive familial love reproduces the distinction between formal and informal care and assumes that only within the domestic domain emotional aspects of care can be found. As a matter of fact, it grants informal care a superior state. Her aim was to conceptualize care in the way of including both familial and non-familial relationships, domestic and private. For this purpose, she stressed the point that care is a work activity (Ungerson 1983; 1987) and the loving elements are subordinated to the tasks involved in the work of caring. Qureshi (1990) questioned the opposition between formal and informal, pointing out that also caring relationships and care work in the formal sphere, in this case elder people, involve degrees of affection and love. Parker (1981) instead looked at the social identity of the care-receiver, which is defined in terms of dependency status and negative connotations of passivity and needs. In order to broaden the concept of care to grab a diversity in terms of age, impairments and disabilities, and reverse the negative connotation of dependency, he identifies caring with the attitude of "tending" to others. Care, he argues, it is not confined to the familial, it may include different degrees of personal familiarity, from intimate familial, through kinship, friendship and neighbourness. The concept of tending was used also in later works to compare public and domestic spheres, paid and unpaid care work.

Hochschild (1983) contributed enormously to changing the way care is linked with emotions. Cleaned from assumptions about a naturality of emotions involved in care, Hochschild pointed out the complexity of the emotional warfare connected to care. First, she presented a reading of care as work of emotions connected to the social role of the person within a care relationship. Each realm has its own kind of feeling rules. If those in the realm of work need to follow the feeling rules of a company, those at home rely on the feeling rules of kin, those in marketized domestic life draw on complex mixes of both work and family cultures.

> A social role-such as that of bride, wife, or mother-is partly a way of describing what feelings people think are owed and are owing. A role establishes a baseline for what feelings seem appropriate to a certain series of events (Hochschild 1983, 74).

Hochschild calls "feeling rules" the social guidelines that direct how we want to try to feel, a set of socially shared, often latent, rules, in her words "guidelines for the assessment of fits and misfits between feeling and situation" (Hochschild 1979: 566). But not always people are successful in following the appropriate feeling rules. Instead, "framing rules" are the rules according to which we ascribe definitions or meanings to situations, implicit rules of an ideological stance, what we are supposed to feel. A frame might also reflect a more general rule about assigning an emotion. Hochschild points out that ideology has often been construed as a "flatly cognitive framework, lacking systematic implications for how we manage feelings" (Hochschild 1979: 566), or, indeed, for how we feel. Feeling rules and framing rules mutually imply each other. This complex mechanism of emotion work is called "emotion management".

This management is also gendered, classed, raced and ableist in relation to care. Emotion management will differ according to the role and the position of a person within caring relationships. While exploring the daily work of flight attendants, Hochschild named years later "emotional labour" the activity to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others. In this study she found that there are both gender patterns and class patterns to the civic and commercial use of human feeling, that emotional labour affects the various social classes differently: “If it is women, members of the less advantaged gender, who specialize in emotional labour, it is the middle and upper reaches of the class system that seem to call most for it” (Hochschild 1983, 20). As well, she pointed out the emotional labour of the nurse involved in listening to a patient’s story, making a joke, patting an arm can be encouraged, or be intentionally dismissed and erased. The work of Hochschild is of paramount importance here because it allows to look at emotion management in care practices, at what happens in terms of rules, norms and negotiation of feeling and emotions in situated practices, at the emotion work that needs to be done in order to sustain and maintain care and identities. Emotion work is therefore deeply intertwined with care work, they cannot exist separately. Hochschild’s interest for both emotion work and emotional labour, or in other words, the work that needs to be done both in daily life and working life, has the advantage of focusing on different intersections at the same time, showing how emotion management circulates, changes and develops through different worlds. These realms, of the private and the public, do not present differences if not in terms of frames and rules, which can change or obstinately survive, be provoked or suppressed.

Tronto’s work, I argue, enriched Hochschild work by adding the attention to the moral and political investment on care. By working on the concepts of care she aimed at providing a stable definition of care in order to use the concept strategically, integrating practical, moral and political aspects of care in current western societies. In her view, to raise questions about care means to question the adequacy of care in our society, which will in turn lead to a profound rethinking of moral and political life.

> The world will look different if we move from its current peripheral location to a place near the center of human life. As we transform current moral boundaries to focus on an integral concept of care we will also need to alter other central aspects of moral and political theory. We will need to rethink our conceptions of human nature to shift from the dilemma of autonomy or dependency to a more sophisticated sense of human interdependence. Furthermore, we will recognize how our current moral and political theories work to preserve inequalities of power and privilege, and to degrade “others” who currently do the caring work in our society. Concept of care as basis for rethinking moral boundaries and, by extension, the terrain of current moral and political life. Current fragmented conceptions of care operate as they do to perpetuate gender, class, and racial structures of power and privilege through the construction of “otherness”. (1993: 101)

Tronto’s definition and first conceptualization of care in the early 1990s has been of paramount importance for sociological work. With the purpose of centring the moral and political theory on care and distancing care from its association with the feminine and the emotional, she conceptualized care as a material practice. From the very materiality of care, we can analyse different material aspects of care: care work as a gendered, raced and classed structure in society; tensions and conflicts that arise from different caring positions; the resources that care needs in order to be operative; the ideals that move care in practice. When care becomes material and the mechanism of power become visible, it is possible also to redistribute care within the society. Caring combines emotional and physical care, it asserts different experiences, meanings, contexts and multiple relations of power.

If care work had always been neglected and invisibilized in Western societies, it is particularly true for the care work that involves the body. Tronto made explicit four elements within care relationships: *caring about, taking care of, care giving* and *care receiving*. Each of them has different weight and privilege in society and it is associated with a certain gender and class. She states that *caring about,* and *taking care of,* are the duties of the powerful. *Care giving* and *care receiving* are left to the less powerful. For example, “taking care of” is more associated with public roles and with men rather than women. Another example comes from the medical profession in United States:

> The most prestigious aspect of doctoring derives not from the association with care, but from its claim to be in the forefront of science. Doctors who are prestigious do less tending to daily care work, the greatest prestige derives from their research status. (1993: 115)

The closeness to bodies it is what makes care devalued according to Tronto, so this is particularly valid for elder care and childcare:

> A vicious circle operates here: care is devalued and the people who do caring work are devalued. Not only are these positions poorly paid and not prestigious, but the association of people with bodies lowers their value. (1993:114)

Being aware to the different positions of people involved in care alerts us to the ways in which care can be implicated in the distribution of power and privilege in society. In her view, the position of the carer is the one who is devalued the most, for its connection with bodies and its misrecognition of utility in society:

> The social value of caring work in our society is determined not only by its low pay and prestige, but also by its instrumental quality. Much caring is only valuable insofar as it allows the pursuit of other ends by those whose needs are most thoroughly met. The distribution of caring work and who is cared for serves to maintain and to reinforce patterns of subordination. Those who care are made still less important because their needs are not as important as the needs of those privileged enough to be able to pay others to care for them. (1993: 116)

Not everyone agreed with Tronto’s position. During the 1990s, the discussion on care was deeply transformed with the debate on disability, influencing also social models of disability. There have been many positions within this debate; the aim here is to provide an account of the critique on care’s implicit focus on the carer, which by default brings an idea of the *cared for* as a passive and dependent actor. Instead the tendency to valorise the caring relationship for its potential to symbolize and be the very embodiment of genuine intimacy and reciprocity is highlighted in these works (Hughes et al. 2005). Barnes noted (2012) that this significant expansion of activism of health movements and collectives, such as the disabled people's movement, the mental health service user/survivor movement and the carer movement, led to personal accounts from diverse perspectives and offered insights relevant to understanding the experiences of care giving and care receiving.

The disability movements originated from the early 1960s in the US and the UK[1]. They claimed a relationship potentially able to restore agency for the care receiver, in which the person with disabilities is represented not as object of care but as recipient of assistance[2]. They criticized the patronizing attitudes embedded in concepts of care and particularly the position of the care receiver as dependent and passive. They suggested a change of terminology in this regard, emphasizing the notion of support and the use of terms like "help" instead of care (Shakespeare 2000). Care was criticized for its tendency to objectify and construct people as dependent, instead of promoting self-determination. Following these views, others rejected the medical model of impairment as well (Hughes and Paterson 1997). According to them, disability is a form of social oppression, not a status of body limitations. Disability has to do with society, including the prejudices and barriers which mitigates against full participation in equal terms (Oliver 1990).

Authors of the Disabled People Movement focused on the societal construction of dependency and argued for the emancipation and support of people with disabilities in order to avoid dependency. For the disable people movement care and its organization is regularly represented as a significant barrier to the emancipation and independence of disabled people. For disability theorists, care plays a central role in the naturalization of disabled bodies, care is associated with institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion (Hughes et al. 2005). Disability theorist and activists claimed that the hierarchy of care works with ableist axes. The care receiver, in a care relationship, is the passive and dependent in "need of care". Care theory, as well as sociology of health, as Williams pointed out, adopted a model of impairment which has in the background biomedical connotations, and which reads the disabled body as a body with limitations. By doing that, they establish a hierarchy of (dis)abilities in which the carer is higher than the care receiver. Instead, disability theorists and activists, as well as the sociology of the body tradition, wanted to highlight forms of oppression within care relationships and society at large (Williams 1999).

On the other hand, the positions of feminist authors, emphasized the shortcomings of a model of independent beings and argued for the recognition of the inter-dependence of people. Hughes et al. (2005) attempted to overcome the opposite positions of care ethics and disability theorists by arguing that the relations of care confine

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[1] Here I refer to the "the Independent Living Movement" (US) and the "disable people movement" (UK) who claimed the rights to form personal and sexual relationships; to be a parent (Wates, 1998), to equal access to a range of settings and the promotion of personal assistance as the key strategy in breaking the link between disability and dependency.

[2] From the perspective of disability activism, care is not enabling, and it is associated with the confinement of disabled people. Instead, the provision of personal assistants (PAs) was seen as empowering and liberating, through the provision of direct payments. The PA works for and with the disabled person, their role is task-centred. No longer represented as objects of care, they become recipients of assistance. In this view, people with disability become subjects, in control of their own lives, active participant in the relationship. In the UK, the Community Care Direct Payment Act came into force in 1997. For a recent review of the "personal budget" in UK see Slasberg & Beresford (2016).

all the subjects involved into a feminized social space. Moreover, they suggest that the feminization of care makes participants in the caring relationships, regardless their gender identity, necessary subordinate.

> To be a carer or cared for, male or female, disabled or non-disabled in either role, is to be found wanting, to be other in relation to the masculine subject of modernity, to be reduced to the other of the same. Those who give or receive care are marginalized, used and wasted bodies, existing, by and large, on the margins of what counts as the truly human community. Participants in the caring relationships are constructed as the vulnerable, the monstrous and the feminine and, therefore, as other to the masculine subject. (2005: 265)

The concentration on the relational aspects of care clarifies the extent to which both parties involved, regardless sex, gender and social status, become constructed as the "feminine other" and therefore marginalized. The dichotomous construction of the caring relationship construes the care receiver as a vulnerable, passive, dependent person: the other to the masculine subject of modernity. This is because, Hughes et al. argue, care, like its sister concepts of love and reproduction, were relegated to the realm of nature, to a private domain of human activity beneath the public sphere where concerns about justice and rights prevailed. The care's constructs as "natural" colonizes gender, race and class, resulting in women as "natural" caring subjects.

> Those who care, who enter into this "world of waste" place themselves in a domain of peripheral value outside the masculinist boundaries that define proper productivity and therefore have no claim upon the values of success, dignity or respect. (2005: 267)

The dichotomy of dependent care receiver and autonomous subject are consequences of the reading of care as ideological work, actively shaping and making plausible the reproduction of gender and (dis)ablment. In this view, in developing a masculine approach to care, the Disable People Movement seeks to promote autonomy but eliminates emotion from the caring process by transforming it into a formal, contractual, exchange relationship.

It is what Fraser and Gordon called the "genealogy of dependency" (1994). These authors, traced the concepts of dependency/independency throughout the history, highlighting how the reproduction of political hegemony of race, gender and class domination constructed the "normal" human condition as independence, while the dependent becomes deviant. Instead, they argue, we need to work on the concept of interdependency. They describe the rise of dependency as a moral and normative category, meaning that those dependent on others are constructed as being morally inferior to the idealized independent person. They show that the concept of dependence has changed over time, fitting the ideological and political demands of respective systems. There have always been groups (women, slaves…) at whose expense this independence has been created.

These works, while problematizing the connection of care with familial and love, highlighted the material dimensions of care. Not only care can also have negative connotations and become abusive, but the emotional and loving dimension of care is also present in paid care work, where we would not expect it to be. Care has profound emotional scripts, feeling rules that tells what a person should feel, how should take care and towards whom. Care is not an abstract concept, it is embedded in the lived and situated positions of the people involved in the caring relationships which are constructed in the intersection of gender, race, class and ability. The profound changes in work and family life on the last century has led to a shortage of people to undertake care work. Where the state is reluctant to provide for care, the burden often devolves to families and their "buying in" care within an increasingly complex array of care options: paid and unpaid, public and private, formal and informal. These changes not only impact on individuals or households, but also have global consequences, what Hochschild called "global care chain" (2000). Care as work is devalued again, paid care work is poorly rewarded financially, undervalued and unequally undertaken by women, migrants, people from minority ethnic groups and others who have little economic power (Ehrenreich and Hochschild 2003).

Given the asymmetrical power relations that care can set in motion, it must be enacted carefully: care's partialities, limits, and effects must be located, situated, and questioned (de la Bellacasa 2017; Martin, Myers, and Viseu 2015). A critical practice of care, argue Martin, Myers and Viseu, would insist on paying attention to the privileged position of the caring subject, wary of who has the power to care, and who or what tends to get designated the proper or improper objects of care. Given the asymmetrical power relations that care can set in motion, it must be enacted carefully: care's partialities, limits, and effects must be located, situated, and questioned (de la Bellacasa 2017; Martin, Myers, and Viseu 2015).

INTERDEPENDENCY: CARE WITHIN RELATIONSHIPS

The recognition that people within care relationships have different positions within a hierarchy of care, in which race, class and gender play an important role has led to the necessity of including the concept of interdependency in the conceptualization of care. According to this principle, therefore, people can only exist in and through (caring) relations. Care, as a fundamental component of human life, has a relational nature (Sevenhuijsen 1998). While our interdependencies are most evident when we are very young, ill, disabled or have become frail in old age, we are relational beings throughout our lives (Barnes, 2012: 15), at different times, in different places and in different ways we will need to be cared for (Williams 2001: 487).

The ethics of care's contributions to the notion of interdependency draws attention to the ways in which mutual vulnerability and need are embodied in caring activities and caring responsibilities. It has had several implications in contesting the binarism dependent/independent and therefore the prominence of the autonomous subject embedded in codes of morality by questioning the dyadic idea of care relationship, of which the case of mother-child relationship is an emblematic case.

Gilligan (1982) first contested the idea of a general autonomous subject that is able to make choices according to universal and generical moral principles. Instead, Gilligan reveals that taking decisions needs the maintenance work of a relational space in which each other's vulnerabilities are recognized. Vulnerability, for Gilligan is the recognition of needs, experience, voice that is possible within the material and symbolic interdependency of relationships. Tronto as well stated that social and political life are imbued by abstract accounts of morality which do not recognize people engagement with others but recognize the role of particularity in judgment. These boundaries are foundational of the autonomous, distant, moral actors who use abstract rationality as their guide. In order to sustain an ethic of care we need to rethink these moral boundaries. Care is not dyadic or individualistic, despite care is often understood as a relation between two, whether the romantic couple in Western discourse or the child-mother relationship[3]. Instead, outside care as dyadic and individualistic, we can better capture the relational and interdependent nature of care, the gendered, raced and classed structure of care work and the function of care both socially and politically. From this point it follows the impossibility of considering care only in virtue of its caring positions. While the naming of carers as a distinct social group has been important in gaining recognition and support (Barnes 2012), some have argued that the term *carer* should be discarded, in part because it polarises two individuals, allocating them discrete roles, rather than focusing on the relationship between them (Molyneaux et al. 2010). What follows is the impossibility of defining *carers* and *cared for*. In order to focus on relationships and understand caring relationships we need to consider the individual and shared biographies of those involved (Barnes 2012). According to Barnes, caring positions can only emerge from the life stories of those involved:

> In emphasising the relational character of care, an ethic of care calls attention to the experience of the care receiver as well as of the care giver, and also the impossibility of defining people according to such a binary distinction. People take on different roles at the same and different times throughout their life course and family life encompasses complex caring histories as family composition and relationships change over space and time. (2012: 59)

Interdependency, according to Barnes, offers a different way of thinking about our responsibilities to unknown as well as known others. It challenges not only the individualism that dominates conceptions of the person within Western social policy, but also the notion that we can reach moral decisions about policies within the boundaries of nation states. The ethics of care's view on interdependency is therefore a positive one and has implications for a transformation of social and political life. However, the concept remains problematic in some ways. Dependencies do exist and create real difficulties for people. Groenhout (2003) for instance warns about the danger of romanticizing vulnerability and dependence. According to Weicht (2015) what is needed is a

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[3] Here Tronto is contesting some authors of the Ethics of care who conceptualized care as a dyadic system of care giver and receiver (see for instance Noddings, Nel "Care: A Feminine Approach to Ethics and Moral Education" (Berkeley: University of California Press, 1984). Black scholars have also pointed out how care is portrait in ways that recall only white middle class families and invisibilize others (Collins 1983).

recognition of the discursive processes that totalize illnesses, vulnerabilities and dependence in a way that fundamentally identifies a person with their role as care receiver.

Furthermore, the concept of interdependency needs to address critically phenomenon of commodification of care and an increasingly specialised, dispersed and fragmented character of care work, undertaken by workers who occupy very different positions within organisational hierarchies and social class relations. The intersection of welfare regimes and migration regimes means that the distribution of care work, the experiences of care workers and the relationships they can establish with care receivers also need to be understood through the lenses of global movements of care, what has been referred to as the "global care chain".

However, the concept of interdependency allows to look at the multiple positions that people perform in caring relationships, by focusing on the situated experiences of the people involved and their interactions that potentially encompass broader networks of care as well as the change of their caring relationships in situated practices. This concept therefore still needs to get the attention it deserves, as De la Bellacasa (2017) suggested:

> for interdependent beings in more than human entanglements, there has to be some form of care going on somewhere in the substrate of their world for living to be possible. And this is one way of looking at relations, not the only one (de la Bellacasa 2017: 5).

CARE AS EMBODIED AND SITUATED ETHICS

Morality and ethics play an important role in the context of care in two ways: firstly, the moral construction of care underlies the practices of care for all those involved in caring relationships. Secondly, care represent a moral ideal in society, seen as an idealized form of people relating to each-other (Weicht 2015). The feminist ethics of care wanted to put care at the centre of the construction of a new morality, from the premise of mutual dependency, without attaching a negative value to this or thinking about an opposition between dependency and autonomy. Fundamental role in the notion of *ethics* of care was the work of Tronto on the ethical principles corresponding to each element of care. In her view, care creates constantly moral dilemmas because the needs for care are infinite, it also poses moral problems. To each element of care (caring about, taking care of, care giving and care receiving) corresponds ethical elements, competencies and values: *attentiveness*, *responsibility*, *competence* and *responsiveness*. These principles have been reworked in later works and other principles have been added by other authors[4]. The significance of the ethics of care for this research, however, is not in the principles themselves, but the fact that ethical elements are unavoidable when dealing with care because they are embedded in the daily care we do, in the specific circumstances where care happens, in tackling issues of resources and conflicts.

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[4] For a review of further elaborations of the principles see Barnes (2012) and Pols (2015).

> Those who engage in a care process must make judgments: judgments about needs, conflicting needs, strategies for achieving ends, the responsiveness of care receivers and so forth. Care rest upon judgments that extends far beyond personal awareness (…) and require an assessment of needs in a social and political, as well as a personal, context. (1993: 137)

Tronto has indeed been criticized of her attempt to formulate a prescriptive ethics of care with a concept of care to be normatively interpreted, by indicating the criteria that need to be met in order to call an activity, relation or practice care. Other care ethicists however, did not follow the normative interpretation. Sevenhuijsen for instance affirmed that the central moral issue is not "what am I obliged to do in general terms?" but "how should I deal with dependency and responsibility?" (Sevenhuijsen 1998). She stressed the importance of concrete motives in social practices of care and the existence of conflicting and contested notions of care. For instance, motherhood should not be simply seen as an identity, but as a series of relationships within which identity and commitment are expressed (1993:26). The focus on relationship practices allows to see, in this view, the shifting of roles and norms. For Barnes care cannot be separated from other aspects of relationships that embody gendered expectations, power relationships and the potential for abuse as well as nurturing. People's capacity to do care well within families is affected by the extent to which care is valued and supported socially and practically:

> we cannot read off from any 'type' of personal relationship within which care is given and received an assumption about whether it is 'good' or 'bad'. They reflect the personal and interpersonal struggles and conflicts involved in care. (2012:38)

An ethic of care therefore is not interested in general care principles and norms, but looks at situated care practices, needs and strategies. If care ethics points out the value and moralities attached to care, it highlights also the impossibility to trace a universal care ethics and emphasize that care can only exist as embodied practices (Twigg 2000). A position that is shared by Barnes when she writes that to understand care we must look at the practices of care or the activities that comprise care in concrete situations, not just the principles that should guide these. Other authors also confirmed the need to look at moral choices within situated contexts. Chattoo and Ahmad (2008) suggested as well that the meaning of caring as an embodied moral practice needs to be understood within the biographical context of negotiation of moral choices informed (rather than determined) by various cultural scripts available. For both the carer and the person needing care, self is constantly reconstituted as a balance between notions of interdependence or legitimate dependence on the one hand, and independence on the other. Bodily integrity played a central role in negotiation of moral boundaries involved in caring as an embodied moral practice, and how these boundaries were informed by particular cultural or religious scripts on gender, relatedness, conjugality and filial obligations irrespective of the ethnic background of individuals. They pointed out the centrality of negotiation of moral economy of self and identity.

Sayer (2011) indicates that people in their daily life do not rely on grand theories of morality or moral actions but rather apply some form of practical reasoning or judgment, characterized by a concern with concrete objects or particulars and based on an individual's character, rather than universal rules. The concrete other becomes the focus of people's actions and ethical concerns. It also includes practical, embodied and tacit or intuitive elements, which focus on ends rather than means or moralities. Ethical being must be understood as a relationship of interest between individuals and the broader context, within specific historical, social political and cultural structures and circumstances (why things matter to people). Care as ethics reminds that care has a strong connection with identity and that decisions to be made in the context of care are done following rules and scripts that inform on the link between personal and social identities. As Sevenhuijsen has described clearly, daily care is everything that has to do with who one is, and who can be, thus with identity. It is inherently linked with embodiment and intimacy. It is part of primary relations and the emotional dynamics with which these are linked (1998).

DEFINITIONS: WHAT IS CARE?

Tronto and Fisher presented a very broad definition of care which has been largely employed till present. It includes any act of care, from support to bodywork, from cooking to bathing. The generic character of this definition allows to conceive care, as we have seen, firstly as integrating maintenance or care work, practical and material actions, and affective and ethical dispositions. Secondly, the focus on vital interweaving web of life, reminds that care is interconnection and interdependency of lives.

> On the most general level we suggest that caring can be viewed as a species activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Fisher and Tronto 1991: 40).

If care is everywhere, it is also true that it is difficult to localize. The nebulous and tacit character of caring actions are however very much connected with identity, as Phillips has pointed out in the following definition:

> Care is fundamental to our individual identity as this is played out in our social interactions and relationships. Care can be part in formal, loving, professional and friendship relationships, it is fundamental to who we are and how we are viewed in both public and private spheres of life. It is often based on a relationship, not only within a family context but with others outside the family in a social or health care setting. In many ways it is a nebulous and ambiguous concept and a part of everyday life which is taken for granted. (2007: 1)

Barnes (2012) considers care in three distinct but related ways. The first one is a way of conceptualizing personal and social relations. In her view, relationships are shaped by care and the other way around, underlining the relational dimension of care.

> Such relationships certainly intense, intimate and personal relationships associated with giving care to those who are old, young, ill or disabled, as well as those that result from interactions in the context of 'care work'. But they also encompass other social relationships that may less usually be thought of as caring relationships. These include friendships or work relationships, relationships generated by political activity or through encounters in the process of policy making; they include the way in which we relate to our physical environment, both those environments we create for ourselves, individually and collectively in our homes and neighbourhoods, and the 'natural' environment that we both find and shape in the world around us. They also include the way we relate to ourselves: looking after our bodies and our emotional and social well-being. (2012: 5)

This first relational way of looking at care, bring us to its interdependent character and the way we position ourselves within caring situations, every time we need to decide what its best to do and how to care. Care is connected with ethics and norms.

The second, it is the set of values, or "moral principles" as Tronto elaborates, that offers a way of thinking about what is necessary for human well-being, flourishing and indeed survival. Here the argument is not solely that we can describe whether or not care is evident in different relationships and contexts, but that we can make assessments of whether personal relationships, work relationships, friendships, processes of political decision making and so on are capable of enabling the conditions in which we can live well (or as well as possible) both individually and together. These normative questions, argues Barnes, are important because of our dependence on others, because we care about things and people. Because of that, we are necessarily evaluative beings, continually having to monitor and evaluate how we and the things we care about are faring, and to decide what to do. (2012: 6)

The third way to consider care is care as a practice in order to see the invisible work involved in care in action:

> we need to be able to recognise what is involved to 'do care' or, as Tronto has put it, we need not only to care about but also to care for. This reflects the significance of a focus on the work and activities of care giving that have been emphasised both by feminist researchers seeking to make visible the unpaid work done by many women, and by carers themselves through their campaigns and organisations. (2012: 6)

Following Tronto, Barnes accounts for all these aspects together in her definition of care. Care can be defined as a broad set of relations that sustain our life and our interdependency. Care encompass values and norms that defines our positionality and identity and how we want to relate to each-other. Care is not abstract but a practice, it is about people *doing* care and different forms of care work.

The major definitions of care have accounted for the variety of care and relationships which include work relationships, family, friends and relatedness, as well as the moralities attached to them and the connection with social justice and reproduction of life. The nebulous character of care leads to the necessity of looking at care in action, at situated care practices. The use of practices allows therefore to look simultaneously at power dimensions of care work and its interdependent nature, highlighting that caring express ethically significant ways in which people matter to each other and build significant and affective relationships.

We learn from feminist approaches that care is not only ontologically but politically ambivalent, it is not a notion to embrace innocently. As Bellacasa puts it, thought and work on care, still, has to confront the grounds of essentializing women's experiences, the persistent idea of the "pure" ethical realm of care and its hierarchies. Complying Donna Haraway's call to "stay with the trouble" (Haraway 2016), de la Bellacasa pushes contemporary reengagements with care to continue "unsettling" care (Martin, Myers, and Viseu 2015). Care, with its normative systems of values and feeling rules, works as well as a classifying, pinning down and naming system which, while including something and someone, exclude others (Bowker and Star 2000). I agree with de la Bellacasa's resistance to categorizing care and rather seek to emphasize its potential to disrupt moral rigidities of ethical questioning. (…)

> Staying with care's potential to disrupt thus is not (only) about making visible neglected activities we want to see more "valued"— for instance, as "productive" activities with an economic worth that should be recognized. It requires engaging with situated recognitions of care's importance that operate displacements in established hierarchies of value and understanding how divergent modes of valuing care coexist and co- make each other in non-innocent ways. (2017:12)

CARE PRACTICES

The notion of *practices* has been of paramount importance to further analyse care. In this section we will see how a first notion of care as practice has been firstly suggested by the ethics of care tradition and expanded alongside practice theory. A concept of care practices that combine both "care" and "cure" is able to move to different places of care, from the domestic to the clinic, as embodied relational activity. The use of practices allows to look at emotional and embodied aspects of daily life actions, and the active doing care from all actors involved, and the ethics that are embedded in those practices. The concept of practice has been able to highlight the acts of relationship making, forms of being together, as emerged from studied on family practices. Care practices are fundamental display mechanisms in the presentation of family forms, values and emotions. They are not necessarily directed and performed within families only, but they are fundamental in the making of and the display of relationship's forms. The focus on care practices therefore consent to maintain a suitable attention to the core element of relatedness, being together and doing family.

Feminist ethics of care has firstly pointed out the fact that this concept brings to the fore material and embodied aspects of care, by giving prominence to them. Care as a practice make visible embodied mundane aspects of doing care, the gendered and classed issues connected to those practices.

Ruddick first suggested seeing care is a form of practical rationality[5]. Ruddick has in fact pointed out that thinking about care in terms of practice allows to avoid over idealizing care on one hand, while on the other takes into account all the necessary component pieces such as needs, concerns, resources and so on. Caring is ongoing, whether a single activity or a process, "a perspective of taking the other needs as the starting point for what must be done". In the attempt of escaping the confinement of care in the emotional and private sphere, Tronto further conceptualized care as practice, with the aim of distancing it from the gendered associated construction of care as emotional rather than rational, public rather than private.

> Thinking of care as a practice rather than a disposition changes dramatically how easily care is contained. As a disposition or an emotion, care is easily to sentimentalize and to privatize. (…) Caring is not simply a cerebral concern, or a character trait, but the concern of living, active humans engaged in the process of everyday living. Caring is both a practice and a disposition. (1993: 118)

The notion of practice is an alternative to conceiving care as a principle or as an emotion. To call care a practice implies that it involves both. A care practice is defined, states Tronto, as an act of care that involves both thought and action, interrelated and directed toward some end. Tronto identifies four dimensions of care (caring about, taking care of, care giving and care receiving), which works as idea types of practices. Importantly, thinking of care as practice has consequences because it involves material and symbolic dimensions: conflicts, resources, the setting of standards and ideal notions of adequate or good care. Care involves conflicts within each of these dimensions and between them. Staying with these tensions, commented de la Bellacasa, exposes that vital maintenance is not enough for a relation to involve care, but that without maintenance work, affectivity does not make it up to care and keeps it closer to a moral intention, to a disposition to "care about," without putting in the work to "care for". (de la Bellacasa 2017:5)

The concept of *practices* focus on what people do in practice when care happens and, most importantly, allows to look at the very material practice such as actors involved, resources, objects and so on. Reckwitz (2002) sought to summarize key features common to the most prominent approaches to practices, to produce a practice theory

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[5] Ruddick, Maternal Thinking, 132–3 (1989).

that could be compared to other cultural theories. Practice theories, in his definition, are distinct in contending that the social is situated in practice. Practices are:

> a routinized type of behaviour (…) forms of bodily activities, forms of mental activities, "things" and their use, a background knowledge in the form of understanding, know-how, states of emotion and motivational knowledge (…) a pattern which can be filled out by a multitude of single and often unique actions (2002: 249).

Shove et al. (2012) definition of practices encompasses relations between materials, meanings and competencies in an ongoing, dynamic and processual routine which involves embodied, tacit knowledge.

> A key feature of our own approach is the emphasis we place on the constitutive role of things and materials in everyday life. In short, we take seriously Latour's statement that artefacts 'are not "reflecting" [society], as if the "reflected" society existed somewhere else and was made of some other stuff. They are in large part the stuff out of which socialness is made (…). In this we redress a partial but significant gap, adding a material dimension to what are otherwise conventionally 'social' theories. (2012: 9)

Moreover, dynamics of social practices provide means of conceptualizing stability and change, as consist of elements that are integrated when practices are enacted and they emerge, persist and disappear as links between their defining elements are made and broken:

> In doing things like driving, walking or cooking, people (as practitioners) actively combine the elements of which these practices are made. By elements we mean: materials – including things, technologies, tangible physical entities, and the stuff of which objects are made; competences – which encompasses skill, know-how and technique; and meanings – in which we include symbolic meanings, ideas and aspirations. We go on to argue that practices emerge, persist, shift and disappear when connections between elements of these three types are made, sustained or broken. (2012: 14)

It has been acknowledged that attention to the senses is central to the analysis of practice (Ingold and Vergunst 2008; Grasseni 2007; Sutton 2010). Examples are the studies of Pink (2012) on "home" everyday practices such as doing laundry and housework; Sutton (2010, 2001) on food, and Rice (2008) on clinical work practices. They suggest that participants sensory practices inform on culturally specific categories, conventions, morality and knowledge. In focusing on the senses, they also remind that practices are about learning and knowing:

> Knowing in practice as embodied and multisensorial way of knowing that is inextricable from our sensorial and material engagement with the environment and is as such an emplaced knowing. (Pink 2009: 44)

Looking at practices in multiple sites needs to think about place and environment. Pink (2012) applies to a concept of place that distances from locality and static contexts but allows them the dynamism of operating within constantly changing constellations or ecologies, constituted by persons, and things in movement, their material and memorial traces and imaginings. This allows both the lived reality of practice and the event of place to be understood as contingent and as mutually interdependent. Places therefore are performed, practiced and reimagined in practical ways. Practices enacted through material objects, as well as non-material objects like senses and memory, are part of what Ingold calls the "meshwork" of place, zone of entanglements (Ingold 2008).

CARE AND FAMILY PRACTICES

Sociological research on care has highlighted the strong connection between care, gender and family. In opposition to accounts on individualization (Beck and Beck-Gernsheim 2002, Giddens 1991) and changes towards ideas of a "pure relationships", Weicht (2015) argues that families still have an enormous meaning for the arrangement of people everyday life and for their construction of care: care within family is seen as the most "natural" arrangement. The family is the first and the last place in which care is given and experienced (Watson et al. 1994). Ungerson (1987), in identifying the process of becoming a carer, found out that this process is intrinsically linked to taking over a particular role within the family. Care as a practice shows strong link with family and family values. Family, in the context of care, is not only about who but about how care is done. Care, as expression of family values, such intimacy and emotional relation, is not restricted to an image of close relationships (Weicht 2015). There is an ideological link between the family and the imagined relationship of care that assign caring roles in relation to gender. Qureshi and Walker (1989) in their study on elderly care, describe how gender linked hierarchy reflect a normative ideal of preferences for cares, which have women of the family on the top.

Care practices that involve physical touching have the potential to promote specific forms of intimacy between strangers. The correct attention to intimacy and closeness seems to be more important than the formal arrangement according to Ungerson (2005). Weicht suggests from his analysis on the discursive practices on the meaning of (eldely) care that care does not fit into the economization of society, nor into the individualization thesis. Rather, care reflects an ambivalent desire for people which can be described as "being there for each other". The construction of family care is a representation of an imagined ideal, which can also be embodied by non-family members. Care has a strong connection with family and in particular on how care is thought about. Research that applied the concept of practices to study the family pointed out that lived family practices constitute the idea of what family is. Families are not stable units and family means different things for different people (Morgan 1996). The assumption with these field of studies is that to understand what family is, it is necessary to look at what family *do* rather than what they *are* (F. Williams 2004), including what they imagine, their memories of what family means for them (Smart 2007).

Morgan (1996) proposed the concept of practices to study family life, contributing to the study of everyday changes and practices of family forms and intimate life. According to this view, there are several advantages of using the concept of practices. First, the use of practices (2011: 6) has a sense of the active: the focus on doing, it moves us away from ideas of the family as relatively static structures or sets of positions or statuses. From this follows that (family) actors are not simply persons defined as mothers, fathers and so on but they also do "mothering" or "fathering". It is possible therefore to look at processes of becoming. Practices have a sense of fluidity because who is included or not is not fixed but it is constantly within a process of doing in the everyday, daily life experiences. Secondly, practices have also a sense of the extraordinary and the ritual events, linking history and biography: individuals do not start from scratch as they go about family living. They come into (through marriage or parenthood) a set of practices that are already partially shaped by legal prescriptions, economic constraints and cultural definitions.

> Family practices are practices which are carried out with reference to others who are defined as family members so that family ties are constructed and reconstructed through the enactment of these practices. The apparently innocent phrase 'with reference to' can include some directly embodied activities such as feeding, physical care or physical punishment. But it can simply mean remembering, taking account of, anticipating. While these are in some ways mental processes, operations that are often invisible to the other's gaze have embodied features (Morgan 2011, 109).

Practices are also embodied and necessarily relational. Morgan, in recalling Reckwitz's definition of practices as "routinized bodily activities" (Reckwitz, 2002: 251) underlines that they may be defined in bodily terms and involve body care and intimacy. It is about bodies in relationships (which necessarily introduce questions of morality and emotions) within social space and time.

> It is important to recognise that this sense of a family 'we' is both relational and embodied. The family members who constitute the 'we' at any one point of time are embodied others who are spatially located (Morgan 2011, 92).

Care within family practices is therefore embodied feature of family relationships. Caring for and caring about for instance are always embodied forms of care:

> While the practices associated with the former (Caring for) are more obviously embodied, caring about is frequently expressed through the deployment of the body whether this be through touching or embracing, through particular forms of eye contact or through some alteration of the tone or level of voice. (Morgan 2011, 99)

Embodied family practices in this regard are at the same time forms of embodied knowledge, as the knowledge that arises out of the interweaving of biographies over time and has a fundamental sensorial component. Despite the fact that they are not the only site of this knowledge, family practices involve the use, the recognition and the generation of this knowledge. The embodied knowledge covers a wider range of possibilities in terms of things like facial expressions, bodily demeanour and gestures; it has a detailed history, the consequence of sharing space, time and experiences; senses of sight and hearing, touch and smell.

Moreover, the exploration of the relationships between *caring for* and *caring about* clearly brings out the ways in which emotions and work interact and cannot readily be separated (2011: 115). Care practices overlap with family practices when considering emotions. Care brings forth emotions in those performing the activities and it frequently involves the emotion management of oneself and others. The characteristics associated with work involve the expenditure of effort in directions which are, or seem to be, necessarily required. For instance, Morgan gives the example of the feeling of being "emotionally drained" after dealing with getting the children ready for school, one the most routinized family practices.

Morgan with that relevantly pointed out that family practices overlap and are intertwined with other practices such as gender practices and care practices. One way in which family practices, care practices and gender practices are overlapping is with body care and eating practices: body care for a family member or a relative is a form of care identified with family, often carried out by a woman or another family member who becomes the caregiver (Finch and Mason 1993). Everything related to food and eating has a close connection with the family. The buying and preparation of food is frequently carried out, not simply in terms of one's own tastes or preferences, but also with references to the tastes, preferences and diets of others and these others are frequently other family members. Family rituals and ceremonies provide important occasions for the working and the re-working of family memories as well as for the generation of the emotions associated with family living and family display (2011: 126). Care (caring for) is demonstrated in the way in which food is prepared in terms of these other reference points or in the way in which implicit reference is made to the health and well-being of partners or children. Food is central to almost any family celebration or form of family display. And the notion of the family meal, and its alleged decline, remains prominent in representations of family life.

Even if not expressed in these terms, Finch and Mason's idea of developing commitment[6] is one of the most important study that looked at the intersection of care and family practices. They showed how the constant giving and receiving care creates commitment when mutual responsibilities are negotiated through a continuous process. Family responsibilities in this way, are created and not predetermined, as processes through which a

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[6] Developing commitment is a conceptual framework which helps to understand the process involved in negotiating responsibilities which Finch and Mason borrowed. According to this concept people "develop commitments over time and in ways which are possibly half-recognized but often not consciously planned (…). Where a pattern of reciprocal assistance builds up over time, each person invest something of themselves in this relationship and becomes committed to it as a relationship through which mutual aid flows. The essence of becoming committed, in Becker's terms, is that it becomes too expensive to withdraw from the situation which is developing. The "expense" is not necessarily calculated in material terms, though it can be. More usually the expense is calculated in terms of people's personal identities and their moral standing in their kin group and in the eyes of the worlds at large" (p. 166).

person develops a sense of responsibility to anyone and not just to members of their family. Finch and Mason write:

> Our main point is to highlight the importance of understanding accumulated commitments in women's lives particularly, and of seeing this as a feature which significantly shapes the actions which they take. We would argue that theories of gender relations need to be capable of accommodating the variations in experience which flow from this kind of process. They need to give due weight to human agency, rather than seeing the experience of women and men as flowing directly from the different structural positions (conventionally defined) which they occupy. (1993: 174)

Following this view, care practices have been at the centre of research which looked at ways in which people matter to each other and build significant and affective relationships beyond the family form. These works have demonstrated the significance of care in building relationships and communities, the so called families "of choice" and friendship among people who are not sharing family ties but instead bonds are sustained trough, such as LGBTQI* people (Roseneil and Budgeon 2004; Weeks, Heaphy, and Donovan 2001). Attached to any form of social relation, care practices are important in the expression and the framing of significant relationships. Family and kinship, for instance, and all their qualitative attributes, need to be displayed, as well as done, because their boundaries are not obvious, and because without their recognition and legitimation, they cannot be operational and work (Finch 2007; Smart and Neale 1999). The need of display, according to informal norms of display rules, occurs when a practice has to be recognized from the outside world as embedded in a particular set of relationship, and can therefore reveal inequalities and unbalanced power relations (Finch, 2007). Display mechanisms give accounts of relational practices that needs to be established as family practices, the ways in which social meanings about the family like nature of one's relationships are conveyed to, understood and supported by relevant others. Although display is potentially a feature of all families that becomes more or less intense at different points in time, the concept may hold a particular relevance for situations of uncertainty and for families whose contours are not easily recognized (Almack 2008). Care practices are therefore a mean for the institutionalization of different forms of relationships in daily interactions. They can tell who someone is for someone else, regardless their social position, care practices can be used to look at how relationships forms are shifting towards different forms. For instance, care practices in LGBTQI* families have been used to explore citizenship, when care is not allowed for someone, it is framed as a right to care (Pratesi 2013).

Mason (2008), in her study of kinships, talks about dimensions of affinity, as different ways of practising relatedness, a work of negotiating and defining kinship. In Mason's view, tangible affinities and kinship relationships are not given but they are creatively achieved through practices of negotiation and fixing affinities, in cumulative and situated interactions and negotiations, over time. Ethereal and sensory affinities are also at play in material care practices. Mason's argument is that these dimensions come into play, beyond the biological, when the distinctiveness of kinship and the criteria that constitute it are being settled upon. I expect to find these dimensions of affinity as tangible, activated through material and emotional engagements, such as sustained caring practices. “Family”, as Weicht, points out, “is not (only) about who but about how care is thought of. Care, thus far, can be described as the expression of family values, such as intimacy and emotional relationships” (2015: 69). The embodiment of these affinities and display mechanisms of significant relationships are fundamental to understand relationship making practices and, more broadly, to a further conceptualization of relational well-being for people in need of care.

CARE AND MEDICAL PRACTICES

We have seen how care practices are intertwined with family and relationships practices, situated ethics and emotion work. Care has to do with identity work, with who we are in the world and how we tend to others. Care has to do with a moral vision of the world, it deals with how we care of each-other and how we would like to care. I have also pointed out that practices of care move along lines of power relations: care is entangled in politics because while caring for some things and lives, it excludes others. Care defines, organizes, classifies, and disciplines bodies. As Martin, Myers and Viseu affirmed, colonial regimes showed us precisely how care can become a means of governance: care makes palpable how justice for some can easily become injustice for others (Martin, Myers, and Viseu 2015). Therefore, questioning who has the power to care and be taken care of, what counts as care and how it is administered are relevant issues for care practices in the clinic. These questions have to do not only with access to medical spaces and practices, but also with daily issues of care in the clinic. Medical practices have, in other words, huge connections with what we have found from the literature on care and family practices.

What does it mean to use a care perspective when looking at medical practices? A first consideration would be to recognize the interdependent relational nature of care, and to not assign a specific place to care nor a specific relationship (as the doctor-patient one). Instead, care involves relationships with different people at the same time. Barnes has in different works highlighted the potential of a care perspective for social care work and medical work, mixing the boundaries between the familial and the clinic. Care ethics have a lot to do with the clinic. Not just because it means dealing with illness and care for someone who gets ill or disabled, but also because it has to do with daily negotiations about “good care”, done by family members and professionals. But care ethics cannot be understood in the abstract, care ethics are instead rooted in clinical practices, personal histories and subjectivities, in contexts of conflicts and power. Care in the clinic has also to do with how dominant discourses of rationality, autonomy and dependence are constructed. Moreover, Barnes also pointed out specific forms of care are embodied in different forms of relationships developed in the clinic, for instance friendship with other service users (Barnes 1999, 2012). Care that is provided through these relationships may look and feel different from that which is given and received either within families or paid care work and this suggests we need to broaden our concept of care. Others have also pointed out the significance of kinship, not as extension of familial relations into community, but as the sphere in which family has to confront ways of disciplining stigma in relation to illness and disability. They highlight how the split between the public and the private is negotiated performatively within the domain of kinship relations. In this split they locate the productive tension that can lead to the recasting of social norms. (Das and Addlakha 2001). These works point out that there are not close boundaries when taking into account care practices. Relational care practices move and circulate beyond relationships forms and has an impact on clinical care as well.

A second connection with the literature on care is about care work: body work that is done in the clinic has similarities with Tronto's analysis of care work that involves the body and the hierarchy that comes out according to gender, race and class[7]. A focus on bodywork in medical practices brings into surface, within its variations of forms, the complex intersection of care, gender, relational and clinical practices. Body work is work that focuses directly on the bodies of others: assessing, diagnosing, handling, treating, manipulating, and monitoring bodies. It is a component part of a wide range of occupations, and central part of healthcare. It is linked to pleasure and emotional rapport as well as to abuse and discipline. It is ambivalently positioned in relation to power, caught in dynamics that can tip either way, "presenting the worker as either a demeaned body servant or an exerciser of Foucauldian biopower" (Twigg et al. 2011, 172). Bodywork and emotional labour reveal gendered occupational hierarchies of healthcare, with the privileged, predominantly male professions relegating the emotional work, along with the other to those lower down the hierarchical order. Working status is marked by distance from the body for medical professions and nursing (Twigg et al. 2011). Nurses, as they progress up the occupational hierarchy, move away from work on bodies to "cleaner" work on machines or other knowledge work like management or teaching, that involves little or no body work at all. The focus on the body work in health care highlights the corporeality of power relations between professionals and patients and allows to see the corporeal interdependence that characterises their interactions.

A third consideration of the applying of a care perspective when looking at medical practices has to do with ethics, moral visions of what good care is. Barnes talks about two, very different, ideological positions that have been unhelpfully entwined in the way in which choice has become the primary value underpinning welfare services in many Western states (p. 65). But it is with "the logic of care", that Mol (2008) makes a step further with sociological analysis of clinical care practices in complex and changing health paradigms. First, Mol focuses on the clinic but claims to use the term "care" to address both *care* and *cure*, defining care as an interactive process that includes humans and technology:

> Care does not have clear boundaries. It is open-ended. This is not a matter of size; it does not mean that a care process is larger, more encompassing, than the devices and activities that are

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[7] For the intersection of gender and class in bodywork see Tronto (1993: 115) in this dissertation (p. 13). Tronto however does not include race in her analysis. For a critic of the whiteness of sociological analysis on care and on the intersection of race, gender and class see Collins 1986, hooks 1981.

> a part of it. Instead, it is a matter of time. For care is not a (small or large) product that changes hands, but a matter of various hands working together (over time) towards a result. Care is not a transaction in which something is exchanged (a product against a price); but an interaction in which the action goes back and forth (in an ongoing process). (2008: 31)

Her point here is that instead of looking at the body that we *have* (which is known from the outside, objective medical knowledge), and the body we *are* (experienced from the inside, from the subject) we need to focus to the most relevant body in the clinic: the body we *do*, as a part of practices. And who does the body and who does care in the clinic? Everyone and everything: professionals, patients, other bodies, significant others. Importantly, Mol points out that care is not other than technology but instead care includes technology, which is not a mere instrument but an "inventive mediator" who interfere with who we are, since "good care involves a persistent attempt to tame technologies that are just as persistently wild" (2008: 50). Holding together the different dimensions of care gives attention to the fact that care is needed to maintain technology, so that they do not become dangerous.

Going back to the point made by the ethic of care tradition, "good care" is not an ideal that can be defended in general terms, as a matter of principle, instead it is something that people shape, invent and adapt, time and again, in everyday practices. But, instead of morality or feeling rules, Mol calls "logic" the implicit and embedded rationale of practices, buildings, habits and machines. A logic indicates what it is appropriate to do, or not, in some situations, because care practices have, in Mol's view, logic attached. Mol defines two different and opposing logics: a logic of care opposed to a logic of choice. These logics work differently in the context of health care.

> For not only does each logic define its own version of the good, each also has its own take on how to 'do' it. How to serve the good actively, in practice? What are the crucial moral activities in the worlds that the two logics presuppose and help to create? (2008: 74)

If what any actor wants to achieve is to do good care, however we need to pay attention to the logic which are embedded in care practices. And medical procedures, programs and records have a logic too (Timmermans and Berg 2003), and sometimes these logics are mixed together. STS (science and technology studies) and neo materialist approaches have shifted the position of practices in health. From a focus on health behaviours of individuals and their "social context", it moved to one that is concerned with their situated everyday practices, emerging from actions and interactions. As we will see in chapter three, the literature on relational-material practices focuses on practices and on how they change through the interdepency-intradependency[8] of their actors (Maller 2015), instead of individuals or macro systems of power. The latest developments in theories of social practice take a post-humanist stance, recognising the agency of materials, technologies and objects in the

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[8] These concepts can be found respectively in the literature on ethics of care (Joan Tronto; Selma Sevenhuisen) and the work of feminist neo-materialists, in particular Karen Barad.

construction of everyday life, as active elements that co-constitute practices (Reckwitz 2002; Shove, Pantazar, and Watson 2012). Care practices, in short, emphasise the materiality of everyday life, foregrounding things, technologies and other non-humans. What de la Bellacasa has named “matters of care” (de la Bellacasa 2017). Studying social practices instead of individual behaviour in empirical research on health avoids blaming patients and brings socio-technical constructions of health into light.

In order to explore the link between care and medical practices in the lived experiences of chronic illness, the next section reviews the sociological literature on chronic illness. The contribution of this literature has been fundamental in showing the hidden care work that people with chronic illness have to do to maintain their identity, lives and their relationships. Furthermore, they pointed out the importance a variety of relationship forms have in the chronic illness work. With this, I want to highlight a clear connection with the literature on care. First, *chronic illness work*, that emerged from the sociological literature, presents different similarities with *care work*. Not just for its hidden character, but also for its relevance in terms of identity, ethics and relationality. Second, the sociological studies on chronic illness have profoundly changed “the subject patient”. As for the care receiver in the caring relationship, *this* chronic illness patient is actively engaging and enacting care practices with a variety of actors, objects and places: the patient becomes a sort of scientist, far from the passive and dependent actor framed by the Parson’s “patient role”. In the exploration of subjective experience of illness, personal and social meanings and the daily management work of illness in the social context have a prominent place. Agency and resistance are key to the illness experience. Even in illness individuals are not passive, the “self” is more than its body and much more than an illness (Charmaz 1991: 258 in Conrad and Barker 2010). We will see in chapter four that the sociological literature on “patient” and “patient’s knowledge” has emerged with the first studies on chronic illness and later developed with STS contributions. Lay knowledge is one of the most discussed issues in contemporary sociological research on health, it will be also discussed in chapter six and eight in this volume.

CHAPTER 2 – CARE AND CHRONIC ILLNESS

Sociological research on the lived experiences of the illness in the last century highlighted the complexity of the intertwinement of care, medical and family practices in daily life through chronic illness work. Research on the lived experience of chronic illness, also called *illness* dimension, defines a body or knowledge which refers to the situated patient's experience, differentiating it from a system of knowledge of the biomedicine, so-called *disease* dimension. The medical model assumes that diseases are universal and invariant to time and place, whereas social constructionist approaches in particular emphasize how the meaning and experience of illness is shaped by cultural and social systems, social interactions, shared cultural traditions, shifting frameworks of knowledge and relations of power (Conrad and Barker 2010). This sociological research on the illness experience highlights the everyday and subjective experience of illness, showing how individuals, by struggling to make sense of it and reclaiming a sense of the self, manage their illness. According to Lupton, these studies have given detailed and intimate view of the suffering that illness often represents, as well as agency and resistance, they have shown ways in which bodies may become inscribed by dominant discourses in the public sphere, how relations of power are exercised and reproduced through medical practices and how medical and public health ideas are incorporated into lay knowledges of health and illness (Lupton 2003). It has been giving back dominant discourses and cultural resources from the lifeworld, including those from folk knowledge about the body and illness, autobiographical and family stories.

A big part of sociological works on health have been devoted to exploring the illness dimension. In the next section I review the most relevant works on chronic illness, encompassing different positions regarding the relationship between experience of illness and biomedical-disease. If they have produced the concepts that became fundamental in medical practices and entered the biomedical realm, the disease dimension, was left untouched by medical sociology and anthropology. The chapter concludes presenting perspectives that attempted to overcome the dichotomy, by placing body, phenomenology and practices at the centre of the investigation.

SOCIOLOGICAL APPROACHES TO CHRONIC ILLNESS

Since the 70s onwards, emphasis has been placed on the meaning and experiences of illness and strategies of negotiation of self and identity in daily life. With the outset of chronic illness, the dominance of biomedical science and its ability to cure all is irremediably challenged, in practice there is no expectation of full recovery, chronic illness cannot be cured. Instead, the self becomes prominent in this field of studies for the first time. Nettleton argues that the branch of research on the experience of chronic illness illustrates the way in which self, identity and the social are intimately related through the concept of biography (Nettleton and Bunton 1995). According to Lupton, the concept of narrative underpins examination of the ways in which people give meaning, sense and structure to the trajectory of their illness (Lupton 2003). Being ill is fundamentally linked with the sense of the self, actively constructing continuity and meanings throughout events and circumstances, explanations of sickness that go beyond biomedical explanations. The reconstruction of all aspects of life and identity, when facing a condition that becomes a fundamental part of the existence, are expected to come from a continuous work on the self: the chronic illness work. This review wants to reconstruct the nodes of sociological investigation of chronic illness and their salient works, which have had an enormous resonance within sociology of health in the last century to enter in a "transitional state" (Scambler and Scambler 2010) in the last decades. The recent blooming of science and technology studies within sociology of health, has endorsed to a renewal.

CHRONIC ILLNESS WORK: TRAJECTORY

The first attempts to examine the illness experience of the individual and family were aimed at improving health care for chronic ill patients. Strauss, Glaser and Benoliel produced a study that would have impacted patient care by suggesting possible strategies derived from key issues of chronic illness. The main areas of interests were patients' family and social life, management of crises, control of symptoms, social isolation, adjustment to changes and normalization of interactions and lifestyle (Strauss & Glaser, 1975). In 1985 was published another study on the social organization of medical work (Strauss et al. 1985). Despite the fact that the study especially focused on the organizational work at the hospital, patient's family and social life are included in the management of illness, from the point of view of all the actors involved. In chronic illness, Strauss has highlighted how patients and their families become integral part of medical work, even if at the expenses of a constant increasing management work. The concept of "trajectory" developed in this study became central for describing patients' experiences of illness and has been largely used in medical practices. As they developed it, it defines the course of an illness over time of patients, families, and healthcare professionals to manage that course, and it is described in terms of work:

> Much of their work is quite invisible to the physicians, nurses, and technicians, because that work is not actually seen, is kept secret, or if it is seen, is not defined as work but just as patients' activity or general participation in their own care. (1985: 191)

The concept of trajectory is especially useful in thinking about the experiential and identity impact of work in hospitals because it brings out the evolving character of chronic illness work over the course of the entire case. The chronic illness work, as observed in the clinic, is very differentiated in kind, including both physical, organizational and emotional tasks:

> The trajectory work may require or involve some among several different kinds of work: comfort work, clinical safety work, machine work, composure, biographical, and other kinds of psychological work, the work of coordinating (articulating) all the many tasks involved in the total arc of work. Second, trajectory work of whatever species involves the organization of resources and a complexity of organization for their utilization. (1985: 39)

According to Strauss et. al., the patient work is taken for granted and goes from the everyday care work to patient-work, emotional labour and communication work. It was, for Strauss and the others, the focus on the everyday lived experience which allowed the shift from a narrative focused on “patient’s compliance” to context-cantered strategies to improve the effective implementation of medical regimes. Chronic illness work, in fact, it is not just the work that patients *do* but also the work that *they are expected* to do while they enter the clinic.

> Ironically, patients are expected to be “cooperative”, in common hospital parlance, while the staff is working hard on their care-meaning not merely that patients should be passive or pleasant but should do the things they are supposed to do in the service of their medical and nursing care. (…) their work is not necessarily conceived of as more than acting properly or decently in accordance with the requirements of their care by professionals and assisting personnel. (1985:191) (…) most patients’ work when at the hospital goes unrecognized: it is taken for granted. Among the unrecognized tasks are nonmedical ones pertaining to personal housekeeping: going to the toilet, putting out the bed light, combing hair, getting out of bed if ambulatory, feeding oneself. Then there are certain things which it is assumed that patients, unless they are infants or non-sentient, can and will do: give information during the entry and diagnostic interviews, for instance. Patients are also expected to report discomforts and untoward symptoms or bad reactions to drugs. Then, there are expectations of them during various tests, as when cardiacs are put on the treadmill. They are instructed to report when angina appears. Certain other patients are instructed how to do necessary things and are expected to do them-to cough postoperatively, for instance. Other tests require patients to put out considerable effort in order that their performance levels can be measured; indeed the staff member may encourage the patient to perform to his or her utmost, often giving approval for successful efforts, as with someone who is having respiratory outputs monitored. And, of course, there is much informal and even recognized teaching of patients how to monitor machines or bodies. When they are deemed responsible and experienced, they are more likely, naturally, to be trusted with the monitoring itself and with reporting the results. (1985: 195)

One of the compelling aspects of trajectory as a concept is the mixing of formal and informal aspects of analysis. The temporal dimensions of trajectory are formal, people, things and arrangements moving at different rates. While expectations, adjustments, quality of life, self-love, are informal, continually renegotiated. With the concept of trajectory, the illness related work is intertwined with everyday life work and biographical work, in a constant search for balance between effort and resources. It is always a precarious balance that can be undermined by competition, ruptures and crises. Concepts of trajectory and the chronic illness work involved became of paramount importance in further sociological works and are now still applied. Strauss works irremediably brings together clinical care work and patient work, in other words the care practices they do together.

MANAGEMENT, ADAPTATION AND IDENTITY WORK

Management and adaptation have been used to refer to emotional and cognitive mechanisms called to of recovering a sense of self-worth in response to biographical disruption. Bury used the concepts of *coping*, *strategy* and *style* to articulate the adaptation process. Coping refers to the strategies that people adopt and the resources they mobilize to preserve their sense of normality; strategy is the focus on the resources and support available, a sort of counting and maximizing in order to minimize possible problems. Style is an interactional mechanism, which aims at preserving or reforming the self in social life (Bury 1991).

Charmaz's notion of adaptation has instead focused on self-preservation strategies. In this view adaptation refers to altering life and the self to accommodate to bodily losses and limits, resolving the lost unity between body and self by struggling "with" rather than "against" illness. Adaptation is a continuous process for chronically ill people, forced to adapt repeatedly. In her study with chronically ill men (Charmaz 1994) she shows how these men come to terms with illness and disability by "preserving self", devoting vast amounts of energy to keeping their illness contained and the disability invisible, in order to maintain their masculinity and limiting the effect from illness in their lives. Strategies to preserve the self, she noted, include also the offering a public narrative in which the illness plays a certain role.

> Adapting means altering life and self to accommodate to bodily losses and limits and resolving the lost unity between body and self. It means struggling with rather than against illness. (…) Chronically ill people are forced to adapt repeatedly as they experience new losses. (Charmaz 1995, 1)

In a previous study (1983) she described the impairment of such presentation by illness as a "loss of self" in a study where respondents reported how they constantly scrutinised encounters with others for hints of discreditation and negative reflections. Slowly the individual with chronic illness, experiencing social isolation, feels their self-image disappear: a loss of self, without the development of an equally valued new one. An experience that leads to living a restricted life, being discredited, and burdening others. Charmaz highlighted that, in order to understand how loss and recovery of body-self unity occurs, we must understand the meanings of bodily experiences of chronically ill people, and the social contexts in which they occur. Such meanings arise in dialectical relation to their biographies and are mediated by their interpretations of ongoing experiences (Charmaz 1983). Charmaz places family and significant others at the centre of the adaptation process, revealing the impact of daily interactions in strategies of adaptation, preservation of the self and management. The research reveal that these strategies are not only moved by the goal of recovery or feeling better, but by identity goals, deeply connected with the patients' surroundings, they do not take action by themselves and for themselves, but to maintain or adjust their identity goals in relation to others. How people define commitments and responsibilities in relation to others has an impact on their identity work. Changing identity goals then takes into account the individual's definitions, significant others' views and wishes, and the interactions and negotiations among them. Once chronically ill people have altered their lives to accommodate to limited identity goals, it takes substantial support to move beyond them. Certainly age, gender, work, and marital status shape, but do not determine, the context in which chronically ill adults change identity goals. Their ways of changing identity goals and adapting to the changes also reflect the content of their lives and the meanings they attribute to their ongoing interactions (Charmaz 1995). As we will see in the next chapters, identity work is prominent in the analysis of this research because of the centrality of this invisible work in the intersection of care, gender and chronic illness work.

Charmaz includes also the experiences of relatives and significant others in the adaptation process, insofar they also need to struggle with or against the illness, they can either be a source of strategical support, or of opposition:

> Whether they welcome adapting or define it as defeat depends on their views and interests. Adapting can cause havoc in the lives of people who depend on the ill person and who cannot or will not renegotiate or relinquish earlier reciprocities. If family and friends believe the proper stance toward illness is struggling against it or politely ignoring it, then they will be displeased to witness their ill person adapting to it. More likely, however, family and friends are relieved when the ill person begins to adapt. As he or she does so, earlier anger, self-pity, guilt, and blame dissipate. Adapting leads to taking responsibility for self. Hence, spouses and partners may feel much less need to monitor the ill person and to patrol his or her activities. Moreover, chronically ill people who adapt do not require their friends and family to construct a fictional present and mythical future with them (Charmaz 1995, 674).

Works on management and adaptation has recently benefit from sociological research on digital devices and software. Recent works have developed at the intersection of sociology of health and Science and Technology Studies (STS). Despite tensions arising, especially in relation to technological determinism Vs agency of technology (Henwood and Marent 2019), digital health is currently being explored in diverse fields of healthcare. New digital media include apps developed to support the self-monitoring, self-care and management of chronic illnesses, used to manage different health needs. Since people living with disabilities and chronic illnesses are active users of the internet to find information and support and they are often targeted as key groups for using digital patient self-care technologies such as smartphone apps and wearable devices to monitor their health, it has been noticed that these technologies contribute to patient expertise and lay support (Kivits 2013). As such, people living with chronic illnesses are encouraged to aspire to the ideal of the “digitally engaged patient” (Lupton 2018, 2013). Online forms of health communication have allowed patients to represent their experiences and find emotional support, and lay people to actively challenge medical expertise and authority, engage in self-diagnosis and generate new forms of knowing and doing (Vicari and Cappai 2016). In doing so, they opened a potential “space for epistemic resistance”, as patients suffering of endometriosis, struggling or recognition (Whelan, 2007). However, research has given mixed results so far.

BIOGRAPHICAL WORK

The notion of biography has pointed out the reflexive work that people do to maintain a coherent sense of self in their lives. Biographical narratives inform on our private sense of self, on how we are able to present ourselves to the outside world (our identity), because narratives of illness are bounded by and constructed in relationship with various individuals and organizations (G. Williams 1984). Through the “biographical work”, trajectory work, management, adaptation and identity work are brought into surface. The most influential concept in relation to chronic illness and biography is Bury’s “biographical disruption”. He defines chronic illness as such (1982):

> that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. (1982: 169)

Chronic illness in this view leads to biographical disruption where the taken for granted aspects of life, body and identity are thrown into question, it refers to a destabilization, questioning and reorganization of identity after the onset of chronic illness. Biographical disruption often entails a reorganization of life on many levels, including the self and of relationships with family, friends who will have to deal with consequences and significance of the illness. This can make certain social situations fraught with risk in terms of safety or of breaking social norms. The disruption caused by the illness is therefore a disruption also for the relationships of the patients and affects the patient’s ability of mobilize resources to advantage. According to Bury, social isolation and dependency flow from these disruptions in the social life as soon as patients begin to “restrict their terrain to local and familiar territory where they are least likely to be exposed to the gaze and questions of acquaintances and strangers” (1982: 176). Bury’s view of disruption of social life, confirms that of Strauss (1975) who already had pointed out that withdrawal from social relationships and growing social isolation are major features of chronic illness. The onset of chronic illness represents a personal crisis, undermining self-identity, sense of security and social relationships, as the “kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury 1982: 169).

More recently, attention was given to perceptions about the future in exploring temporal aspects of narrative accounts (Faircloth et al. 2004) also to extend and introduce possible alternatives to the notion of biographical disruption. Examples are the concepts of biographical “continuity” (Williams 2000); “biographical reinforcement” (Carricaburu and Pierret 1995) in which there is a close link between illness and identity with experiences of HIV positive men; “flow” (Faircloth et al. 2004) which describes experiences of illness, for example in context of older age, as “natural” course of life events; “narrative reconstruction” which includes reflections on biographical pasts including reactions to personal crises and turning points, and reconstruct a sense of order from the fragmentation produced by chronic illness, by establishing points of reference between body, self, and society (Williams 1984); "re-casting" (Corbin and Strauss 1991) that makes sense of illness experiences by reconciling the past with the present. Studies have also questioned the notion of disruption, especially when intersecting with class and gender. Class can also mitigate the extent to which the onset of chronic illness is experienced as biographical disruption. For example, people who experience a states of disruption because of precarious work or economic uncertainty (Williams 2000). Gender also has a profound effect on the extent to which chronic illness is experienced as biographical disruption (Wilson 2007). Research on biographical work highlighted that *doing* biography is the activity that gives shape to the overlap of bodily experiences, like symptoms or emotions, and sense of self. The action the symbolically perform the relationship between body, self and society, in contrast with definitions of functional incapacity or activity restriction in biomedical terms.

Given that embodied experience is also orientation towards the world, routinized cultural, social and discursive scripts, the rupture in the ability to enact habits and routines results not from the outset of novel impairment but it is due to the breakdown of one's ability to enact one's embodied orientation towards the world (Engman 2019). The experience of illness is never simply the experience of illness, but rather the experience of the impact that illness has on people's ability to participate and enact the life that they were immersed in prior to becoming ill, an inability to utilize all of the accumulated embodied knowledge that previously organized daily life.

Narratives are fundamentally embodied and are central to the coherence of our lives, shifting dominant cultural metaphors of illness away from passivity to activity, from "fate" into "experience" and reclaiming pain and human suffering from exclusive biomedical jurisdiction (A. Frank 1995). By doing narrative bodies are joined together in a shared sense of vulnerability, when illness is told, its "lack" becomes "producing" (Frank 1991). Three basic narrative types of illness stories have been identified by Frank: the "restitution story", the "chaos story" and the "quest story". The first focuses on regaining control, becoming well and doing something about the illness. In these stories, medicine is the weapon of choice against the illness. The second gives emphasis on the physical decline, loose of control and uncertainties. The last one focuses on the positive sites of dealing with the illness as a transformation and quest, a change of life, of valuing things and relationships (Frank 1995; 1998).

STIGMA

In stigma (1963) Goffman reversed the idea of impairment itself by focusing at the social and personal meaning that visible and invisible stigma acquires via social interactions. Social meaning of illness does not come from illness itself but from the fabric of everyday life. The stigmatized person, according to Goffman, loses the characteristics of “a person”[9]. Goffman was particularly interested in how stigma circulates in “mixed” interactions, when both the stigmatized persons and the “normals” meet. These encounters may be disrupted by the known-aboutness of the illness from the people who participate, and the attempts of the stigmatized person to “pass”.

Goffman’s theory of stigma has been largely used with reference to chronic illness. An invisible chronic illness, whether physical, emotional or cognitive, whether treatable or curable, communicable or not, it is one that entails all the characteristics and combines the attributes of invisible stigma (1963: 65). It is unseen, a condition that is not perceptible, not noticeable and not evident to others, and may entails other invisible traits of character or morality, for instance laziness or mental issues. The stigmatized person, in order to feel comfortable in a society that wants to isolate him/herself and needs to find strategies to cope with the “normals”, which can result in further isolation or the connection with groups of people with the same stigma. The person also needs to control the information that circulates in order to “pass”. With this Goffman highlighted the work that needs to be done in terms of restrictions, in order to be socially accepted:

> It seems to be assumed, and apparently correctly, that he who passes will have to be alive to aspects of the social situation which others treat as uncalculated and unattended. What are unthinking routines for the normals can become management problems for the discreditable. These problems cannot always be handled by past experience, since new contingencies always arise, making former concealing devices inadequate. (1963: 88)

However, the person can also decide to unlearn to pass, and denounce themselves as stigmatized individual.

> He can voluntarily disclose himself, thereby radically transforming his situation from that of an individual with information to manage to that of an individual with uneasy social situations to manage, from that of a discreditable person to that of a discredited one. Once a secretly stigmatized person has given information about himself it becomes possible, of course, for him to engage in any of the adaptive actions previously cited as being available to the known-to-be stigmatized, this accounting in part for his policy of self-disclosure. (1963: 100)

Stigma has directed the attention on the social and personal consequences of stigma and on the cultural meanings of stigmatized illness. Illnesses have indeed metaphorical connotations (Sontag 1978) and cultural meanings embedded. In later works, Goffman pointed out the importance of body control and image for social representation and interaction.

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[9] The becoming of “non person”, in Goffman terms, has been referred also for people who perform invisible work. It is a consequence of invisible work itself (Star and Strauss 1999).

Studies that used Goffman's approach pointed out that people living with chronic illnesses may internalize, experience, and anticipate stigma, by looking at the relationship among stigma, illness and identity. Vickers (2001) described how invisible stigma circulates in the workplace and its consequences for the chronically ill people. People living with chronic illnesses may experience (internalized, experienced, and anticipated) stigma within healthcare settings. Internalized stigma is the extent to which people endorse negative beliefs and feelings associated with their stigmatized attribute and apply them to the self (Kilinc and Campbell, 2009, Mak et al., 2007). Internalized stigma is an intrapersonal phenomenon, embodied by people living with chronic illnesses and therefore may be brought into a variety of social contexts, including the workplace and healthcare settings. Experienced stigma instead is the daily lived experience of discrimination, abuse and oppression. People living with other illness-related stigmas, such as obesity, report that healthcare workers feel frustrated with them, complaining of their "non-compliance" (Rogge 2004). Having a stigmatized identity may result in compensatory behaviours that can influence subsequent health outcomes. For instance, anticipating stigma from health care workers and relevant others, may result in decreased quality of life. Internalized, experienced, and anticipated stigma within healthcare settings likely act as barriers to care access, because they feel that they do not deserve care or that care may not work for them or because they do not want to face additional negative treatment.

DISEASE, ILLNESS AND SICKNESS

In a historical perspective, Lupton (2003) noted, the illness and disease categories have always been in conflict: assuming the capacity of medicine to provide cure for illnesses through a systematic observation and classification, medicine became dominant from the late 17th century. However, Lupton pointed out, despite their rationalistic epistemology, medical practices included something else, for instance the signs of illness were interpreted on the sick person's account, their bodily events, subjectively defined sensations and feelings. It was not until the development of the biomedical model of disease, grounded on scientific techniques of objective observation, that the importance of the patient's explanations and interpretations of their symptoms was substituted by the hospital and laboratory models. A shift from a person-centred cosmology to an object centred cosmology, when the person became the patient, "designated a passive and uncritical role, subject to rules and regulations of the hospital" (Lupton 2003, 84). However, as highlighted by Armstrong (1984), by the 1950s the medical gaze was in a state of transition; the passivity of the patient started to be challenged with another strand to medical perception that viewed illness as existing in the social spaces between bodies. Consequently, this space needed to be monitored and patients' views needed to be heard. Then central problem to address, from the 1960s, was that of communication between health professionals and patients. And to improve communication, would have meant to improve compliance and satisfaction from the patient's side.

Sociology of health and illness, according to Lupton, did not challenge the biomedical authority until the 80s, when constructionist, postructuralist, Foucauldian and feminist critiques of medicine instead presented medical knowledge as a series of relative constructions dependent upon socio-historical settings, constantly re-negotiated. Biomedicine in their view, is as much as a social product as lay knowledge of medicine. Social construction of medical knowledge shows how medical knowledge is conditioned by the social context in which it is developed. Specifically, these scholars explain that what qualifies as biological disease or biomedical evidence is often socially negotiated and interpreted.

> As feminist and science studies have demonstrated, medical knowledge about disease is not necessarily given by nature, rather it is constructed and developed by claims makers and interested parties who frequently have a strong evaluative agenda. Diseases and illnesses are as much as social products as medical and scientific ones. (Conrad and Barker 2010)

Consequently, this approach sees disease categories as not fixed but instead as built and changing according to the emerging of new classifications and prevention standards. The fact that “disease” is socially constructed means that disease categories are not accurate descriptions of anatomical malfunctioning but are socially imbued. Consequently, in this view, medical beliefs systems are contingent upon the society which produces them and there is correspondence between modes of organization, technological forms and medical knowledge. Technologies and practices co-construct knowledge of the body, in this way, the disease side of the disease/illness conceptual distinction became ready for social constructionist analysis.[10]

While social constructionists, argue that the categorizing of disease is influenced by the historical, social and political context as it is the definition of illness, others have argued that disease and illness are distinctive categories and states (Kleinman 1988). The issue of the disease/illness divide crossed the medical sociological and anthropological production and it is still very relevant in particular with reference to chronic illness. The biomedical model of disease, according to the formers (e.g Lupton), is not a rational scientific reality which is internally consistent, rather it is open to differing interpretations even among health care professionals. The distinctive, and sometimes opposing, positions that will be described in this section are fundamental to understand where sociology of health and illness locates itself, what is its ontology and its epistemology, and what kind of knowledge of chronic illness it wants to promote. This debate has seen medical anthropology particularly active and here I want to review these contributions. Medical anthropologists have traditionally been concerned with the interpretation and lived experience of illness, through an approach that views disease and illness as a form of communication through which “society, nature and culture” speaks simultaneously (Scheper Hughes and Lock, 31 in Lupton).

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[10] Foucault (1977) stressed how medical discourse constructs knowledge about the body, including disease. As Bryan Turner (1995) noted, “We can no longer regard diseases as natural events in the world which occur outside the language in which they are described. A disease entity is the product of medical discourses” (p. 11). In turn, medical discourse can influence people’s behaviors, impact their subjective experiences of embodiment, shape their identities, and legitimate medical interventions. For a further reconstruction see Conrad and Barker (2010).

In the 70s, Kleinman, Eisenberg and Good, members of the first medical anthropology school of Harvard, contextualized biomedicine as cultural category in which specific interpretations of illness are described and narrated (Kleinman, Eisenberg, and Good 1978). According to Kleinman, Eisenberg and Good, disease is an alteration of functioning or structure of the body and it is culturally described by doctors. Illness instead, or "illness narrative" is the meaning of the experience of suffering from the point of view of the person and its social, familial and historical context. Disease and illness are, in this view, different and mutually exclusive models. The relationship professional/patient is therefore particularly explicative because two different construction of reality are performing and are in communication with each other. These authors see that communication problematic as it brings often conflicts and a cause of non-compliance from the patient side. In fact, while the doctors frame the problems in biomedical terms (disease), patients do it referring to cultural interpretative models that identify the problem with life experiences (illness). Illness refers to the social, lived experience of symptoms and suffering which is innately human.

It follows that this view wants to explore illness as category of analysis, with the relationship professional/patient, to look at medical systems and their application. Discovering the illness dimension means to promote the clinical efficacy, a sort of clinical social science. The study of illness is in this regard, a necessary supplement of disease because explores the patients experience of suffering and healing. If biomedicine is efficient in curing the body, it is not in caring for the patient's experiences and subjectivity. While disease would have evoked doctors, hospitals, emergency rooms and organs, illness would have evoked patients, culture, identity and daily life stories. In other words, disease has been the realm of biomedicine, and illness the realm of the social. It has been pointed out that this view leaves the dichotomy mind and body unattended and, by defining the disease and illness as cultural systems, it eludes other social, economic and political mechanisms. It does not break with the epistemological and ontological premixes of biomedicine.

In opposition to this view, Young proposes to abandon the study of cultural construction of the personal experience of suffering, instead wanting to explore the "sickness" dimension, the process of production of medical knowledge and diseases: they are social processes that determine "medical problems". Young wanted to switch from an individual centric perspective beyond the interaction professional/patient to one that embrace socioeconomic and political processes (Quaranta 2006). Disease categories are not only constructed but they are always changing according to different and conflicting socio-economic and political interests. In this view, disease categories can be constructed, stabilized, changed or dismantled. Medicine therefore produces medical practices that invest not only personal health and healing but also broader social processes that have to do with prevention medicine, commercialization, class interests and so on. Importantly, Young points out that disease and illness are socialized through arrangements which determines who gets what practitioners and interventions and through specific views of social order embedded in medical beliefs. Medical practices are in this view simultaneously ideological practices when they justify the social arrangements through which disease, healing and cure are distributed, and the social consequences of sickness (Young 1982: 270). Twaddle's triad[11] has in particular been prominent in sociological works and has been and further defined and expanded it in later works (Twaddle 1994). Maturo introduced the concepts of "sickscapes" (Maturo 2007).

While for the first approach, biomedicine can be explored as a cultural system, for the others it works as ideology. However, none of these perspectives, challenged the dichotomy body/mind in scripted in the categories, nor problematized the disease category together with its territory: the body. Scheper-Hughes and Lock claimed an approach for medical anthropology that sustain a radical problematization of the body itself, nor as an entity outside of cultural or social processes, but as a constructed social object. In fact, they argue, the dualism mind-body is specific of the western culture and no other contexts. They want to adopt a phenomenological approach with a symbolic approach to look at the relationship between experience and socio-cultural representations. In their view, we all have a body which is culturally constructed, but also, we are bodies who live in the world and produce socio cultural meanings and experiences.

Bodies are already social discourses, they do not need to be interpreted through socio and cultural meanings. Not an object of medicine but subject of broader processes. Illness is, in this view, a body technique, a product of, and resistance to, dominant ideology (Lock 1991). Illness is something that bodies do through the lived embodied experience, nor only through the illness categories of personal experience nor sickness, discursive dispositives that are foundations of systems of truth. It is a cultural practice through which the body express itself through its constructed cultural repertoires, positioning the subject in dissonance of its social world.

They therefore propose to investigate the three bodies through an embodiment perspective: the body self as subjective experience, which can be investigated through phenomenology; the body social as embodiment of cultural meanings, and the body politic as systems that value and legitimate certain forms of control and

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[11] Biomedicine has focused on the disease, meaning pathological states, the physical abnormalities of organs and organ systems. The malfunctioning of the disease causes a physical reduction of capacity or life expectation. 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. Ontologically, disease is an organic phenomenon (physiological events) independent of subjective experience and social conventions. Epistemically, it is measurable by objective means (Twaddle, 1994a, p. 9).
Illness refers to a person's perceptions of certain socially disvalued states connected to the disease. Twaddle defined Illness as follows: ''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 feelings of competence'' (Twaddle, 1994a, p. 10).
Ontologically illness, then, is the subjective feeling state of the individual often referred to as symptoms. Epistemically this can only be directly observed by the subject and indirectly accessed through the individual's reports. Illness changes the actions of the individual, making him or her communicate his or her personal perspective of the negative occurrence to others, for example by calling for help. Illness is negative bodily occurrences as conceived of by the person himself (Hoffman, 2003).
Sickness is a social identity of the person which involves disease or illness, a societal label of the sick person. Sickness is defined by Twaddle in the following way: ''Sickness is a social identity. It is the poor health or the health problem(s) of an individual defined by others with reference to the social activity of that individual'' (Twaddle, 1994a, p. 11).
Sickness in this sense is a social phenomenon constituting a new set of rights and duties. Ontologically Twaddle conceives of sickness as ''an event located in society ...defined by participation in the social system'' (1994a, p. 11).
Sickness calls for a determination of the social status of the sick person, deciding who is entitled to treatment and economic rights and who is to be exempted from social duties, it is negative bodily occurrences as conceived of by the society and/or its institutions (Hoffman 2003).

surveillance (Scheper-Hughes and Lock 1987). They claim, with this approach, to broaden the ontology and epistemology of biomedicine and overcome the mind-body dualism.

The problematization of body as personal and social processes has led to describe health and illness as human construction to analyse in terms of their process of production: the body as cultural and social constructed and the body that actively does and produces meanings and experiences. Illness therefore it is not an entity, as biomedicine would claim, but a process which is both personal and social. Human suffering in this view, are embedded in individual experiences, and at the same time are the marks of society on the bodies.

Alan Harwood suggests that an unanticipated side effects of the triad is that it has created a single discourse for anthropologists and clinicians that has allowed physicians to claim both disease and illness, curing as well as healing for the biomedical domain. Consequently, Scheper-Hughes argues, the social relations contributing to illness and other forms of disease are in danger of being medicalized and privatized rather than politicized and collectivized (Scheper-Hughes 1990: 66), as medicalization inevitably entails a missed identification between the individual and the social bodies, and a tendency to transform the social into the biological" (Scheper-Hughes and Lock 1987). This issue, we will see in the next chapter, has been particularly urgent in reference to the emerging concepts of lifestyle and risk.

> Everything from marital discord to poor school performance, from worker bum-out to existential doubt in the nuclear age can be appropriated and treated by medicine in new (and improved) therapies. Ironically, the conscious attempts to temper the materialism and the reductionism of biomedical science often end up inadvertently recreating the mind/body opposition in a new form. (Scheper-Hughes and Lock 1987)

As Timmermans and Hass stated: "While the focus on illness has allowed sociologists to claim a subject matter, a price was paid for the restriction of a sociological perspective and of ignoring the "technical" or "biological" aspects of health, for example, we may know much about the effects of chronic illness on identity but fail to establish the health consequences of this identity formation" (Timmermans and Hass 2008). According to Mol (2002) and Mol and Law (2004) the dichotomy mind-body is still embedded in social science. The disease/illness dichotomy is rooted in the epistemological western tradition that tries to articulate the relation between the "object of knowledge" and "knowing subject". They argue that the inclusion of experiences of illness, self-awareness and self-knowledge in medicine leaves the modes of knowing untouched because it is assumed that it is knowledge that is central.

> A debate with the way in which the social sciences have studied the body and its diseases in the past. For a long time, social scientists have said that there is more than the physicalities treated by doctors. And then they used to study this "more": a social and an interpretative reality. They have differentiated between disease and illness, taking the latter as their object of

> study. More recently, the medical perspective on disease has been included in the studies, too. This book is among those who try to take the next move. It says that a study of the enactment of reality in practice makes it possible to ethnographically explore the body multiple and its diseases in all their fleshiness. (Mol 2002, IX)

If, in their view, illness was the space of the subject of knowledge, the category "disease" has been neglected from sociology and anthropology, remaining as the unmarked category of anthropology and sociology of medicine. The categories of disease/illness reflect the biology/culture divide and need to break down because they are no longer valid.

> One might conjecture that it isn't only knowledge of "disease" that holds power over patients these days. Knowing "illness" also does; for example, the "quality of life" so important in framing present-day health care is defined in sociological terms. One of the dominant ways Western cultures live their "illnesses" is by taking them to be "diseases". Things doctors know about. But recent transformations in health care, like those that make patients into the guardians of their own therapies, are in the process of undoing the former divisions. (Mol 2002, 21)

As a category, she argues, it cannot be left behind, leaving "disease" in the hands of physicians alone is a political weakness. In claiming the disease category, Mol connects to Haraway who, discussing the categories of sex/gender warned about the price feminists have paid by leaving the "sex" unanalysed and unquestioned. "Thus, formulations of an essential identity as a woman or man were left analytically untouched and politically dangerous". They instead are interested in understanding what is a body in the conditions of possibility at the beginning of the 21st century?

> For by entering the realm of meaning, the body's physical reality is still left out; it is yet again an unmarked category. But the problem has grown: this time the body isn't only unmarked in the social sciences, but in the entire world they evoke. In talk about meaning and interpretation the physical body stays untouched. (Mol 2002, 12).
>
> Asking the question 'What is a body?' is worthwhile in quite a different way. It is a way of shifting the grounds on which questions about the reality of bodies may be posed. It moves us to a place where gathering knowledge – whether objective or subjective – is no longer idolized as the most important way of relating to and being in the world. (Mol and Law 2004, 45)

The interest in lived body's approaches brings lived experience into surface, sustained care practices. Framed as a general turn in epistemology they want to explore illness as a practice, or even better, multiple practices. It is, in this view, not a matter of subjective knowledge versus objective knowledge, but instead "knowledge of action" (Mol and Law 2004), or knowledge incorporated in practices (Mol 2002). The question is how people *do* their bodies, to find out that bodies interact with machinery, surroundings and have permeable boundaries, they are doing actions all the time, they are trained to feel, and they live with the tensions that come from medicine. In practice we enact bodies, argue Mol and Law: “If the body we have is the one known by pathologists after our death, while the body we are is the one we know ourselves by being self-aware, then what about the body we do? And what are the consequences if action is privileged over knowledge?” (Mol and Law 2004:45)

Mol thus focused on disease rather than illness experience, showing that a disease has multiple meanings depending on medical disciplines and becomes a rallying point that co-ordinated different people, objects, and actions. Rather than worrying whether atherosclerosis is real, she was satisfied with the observation that atherosclerosis, as disease, existed and she investigated what its existence consisted of. A sociological approach to investigate diseases, inspired by STS, is to focus on practices and observe how diagnostic categories facilitate particular actions. With practices we can look at performing tasks, doing work together, and transforming something into something different, situating who does what, when, where, and with what consequences, trajectories that are simultaneously deeply clinical, social, therapeutic, iatrogenic, political, and bureaucratic (Timmermans and Hass 2008).

CHAPTER 3 – CARE AND RELATIONAL MATERIALISM

Neo-materialism in social sciences denotes a range of perspectives that have in common a "turn to matter[12]", emphasizing the materiality of the world, both social and natural. New materialisms consider the world and history as co-produced by materialities, as plural and relational, including the physical, the biological to the psychological, social and cultural (Barad 2007; Latour 2005; Braidotti 2002). By challenging the distinction between the materiality of the physical world and the social constructs of human thoughts and desires, it opens up the possibility to explore how each affects the other, and how things other than humans can be social "agents" and making things happen. New materialist sociology is thus a posthuman sociology that can engage with the world beyond the human: with other living things, and with the wider environment of matter and things. Sociology thus aspire to explain the continuities, fluxes and "becomings" that produce the world, by exploring the relational character of these entanglements. Despite differences in neo materialist approaches, relational ontology is a common ground (N. J. Fox 2015; Alldred and Fox 2017). It asserts the fundamental relationality of all matter: bodies, things and social formations only exist in relationships with others. Actions and events are assemblages (Deleuze and Guattari 1988) of these relations that becomes networks and connections always in flux, always reassembling in different ways. Furthermore, human agency is replaced with the notion of affect, borrowed from Spinoza (Deleuze 1988): the world is produced and reproduced through the agential capacity of all matter to affect and be affected (Barad 2007). Affects, within assemblages, act on bodies, things and social formations, and in doing so they alter their capacities in different directions and towards each other. Relational materialism, in other words, do not rely on systems and structures but on micropolitics at the level of assemblages.

New materialist approaches and science and technology studies have prompted the attention to the significance of materialities within sociology of health and illness (Buse, Martin, and Nettleton 2018). In blurring the distinctions between nature and culture, humans and other living forms, technology and organism, this materialist turn destabilizes and displaces the view of care as "other" than technology, opening up to more than human relations in technoscience, of agencies previously neglected from descriptions of technology, a contribution to was well as possible worlds (de la Bellacasa 2017). A feminist relational materialist vision of care represents concerns with persistent forms of exclusion, power and domination to which sciences and technologies also contribute, and, in doing this, again, at the centre of investigation is bringing into surface the invisible things.

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[12] The idea of "matter" is the staging of things as lively. Latour in particular develop the concept of matter of concern, aiming at re-uniting two words, that of humans, and therefore the social, and that of objects, animals and other non-humans, therefore nature. In this view, everything is both construction and reality, when things gather around a common concern, they become a collective "matters of concern" (Latour 2005). The importance of this notion for our purpose it that concerns need to be handled with care. Both Mol (2008) and de la Bellacasa (2017) refer to this vision of care, animated by the purpose of treating things as matters of concern: to engage with the becoming of a thing, including all the concerns attached to it, all those who care for it.

These approaches focus on the "experience and feel" of care in practice (de la Bellacasa 2011; Abbots, Lavis, and Attala 2016) and how these practices become sedimented over time. With care practices materials and memories are shared between people, they "stand in" for caring relations and may shape, enable or constrain practices of caring. Materialities play an active role in constituting relations of care (Buse, Martin and Nettleton 2018) because, physical and emotional aspects of care are impossible to disentangle, material practices are generative of, and imbued by, affect and emotion. For instance, Pink (2012) considers care practices in relation to places, on how different processes and things combine to create the world as it is experienced. Maller (2015) looks at buildings and infostructures such as parks and roads as part of the infostructures in health.

The sociological attention has changed concerning health from a focus on health behaviours of individuals and their "social context" to their everyday practices that are situated, composite and contingent, emerging from actions and interactions. The concept of "assemblage" (Fox 2011; 2015) is increasingly used to situate the body within of material, physical and psycological relations and affects. Assemblages, the coming together of disparate sets of resources and elements, may include a range of human and non-human elements, such as health technology, organs, the arrangement of a room, clothes, friends. Assemblages are processual, relational and dynamic, shifting across situated contexts. Ethnography of health practices therefore focus on how the relations between elements are engendered, maintained and transformed in everyday life (Moreira 2018). For instance, Star and Bowker have been interested on how categories and standards make visible what normally lies in the background (Star and Bowker 2000) and Moreira is interested on how the complex ecology of standards and measurements interact in practice, how they assemble different moral and technological worlds, how they generate "difference and spark the moral imagination". (2018: 256)

> From the perspective of everyday practices health is experienced, lived through, reflected upon and experimented with in a situated and evolving relationship with other elements of people's lives. Even practices that can be seen sorely focused on health monitoring, maintenance and enhancement, such as self-tracking, are significantly underpinned by identity work and belonging, as well as particular technoscientific imaginaries. (2018: 255)

Ultimately, Moreira wants to emphasize, through ethnographic and praxiographic practices, how is health produced and what it produces:

> What are the practical, normative, consequences of measuring health in a particular way? To what extent are everyday lay enactments of health implicitly indented to long established biomedical ways of knowing and measuring health, such as the absence of disease? do everyday practices question or transform such standards of living? (2018:257)

The concept of praxiography was developed by Mol (2002) and Mol and Law (2004), with the aim to studying multiple practices. Multiple because, says Mol, the "disease, that ethnographers talk about, is never alone. It does not stand by itself. It depends on everything and everyone that is active while it is being practiced. This disease is being done" (2002: 32). The investigation therefore needs to look at how materials are assembled, put together, and "turned into an object that subsequently goes out in the world all by itself":

> If one doesn't stay within the confinements of the body but follows the various practices in which atherosclerosis is enacted throughout the hospital, the topography of the relation between pathology and clinic appears to be completely different. (…) If the practicalities of enacting disease are bracketed, disease is located inside the body. If reality is enacted differently from one site to another, the question about where these sites are cannot be answered by a finger pointing at the regions of a body. (Mol 2002, 1)

Since, according to this view, the disease is being done through relational material practices, there are different ways to display the illness and the body. The body and the disease flow into each other in multiple ways. Mol gives the example of disease arteriosclerosis, particularly leg vessels, in which an anatomical version of the body consists of vessels, stenosis and plagues. At the same time, there is a laboratory body with blood pressure in the arms and the ankles, and a disease that emerges in the consulting room, that consist of pain upon walking. There is also a physiology's suggestion that says that there is a processual, transforming body in which plague may gradually form. Each version of the body is done by different measurements, different discursive practices, each with practical consequences and often tensions, that ethnography need to look at. The body multiple can be observed in practice, wondering what each element of the scene can suggests about the reality (problem concern) at stake in that practice. By looking at the body "we" do in that setting, we look at the "we" done by all kinds of people and apparatus involved.

> It is possible to listen to people's stories as if they tell about events. Through such listening an illness takes shape that is both material and active. It is an illness that consists of lying on a sloping table. Of arguing with your anesthesiologist about the cloth in front of your eyes. It is an illness made up of scars on your legs that do not stop you from becoming a new person. This illness is something being done to you, the patient. And something that, as a patient, you do. (2002:20)

Mol does not say that doctors and patients ascribe meaning in different ways, she goes beyond that to tell an additional story, which is that doctors and patients perform, or enact, reality "together". So rather than the difference between them, the conflicts and the communication, her focus is their *collaboration*. The linguistic repertoires relevant to this collaboration do not come "after" them, somewhere to be discovered, they are a "part" of what happens in hospitals. With this contribution, relational materialism brings about an ontological shift. Ontology is not given but ontologies are brought into being, sustained and allowed through daily socio material practices. Praxiology therefore consist in an epistemological turn as well. It is not a matter of objective or subjective knowledge, but *knowledge of action*, knowing is a practice, knowledge as manipulation. So, the question for social scientists would concern ways in which objects are handled in practice.

> Medical interventions hardly ever bring pure improvement, plus a few unfortunate 'side-effects'; instead they introduce a shifting set of tensions. (…) Our suggestion is different. It is that instead of adding a further layer of knowledge, medicine should shift its self-understanding. Medicine should come to recognize that what it has to offer is not a knowledge of isolated bodies, but a range of diagnostic and therapeutic interventions into lived bodies, and thus into people's daily lives. (…) For this is where patients come in again: aware, not just self-aware, but equally able to tell stories about medicine and the effects of its interventions. The overall aim of a multi-voiced form of investigative story telling need not necessarily be to come to a conclusion. Its strength might very well be in the way it opens questions up (Mol and Law 2004, 58).

The knowledge they talk about emerges from what patients need to work out, counteract or avoid, how they do it in practice, which involves measuring, counting and self-awareness, something that can be trained and cultivated. Same goes for people of the patient's family and significant others: well prepared surroundings become part of the active self, they need to be ready for action. Measuring, in this view, is not a simple individual action that depends on an isolated body. Materiality and sociality, Mol and Law argue, are therefore produced together: when we look at the social, we are also looking at the production of materiality and when we look at materials, we are witnessing the production of the social (Law and Mol 1995). This brings to important consequences for ethnographic practices in medicine: we are never in front of a coherent, whole body. Instead, *that* body hides a lot of work that has to be done in order to keep it in balance, in order to resolve the different sort of tensions that emerge and that can be between organs of the body, or between the ill body that has certain needs and other needs that occur in daily life. In the case of diabetes for instance, there are often tensions between the body with diabetes and the sport-person, or between avoiding a hypo and having a stable blood sugar level. All these tensions and conflicts have a role in doing diabetes, as the strategies and knowledge that the person with diabetes has to learn to practice in order to make it work, to keep in balance, to keep oneself "whole" (Mol and Law 2004).

Some authors have however highlighted that there might be tensions when applying for socio-material approaches and practice theory, tensions that continue to emerge between sociology of health and illness and STS. While socio-materialist approaches offer a point of overlap between sociology of health and STS, creating a space within which to examine the heterogeneous practices of health, a focus on practices addresses *how* things happen, instead of *why* they happen. Critiques to socio-materialist approaches have therefore pointed out that the concept of practice potentially resists the search for causal explanations, embracing the idea that practices are contingent on a whole variety of social and material factors. In this way, they argue, an analysis of social determinants or health inequalities, as more explanatory/causal theories, are neglected (Henwood and Marent 2019). Science and technology studies and relational materialities however refuse approaches based on technological determinism and social essentialism, close to the sociology of health and illness critical tradition, which either overestimate the power of technology to change society or underestimate the role of medical technologies viewing them as mere tools (Henwood and Marent 2019; Timmermans and Berg 2003). Timmermans and Berg propose a focus on technology-in-practice, aiming at looking at what technologies and materials *do*, leading to a broad definition of technologies which encompass a range of mundane to sophisticated technologies, drug therapy, and organizational instruments such as patient records, protocols, programs. Since technologies are embedded in relations of other tools, practices, groups, professionals, and patients, it is through their location in these heterogeneous networks that treatment that care, cure and any other action is possible. Furthermore, the heterogenous character of the assemblages, makes difficult to isolate a single technology in use, as physical things, but instead they are located within assemblages that comprise a wide range of different relations drawn from natural and sociocultural, human and nonhuman, physical and semiotic realms, to be analysed in terms of what they do, within the assemblages that enable them to work. An analysis that does not escape broader socio-political elements:

> As to the medical technologies that await our investigation, we would like to repeat our plea for the seemingly mundane, 'infrastructural' technologies – such as records, information systems, standards, small home-care technologies, clinical research guidelines – that do not have the immediate attraction of reproductive technologies, HIV-AIDS, or genetics. It is often in the seemingly 'technical' matters that deeply relevant, social issues are 'hidden' – such as inclusion/exclusions of certain groups or voices, or the subtle restructuring of patients' or professionals' identities. Similarly, in being ubiquitous, small, home-care technologies such as insulin pens, or asthma peak-meters, might have far-reaching impacts that would otherwise escape the sociologist's eye. (Timmermans and Berg 2003, 108)

De la Bellacasa places care, with all its tensions and power relationships, at the centre of this relational materialist turn, with the conceptualization of "matters of care" (2017). For her, care is a central element for the organization of material practices and the set of critical questions that suddenly emerge. The doing of care can be found in many sociotechnical spheres, in health care, as in the responsible maintenance of technology or in design plans. Following Mol's suggestion of treating technology with care, Suchman for example, in describing a form of design that recall the image of slavery, fosters interest about a particular human-machine assemblage which engage humans in neglecting relations of care (Suchman 2007). Sociotechnical assemblages that reassemble human/non-human agencies, can reinforce in this analysis asymmetrical relations that degrades care or promote forms of neglection. For de la Bellacasa, representing a socio-techinical assemblage as a matter of care can give ethico-political significance to particular socio material practices by "generating care for undervalued and neglected issues" (2017: 57). However, the notion of matters of care is a proposition to think with, to engage with, so it can generate more caring relationalities, it is a "speculative affective mode" (66), that transform the potential to affect others, whether plants or animals. She proposes an ontology grounded in relationality and interdependence that acknowledges heterogeneity but also that "cuts" create heterogeneity; since care itself orders relations, connecting some, like web of relationalities, and excluding others.

ETHICS OF CARE REVISITED

Relational materialist approaches have placed the concept of situated care practices, the interdependency of humans and non-humans and ecological analysis at the forefront of sociological accounts. If we cannot elude the moral dimension of care, therefore we need to refuse an ethics of care that aims at defining what "good care" is. Instead, situated care practices can tell us about the tensions that arise with care, the moral and material dilemmas when people are caring for each-other. A politics of care involves affective, ethical and hands-on agencies of practical and material consequences, as Mol has clearly written:

> Chronic illness patients are active in the sense that they need to do a lot in daily life and within this effort, there is no use of treatment or service to use or choose, but care practices to do. It follows that the logic of care has no separate moral sphere because ethics intertwine with facts, and caring itself is a moral activity, there is no such thing as an (argumentative) ethics that can be disentangled from (practical) doctoring. "You do what you can while watching out for the problems that emerge – in bodies or in daily lives, caused by the disease or by its treatment. What goes wrong, where does it hurt?". (2008: 79)

Janette Pols contributed to this endeavour by working at empirical ethics of care as methodology, which, first of all, does not define beforehand what care is and if it is good but focuses instead on the *doing* good care:

> Empirical ethics has a specific preference for the study of doing good. Traditionally, ethicists worry about the question what is good to do. That we will then, without hesitation or problem, move on to do good is taken for granted. But doing good is a complicated activity, and when we try to do it, more often than not that good changes into something else. For instance, technologies are implemented to release the burden on professional care, but turn out to make professional care more intense (Pols 2013a: 20).

Empirical ethics, according to Pols, need to be conceived within the "chronification" framework. Within the framework of chronic illness, empirical ethics are the result of different shifts that occurred with the transformation of disease into chronic illness. A first shift moves away from an ethics of the individual towards an ethics of the social. Here the social includes material matters, such as technologies and buildings. Empirical ethics is an ethics of social and material relations:

> When disease and treatment are not one-time events, or short interruptions in the life of one person, it becomes important to look at how care practices are shaped over time. As an ethics of the social, empirical ethics studies everyday care practices, in which dramatic situations do emerge. But by connecting sensational events to daily routines, the everyday aspirations of caregivers and to the workings of technology, these studies may teach us something about the conditions that allow particular dramas to emerge. (…) An ethics of the social analyses how patients, their carers, technologies, and ailments accomplish specific ways of living together (…). An ethics of the social that considers chronic illnesses does not take as its object an individual facing a Difficult Decision. Rather, in care practices as ways of living together, rules meet with values and true-isms, habits and routines come together. (Pols 2013a: 22)

According to Pols, empirical ethics are intra-normative, where intra-normativity is a "normativity that exist in different forms within practices where participants act to deliver good care with the help of devices, routines and concepts (Pols 2015:83). Intra-normativity refers to the problems the participants have to solve, the appreciations they make and the values they shape in their relations with technology and disease. Empirical ethics takes this as a starting point, by looking at different and sometimes conflicting notions of what is good care within care practices, a re-scriptive, rather than descriptive, ethics. An empirical ethics also does a step further, it aims at studying how the knowledge of patients and clinicians works in practice, it poses questions like: what ideas about the good of medicine are emerging and what type of knowledge is embedded in these ideas of good medical practice? (Pols 2013a)

> The notion of intra-normativity wants to direct attention towards the everyday ways of doing good. Ethics is not added to these practices, it is part of them. Intra. It is part of the ways in which participants try to do what is good. (Pols 2013a: 23)

A second shift moves away from ethical principles towards aesthetic values. Aesthetic values in care and daily life refer to what people find proper, tasteful, stylish, or pleasant. They refer to what people appreciate and value. Quality of life becomes important when illness chronifies. Aesthetic values are social values. The shaping of aesthetic values leads to practices, and hence intra-normative ways of living together.

The third shift comes with re-orienting health care towards living with chronic disease, a shift in the kind of knowledge needed to deal with chronicity. The issue of knowledge is referring not only to patients but also to clinicians, they are both invested. While clinical knowledge is struggling between the "objectivity" of Evidence Based Medicine (EBM) and the intra-normative clinical work of practices, with traditions and embodied routines, devices, facts and skills, patients are seen as containers of information or technology users, actors who manage their own illness, change their lifestyle and ability to make good choices. But, argues Pols, it is not that easy: lots of work must be done before information and technologies do anything at all. People need to actively shape their relations with their devices, before they make that information as transferable knowledge. And this requires further exploration.

The empirical ethics methodology is grounded on the praxiographic approach that studies things and people in their relations, assuming that people who do care, embedded in care practices, perform care work aimed at improving the situation of those cared for and shaping goodness in daily life and care. This approach also pays attention to the material (and virtual) objects, methods and techniques scientists use to produce their knowledge. In this view, relationality is a tool for analysing care practices as the product of mutual relations. The precise identity of all the relational elements (people, technology and so on) is not given but it is an outcome of the way they had built their relations. Questions such as how to be a patient or how to live with a chronic disease is not a singular, natural or biomedical given, but it is shaped differently in practices in which technologies and other people play a decisive role. Rather than reasoning about what is good, the focus is on the participants' attempts to put something good into practice. Moreover, what type of problems people with particular diseases have is not given, but it is shaped in the way the devices help people understand what is wrong with them and how they should act.

According to Pols, care practices that are shaped and known relationally are inherently normative. They are practices where people and devices shape some problems and proper ways of dealing with these, while making others less obvious. In the care practices she investigated, she found that a first value of importance for the patient is the prevention of crisis. The investment in nursing control is meant to prevent patient's conditions to become worse, but especially for the patients to avoid hospitalization. But what happened was that the responsibility of nurses made the patient feel safer. Their webcam practice had the value of connecting patients, who share common knowledge that stems from embodied experience and shared skills. In this way, patients become carers and advisors of each other, "taking things seriously". (Pols 2015)

> An empirical ethics way into these matters is to not attempt to ground knowledge, but to study how the knowledge of patients and clinicians works in practice. I am suggesting we analyse the practices, which use and develop this knowledge: the concepts needed to do this, the methods, the ways in which the object of knowledge takes shape, and the normative orientation of this knowledge, i.e. the goal of collecting and using it. To live with chronic disease, for example. Or to treat individual patients. (Pols 2013: 29)

De la Bellacasa writes about "transformative ethos" instead of ethics, to underline the shift from individual to entanglements. She has vividly written:

> Because care eschews easy categorization, because a way of caring here could kill over there, we will need to ask, "how to care?" in each situation, without necessarily giving to one way of caring a role "model" for others. It means too that as a doing, I look into caring as a

> transformative ethos rather than a normative ethics. This view remains attuned to ways of knowing on the ground, involved with effects and consequences, with an ethicality involved in sociotechnical assemblages in mundane, ordinary, and pragmatic ways. But formulating the necessity of care as an open question with the potential to transform a terrain from within does add an obligation for the ontological constructivist ethos beyond the power of critique: cultivating a speculative commitment to living worlds. As a transformative ethos, caring is a living technology with vital material implications for human and nonhuman worlds. (2017: 67)

The notion of care presented here is that of a doing rather than a moral intention. A doing that it is not limited to human subjects. Barad's suggestion to move ethicality from intentional agency only involves a notion of intra-action: knots of relations involving humans, nonhumans, and physical entanglements of matter and meaning that interact with each other. Ethicality practices, entanglements of relationality and distributed agency, refuse a normative perspective. Materialist ontologies have the potential to displace ethical research beyond its focus on moral orders and human individual intentionality. In this perspective, de la Bellacasa has reworked Tronto and Fisher's definition of care to speculatively address "more than human worlds", as a "politics of knowledge at the heart of technoscientific and naturecultural worlds" (2017: 15). In need of disruption of the subjective-collective behind the "we" and the intra-actions of agential subjects, Tronto and Fisher's definition of care is modified as such:

> care can be viewed as "everything that *is* done, all the relations [that] maintain and repair a world so that *all*, humans and non-humans, can live in it as well as possible in a complex life-sustaining web" (Puig de La Bellacasa, 2017: 97, 161).

De la Bellacasa proposes a notion of care as ethico-political practice and affective engagement within knowledge production about technoscience. In this way, thinking about and with care offers possibilities for thinking commitment and obligations as non-normative forms of ethical engagement that decentres human agency and privilege in favour of situated ethical obligations and commitments. Thinking this way follows the requirement of looking at the specificity of moments, particular relations, of ecologies where the ethical is both personal agency and embedded in the "ethos" of a community of living, where caring modes of attention are directed to marginalized experiences. In this call for an ecological thinking and politics of knowledge of tangible experiences, bodies and relations, the work of Susan Leigh Star is particularly compelling. The concept of "Ecology of knowledge" is employed by Star to emphasize that science is a form of social practice and describe the complex interdependencies between the social dimensions of science and its constitutive knowledge and material practices (Star 1995). In contrast with the concept of "network" that was largely employed in STS, Star suggest the metaphor of ecology which highlights that the dominant existential drive of an ecology is not so much to extend itself but to hold together resilient relationships, as de la Bellacasa has written: "Ecological thinking involves the acknowledgement of finitude (and renewal) and therefore a certain resistance to the deliriums of infinitude of extension metaphors. That is also why ecological thinking cannot avoid ethical and political thinking of consequences of world-destruction and, as a corollary, of the possibilities of regeneration (de la Bellacasa 2016).

CHAPTER 4 – DIABETES

THE CONSTRUCTION OF DEFINITION AND CLASSIFICATIONS

From a clinical standpoint, the physiology of diabetes is relatively well understood. Diabetes is a metabolic disorder, characterised by elevated blood glucose (hyperglycaemia) with disturbances of carbohydrate, fat and protein metabolism resulting from the dysregulation of glucose due to a combination of lack of insulin production, insulin insensitivity, or insulin resistance (Timmermans and Hass 2008). According to the WHO, the effect of diabetes mellitus includes long-term damage, dysfunction and failure of various organs. Several pathogenic processes are involved in the development of diabetes. These include processes that destroy the Beta cells of pancreas with consequent insulin deficiency, and others that result in resistance to insulin action[13].

However, the causes of diabetes mellitus are yet not known. Since it is an intricate metabolic disorder, the understanding of pattern of these connections is difficult. Feudtner, in his reconstruction of the cultural and historical landscapes of the illness, noted that despite the enormous developments in the last century, treating diabetes remains very complicate, and suggested that in medical schools today, a student will typically learn about this complex disease half a dozen times or more, and subsequently forget most of the lessons. Physicians require years of study and clinical practice to learn how to care for diabetic patients (Feudtner 2003).

Today there is a widely agreement on the existence of two major forms of diabetes mellitus, but it was not always been like this. In 1985, the WHO modified the diagnostic criteria[14] by lowering the diagnostic value of blood glucose concentration to 6,1 mmol (110 mg) and above, from the former 6,7 mmol (120 mg dl). In the same report, it was published the widely accepted, and internationally used, classification of diabetes mellitus that we know today. Already ten years earlier, a definition of "metabolic syndrome" was proposed for the first time[15], it is today largely used in particular to identify individuals at risk of developing type 2 diabetes in the future. Despite significant differences in terms of treatment, both diabetes types are deadly if left untreated. Patients with either form are susceptible to complications even if the disease is treated appropriately: vulnerability and uncertainty are a common experience for all diabetic patients (Feudtner 2003; Mol and Law 2004).

The onset of new cases of type 1 disease appears to be increasing throughout the Western world for reasons that remain unclear, and it is currently not preventable. It is generally agreed that type 1 diabetes is the result of a

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[13] WHO – Definitions, Diagnosis and Classification of Diabetes Mellitus and its Complications, 1999.

[14] See: World Health Organization, Diabetes mellitus: Report of a WHO Study Group. Geneva, 1985.

[15] The ultimate importance of metabolic syndrome is that it helps identify individuals at high risk of both type 2 diabetes and cardiovascular disease. Several expert groups have therefore attempted to produce diagnostic criteria. The first attempt was by a WHO diabetes group in 1999, which proposed a definition that could be modified as more information became available. The criteria had insulin resistance or its surrogates, impaired glucose tolerance or diabetes, as essential components, together with at least two of: raised blood pressure, hypertriglyceridaemia and/or low HDL-cholesterol, obesity (as measured by waist/hip ratio or body-mass index BMI), and microalbuminuria. The American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD) published critical papers on the syndrome, questioning the purposes of the identification of a specific syndrome (Alberti, Zimmet, and Shaw 2005).

complex interaction between genes and environmental factors, though no specific environmental risk factors have been shown to cause a significant number of cases. Type 1 diabetes is characterized by deficient insulin production in the body: pancreatic cells that make insulin are destroyed by a process that still is not well understood but probably is some form of an autoimmune reaction. Patients cannot manufacture insulin[16] on their own, therefore they require a daily administration of insulin to regulate the amount of glucose in their blood. Insulin injections before meals prevent ketoacidosis, coma and death. Most of the type 1 diabetes occurs in children and adolescents. For this reason, it was previously classified as "insulin-dependent", "juvenile or childhood-onset diabetes". The slowly progressive form that occur in adults is referred to as latent autoimmune diabetes in adults (LADA). Symptoms include excessive urination and thirst, constant hunger, weight loss, vision changes and fatigue.

Type 2 is the most common form of diabetes and accounts for the vast majority of people with diabetes around the world. Symptoms may be similar to those of type 1 diabetes but are often less marked or absent. As a result, the disease may go undiagnosed for several years, until complications have already arisen. For many years type 2 diabetes was seen only in adults, but it has begun to occur in children. Differently from type 1, it stems not from too little insulin but rather the body's inability to respond appropriately to the insulin signal, preventing their body tissues from ''hearing'' the message that insulin carries, and this type is treated with diet, drugs taken orally, and sometimes with insulin. For these reasons type 2 diabetes was classified as ''adult-onset'' or ''non-insulin-dependent'' diabetes. (Feudtner 2003; World Health Organization 2016).

As for the type 1, for the type 2 the specific reasons are not yet known, but it is associated with risks determined by an interplay of genetic and metabolic factors. WHO reports (2016, 1999) indicate several risk factors as causes of diabetes: the excess body fat, in particular the concentration of adipose tissues around the abdomen, is the strongest risk factor for type 2 diabetes, both in terms of clearest evidence base and largest relative risk. Overweight and obesity, together with physical inactivity, are estimated to cause a large proportion of the global diabetes burden. Higher waist circumference and higher body mass index (BMI) are associated with increased risk of type 2 diabetes, though the relationship may vary in different populations. Populations in South-East Asia, for example, develop diabetes at a lower level of BMI than populations of European origin. The risk of type 2 diabetes is linked to ethnicity, family history of diabetes, previous gestational diabetes combined with older age, overweight and obesity, unhealthy diet, physical inactivity and smoking.

Several dietary practices are linked to unhealthy body weight and/or type 2 diabetes risk, including high intake of saturated fatty acids, high total fat intake and inadequate consumption of dietary fibre. High intake of sugar sweetened beverages, which contain considerable amounts of free sugars, increases the likelihood of being

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[16] Insulin is a hormone that helps the body use glucose for energy. The beta cells of the pancreas make insulin. When the body cannot make enough insulin, it is taken by injection or through use of an insulin pump.

overweight or obese, particularly among children. Recent evidence further suggests an association between high consumption of sugar-sweetened beverages and increased risk of type 2 diabetes.

Gestational diabetes (GDM) is a temporary condition that occurs in pregnancy and carries long term risk of type 2 diabetes. The condition is present when blood glucose values are above normal but still below those diagnostics of diabetes. Women with gestational diabetes are at increased risk of some complications during pregnancy and delivery, as are their infants. Gestational diabetes is diagnosed through prenatal screening, rather than reported symptoms. Diabetes type 2, in fact, occurs more frequently in women with prior GDM and in individuals with hypertension or dyslipidaemia. Impaired glucose tolerance (IGT) and impaired fasting glycaemia (IFG) are intermediate conditions in the transition between normal blood glucose levels and diabetes (especially type 2), though the transition is not inevitable. People with IGT or IFG are at increased risk of heart attacks and strokes.

Definitions and classifications of diabetes are not stable but instead have been changing as a result of diagnostic, treatment and technological interventions. We will see in this section how diabetes entered the frame of chronic illness and which kind of concepts and categories are now in use for prevention and care purposes. A sociology of disease in this regard holds together different dimensions of diabetes by focusing on practices, and in doing that, gives light to the uses of concepts, categories and classifications.

A HISTORICAL PERSPECTIVE ON DIABETES: THE TRANSMUTATION OF A DEADLY DISEASE INTO A CHRONIC DISEASE

The life of people with diabetes has drastically changed in the last century, at least in some part of the world. The prognosis was forever rewritten only in 1921. According to Feudtner, no story of medical progress has been more influenced by this technology ethos than the history of diabetes. In the US, at the end of 1700, diabetes was considered and conceptualized as a highly deadly disease, reserved to the only Jewish population[17]. Diet was the only treatment available, but all the diets, however, were ultimately of minimal benefit in starving off death. Given the best medical care, patients under ten years of age could hope to live no more than three years after they were diagnosed, while those aged sixty years or more lived about six years, living these terminal years in a semi-starved state that ended in either coma, infection, or starvation. Just few years before the commercialization of insulin, in 1919, half of newly diagnosed people died within two years, and fewer than 5 percent were still alive after ten years. By the autumn of 1922, insulin was being made commercially. In the years after, the results were published in major medical journals with powerful visual rhetoric of before-after treatment images of children with diabetes (Feudtner 2003:6). By the mid-1920s, the majority of articles appearing in general medical journals indicated that diabetes could be conquered by daily insulin injections. In 1959 most patients survived their first ten years of living with diabetes. The changes of diabetes definitions, classifications, medical

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[17] see Tuchman (2011) “Diabetes and Race: A Historical Perspective”.

interventions and technology have reshaped the experiences and the cultural assumptions about diabetes and transformed diabetes from being a highly deadly disease into a chronic illness in less than a century (Feudtner 2003).

Stories of insulin have served various needs while reinforcing deeply held beliefs of twentieth-century Americans, according to Feudtner: "a parable of salvation, the tale of diabetic deliverance has spoken to the imagination of doctors and laypeople alike, serving as a potent and often cited symbol of scientific progress and the prospect of human mastery over disease. One of the most impressive stories about modern medical miracles, the tale of insulin saving diabetics has legitimated the prestige and power that Americans have invested in scientific medicine and its technical wizardry" (Feudtner 2003, 9). What in fact is the history of success and miracle leave hidden aside concern all the new problems created by the transmutation of diabetes into a chronic disease. Although much of the public believes that diabetes has been cured or at least tamed, the health statistics present a very different picture.

Globally, an estimated 422 million adults were living with diabetes in 2014, compared to 108 million in 1980[18]. The global prevalence (age-standardized) of diabetes has nearly doubled since 1980, rising from 4.7% to 8.5% in the adult population. Over the past decade, diabetes prevalence has risen faster in low- and middle-income countries than in high-income countries. According to the WHO's global report, this "reflects an increase in associated risk factors such as being overweight or obese" (2016, 6). Even though separate global estimates of diabetes prevalence for type 1 and type 2 do not exist, they assume that the majority of people with diabetes are affected by type 2 diabetes.

Numbers portrait a picture of "chronification" (Pols 2013a) of diabetes in societies. Diabetes today is responsible for complications that can themselves cause death, disability and other severe pathologies. People with diabetes live with a substantial risk of heart attack, kidney failure, heart failure, end stage renal disease, lower extremity amputations and loss of vision, among others (World Health Organization 2016). Infants born to diabetic mothers are more likely to have congenital problems and to die either in utero or shortly after birth. Even for those patients who do not develop complications, their lives are irrevocably altered by the diagnosis of diabetes: they need to monitor their diets and either take oral medicine or inject or infuse insulin. The ''cure'' of insulin has become the accomplice to a newly created disease of complications, "Not only was the length of diabetic life transformed but also the kind of life—and ultimately, the cause and kind of death":

> In the early years, almost all diabetic patients who died did so in ketoacidosis coma; by 1950, fewer than one in ten fatal cases died comatose. But in place of coma, other menaces had emerged, such as cardiac arrest or nephritis and renal failure. Between 1922 and the 1960s, the

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[18] WHO "Global report on diabetes" (2016). In an effort to address this growing health challenge, since early this decade world leaders have committed to reducing the burden of diabetes as one of four priority noncommunicable diseases (NCDs). As part of the 2030 Agenda for Sustainable Development, Member States have set an ambitious target to reduce premature mortality from NCDs – including diabetes – by one third; achieve universal health coverage; and provide access to affordable essential medicines – all by 2030.

> medical community was confronted with an epidemic of newly created patients: chronic diabetics (Feudtner 2003).

CYCLES OF TRANSMUTATION OF DIABETES: TREATMENT AND RELATIONSHIPS

According to Feudtner, diabetes has transformed through the decades following “cycles of transmutation” as dynamic and interactive cycle of disease change, which begin with the advent of a novel therapeutic-technological innovation, such as rigorous diets, insulin, or antibiotics. These medical interventions would ameliorate one set of problems but generate or reveal another set, effectively exchanging old concerns for new ones. Almost immediately, physicians and patients would recognize certain short-term consequences, positive and negative, of this exchange. For example, insulin could avert life-threatening conditions such as coma but at the price of several injections each day and the risk of causing hypoglycaemic reactions, and coma. While these short-term consequences of the newly transmuted disease were readily apparent, the long-term sequelae emerged gradually, as more patients were treated and lived with the medically altered disease[19]. Diabetes is a “metabiotic” system according to this view, where biological, psychological, social, and cultural processes are combined in the *doing* of diabetes, which does not exist per se, but it does as a *metabiotic* interaction, a manifestation of emotional and social aspects, biological and cultural realms.

Diabetes, as it is known in a certain time and space, is therefore a manifestation of interactions of different actions, in which therapy and treatment cycles have a huge impact. Interactions include not only physiology, forms of diabetes and complications, but also the chronic illness work of patients and professionals. Thus, in Feudtner’s view, across the twentieth century, these cycles of therapeutically induced transmutation (such as rigorous diets, insulin, antibiotics or insulin pumps, among others) altered the biology of diabetes sufficiently to create variations of disease over time. We take the example of hypoglycaemia that was firstly caused by insulin use among type 1 diabetes, now common with type 2 patients when diabetes is treated partially with insulin. Cycles of therapeutic innovations and treatment changed chronic illness work of patients, ameliorating some problems while creating new ones, in the constant work of adaptation. As diabetics began to live longer, also daily lives of diabetic health care specialists were also transformed, in terms of increasing specialization, infostructures, relationships and responsibilities between patients and professionals. Therefore diabetology, as a specialised field, emerged since the early 20th century (O’Donnell 2015). Each cycle of management system requires work from all actors involved, a “ceaseless drudge of daily work” that comes from interactions with and within this system of health care providers, diabetic specialists, outpatient clinics, educational nurses, dieticians, social workers, laboratory technician and so on.

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[19] From the late 1930s onward, patients and physicians strove to understand, prevent, and treat the long-term consequences of transmuted juvenile diabetes, sequelae such as obstructed blood vessels, failing vision, and damaged kidneys. As new sets of problems would appear, they would become the focus of subsequent efforts to develop additional interventions, which in turn would initiate another cycle.

However, despite there is today a general agreement on standards of diabetes care, there are huge geographical differences worldwide in terms of treatment as a result of availability of specialized professionals, accessibility of diabetes care and costs of technological and therapeutic interventions[20]. Insulin and oral hypoglycaemic agents are reported as generally available in only a minority of low-income countries. Moreover, essential medicines critical to gaining control of diabetes, such as agents to lower blood pressure and lipid levels, are frequently unavailable in low- and middle-income countries (World Health Organization 2016). The course of diabetes varies according to the options available in situated contexts, and according to the choices that patients and professionals do together. This is also a fundamental part of the metabiotic interaction.

Diabetes requires monitoring blood glucose level. This is a taken for granted action that lies in the background of diabetes care. There are variations of frequency of monitoring according to diabetes type and the health status of the person (Timmermans and Hass 2008). Diabetes type 1 patients need to monitor the glucose level different time per day, before each meal, exercise and bedtime, while for diabetes 2 patients, the frequency might be lower. To monitor the glucose level there are different options available: from the glucometer[21] to the continuous glucose monitor[22] (CGM). The standard treatment for those whose bodies does not naturally produce enough insulin, for type 1 and in some cases type 2, is the injection of exogenous insulin, most frequently with the use of insulin pens. Continuous glucose monitoring has an important role in assessing the effectiveness and safety of treatment for patients with type 1 diabetes and type 2 diabetes[23], for this reason, the frequency of testing is decided with the specialist in the treatment plan.

Diet has always been fundamental for diabetes care. As insulin sensitivity might be increased by weight reduction and increased physical activity, clinicians encourage weight loss and management through physical activity and diet. These two are in fact two pillars of diabetes care. It is usually recommended to control the intake of carbohydrates based on standards developed by the clinical community, to avoid intake of sweetened food and drinks and to get in contact with nutrition specialists. It is also recommended that consideration of both the quantity and the quality of carbohydrate, particularly the glycaemic index (GI) and glycaemic load (GL), will

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[20] http://www.ansa.it/canale_saluteebenessere/notizie/diabete/2019/03/05/diabete-laccesso-alle-cure-in-italia-e-a-macchia-di-leopardo_30c1b768-310d-4ded-be5a-e319daa5fe48.html

[21] Glucometer is a small, portable machine used by people with diabetes to check their blood glucose levels. After pricking the skin with a lancet, one places a drop of blood on a test strip in the machine. The meter (or monitor) soon displays the blood glucose level as a number on the meter's digital display.

[22] CDM is a device that is attached to the patients under their skin. This device is always checking the interstitial glucose (it measures glucose but not in the blood) and may help to alert when the sugar level is going too low or too high.

[23] American Diabetes Association, Glycaemic Targets: *Standards of Medical Care in Diabetes—2018*, Diabetes Care 2018 Jan; 41(Supplement 1): S55-S64.

help contribute to achieving a variety of clinically relevant goals, including glycaemic control, lipid profile and healthy body weight[24].

Studies have demonstrated the role of physical activity on glycaemic control and weight control, therefore clinicians and nutritionists recommend performing a moderate and continuous physical activity and sport. Current recommendations concerning diabetes 2 patients are focused on improving glycaemic balance, weight maintenance, and reducing cardiovascular risks. The physical activity guidelines suggest that individuals with type 2 diabetes should accumulate at least 30 min of moderate-intensity physical activity on most days of the week[25]. It is also suggested to do a minimum of 150 minutes per week of physical activities split in three times per week, with maximum of two consecutive days without physical activity. Thus, physical exercise might be part of therapeutic strategy to slow the development of type 2 diabetes in high-risk individuals and to improve glucose control in type 2 diabetes (Duclos et al. 2013). Furthermore, training is suggested for long term outcomes as it produces multiple effects on glucose metabolism and long-term effects on complications such as cardiovascular ones.

With the shifting of diabetes towards chronic illness, care management is reconfigured as a responsibility in the hands of the patients, in terms of diet, physical activity, control of glycaemic level and adherence. As we will see further, sociological interventions contributed to highlight that risk and prevention medicine exacerbated the tendency according to which individuals are responsible for risks in relation to health, expected to make lifestyle choices accordingly and inform themselves choosing from a range of health expert knowledge. Sociology, when looking at emerging concepts, has pointed out how to an increasing responsibility given to individuals, corresponds less responsibility given to institutions, welfare, corporations, social inequality and the environment. Moreover, the tendency to define risk factors and population at risk, pursue medicalization purposes.

Despite epidemiological evidence that shows how the risk of the disease increases with age and social disadvantage and it is associated with stress and discrimination, segregation and the environment, nonetheless biomedical understandings tend to focus upon individual-level risk factors. Whilst type 2 diabetes may have a genetic component, the disease’s growing prevalence can be attributed to lifestyle changes (e.g. poor diet or low levels of physical activity), which can themselves lead to an additional risk factor: being overweight/obese.

Diabetes, and diabetes care needs further sociological attention for several reasons. First because diabetes prevalence is rapidly increasing worldwide, it is involving people of all ages including children, to the point of being considered epidemic. This raises new challenges in diabetes care. Second, the transmutation of diabetes occurs under our very eyes, every time a new treatment or device is on use. Diabetes care therefore needs to be seen within broader diagnostic, treatment, clinical and technoscientific interventions. Diabetes constantly

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[24] American Diabetes Association. Standards of medical care in diabetes – 2007. *Diabetes Care* 2007; 30: S4–S41.

[25] *Ibidem.*

impacts and interacts with other physiological elements, in terms of complications, and with others, within relationships. Transmutations shape different forms of relationships and interactions among patients and professionals, but also among professionals and their modes of work and care, and among people with diabetes and not. This makes diabetes particularly interesting when looking at broader transformations in health care towards the involvements of chronic illness patients into EBM and the involvement of patients' groups as stakeholders. As we will see in this study, diabetes care has dramatically changed through the instrument of education practices, shared between professionals and patients, and the involvement of diabetic patients' organizations in health care. Finally, diabetes care, in virtue of its connections with social practices and biomedical discourses, allows to look at broader issues concerning chronic illness and care, in particular, on how narratives on lifestyle, risk and self-care are used in daily care practices of people with diabetes. This is what it will be explored in the next section.

SOCIOLOGICAL CONSIDERATIONS ON GLOBAL BURDEN: WHOSE RESPONSIBILITY?

In 1948 the World Health Organization defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"[26]. Health is not described just in biomedical terms but includes the physical, mental, and social realms. On 12 September 1977, a major international conference held in Alma Ata in the Soviet Union issued a declaration on primary health care which resulted in global support for the proposals, adopting a broad definition of health and primary health care (WHO 1978). The Alma Ata declaration endorsed the view that health is more than the absence of disease or infirmity; it is the attainment of the highest possible level of health as an important social goal. Not only is it a fundamental human right, but it requires a concerted effort by "other social and economic sectors in addition to the health sector".

Thirty years later, WHO (2005 report) defined chronic illness as epidemics, leading cause of death and disease burden worldwide:

> it is the looming epidemics of heart disease, stroke, cancer and other chronic diseases that for the foreseeable future will take the greatest toll in deaths and disability (…) the total number of people dying from chronic diseases is double that of all infectious diseases (including HIV/AIDS, tuberculosis and malaria), maternal and perinatal conditions, and nutritional deficiencies combined. (…) It is vitally important that the impending chronic disease pandemic is recognized, understood and acted on urgently. (2005: 35)

In the Global Burden of Disease 2015 study confirms that, from 1990 to 2015, the world as a whole has been undergoing an epidemiological transition.

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[26] WHO.ConstitutionoftheWorldHealthOrganization.2006.www.who.int/governance/eb/ who_constitution_en.pdf.

> Long-held notions about the nature of chronic diseases, their occurrence, the risk factors underlying them and the populations at risk are no longer valid (…) The disease profile of the world is changing at an astonishingly fast rate, especially in low- and middle-income countries.

Omran already in 1971 called "epidemiological transition" the change of perspective in dealing with chronic illness. With a rapid decreasing of mortality and morbidity and the disappearance of infective disease, chronic and degenerative illnesses connected to ageing emerged and transformed the society into what Frank named "remission society". Today illness patterns are distinguished mainly by the high incidence of chronic degenerative diseases, replacing infectious diseases.

Chronic illness is therefore a central concern of international health organizations today. Chronic illness is also mentioned as "non-communicable disease" or "lifestyle-related diseases", with the latter being a term sometimes used to emphasize the contribution of behaviour to the development of the illness. In this framework, the identification of risk factors is necessary to tackle the causes that might lead to the development of the disease. In the "Global Burden of disease" study of 2016, it is stated that that the increase of BMI, the absence of glycaemic screenings, air pollution and the use of drugs are impacting the most. In the case of diabetes, lifestyle and risk factors such as BMI, obesity and lack of physical activity are even more pronounced, despite the fact that are indicated only for diabetes type 2, since there is no prevention strategy for type 1 diabetes (World Health Organization 2016). Considering the alterable nature of the risk factors, governments are encouraged to implement health care strategies and policies to reverse them (Global burden of disease study 2016).

These definitions were not prominently used in the medical literature before. O'Donnell, in tracing the history of causation and management of diabetes from 1800 to 1950, highlights how, although the connection between lifestyle and diabetes was well established among physicians, individual-level explanations supplanted the emphasis on social organisation only when diabetes began to make the transition from being a disease of the rich to one of the poor. In the years prior to this emergence, medical experts drew upon multiple narratives when considering the condition, the most popular of which being the role of social organisation and the interplay between mind, body and environment. O'Donnell argues that this discursive shift was shaped by dynamics of class relations rather than any new forms of scientific evidence developed at the time (O'Donnell 2015). Why then international organizations as WHO define chronic illness in these terms? and who are the actors who need to deal with the epidemic? These questions concern primarily the issue of responsibility. It is the primary care system that needs to take care of chronic illness, or it is the individual, who holds responsibility for lifestyle choices, and consequently for the prevention, management and control of the illness?

Diabetes has been a long-standing interest of medical sociology and anthropology, however most of the studies reflected the separation between illness and disease, focusing respectively either on the illness experience of the patients or on issues linked to specific forms of diabetes care. Clinical investigations of diabetes are fundamentally limited in the former; as experiential phenomenon, they do not address the socially constructed patterns of consumption, lifestyle, and behaviours, while the latter provides little insight into material processes by which the social world comes to be embodied. Sociology has also been interested in looking at emerging concepts in relation to diabetes specifically, and chronic illness in general, trough approaches of biopower and biomedicalization. The recent call for a sociology of disease instead includes the study of disease and its proximate biopathways, it integrates the study of human wellbeing as simultaneously both a biological and social phenomena (Timmermans and Hass 2008; Mol 2002). A historical account of diabetes as a disease thus highlights how concepts, definition, classification and aetiology of diabetes come to be in use in a defined time and place, as a result of practices and interaction of class, gender, medical specialization, technocultures, economic and productive systems, urbanization and forms of urban planning. The current definitions of diabetes, obesity or metabolic epidemics are alike a result of these interactions.

At the microlevel, there is epidemiological evidence demonstrating that risk of diabetes incidence is strongly patterned along sociodemographic characteristics, through a variety of psychosocial and material pathways, with large disparities in risk by level of income, educational attainment, and across racial-ethnic (Maty, James, and Kaplan 2010; Smith et al. 2011) groups. Moreover, if these risks are concerning explicitly diabetes type 2, there are issues of accessibility to health care and treatment that are fundamental for people with diabetes type 1 that respond to similar population's characteristics. However, while some of these differences can be explained by group patterns of diet and physical activity, these lifestyle and behavioural factors that are clearly indicated by WHO as risk factors for diabetes, do not fully explain health disparities. A clinical description does a rather poor job of describing the causal processes by which individuals ultimately come to be diabetic and does not it adequately describe why large differences in prevalence rates exist between social groups. Or why some diabetics fare much better than others (Timmermans and Hass 2008). In other words, the ways in which such lifestyle and behavioural factors are themselves products of the social environment are ignored.

O'Donnell pointed out that, in the case of diabetes and obesity, dominant discourses that in the last century blamed the individual through a combination of lifestyle choices and genetics (O'Donnell 2015) developed in a framework that was as much moral as it was scientific (Saguy 2013; Rasmussen 2012), indicating that a disease is often shaped and negotiated through the dynamics of relations of class, ethnicity and gender, as well as through the interactions between doctors and patients and the asymmetries of power that lie in them (O'Donnell).

Patterns of consumption, residential and commercial development, and public policy are few examples of large social forces that structure individual-level characteristics that have an impact on diabetes risk factors such as obesity or physical activity. For instance, there might be a link between rising diabetes rates in children and the increasing consumption of high fructose corn syrup (HFCS), responsible alone for 10 times higher sugar consumption per capita in the US than it was in the 1970s (Haley et al. 2005). HFCS has been subsidized by government and it is increasingly used in the food industry worldwide. Moreover, it has been suggested that obesity and diabetes also results from the way we have structured the cities and neighbourhoods in which we live and work that discourage walking (Santana, Santos, and Nogueira 2009) and other forms of physical activity, or the use of private cars (Lopez-Zetina, Lee, and Friis 2006). Studies on diabetes from a postcolonial perspective (Fee 2006) have also highlighted the impact of colonialism and segregation (S. M. Frank and Durden 2017) in ethnic neighbourhoods on diabetes and diabetes care (Piccolo et al. 2015). Therefore, to understand the sequelae of causality involved in diabetes, its epidemiology, and the population health implications of the recent substantial rise in diabetes requires a sociological perspective focused on the role of social institutions and other aspects of social structure. Diabetes would appear to be a prototypical case in which to illuminate the social milieu connecting the difficulties of individuals (disease pathology) to larger social problems (the rise in obesity, social disparities in health) (Timmermans and Hass 2008). Interestingly, a study that explored perceptions and understandings of disease causation among white British and South East Asians (Pakistani and Indians) type 2 diabetes' patients, pointed out differences in the ways in which these respondent groups attributed responsibility and blame for developing the disease. Whereas Pakistani and Indian respondents tended to externalise responsibility, highlighting their life circumstances in general and/or their experiences of migrating to Britain in accounting for their diabetes (or the behaviours they saw as giving rise to it), white respondents, by contrast, tended to emphasise the role of their own lifestyle choices and personal failings (Lawton et al. 2007). These results are in line with others, like a study of Guadalajara Mexicans, in which Mercado-Martinez and Ramos-Herrera (2002) similarly observed that respondents tended to see their diabetes as being "imposed" by negative emotions such as anger or fear linked to work and family distress. In this regard, a focus on ethnic minorities gives insight on experiences of diabetes onset that are, in opposition with biomedical focus on lifestyle, direct consequence of inequalities linked to race and class.

Diabetes is enlightening in this regard because it shows the complex intertwinement of the social, political and individual on diabetes and diabetes care. How do people explain diabetes and its causes, how they do diabetes care and who is hold responsible and part of daily diabetes care are relevant questions that emerge when looking at care practices. As we will see in the next chapters, people with diabetes constantly work and rework, through care practices, relations of consumption, the environment, stigma and identities, often shifting from the individual level to the social and the political, in a constant redefinition of relationships and the self.

Feudtner notes, there have been three constant features concepts of diabetes care which have remain stable, despite all the shifting meanings that these concepts went through. Medically and culturally linked, concepts of "management", "control" and "responsibility" have always existed, through them patients and physicians tried to communicate their fundamental views about living with disease. For example, in the pre-insulin times, management was about a very strict diet and urine tests. Control instead has constantly evoked the stable idea that if patients would control their disease, they would remain healthy. The meanings and the experiences of living with diabetes are therefore, with this view, always situated and the result of the interplay of management, control and responsibility across time and space. In this view, the concepts of "risk", "health promotion" and "lifestyle" have developed only recently and carry a different interplay of meanings of management, control and responsibility. In the last decades of the 1900, the sociological debate started to focus on these concepts, and concerned in fact issues of individualization, inequalities, risk and control[27] and these concepts have gained a paramount importance in the language currently used when referring to diabetes, as well as in the sociological debate about health.

Nettleton argues that the term “health promotion” was hardly used before late 1970s but at the end of the last century figured as a key policy issue on the agenda of many Western states. The changing nature of health programmes within the health promotion project, they argued, served to contribute to the construction of a new type of patient with a different range of responsibilities, who is encouraged to actively interact with community groups, media campaigns and take responsibility for their own health regimes. A result of fundamental discursive shifts (Nettleton and Bunton 1995). Furthermore, they argued that It was against the background of escalating demands for health care caused by lifestyle related ill health, and the political imperative to reassess the notion of preventative medicine and health education, that health promotion was born, with the WHO taking a leadership role, since (WHO) launched its Health Promotion Programme in 1981. Lupton alike, in focusing on risk, noted how, at the turn of the twenty-first century, the concerns of public health have moved from containing infectious disease to exhorting people to take responsibility for maintaining personal bodily health. Contemporary public health directed at health promotion narrows its focus on the individual by associating the so-called lifestyle diseases with individual behaviours, as “risk” is seen as something that can be managed through human intervention, therefore easily associated with notions of choice, responsibility and blame (Petersen and Lupton 1997, Lupton).

> Health promotion messages such as ‘be active’, ‘eat healthy’ and ‘lose weight’, are boisterously propagated throughout Western neoliberal societies as the panacea to modern day health concerns of chronic diseases. (…) They are seen as being both the cause and the solution to potential health problems and thus are made to be accountable for their own health. However, when exercising one’s autonomy and freedom, it is expected that the responsible citizen will allow his or her lifestyle to be guided under the auspices of knowledgeable experts and normative prescriptions of what it means to be healthy. This requires attending to one’s own health in ways which have been socially approved and politically sanctioned. (Ayo 2012: 104)

Social constructionist approaches argue that risk is a central cultural and political concept by which individuals, social groups and institutions are organized, monitored and regulated in Western societies. Risk is never fully

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[27] Already in the 1990s the sociological debate addressed these issues arguing that these definitions lead to individualization and the invizibilization of the inequality structures that produce health inequalities and illness patterns. Instead, it is the very nature of the disease that produces inequalities as a consequence, and not the other way around. Medical sociology itself, in providing accounts for chronic illness, has been accused of embracing these concepts and endorsing this view of the impaired body, instead of seeing chronicity as an outcome of body pathology and bad choices, the lenses must be directed on social (dis)organization (S. J. Williams 1999). By stating that, the responsibility of the illness sticks to the individual, as a body trapped in impairment. (S. J. Williams 1999).

objective or knowable outside of belief systems and moral positions in which this knowledge is generated, whether in relation to scientists, experts' or lay people's knowledges. (Lupton 2013: 43)

The interest on the interaction between body and class was already initiated by Goffman and Bourdieu's focus on the body as a bearer of symbolic value and its relationship to the (performing) self. In fact, lifestyle is, in this view, a manifestation of class culture within the habitus, a structuring feature of stratification. The search for social distinction and consumption must therefore be found trough class, body and lifestyle, which are intimately related. Crawford (2006) has been particularly interested in the concept of "control" within health practices. Control, in his view, is a "pillar of middle-class identity", a defining feature of middle-class culture. It is essential in the construction of the self as bounded, in control from others, and also as a class identity construction. Control, associated with body, is a powerful symbol of the correct attitude, it fosters a special notion of what is natural, what is right for the body and the self (Sassatelli 2000). Therefore, health practices define structures of normalization. In earlier studies, Crawford named "victim blaming ideology" the cultural politics for constructing the self in conformity with mandates of self-control and bodily discipline (2004), personal responsibility of at risk behaviours (Crawford 1977: 668) and individual lifestyle choices. In this way, the ideology serves to justify the retrenchment from rights and entitlements for access to medical services, and to divert attention from the social causation of disease hence its possible political responses, to the commercial and industrial sectors.

Approaches based on governmentality and biomedicalization have been particularly influential to read these discursive changes and the ways in which humans come to engage in self-constituting practices. In other words, how individuals are made into particular types of subjects such as the "health-conscious citizen", or the "expert patient" (Fox and Ward 2006). Based on Foucault's notion of *governmentality*, these approaches see expert knowledges as integral to the reflexive techniques and practices of subjectification: the formation of certain types of subject. In providing the guidelines and advice by which populations are surveyed and profiled, trained to conform to norms and rendered productive, discourses about health, risk and lifestyle contribute to the constitution of selfhood, or subjectivity, and thus are part of the panoply of "technologies of the self"[28]. Risk, from Foucauldian perspectives, is "a moral technology" in the context of contemporary neoliberalism, with such as social control not overly coercive, operated by autonomous individuals wilfully regulating themselves in the best interest of the state (Ayo 2012; Lupton 2013). Within this perspective, the individual, in order to maintain their own health, needs to accomplish the rule of the responsible, health conscious, neoliberal citizen who buy

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[28] In "Technologies of the Self", efforts humans make to 'transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality': through technologies of the self, aspects of self-constitution are carried out rendering particular images, statuses and identities into being (Foucault 1988). Foucault explored the work on the self through which individuals act on their bodies, souls, thoughts and behaviour, to "transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1988). What is interesting for us is not only the Foucault's focus on the regulatory purpose of medical institutions today, but also the significance of emerging concepts, such as lifestyle, in the pivotal political role they play in both the discipline of individual bodies and regulation of populations, as well as resistance. In this view, resistance to the bio-power and government of the individual is possible through the formation of a shift from the "objectivization" to the "subjectivisation" of the subject.

and choose the best services, technology and experts from markets of experts and corporations, while the health determinants are set on the background by neoliberal's position of minimal government intervention:

> In this way, what were once seen as social problems, a failure of the state even, has come to be seen as a personal failure requiring personal accountability. (…) Rather than the state focusing on the determinants of health, 'experts' and corporations alike are encouraged to offer their goods and services through the free market, whereby, it is expected that the responsible, health conscious, neoliberal citizen will buy into them. (Ayo2012: 102)

It is this transformation of relationship between expert knowledges and lay consumers that the biomedicalization perspective (Clarke 2010) emphasizes. Technoscience in this view, transformed biomedical institutions and practices (diagnoses, treatments, interventions), life sciences and technologies, shifting from medicalization to biomedicalization. New individual and collective technoscientific identities emerge in alliances[29] and comprise new forms of "biological citizenship" (Rose and Novas 2005). Consumers-patients make choices as persons embedded in networks of social relations that constrain technological choices. Rose (2007) has named "optimization" the increasing link of enhancement and biological citizenship, on how patients, as users-consumers, and providers-producers, engage with new technologies so that policies and procedures for their use might be improved to better and more equitably meet people's needs and desires.

Clarke (2010) notes that biomedicalization is interpreted as an essentially negative phenomenon while it should not always be the case. These approaches have been criticized for devoting too much attention to discourses and strategies and not enough to how people actually respond to them as part of their everyday lives. The question of how risk-related discourses and strategies operate, how they may be taken up, negotiated or resisted by those who are the subject of them, remains under-examined (Lupton 2013). These approaches have been accused to have ignored what happens in the black box of interactions and social practices. Timmermans and Berg expressed well their critiques to this vision of technology as merely surveillance:

> there is little agency for patients or physicians, only a medical-industrial complex with dark motives and dependent victims. The mere presence of the technologies and their presumed effects constitutes proof of the conspiracy (Timmermans and Berg 2003, 98).

TOWARDS A RELATIONAL MATERIALIST SOCIOLOGY OF DISEASE

I argue, following relational materialist approaches and STS, the importance of looking at care practices in health. As we have seen in the first chapter, praxiography (Moreira 2018; Mol 2002), instead of focusing on macro systems of power and health identities, looks at how different practices interact and, while doing that, *do*

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[29] Such as "Interliteracies" that connect clinicians to policy-makers, representatives of government to social scientists, and patient groups.

the disease, control and responsibility. But how diabetes, control and responsibility are done in practice has implications for the intersection of multiple practices of care. What happens when we use "care" and not "power" as the lens for our inquiry into clinical relations?

Yates-Doerr (2012) in her research on dietary choices in Guatemala, found the approach of biopower insufficient for understanding the varied interactions of clinical exchange, arguing that medical anthropology needs another approach that, besides constrains of hierarchy and control, employs compassion, concern and relationality. Following Mol (2008) she noticed that treatment was a highly relational process. For instance, medical encounters with nutritionists were directed toward specific context-dependent desires and needs, dietary recommendations downplayed personal choice, the first person plural tense (i.e., "us" and "we") was largely employed and between patients and nutritionists were established emotional connections. These results could have not been written with approaches focusing on (bio)power and (bio)medicalization. As Mol has pointed out, social scientists' focus on medical power and the problematic ideal of health, while valuable, has left us without a language for describing practices of "good care" (2008: 89–90). Instead of seeing these patients as victims of imposing imperatives of biopower through dispositive such as BMI, recalling postcolonial literature, Yates-Doerr suggests that the diet was simply a template on which teaching, and learning could be set into action, to be instructed in knowledge or skill requires significant malleability and that the work people undertake to achieve this malleability "carries less a sense of passivity and more that of struggle, effort, exertion and achievement" (Yates-Doerr 2012).

Another element that is brought into light by focusing on care practices is the centrality of senses, affects and affinities of collective entities. From a feminist materialist perspective, human subjects are not just knowing: they are also sensing, embodied, affective assemblages of matter (objects, places, memories, things, bodies), thought and languages. From this perspective, agency is relational and enacted, generated in, with, and through interactions and entanglements of people with technologies as part of more-than-human worlds (de la Bellacasa 2017). Humans come together with non-humans to configure assemblages that are contingent and emergent, constantly changing as they move through time and space. Together, they generate affective forces and agential capacities that are continually made and reconfigured, responding to these movements, encounters, and actions (Lupton 2018). Following a feminist materialist perspective, Lupton (2018) has focused on identifying what bodies can do, adopting an analytic that pays attention to the flows of affective forces, relational connections, and micropolitics which give vitality and power to assemblages. When looking at food-tracking apps, she found that the apps operated as biopedagogical tools, helping women to learn more about the nutritional components of food and also about their bodies. When women come together with the apps, affective forces are enacted in ways that can be both empowering and constraining, they can reify experiences and discourses and norms that seek to discipline and punish their bodies, as well as empower them. A feminist vision of care can represent concerns with persistent forms of exclusion, power, and domination to which sciences and technologies also contribute. Therefore, the analysis should be attuned to the micropolitics of power as enabling and vitalising, as well as constraining. The value of the materialist approach rests in understanding humans as part of a material, micropolitical field, and their capacities as always contingent, produced and reproduced by the ever-changing fluxes in assemblages (Alldred and Fox 2017).

A sociology of disease focuses on practices, on the doing, learning and knowing in action, in a context in which certain categories, classifications and concepts are on use. What emerges from practices, in terms of knowledge, objects, relationships, is relational agency in action, between all actors involved, including material and non-material actors such as programs and protocols. There is the need to focus on practices of collaboration, of actors that together do good care, to understand how relational good care is done, and how knowledge circulates.

Beside the attention towards macro structures of power, and discourses on risk and prevention, it is also needed and approach that pays attention to what happens with patient centred health care, with expert patients and patients knowledge, the involvement of patients' organizations, users and activist groups, and broader transformations of health care that, as Moreira notes, are becoming pervasive but are, yet, understudied (Rabeharisoa, Moreira, and Akrich 2014). Examples are the increasing use of Evidence Based Medicine (EBM), the proliferation of diagnostic and therapeutic protocols, employment of accountability in health care, also through the involvement of patient's groups and the emergence of legislative frameworks that recognize patients and users as stakeholders in health policies in Western countries. What happens when these programs and protocols are on use, what and who is left out from categorizations (Bowker and Star 2000), what does this means in terms of distribution of care (Martin, Myers, and Viseu 2015) and in terms of lay knowledge (Pols 2014) are relevant questions today.

PATIENTS

After the establishment of the Expert Patients Programme (EPP) in 2001, for which the UK Department of Health has sought to enhance NHS patients' self-management capacities[30], the sociological attention for expert knowledge in patients has been grown in sociology and social policy. Sociology has been attentive to catch the changes of expert knowledge and identities in the last decades, and in this section, I review these contributions.

Expert knowledge has been investigated firstly as consequential of health care recalibration and retrenchment, which policies' objectives increasingly have been directed to expert patients. In this new scenario, the establishment of the EPP in the British NHS can be seen as a single step in a much larger social process that might broadly be termed care transition (Taylor and Bury 2007). People in need of care, as well as their families, communities and voluntary organizations, are expected to actively do care labour for their family and

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[30] See Wison et al. "The Expert Patients Programme: a paradox of patient empowerment and medical dominance", Health and Social Care in the Community (2007) 15 (5), 426–43.

community, to “participate” to each other life and in the creation of health care spaces and their organization. As de Leonardis (2002) pointed out, welfare policies and organization have normative accounts, they promote and recognize certain principles and categorizations, judgments about what should be considered desirable and proper. Reforms of the welfare state go beyond changing rights and duties. Reforms tell citizens what they are worth, how they are valued and judged, and how they are supposed to feel about the new arrangements. Therefore, welfare policies and institutional narratives are never neutral, neither are the social actors who are defined by these policies. Tonkens, in this respect, defines “citizenship regimes” the institutional arrangements, tangible practices and routines, laws and informal rules, understanding that guide and shape framing rules, feeling rules and claims-making by citizens (Tonkens 2012; Tonkens, Grootegoed, and Duyvendak 2013). New citizenship regimes, and thus new feeling rules, emotional demands and emotional labour, co-exist and compete with the old ones, and are also influenced by the increasing marketisation and commodification of care and social relations (Weicht 2016). In this context, individuals in need of care have to manage feelings and deal with fuzzy demands towards participation and collective responsibilities on one hand, welfare retrenchment and the lack of support from the state on the other hand. According to this view, the expert knowledge is directly linked with certain policy and welfare reforms that want to give more responsibility to the expert citizen towards their health, promoting expert knowledge, patient’s adherence and compliance. Following this view, there has been interest also towards policy’s concepts of patient’s “activation”[31], “engagement” and “participation”. When looking at public policies and health care policies, it has been pointed out that these concepts reveal a tension between more democratic instances and consumeristic instances based on clients’ choice. A tension that is never solved with one model above the other, instead they often overlap through hybrid discourses and assemblages: there can be found different ways in which public policies, places, practices, techno-governance and resources are combined into and apparent coherent form (Newman and Clarke 2009).

As we have seen previously, also the framework of “biological citizenship” (Rose and Novas 2005) has been largely used to look at forms of governance in which patients are supposed to follow biomedicine and certain codes of behaviour. Patients are citizens-consumers who, in engaging with providers-producers, are interested in claiming rights on health on the basis of biological terms, producing consequently a stratified notion of biocitizenship which excludes the non-adherent patient citizen. Aside this process, new individual and collective technoscientific identities emerge in alliances and comprise new forms of biological citizenship: patients and professionals are willing to engage with technology and other actors who make the hope of future treatment possible (Rose 2007). Fox and Ward (2006), in focusing in health identities, argued that in a society that is increasingly interested in all aspects of health and embodiment identity will be forged within the context of these kinds of health-related practices. In this perspective, health technologies are also identity technologies, and the consumption of these technologies may forge associated health identities. In their study they identify on the

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[31] For a reading of activation in the Italian context see Vicarelli, G. (2016), “Oltre il coinvolgimento: l’attivazione del cittadino nelle nuove configurazioni di benessere”, Bologna, Il Mulino.

forging of different health identities and how these relate to systems of thought and expertise, such as the “expert patient” and the “health consumers”. Their research into health identities suggests that there is a continuum of identity practices, from a relatively medicalized “expert patient” identity to an independent consumer of health information and products. For instance, the “resisting consumer” identity, develops constructing notions of health and illness in contrast to the biomedical or professional perspective. The “expert patient” identity, in their view, is grounded on medical knowledge, therefore the most medicalized one on the spectrum, while other identities might be lighter version of it, something opposing, sometimes alongside, biomedicine. Importantly, according to them, health identities can be mapped in relation to a dimension of autonomy/dependence from medical knowledge and biomedicine.

Pickard and Rogers (2012) in their analysis of the expert patient program in the UK, stated that EPP valorises cognitive practices, focusing on improving self-efficacy and general coping strategies, healthy eating, improved communication and working with health-care professionals. In doing this, it resembles that of “rational man” privileging objective, logical and autonomous decision-making, intended to inculcate an ideal typical late-modern patient: responsible, self-directed and managing her own health. NHS’s strategy has been, according to them:

> This, it is hoped, will remove the need for secondary care and thus support the continued financial viability of the NHS. Meanwhile, the structures and processes through which the Chronic Disease Management is delivered in primary care are, following the introduction of the Quality and Outcomes Framework, increasingly standardised and bureaucratised around adherence to specific measurements of bodily normality derived from epidemiological evidence and applied to single diseases in isolation from others that may be experienced simultaneously by patients (Pickard and Rogers 2012, 102).

Instead, they argue, self-care employs an embodied, practical knowledge that is very different from the abstract, rational model of patient knowledge assumed in programmes like the expert patient program. Their knowledge is not something you have or acquire but something you do, and in a social, biographical and clinical context, that contains objects and other people as well as one’s own body. Therefore, self-care expertise lies not in a technology or rational understanding but simply in the embodied self-care practices. Importantly, they remarked that self-care is integrated in daily life into life strategies, thus they do not follow hierarchical structures and processes which are linked with the dualism in which the biomedical tradition is rooted. (Pickard and Rogers 2012).

Mol calls “patientism” (Mol 2008) the establishment of the citizenship as the standard of normality for patients: just like “feminism” refuses the idea that men are ideal humans, “patientism” refuses the illusion that being fully healthy is the standard situation in life. Mol traces the logic of choice back on the ideals of patients-consumers and patients-citizens, autonomous, active and informed individuals able to know what is better for them, guided by the ideal of individual choice. With the logic of choice patients are addressed as consumers: they can buy whatever they need in "careland", divided into target groups and easily charmed by the market, they detain the responsibility of the use of a product in their hands. The citizen as well is in control of *his* body and participate in the public sphere while others (e.g women) are doing care work for *him*; *he* is marked by civilization and autonomy, recalling the image of the bourgeois man that does not have a body when able to attend meetings without feeling cold or hunger. The logic of choice framed by the citizen is in contrast with the logic of care as well as it does not include vulnerability and interdependency. Going beyond the logic of choice for Mol implies to question

> not how "active" patients are but what kind of activities they engage in, what do treatments demand and what patients are asked not to do. (…) How to include treatment in your daily life without messing too much with other things that are important to you? the point is not or choose between 'measuring' or 'not-measuring', but to find out how to measure. How to go about it. (2008: 53)

Pols, in this regard, propose to look at patient's knowledge as a form of practical knowledge that patients use and develop in order to relate to medical knowledge. Patients learn to translate medical knowledge, in order to make it useful to their daily lives and coordinate health care aims with other aims in life. They are not interested in legitimation, instead they try out strategies that may work in specific situations, even if temporarily (Pols 2013b, 2014).

These approaches have highlighted the link between citizen's codes and health, particularly intertwined with the figure of the expert patient, who, as an abstract identity, encompass the virtues of the good citizen who knows his rights and duties and knows how to express his concerns and claims towards other experts, appropriately and clearly. They also point out that patient's and lay knowledge assumes different features according to the contexts in which it is used, and that it is often associated with biomedical knowledge, health care policies and their organizational practices. Alongside this, consumer culture plays a big role and not necessarily follow a different logic than of biomedicine. Instead they appear to be often integrated, sedimented alongside positions of dependency-independency from professional biomedical knowledge. However, the focus on care practices and awareness allows to cross the divide, integrating expertise into life strategies and daily care practices. In a relational materialist perspective, policies and organizational arrangements are of paramount importance when interacting with medical and care practices within assemblages: in doing so they provide a logic to be followed in order to become a good patient. There is more research that needs to be done on this issue. The involvement of patient representatives in health technology assessment is increasingly seen by policy makers and researchers as key for the deployment of patient-centred health care, but there is uncertainty and a lack of theoretical understanding regarding the knowledge and expertise brought by patient representatives and organisations to HTA processes (Moreira 2014). In Moreira's view, research that should shift from focusing on individual, embodied knowledge, derived from living with an illness, towards an understanding of knowledge as amassed and deployed by networks of variable complexity. Moreover, experiential knowledge should not be seen in opposition with professional (or biomedical) knowledge, especially because health social movements challenged the established expertise, diversified the range of networks in which they operate and collaborate across expertise lines. They therefore assume a hybrid identity and have a paramount role in the making of scientific knowledge (Moreira 2014; Rabeharisoa, Moreira, and Akrich 2014). Therefore, according to these authors, patients' organisations' engagement in biomedical research are a particularly interesting locus for social scientists to study lay people and their representatives' contribution to the fabric of knowledge society, and lay people' involvement in technosciences, crucial issue for democratising democracy (Rabeharisoa, Moreira, and Akrich 2014).

CHAPTER 5 – ETHNOGRAPHY

RESEARCH PURPOSE

Following the theoretical chapters, the purpose of this ethnographic research is to explore the relational dimensions of diabetes care, by looking at relationship making practices, practices of care and feelings in the context of current transformations in health care settings. The aim is to make use of the complexity of the concept of care to explore multiple dimensions of care practices, particularly family, gender and medical practices. The exploration of care practices has two advantages: bringing into surface invisible work, (particularly chronic illness work, care work, identity work and emotion management) and the consequences of their intersection, in the daily life of people with diabetes; secondly, the exploration makes explicit situated knowledge embedded in care practices. Care practices show how invisible work and knowledge circulates in interactions of daily life, including the conflicts, tensions, and transformations that arise. Care practices include both material, emotional and sensorial practices and they are considered in the role they have within the frame of interactions that people with diabetes have with others with whom they share the same conditions, with their relational arena, families, friends and with health care professionals. Because care is relational and interdependent, care practices are always relational. Therefore, care practices are always relationship-making practices. Embodied ways of experiencing care with others, they lead to the construction of relationships in which those care practices are embedded. The understanding of how people with chronic illness do good care, their hidden daily relational work, their situated knowledge are important for digging a light into the chronic illness work that is part of their daily life, as well as to make visible care practices that are yet invisible in the medical realm despite the importance that they assume for health and well-being. Health care practices for chronically ill people and people with diabetes can benefit from this understanding.

This investigation has also relevance for policy making. The nexus between relationality of chronic illnesses within the framework of changes in health care has social and political implications. The implications of the intersection of invisible works and the circulation of knowledge in diabetes care are in current times yet unexplored. Social relationships, especially those named as “family” and “community”, are increasingly called for from social policy, patients are increasingly called for involvement into health care programs. Both for social policy and sociological accounts, becomes of paramount importance to understand how individuals, family, community and other relational forms, including the ones who are invisible at the policy level, interact when care practices are at play. It is possible that assumptions are being made and incorporated into social policy, which do not align with the ways in which individuals operate in practice and which contain unrealistic expectations about what individuals, groups and civic society organizations can do for each-other (Finch and Mason 1993).

Theoretically, I brought together different fields of sociology that have looked at care and care practices from different angles. They all need each other to work towards a sociology of disease that is not blind towards relationships and that critically analyse biomedical concepts, standards and programs from the point of view of practices, of the doing of good care.

This chapter focuses on the ethnographic practice that guided the methodological choices of the research. Despite there is not a standard definition of ethnography but a broad set of ethnographic practices (Hammersley and Atkinson 2007), this approach has been chosen mainly for the centrality that actions and interactions take according to the ontological perspective and the epistemological position of this research, its explorative orientation and open ended approach. Explore relationality it is not an easy task and in order to make visible and let relationships and care practices emerge I have decided to focus on sustained interactions, “situated practices of looking and telling” (Garfinkel 1967) that are imbued in the daily life of people who have been diagnosed with diabetes. This ethnography has been inspired particularly by STS and relational materialist approaches, to explore care practices by taking into account different actors: patients and their relational arenas, professionals, technology, health care programs and spaces, and different kinds of material and non-material objects that, together, *do* care.

Following models of ethnographic research, concepts such as “relationality”, “interdependencies” and “care” have been operationalized by the identification of *care practices*, reciprocal, constant and visible through social interactions. I focused on interactions among different actors with each-other: patients, their significant others, professionals, technology, material and non-material objects. To explore these interactions, data have been collected through participant observation. Moreover, semi structured interviews have been employed to explore people’s accounts, narratives and biographies. Alongside the fieldwork, observational focus, concepts, themes, and research questions have been continuously shaped a re-defined.

The sampling of spaces, groups and events constituted paramount importance for the research design. Due to the fragmentation, or regionalization, of the National Health Care System in Italy, I decided to choose one specific region to focus on. Emilia Romagna emerged as a suitable case, both for its changes in health care policies and spaces and chronic illness programs in the last decades, but especially for its welfare model which focuses on participative processes. The case selection and description of case study is developed in the second part of this chapter. The next section describes the research design: the research questions and theoretical stances, the case selection, the setting, methods, and ethics. Finally, a description of the analysis process is presented.

RESEARCH QUESTIONS

The formalization process of these questions has followed paths of ethnographic models for ethnographic research in which fieldwork has altered to some extent the focus and the theoretical questions being investigated (e.g Silverman, 1985). The research started out from an intellectual puzzle (Mason 2002) and a specifies set of questions and general area of enquiry that allowed both a sharpening of the questions and a gradual development of a theoretical explanation as a part of the ongoing interplay between theorizing and collecting data.

Following the aims of the research stated above, the research questions want to explore and let emerge the invisible work and knowledge embedded in care practices for people with diabetes in the larger context of chronification and social and political transformations in health care. In order to answer this main question and since care practices intersect medical, gender and family practices, an analysis that considers care in its totality need the formulation of sub-questions.

With the first sub question I want to explore care practices of people with diabetes and their relational arena, and particularly the nexus between these care practices, chronic illness management and significant spaces. Following the theoretical framework on care work, chronic illness work and emotion work, this will result in emerging different types of work that people with diabetes have to do in their daily life, the conflicts and tensions that emerge in different spaces such as home, health care spaces and other institutional health care spaces.

- Which multiple types of visible and invisible works are people with diabetes doing in their daily life? What are the conflicts and tensions that emerge and where?

A second sub-question focuses on the relational arena of people living with diabetes and their relationship making practices. In other words, it aims at exploring collective care practices of people with diabetes and their role in diabetes care. With relationships I want to include patient's groups and organizations, but also family, kinship, friendship, patient-professional relationship, the living together and all forms of relatedness. Importantly, the patient here is not considered as having only one position in care; following the hypothesis of the interdependence of care, I expect to find patients in multiple sides of a caring spectrum.

- How relationship practices (collective care practices among people with diabetes) do care?

A third sub-question explores empirical ethics of care that are part of these practices, which are, not ethics of the individual but ethics of the social (Pols 2013a). It refers to ways in which people try to make good care. Practices are also not just about ethics, but also aesthetics, what people find proper, tasteful, stylish, or pleasant, what people appreciate and value.

- How do people make *good* care?

With the last one, I will explore patient's knowledge, which refers to the different types of care work that patients need to do to live with the illness and to maintain significant relationships: a work that requires knowledge, from biomedical knowledge, to practical knowledge of adjusting spaces and times, communication and emotion work.

- Which situated knowledge, embedded in care practices, circulates?

Ethnography however is an excellent practice for generating data but it is also, or perhaps more importantly, a device for generating questions (Moreira 2018).

DOING ETHNOGRAPHY

ONTOLOGY AND EPISTEMOLOGY

This work has been highly influenced by early works on STS and in particular "Notes on materiality and Sociality" (Law and Mol 1995) and "The body multiple" (Mol 2002) whose point of departure are multiple ontologies, visible through social practices and interactions. The idea is that there are multiple realities, not only one that needs to be discovered, in medical practices. Ethnography, in this regard, can explore multiplicity of ontologies, that, in their interaction and co-existence, produce something, *make* and *do* care. Mol therefore does not consider ontological stances a mere exercise and choice in sociology and anthropology, ontology is not one and given, instead ontologies are sustained by everyday practices, they are "informed by our bodies, the organization of our health care systems, the rhythms and pains of our diseases, and the shape of our technologies. All of these, all at once, all intertwined, all in tension. If reality is multiple, it is also political. The question this study provokes is how the body multiple and its diseases might be done well" (Mol 2002: 7).

Grounded on the epistemological framework of social constructivism and phenomenology, this research draws its theoretical perspectives from different approaches such as symbolic interactionism, ethnomethodology, interpretivism and ethnographic approaches. They have been employed and critically combined to study interactions and meanings' construction without losing the focus on the lived body experience of care and biographical accounts. According to these approaches, the individual actively participates in the construction of their own social worlds, including the selfhood, via social interaction. The illness, in this view, is explored as experienced in daily interactions, which in turn effects the performance of the self (Goffman 1961, 1963; Blumer 1969; Charmaz 1995). Phenomenology in particular has been influential in early studies on chronic illness which explored how people make sense of their illness, how they cope with changes and adapt to new situations (Conrad and Barker 2010).

In micro sociological approaches, social organizations are conceived as sites of interactions between individuals and groups, in which meanings, social learning and social order are constructed and reconstructed. Particularly relevant for the case of this research is the interactionist's close-up on everyday life's interactions and actions. When dealing with everyday problems, people's actions need to be justified or questioned reflexively with significant situated others, which they may be also generalized others. This process is seen as foundational of meanings, action and selves' phrasing and definitions. Moreover, in ethnomethodological terms, the focus is in on unsettling norms and rules and use them as analytic resources, framing their use as topics in their own light. The framework of ethnomethodology suggests looking at the actors' strategies to make sense or disrupt the social order, and to use methods and topics that reveal the “sense assembly equipment”, the taken for granted assumptions and practices, features of lived ordering (Garfinkel 1967). The approach implies a sensitivity to how “naturally accountable” actions invokes and presupposes an unarticulated background of knowledge and understanding.

Importantly, STS and relational materialist ethnographic approaches influenced the theoretical underpinnings of this research in many ways, in particular with focusing on the exploration of health as a practice. In this, ethnographic practices are called for a shift towards everyday practices that are situated, composite and contingent that emerge out of actions and interactions of individuals, instead of merely mental processes or behaviours. These approaches warn out about the fact that all health practices are underpinned by identity work, technoscientific imaginaries, entangled with patterns of institutional life, cultural practices and innovation processes. It is an ethnographic practice that emphasises and investigates the material and symbolic elements of such practices, of the times and spaces involved in this kind of situated activity and of how such features emerge and permit the co-evolution of practices (Star 1999; Clarke and Star 2008; Moreira 2018; Lupton 2018; Mol 2002). Some of these studies also call for combining ethnography and praxiography of health, to bring forth a pragmatics of health, intended to understand of how formal definitions, measures and forms of valuing health are crafted, sustained and transformed. Praxiography, according to Mol, is a story about practices of doing disease:

> an ethnographer/praxiographer out to investigate diseases never isolates these from the practices in which they are, what one may call, enacted. She stubbornly takes notice of the techniques that make things visible, audible, tangible, knowable. For the techniques that make atherosclerosis visible, audible, tangible, and knowable. (Mol 2002, 33)

METHODS AND DATA GENERATION CHOICES

This ethnography is grounded on extensive participant observation and ethnographic interviewing as main methods for data generation. The process of data generation was located in the specific setting, the field, chosen as observational setting and further described in the next section. Fieldwork and the active participation to activities and events aimed at gaining access to interactions and significant relations of people dealing with diabetes, at producing written accounts and descriptions with the use of fieldnotes, at the sharpening the research questions and the operationalization of sensitizing concepts (Blumer 1969; Hammersley 1989) from which the research started, at allowing the preparation of the semi structured interviews through recurring themes, “stories” and language.

The constant interplay between observing, participating, data collection, interviewing, strategic questioning and feedback, has allowed to maintain the focus on bodily experiences, on practices and interactions without overlooking broader structural changes in which these situated practices and interactions are embedded. Moreover, sustained participant observation enabled to establish an ongoing relationship based on trust with the respondents, which assigned central value to life experiences and circumstances, expressed by members' own language. Feedback from the participants, especially the informants and the gatekeepers, has played an important role both in defining and redefining the research tools, my role as a participant researcher, and the theoretical and analytical frameworks. Feedback to my work as researcher, moments of "giving back", my presence in the field and my role have been important for constituting a relationship and for data collection.

For the interviews, a semi structured approach was preferred from structured ones to give maximum opportunity for the construction of contextual knowledge and the exploration of situated processes and personal stories. More than an excavation of knowledge, meanings and understandings are created in the interaction (Mason 2002). The principal research strategy adopted for interviewing is participant observation, based on thematic, topic centred, biographical or narrative approach (Plummer 2001), with biographical starting point of discussion, which let specific stories, that had previously emerged, to be told. The sequence was not fixed but a structured and flexible approach was preferred (John Lofland et al. 2006), allowing the development of unexpected themes and the discussion to flow. The aim was to offer a structure on the interaction useful to explore the themes and topics central to the research. In some case non-directive questioning was employed, designed as triggers that stimulate into talking about a broad area (Heyl 2001). This included entering the interview with positioning myself, a list of issues to be covered and sometimes, and, if the case, the use of other's people opinion or the mentioning a discussion in which the interviewee took part.

REFLEXIVITY

It has been the first time, for me as researcher, to enter the clinic. While preparing fieldwork, I was influenced by works and considerations of medical anthropology, works that made me aware of the role of the researcher as a sort of "cultural broker" between medical knowledge and social knowledge. I was afraid of falling into what Scherper-Hughes has defined serving "in the clinics like early anthropologists were serving in the colonies". Or, the anthropologist's dilemma in the clinical context, in Kleinman's words: "of taking up a stance that is intrinsically divided, collegial, concerned with the practical resolution of clinical problems and yet at the same time, autonomous, concerned with clarifying an independent anthropological theory of illness and healing that can stand on its own" (Kleinman 1982: 12). The danger of constructing a sociological object into which transfer the properties of the conceptual apparatus used for the research or the taken for granted systems of knowledge, as a "panoptical gaze". I knew, in other words, what I did not want to do, more than what I wanted my ethnography to be. I was also aware that I had personal motives and feelings that linked me with chronic illness and that my personal biography was orientating, to some extent, my perspective on the field.

In the attempt of keeping track of changes of my presence in the fieldwork, I found myself identity and role in a continuous evolution while doing fieldwork. I agree with Hammersley and Atkinson here when they say that roles and identities of the researchers are co-constructed during the fieldwork process by the researcher themselves and the participants (Hammersley and Atkinson 2007). If when I entered the fieldwork I was perceived, despite my age, as a young student interested in diabetes, with time and my involvement in events, education and training, I became at the same time accountable and someone with a personal life that I never tried to hide. I used my biography different times, to let understand better where my interest was coming from, and to construct a more intimate relationships with the respondents, in particular in moments of restitutions and giving back.

The reciprocal trust and understanding, that was growing with time, had a big importance for the data collection. I refer, in particular, to moments of exchange of daily life stories and issues, that were following an encounter or a goodbye. To overcome this tension between formal and informal moments of data collection, I found useful to plan moments of giving back to the respondents. If some of those moments were planned by myself, structured in advance, other times the giving back was asked by the respondents themselves, as a curiosity and, I hypothesize, as request of commitment to the group. Navigating these requests, made me aware of identity constructions and the different roles I decided to assume during the fieldwork. The so called "collective social dimension" of reflexivity involves the reflexive processes of co-construction of the world studied, a process that takes the form of interactions between the respondents and me. Instead of minimizing reactivity I decided to explore it, to give attention on how people responded to my presence as researcher. It has been interesting to see that my focus during fieldwork on family practices has had an impact in group dynamics and that some respondents pointed out how my questions and interest on that topic made them aware of it. In particular one of the respondents, after having talked about the group of people with diabetes as "family" in the interview, decided later on to use that term in public, to address the group, described as "family" for the first time.

ETHICS

There have been different occasions in which I had reflexively thought about and questioned my presence and my role in fieldwork, and I had different issues according to the spaces I was passing through. However, when these situations occurred, I asked advices and confronted myself with the psychologist of the group and Eva, the nurse.

My participation in observations in the clinical space has always been revealed, either my myself, the nurses, or Doctor Z, the diabetologist. I asked people to ask me questions whether they felt the curiosity to do so. However, I did not request a permission to the ethical committee to enter the clinic. Firstly, because that would have taken quite long time, second because I was already gathering information about interactions "inside the examination rooms" from different points of view, and I was not interested in those particular data. Therefore, all my observations inside the clinic were set in the waiting room, during different kinds of activities.

There have been other issues when I entered other spaces. At the end of the first phase of fieldwork I joined the support group, where people with diabetes talk and confront freely about their struggles and issues they want to bring to a broader group. It is a closed group: people need to ask for a meeting with the psychologist before entering the group. So did I and I was asked to not take notes or intervene during the session. I also took the commitment to not reveal any discussion nor even in the anonymous form, but I was allowed to use the topics of discussion as emerging concepts for the construction of the interview structure. During the interviews I asked the permission to record it and I did not use any real name, all the names in fact are names of fantasy. I later transcribed the interviews, and, under request, I gave a copy of the transcription to each respondent.

CASE SELECTION

The aim was to choose a setting where interactions were rich enough to generate consistent observational data and that, a site of "negotiated order" (Strauss et al 1963), that could have informed on broader changes as well. In other words, a sample with high leverage which is the power of "explaining as much as possible with as little as possible" (King et al 1994) and which enables to speak about interactive care practices in a more interpretative sense. Moreover, the setting had to be feasibly and physically accessible.

The case selection has been guided by strategic sampling, aimed at generating a close up, detailed or meticulous view of the situated contexts or phenomena involved that increases the chances of being able to use that very detail not only to understand how things work in specific contexts but also how things work differently or similarly in other relevant contexts (Mason 2002). The sampling was also informed by the theoretical sampling (Strauss and Corbin 1990), guided by a combined empirical and theoretical logic, linking sampling to the process of generating theory and explanation inductively from or through data. The intellectual puzzle for the case selection consisted in three main features: a high leverage of care practices, which can be translated in interactions between patients (also in the organized forms), professionals and other relevant actors; one, (or more), specific settings that could be used as emblematic cases considering the available literature on transformations in health care, patients' involvement in particular, and that adopts chronic care model and other EBM programs directed to diabetes.

The choice of the setting was driven by the intellectual puzzle (Mason 2002) and specifically by the centrality that interactions and relationships perform in that setting. The sampling main strategy was thus finding a sample to gives access to data that allows to develop empirically and theoretically grounded arguments about transformations of practices and knowledge, focus of the research questions. The reliable sampling model needed ideally to account for interactions so to conduct the sample on interactive units such as social practices. In this case the presence of patient's groups, the cooperation of groups with professionals and the institutional support to actors' interactions have been considered as fundamental features for the selection. Therefore, the documented and reliable presence of patients' organizations in the territory has been considered an element of significance for the case selection.

A second point was the position taken by health care institutions in Italy, in terms of health care policies, considering overall transformations of health care which are already explored by the literature. The process of health care recalibration has at present different shapes in Italy, consequently to a juridical system that allows regional autonomy over health care policies and expenditures. One of the main tendency it is to re-design the dynamics between the actors (state, regions, market, third sector and family) aiming to diminish the pressure on the state, by designing solutions in relation to care which are context based, on a local scale, through participative processes (Ingrosso 2016; Ferrera 2012; Maino 2012; Newman & Tonkens 2011). Current and popular categorizations of social actors, especially promoted through health care policies, include "family" and "community". In this new scenario, people in need of care, as well as their families, communities and voluntary organizations, are expected to actively do care labour for their family and community, to "participate" to each other life and in the creation of health care spaces and their organization. The active role that care institutions take in promoting participation, feed directly in the research strategy. Considering distinctive patterns of change in health care in contemporary Italy and broadly, such as the increasing use of Evidence Base Medicine (EBM), involvement of patients' organizations, the proliferation of diagnostic and therapeutic targets, and the complex regulation of the markets of drugs and medical products (Moreira 2014) the reconfiguration of care spaces and the fragmentation of care settings in the Italian territory, the sample strategy focused on finding a specific Region with a pivotal significance in relation to the features highlighted.

The Italian National Health Service (SSN), based on principles of comprehensive, universal and free at the point of delivery services, has gone through a recalibration and fragmentation process. The national health service is at present differentiated per region and per ASL (Local Health Organization). While SSN is supposed to guarantee the universal health rights to care and access by giving indications about targets and the basic levels of care ("*Livelli essenziali di assistenza* LEA") on the overall national territory, regions are the ones to produce legislation, targets and guidelines about health care delivery in the regional territory, if not in contrast with the national guidelines. Moreover, regions are responsible for the expenditure, the management and the delivery of health care services. They have autonomy about funding financial management of the local health organizations and hospital organizations (ASL and AO) of the regional territory, which they control and coordinate through guidelines. The consequence of this fragmentation is that each region can implement a certain health care regime and follow different models of welfare delivery. Moreover, each ASL (*Azienda Sanitaria Locale*, literally "local health organization") has also a certain autonomy regarding health care services. Consequently, there might be a high differentiation in terms of infostructures and health care delivery within the same region or even province.

Because of the impossibility of reconstruct a universal infostructure for people with diabetes in the overall Italy, the sampling strategy adopted for this research was finalized at finding a setting "Region" that presented the following features:

- health care policies which aim at supporting citizens participation in health care, specific programs and infostructures for diabetic patients;
- implementation of primary care and territorial services, EBM and chronic care model;
- health care spaces where to carry observations;
- high degree of diabetic patients' organizations.

On the basis of the last ISTAT report published in 2017, the population with diabetes doubled from 2000, due to different facts: aging population and a reduction of mortality of 20%, combined with a progressive anticipation of the onset, which concern people from all ages, including children. In 2016 there are over 3 million and 200 thousand of people with a diagnosis of diabetes in Italy, the 5,3% of the entire population. The 16,5% of them are older than 65 years old. The report affirms that diabetes is strongly linked with socio-economic disadvantage especially in women of all age. The morality level is also higher among women with diabetes and particularly in those living in south of Italy. Compared to 2000, the hospitalization rates dropped of 66,4% in the overall territory (ISTAT 2017). Considering that the increasing number of new diagnosis, access and follow up of newly patients are mostly done within the areas of primary care and territorial services. However, because of the fragmentation of the health care system which is translated in enormous differences in terms of infostructures, tracing a picture of diabetes in the overall national territory is not an easy task, there are however data available in some contexts.

CASE STUDY

EMILIA-ROMAGNA REGION

Due to its long tradition of associationism and civic participation, the health care of Emilia Romagna has, since the 90s, developed its own social health care model, called "generative welfare" (Vecchiato 2013). The regional care policies have orientated their actions explicitly towards integrated care, concerning chronic illness, primary care, territorial assistance and the engagement of civil society through networks of community hospitals, social and territorial services. Moreover, the third sector is indicated as factor of well-being and health, because it produces relationships, networks and social capital. The acknowledgment of the importance of the community and civil society is also seen as part of the identity and the cultural tradition of the citizens (Delibera Giunta Regionale 2016, 2018). The guiding hypothesis was that in Emilia Romagna the combination of a specific welfare model and its direct support to social health organizations, with the presence of structured and spread out patients’ organizations, facilitated the emerging of forms of participation and care practices that are peculiar of this territory.

In the Health and Social Plan of the Emilia Romagna Region 2017-2019[32] changes in the health care delivery are presented as corollary of a changed socio demographic landscape. The growth of the population, at present between four and five million inhabitants, is concentrated in urban areas, while hinterlands are increasingly depopulated, also due to the economic crisis that has decreased the number of metal workers. The population is therefore growing only in certain areas, while the overall population is aging (age index[33] was 175,5 in 2016) and the average family unit reduces to 2,25 in 2011. 40,2 percent of the total population between 15 and 64 years old in the region have currently care burden towards one or more people of the family (whether a child or elder), and the majority of those are women. With these premixes, the Region wants to support a generative welfare system that could reconnect social bonds and networks and give more strength to territorial a community welfare system of the region, worn out by the above mentioned demographic and social changes. With that document, the region wants to govern social innovation and planning, leading community participation and strengthening the integration of social, health, housing and education policies.

> The territorial and community welfare model that we promote is constituted on the basis of programming, a fundamental function of public systems which need to intercept changes, the emerging needs and new resources (…) it is a result of a mix of public and private investments, under the direction of the public and citizenship, a generative one, in which citizens could feel represented and play a role, everyone according to their possibilities, dedicating their time and skills to actions for the collective interest. Local organizations and ASL, as public organizations with governance competencies, are called to empower the role of regulation and control, support to participative processes and self-organization, connecting community initiatives and actors of civic society with institutional interventions.

Health and social care services in this view, need to be oriented to the territory, adapted to the specific characteristics of a territory. The implementation of spaces devoted to primary care goes towards this objective, together with a legislation that gives recognition to the third sector, now legally capable of being welfare provider.

Emilia Romagna therefore identified specific locations, Casa della Salute, literally health homes[34], that could represent this effort, combining health care services, civic society organizations and local organizations together, to stimulate active citizenships. The aim is to support a transition from a medicine-centred space to a space that

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[32] Il piano sociale e sanitario della regione Emilia-Romagna 2017-2019.

[33] Age index is ratio between the number of persons aged 65 and over (age when they are generally economically inactive) and the number of persons aged between 0 and 14.

[34] Casa della Salute, will be from now on abbreviated with the acronym CDS.

"valorizes all the professions in health care, towards the construction of relationships which support resources and energies of the user-citizen, holding them responsible of their objectives, lifestyles and compliance". The support of mutual help groups and patients organizations, they state, goes to that direction. Emilia Romagna region implemented health care spaces devoted to primary health care and sites of territorial services, also indicated as sites of community participation, health promotion and patient's empowerment. CDS, commissioned and funded by the Ministry of Health[35] in the overall territory, promoted as sites of participation and inclusion of citizens, families and civic society organizations. However, only in few regions CDS have been implemented, in this regard Emilia Romagna is the most successful case (Brambilla and Maciocco 2016) as the implementation of CDS has been approved by the Emilia Romagna Region already from the early 2000s. By the end of 2017, there were in the overall regional territory CDS 87 in total, 35 programmed, serving 44% of the overall population in the Region which is in total four million and five thousand inhabitants[36]. CDS are classified as big depending on the numbers of services offered. The spaces of CDS can either be old hospitals that have been dismissed or reconfigured, or other types of buildings given by the municipalities, or new buildings.

CDS are also indicated as sites for health services integrated management for what concerns chronic illness, and therefore diabetes in particular. In the 2016 Regional report on diabetes it is stated that due to integrated assistance (network of primary and secondary care, social and territorial services), the following complications have significantly dropped since the implementation of integrated services in 2010: mortality (-2,5%), coma (-42,1%), hearth attack and ictus (-34%), vasculopaty (-7,1%), amputation (-19,2) and retinopathy (-38,2). Emilia Romagna Region has been focusing on the advancement in the territory of a model of "integrated" management of health care delivery (*assistenza a gestione integrata del paziente*), where the term "integrated" means that it encompass several professionals namely family doctor, diabetologist, diabetes nurses, nutritionist and the patient themselves, as active part of the equipe (*Gestione integrata della salute in Emilia Romagna*[37]) and when needed social territorial services.

In Emilia Romagna the diabetes prevalence is around the 7% in 2016, 7,5 of men compared to 6,5 women, a 16% over 65 years old and, as the national overall picture, is higher in lower socio-economic classes and social disadvantage[38]. People with a recent diagnosis of diabetes type 1, type 2 or gestational diabetes are followed up

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[35] The realization of 'case della salute' is part of the 'New deal of health care' Ministry of Health, 27 June 2006. Among their activities, they encourage and support practices such as 'health education', 'self-organization of chronic diseases', and 'voluntary based participation'. In this regard, the case study is an example both of 'collaborative care', according to the definition that Ingrosso provides (2016), and new participatory welfare models (Bifulco 2015). However, despite Emilia Romagna is the Region that implemented CDS the most, only in few cases civic society organisations are present and operate inside the physical space of CDS, but, in most of the cases, there are no organizations inside and the process of involving them is difficult and conflictual, and remains, until now, unhatched. It is mainly in contexts where voluntary organizations and mutual groups were already active that participative processes within CDS developed.

[36] Giunta Regionale 2017.

[37] http://salute.regione.emilia-romagna.it/cure-primarie/diabete

[38] Diabete Mellito in Emilia-Romagna 2016, *Regione Emilia-Romagna and Servizio Regionale.*

by the diabetes territorial services (*servizi diabetologici territoriali*, Hub), the peripheric clinics *(ambulatori periferici*, spoke) and the family doctors. In the overall regional area, there are 23 Hub and more than 60 spoke. Patients with diabetes type 2 which does not present complications, or with a stable balance, are followed up by the family doctor, in cooperation with the nursing staff of the chronicity unit in the CDS, only in case of need by the diabetes territorial services. This program is called *gestione integrata*, GI[39], literally "integrated care management". We will look more at that in the next chapters.

While the Region gives guidelines and planning, Local Health Organizations are autonomous units, responsible for the delivery of health care services. In the overall region there are 8 AUSL[40] (Piacenza, Parma, Reggio Emilia, Modena, Bologna, Imola, Ferrara, Romagna) responsible for territorial health services, health departments and hospital units. Each AUSL is divided into different Districts[41], which are separate organizations devoted to territorial services and primary care and has autonomy over financing and management. Districts are therefore responsible for the organizing and delivery of integrated care services. Due to this fragmentation, at present, there is no uniformity of diabetes services in the overall Region. Hospital and diabetes clinics present differences in terms of treatments, procedures, standards, staff and working hours. It is only recently that, as we will see, there have been attempts to uniform diagnostic and therapeutic plans (PDTA and GI).

PATIENTS ORGANIZATIONS

Since the 70s and 80s, issues as the social construction of health through the health systems, the issues as of the involvement of community and social sector, the critiques of the social movements, the centrality of the self-care, entered into the sociological debate about "health". Tognetti Bordogna, in her reconstruction of mutual help and patient's groups in Italy (Tognetti Bordogna 2005), argued that was in these decades that mutual help groups, social movements and groups of patients were bringing experiences which were until then relegated to the private sphere, and from then outed in the public discourse, subject of public policies. New subjectivities were taking the space which was before taken only by health professionals. Psychiatric patients and women's groups wanted to have recognized the authority to be part of the discourses and the medical practices, opposing themselves to the institutional system which was socially controlling and repressing their subjectivities and where there was no space for their experiences to emerge. The main objects of the first mutual groups have been the organization of alternative spaces, the demand of their own knowledge and practices in the healing process,

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[39] Gestione integrata is a management system that became operative after the Diabetes National Plan in 2013 and the National Plan on Chronicity on 2016. It is based on the intervention of different professionals (diabetes professionals and diabetes clinics) among which the GP is the most important, with a gatekeeping role. The patient has an active role in this system. Gestione integrata is a fundamental change that occurred with the reform of primary care, which happened not in the overall national territory. Patients who enter the gestione integrata are not followed by the diabetes centre but by their GP, who is supposed to intervene when it is needed. For instance in the case of a relapse, the patient is encouraged to get an appointment at the diabetes clinic in order to revise the therapeutic plan.

[40] Azienda Unità Sanitaria Locale.

[41] Distretto sanitario.

as well as the recognition of solidarity networks and relationships. The first generation of mutual help groups focused primarily on community building and the sharing of experiences which were before hidden and pathologized, training of health professionals and information campaigns. The 1990s in particular, have been a turning point from group's action to a more political reflection on action. The second generation had organization units more complex and different objectives, often integrating or communicating with institutions and broader networks. The use of technology and different sorts of tools has also been part of the experience of the second generation's mutual help groups, such as professionals taking part of the groups, such as psychotherapists, mediators, or facilitators that were supposed to support the group and its members (Tognetti Bordogna 2005).

Giarelli, Nigris and Spina reconstruct in their volume how self-help groups and patients' organizations have increased their number in the last decades in Italy, despite differences in terms of geographical distribution, organization, internal structure and objectives. Relevantly, groups have mostly a micro-social character, operating in small units and on the local scale. They are widespread more in the north of Italy than the central and the south of the country, probably due to a combination of social capital and healthcare institutions in the area, showing in this way a nexus between the presence of health care institutions and patients' participation. Interestingly, this link is reflected also in the exchange found between groups and health care services: when analysing the language of the relevant actors it has been noted the importance of the figure of the facilitator, who, often by using the language of science and medicine, influences the language of the whole group. In this way, the "inside" of the organization appears as "inside-outside", permeable and in dialogue with healthcare services, often embracing multiple knowledge, from the purely experiential to the biomedical knowledge. This is reflected also in the motivations that have pushed these groups to operate: more than mutual-help they are configured as associations of citizens, open to all, for which the mutual-help is only one of the objectives but not the only one. They go beyond the issues for which they have been created, embracing a broader perspective oriented towards (self) responsibility on health and promotion of a new public discourse of empowerment of the chronically ill and the person with disabilities. The patients groups that have been analysed in Giarelli, Nigris and Spina's research in Italy, highlight a partial development of networking processes towards others civic society's organizations and a limited degree of institutionalization with health care and social services, especially in comparison with patients groups in other European contexts (Giarelli, Nigris, and Spina 2012; Giarelli and Spina 2014).

For what concerns diabetes, there are several diabetic patients' organization in Italy among which FAND[42] (Associazione Italiana Diabetici) is one of the most active, in particular providing materials for training purposes, advocacy and information regarding diabetes. In the context of Emilia-Romagna, the regional umbrella

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[42] https://www.fand.it/

association of diabetic patients (Fe.d.ER: Federation of diabetes in Emilia Romagna)[43] gather together more than 20 local patient's organizations, spread in the overall regional territory, most of them located in CDS. Feder participates in working groups on diabetes at the regional level, in particular for what concern the programming, the organization and evaluation of diabetic health care delivery. Together with the regional health agency and representatives of the ASL, Feder is part of the regional committee on diabetes (*Comitato di indirizzo della malattia diabetica*). Feder has been part of the restructuring of several territorial diabetological services in different ASL and directly promote the implementation of the expert patient model and the direct involvement of patient's organizations in the CDS. Moreover, the umbrella organization delivers questionaries' each year aiming at gathering information from the patient's point of view regarding health care services and other public services (e.g schools). Feder has also been involved in several HTA and has autonomously produced data regarding diabetes in E.R.

RESEARCH SETTING

Since within the same Region there are different implementation conditions and complex restructuring processes, the initial phase of fieldwork was devoted to find a territorial setting that could allow both the access and the presence of the above-mentioned features of the case:

- health care policies which aim at supporting citizens participation in health care, specific programs and infostructures for diabetic patients;
- implementation of primary care and territorial services, EBM and chronic care model;
- implemented care spaces (CDS) and diabetes services which cooperates with patients' organizations where to carry out participant observation;
- high degree of presence of patients' groups and civic society organizations in the territory;
- element of cooperation between patients' organization and professionals, since the focus of ethnography is on care practices (e.g social activities and events, training, conferences and so on).

This pre-fieldwork exploratory phase aimed at finding a setting which would contain all these elements together.

After collecting and subjecting to preliminary analysis any available documentary evidence available about the setting, from December 2017 to February 2018 I carried out exploratory interviews with four informants that I initially identified as such and I made brief visits in several CDS in the Bologna's ASL. The pilot research aimed at assessing the suitability, feasibility of carrying out research in CDS and at managing access policies. The main activities in this phase have been useful to understand the regional and local contexts as well as relevant actors'

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[43] http://www.federdiabete.emr.it

views concerning regional policies and health care spaces. Furthermore, this phase set the stage for the negotiation process with relevant actors, such as the heads of organizations involved, ASL and Emilia Romagna Region, and patients' organizations[44]. These informants and guarantors have helped setting up the relations between me and the group and involved me in several training events organized by the association in collaboration with the Emilia Romagna region and several ASL in Emilia Romagna. Through them I gained access to a specific territory where to carry out participant observation and to the broader setting of the Region where to observe interactions between institutional actors.

Importantly, I acknowledged that the CDS was not a homogenous category of sites, instead they must be broken down into a number of sub types which have significantly different characteristics (Hammersley and Atkinson 2007, 29), and were expression of situated negotiations between the region, ASL, municipalities and the structured presence of civic society organizations. Nonetheless, care policies concerning diabetes and infrastructural nodes were also situated and results of situated policies, interests and negotiations and it was therefore impossible to reconstruct a unitarian pictures for the whole regional territory.

The access was since the beginning the main issue. Since my presence in health care spaces needed to pass through an ethical committee of the different referral ASL, a process which normally can take up to 6 months, I decided to simplify the accessibility's issue through patients' associations and groups. The Emilia Romagna Region and the diabetes umbrella organization (Feder) agreed on letting me carry out participant observation in the health care spaces, through a formal agreement with the University of Milan and the formal consent of health care professionals and patients in specific spaces. As an exchange, I would have had to submit questionnaires to patients in a CDS for few months. The questionnaires are investigating their experiences with diabetes and their knowledge of the illness. The questionnaires have been developed by Feder itself who was willing to gather as much of questionnaires as possible to start a preliminary analysis by the end of 2018.

Together with informants and guarantors from the Region and the patients' umbrella organization, few possible suitable sites where to conduct ethnographic fieldwork have been identified, considering distinctive features of emblematic settings: average, excellence and emerging. These features have been found in the CDS "Terre e Fiumi" di Copparo, Ferrara's province, Ausl of Ferrara, where the local association of diabetics (Adico), besides

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[44] As intermediary, Brambilla, former head of department of 'Primary Care' of the Emilia Romagna Region, created the contact and established the communication between me and certain members of the group. He was identified as key informant due to his involvement in the primary care reforms of in the Emilia Romagna Region and his recent study on the development of Casa della Salute in Emilia Romagna and Tuscany. In the interview he confirmed the choice of CDS as a key space for the research but suggested not to focus on the area of Bologna. Through him I got in contact with I.C from the coordination and development of health care regional systems, and R. S., President of the regional umbrella organization association of diabetes (Feder). Furthermore, M.L. L, head of the primary Care department of Bologna, confronted with the complexities of processes of restructuring and coordination of resources, and with the fact that each Asl has the autonomy to program a different plan concerning health care. The Asl Bologna is also a peculiar case, because the city of Bologna itself, due to its dimensions and complexities in term of population and history, is the biggest focus of interventions and the CDS in the urban settings are still at an initial implementation phase. Differently, both the Primary Care department at the Emilia Romagna Region and the Fe.d.e.r organization consider CDS as major spaces to understand processes of participation and new narratives of health and care and they helped me with a screening of potential settings which included all the features I wanted to explore.

their own activities and events, cooperates with the diabetes clinic and services in the health care spaces of the CDS.

Ferrara AUSL is divided into three districts, serving an overall population of 348.030[45]. The overall picture is a territory that has seen the rapid depopulation towards the urban area of Ferrara. While the city is dealing with a rapid growth, the rest of the territory, including Copparo, is dealing with an increase of aging population. The aging index in 2018 was 251,3 (2,5 people older than 65 years old for 1 person younger than 14 years old), higher both than the one concerning the overall Region (180) and the national one. The dependency index[46] is in this area is 63,3, higher both than the regional level and the national one, meaning that only 37 people to 100 have to take care of the remaining 63. The Ausl of Ferrara presents also the highest prevalence of diabetes of the region both for men and women (31: standardized mortality rate 2017), including the mortality due to diabetes, higher than the overall regional data which is 23,5. It is therefore a territory at high fragility. Diabetes in the Ausl Ferrara increase with age, poverty, lower education. It is more common among men than women.

The CDS "Terre e Fiumi" is classified as large, for the numbers of patients and the operative medical and social services. Former hospital, from the 90s went through a restructuring process that involved the community and the municipality and led into its conversion to a "community hospital" first and CDS later. The overall population served by the diabetes clinic is around 40.000 inhabitants spread among several Municipalities[47]. That site appeared to be average CDS site, with a long lasting and established cooperation of institutional and third sector organizations. Particularly suitable appeared to be the Diabetes Clinic inside the CDS. From the pilot research emerged as site of vanguard for the diabetes treatment, regarding specifically therapeutic education and the cooperation with the local patients' organization. The professional staff, nurses and the diabetologist, have been participating and have themselves organized public events on education in diabetes care practices and have themselves received and given training to other professionals in the region and Italy. The fact that that diabetes clinic is at forefront of diabetes care appeared clear from the amount of training that the staff was giving to other professionals of the Region. The high quality of the diabetes clinic concerning the relationship with patients was considered a feature of excellence, recognized by all the relevant actors interviewed in this phase.

The local patient's organization, Adico, was formed in 2008 by the initiative of a small group of people with diabetes. Since the beginning the aim was to participate into the CDS spaces and in particular cooperate with the diabetes clinic, to improve the conditions of diabetes treatment and disseminate good practices and prevention activities. In line with the regional policies and objectives of the CDS, the local organization and its activities

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[45] Data from "Il profilo di Salute della Comunità Ferrarese. Dicembre 2018". Edited by Servizio Sanitario Regionale Emilia-Romagna.

[46] The dependency ratio is the number of dependents in a population divided by the number of working age people. Dependents are defined as those aged zero to 14 and those aged 65 and older. Working age is from 15 to 64. The ratio describes how much pressure an economy faces in supporting its non-productive population. If it is higher than 50 percent, that means that more than half of the population depends economically to less than the half of the population.

[47] Municipalities of Copparo, Tresigallo, Formignana, Jolanda di Savoia, Ro e Berra.

stood out as emerging features. Despite there can be found many other local patients' organizations, only in Copparo they cooperate with the clinic to the extent of organizing education activities together in a health care space. In particular their cooperation includes training and education activities directed to new patients as well as to professionals. However, the organization does not depend on the CDS, its funding relies completely on members donations and annual fees, as well as on their involvement in organizing. Considering the degree of patients' organizations and activities, the CDS of Copparo was considered emerging case. Despite the initial design considered to follow two cases, unfortunately I only could complete fieldwork in Copparo and followed only this case due to time restriction and access issues.

After having gathered socio-demographic information I contacted the president of Adico and after a first meeting at CDS we agreed on the research plan. During this phase of the fieldwork, from March 2018 to August 2018 participant observation has been the main activity that I have been carried on in different spaces and events, and that served the general scope of generating data through fieldnotes but most importantly to achieve social access, acquiring meaning to my presence in the community and build mutual trust with the professionals operating in the diabetology unit as well as the members of the local diabetics organization (Adico). Informants and gatekeepers emerged as the research proceeded. They accelerated the understanding of the group organizational culture, helped the construction a network of relationships with reliable informants who enabled to grasp the meanings of actions, words and symbols.

PARTICIPANT OBSERVATION

Participant observation, starting from March 2018 till May 2019, was set in different spaces. It focused on situated interactions of patients (with professionals, with significative others and with other patients), the caring practices expressed verbally and not verbally during the different activities and the emotional mechanisms connected to them. Through participant observation I identified relevant themes and issues that I included in the semi structured interviews, which occurred from June to December 2018. I conducted participant observation twice per week, initially at the diabetes clinic where I submitted questionnaires to patients in the waiting room and I attended other activities organized by the clinic and the patient's organization in the clinic, namely the sessions of the support group therapy and therapeutic education (see Annex B Map of the Diabetes Clinic at the ground floor of the CDS). Outside, I attended the organization's activities, following the participants in the spaces where the organization operates. The activities can be summarized as follows:

- Questionnaires at the Diabetology clinic:

I have been present weekly at the diabetology unit during the visiting hours since March 2018. My access was facilitated by the fact that I was submitting questionnaires to patients and their care givers. Questionnaires, developed by the regional umbrella organization of diabetics (Feder), aimed at gathering information about patients' awareness about complications and in particular on diabetic retinopathy. This task allowed me to be present in the clinic continuously on time.

- Training at the Diabetology unit:

I have been participating to training activities, Conversation Maps™[48], for patients who have recently diagnosed of diabetes. During these activities, done by the nurse (facilitator) and an observer (expert patient from patient's organization, myself as observer), patients are alphabetized on the physiology of diabetes, including different types of diabetes, food and nutrition, techniques of management of the illness, symptoms of complications and hypoglycaemia. During these training sessions there is also a space to ask questions and issues that needs to be further explained.

- Patients organization activities, at different spaces of CDS and other social spaces:

The local association of diabetics (Adico) carries out social and educational activities for people with diabetes on regular basis. The main events are the support group (*gruppo di ascolto* in Italian), facilitated by a psychotherapist twice per month; a kitchen Lab which takes place in a kitchen school where participants prepare an entire lunch and eat together afterwards; walking days organized in several areas but mainly in nature; social lunch, for instance Christmas lunch, and a lunch called "guided kitchen" which takes place once per year and wants to share awareness on issues of nutrition. These events are usually attended by patients and their significant others, in particular family members and friends.

- Educational campus

It is a yearly event which lasts a weekend. From March 2018 I have been following several group meetings and I joined the campus in May 2018 and May 2019. The Campus lasts three days and includes of different activities: from education on food and sport and other issues, to walking and sport activities, to moments of sharing ideas and feelings that resemble the support group and more social moments of eating together, watching movies and games.

- Course on "competent and active citizenship" directed to professionals and patients' organizations

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[48] Based on ample evidence that group diabetes education is more efficacious than individual as well as the fact that diabetes is a complex chronic disease demanding active involvement of patients in its management, a program has been developed promoting diabetes self-management that educates and empowers the patient. This is known as the "Diabetes Conversation Map program" consisting of conversation maps™ (CM), a tool created by Healthy-Interactions in collaboration with the International Diabetes Federation Europe. The program, which is currently being used in 105 countries in 34 different languages, includes two formative steps: (1) healthcare professionals' (HCP) training through continuous education in medicine (CMe) and (2) patients' education by trainers. Diabetes conversation maps comprise a simple and consistent delivery of educational therapy. This program is patient-centred and conversation-based and composes a verbal and visual learning journey. Through the active involvement of the patient, conversation maps facilitate patients' diabetes knowledge by improving their awareness about the disease, health self-management, and treatment adherence. The program consists of four maps: each CM includes images and metaphors reproduced on a card table focusing on a specific topic (living with diabetes, how diabetes works, healthy habits, and starting insulin treatment). The interactive discussion about each map facilitates group education resulting in patient empowerment. Local certified trainers have also started educational sessions for patients with this new methodology.

I attended a course named “the competent citizen” *(il Cittadino competente,* in Italian), organized by the regional umbrella organization of diabetics (Feder) at the Emilia-Romagna Region. The course was directed to professionals of different ASL in Emilia Romagna, to organizations of people with diabetes spread out in the Region. The aim of the course was to inform the associations about the current state of care policies, care policy interventions, the reform of the third sector in Emilia Romagna.

SEMI STRUCTURED INTERVIEWS

Interviews were held from June to December 2018. The final interview structure (Annex A) started with biographical accounts on the life and illness history of the respondents “when did you meet diabetes for the first time”, to then explore issues of support and shared practices with others, in particular food. Particular attention to practices has been given in the interview to get accounts of care practices that belong to the private realm of family life and that could not be reached by participant observation. Accounts are sources of information revealing the perspectives and discursive practices of people with diabetes, examined as occurring in, and shaped by, that particular contexts (Heyl 2001). This added situated sociological knowledge, but also light on the kind of threats to validity that we may need to consider in assessing the information provided by an account.

Because I established throughout the participant observation an ongoing relationship with the person being interviewed, questions and points made during the interviews are with reference to shared moments, informal conversations in the course of other activities and formal meetings, with awareness of mutual commitment. I employed ethnographic and feminist accounts (Devault 1990), which favoured a dialogic approach that welcomed the effect of the relationship with the informants. In this regard, ethnographic interviewing has been chosen as a form of interaction that allowed the process of sense making and construction of definitions to emerge, a way to reach the symbolic content of interaction. The interview was, in most of the cases, anticipated by positioning myself and stating my objectives and expectations from the interview. I often declared that I was unfamiliar with diabetes, and that I had to learn its language and practices during the research. These differences sometimes facilitate the process instead of being a barrier, and created a space where to share identities, defined and redefined during the interview (Hammersley and Atkinson 2007, 109). This process of active interaction with the interviewees shifted after I participated to the campus in May 2018. Besides the amount of time spent together as a group, I was involved in the activities and encouraged to share the challenges of exercise and eating, which are part of their daily chronic illness work, and that I had to experience at the first place. In these shared moments I have been asked by the respondents several times to give back to them the observations I was carrying out, a personal opening regarding my family history and the motivations to engage with the research has been requested as well. The more I was entering the field, the more our identities were revisited or reconstructed over the course of the research.

Most of the interviews took place at the CDS in Copparo, in the room of the patients' organization at the first floor. This location was generally chosen by them, after me proposing it to them as an option, leaving them free to come out with a space of their choice, with the only requirement of being quiet for the recording. Despite in most of cases the interviews have been scheduled in advance, in other cases, unexpected interviews occurred during the observation at the diabetology unit, alongside the check-ups, or during an event of the organization.

Interviewees were patients who are assisted by the diabetology clinic and patients that are in GI, that have been before assisted by the clinic. However, all of them have been patients of the diabetology unit either at present or in the past, in some cases they recently had to "come back" because their treatment therapy needed to be revised. All the interviews are individual interviews except one case in which the partner joined the interview. The presence of the wife had a significant effect (Hunter 1993; Chandler 1990), transforming the interview and giving more space to issues as conflicts within the family.

The strategy adopted to sample was to think about relationships instead of individuals and divide the sample into two categories that are representing practices and interactions instead of real life categories (Mason 2002), by using variables interpretatively instead of categorically. The sample represents a difference of social experiences into two types: be part of the patient's group or not. Deviant individuals, cases that do not fit with that category or that cannot be accounted for the explanation which I am developing, are selected as well (Denzin, 1989). The aim was to search for someone who has support relationships but does not have group experience, or someone who is active in the group but who does not have awareness. While part of this sample has been part of interactions which I observed, the other part has not been part of observed interactions but has been only interviewed.

Emergent categories may be either "member identified" or "observer identified" categories (Lofland 1976). While the former is employed by members themselves, encapsulated in the situated vocabularies of a given culture and expressed in interactions, the latter are constructed by the observer. Both intertwined with the development of analytical ideas and strategies for the collection of data.

People have been selected according to the mentioned categories, selected by either themselves or after being solicited by myself or a professional. Sometimes have been indicated by other interviewees (see Cannon, 1992 case of people with breast cancer) in virtue of a therapeutic value of interviewing. The nurse supported the selection process by trying to involve people with different characteristics, such as people with diabetes type 1, but especially by reaching out patients who were not part of the organization and therefore unattainable. All the respondents live in the area of Copparo or they have chosen that specific diabetes clinic because of its features of good care.

Total interviews: 30 patients; 3 professionals (1 nurse, 1 doctor, 1 retired doctor now involved in Adico) and 2 respondents from other patients' organizations (1 president of Feder, 1 president of another diabetes organization).

Group interactions: 20 people are to some extent part of the organization Adico, with some very involved and others not frequently involved or involved in the past but not so much in the present, 10 people have never participated to the organization's activities and have been selected through the diabetology unit.

Diabetes type: 4 people with diabetes type 1; 11 people with diabetes type 2 with insulin treatment; 15 people with diabetes type 2. I decided to include types 1 and 2 diabetes because of several reasons. The main reason concerns with interaction practices and aspects of mutual learning and support that people give each other that I had observed in group interactions. Secondly, even if there are differences in terms of chronic illness work, there are also important similarities and therefore I decided to treat diabetes types as continuum in which the control of the sugar level is performed primarily through food (commonalities) and insulin treatment (difference). Some of the type 2 diabetes use also insulin, which make their treatment similar to the ones of diabetes type 1, and at risk of the same side effects, for instance they all are at risk of hypoglycaemia.

All the respondents are white with Italian nationality. That was not a choice I made beforehand but a result of a territory that is predominately white, also due to an economic crisis that perdures since a decade. Moreover, I had the feeling that people with a different background are less encouraged to join voluntary organizations, in particular those in relation to health. The age from 40 to 73 years old, with average of 60,8. The following Tab has the advantage of make explicit the relationships among people interviewed, their connections among people of Adico and connections with other organizations (Biographical interviews Tab):

	Gender	**Age**	**type**	**Adico**	**Biographical info**
Aldo	M	63	I	yes	Very active in support of T2 patients especially those who start to use insulin. Former construction worker, now retired.
Alba	F	66	I	yes	Active in both Adico and support group for families with Alzheimer, together with her friend Loris. Her parents had Alzheimer and diabetes. Retired.
Arturo	M	67	II IR	no	Non connected with Adico. Former worker now retired.
Anna	F	72	II	yes	Active in voluntary organizations: mental health and palliative care. She talks about these experiences often with the group, she is very active in support. Friend of Nora.
Carlo	M	60	II IR	yes	He is very active in Adico, so they are two of his four children. He has a very active role in support. Entrepreneur.
Diego	M	61	II IR	yes	Bridge between Adico and walking group. Former worker, now retired.

Donatello	M	63	II	no	He just moved to Copparo, he has disability because of cardiopathy and lost his job. This was mainly the topic of the interview. Not connected with Adico. Former worker.
Elena	F	49	I	no	She developed multimorbidity in the last two years. She had a breakup, lost her job and moved back with her parents. Not connected with Adico. Beautician.
Eleonora	F	61	II	no	Non connected with Adico even though she knows Eva and doctor Z. She refuses to socialize with other people with diabetes. Nurse.
Flora	F	63	II	yes	Very active in support within Adico.
Lele	M	60	II IR	no	Not connected with Adico. Sales representative.
Gianna	F	50	II IR	yes	She recently came out as diabetic and joined Adico. Unionist.
Guido	M	62	II	yes	Organizes Christmas lunch and is in Adico’s board. Sales representative.
Gioia	F	52	II	yes	Very active also with a theatre group that started to join Adico’s activities and fund raising.
Ivan	M	70	II	yes	He joins social lunches but not very active in organizing. He likes to sport and he is considered an expert of walking. Former Sales representative, now retired.
Frank	M	40	II	yes	Recently joined Adico, before he did not feel like socialize with other diabetics. He is supported by friends. Accountant.
Lilith	F	51	II	no	Not connected with Adico yet. Office worker.
Linda	F	65	I	yes	Close friend with Alba, (she says Alba is more than a sister) they met when they were 12 and had diagnosis of diabetes. Former office worker, just retired.
Loris	M	73	II IR	yes	With Alba very active in the group of families of Alzheimer. He recently lost his mother and his wife. Close friend of Alba. Former worker now retired.
Maia	F	58	II IR	yes	She works far from home, she had often relapses in conjunction with illness and death of her parents. Office worker.
Marco	M	65	II IR	no	Institutional role and very well known but he decided to leave Adico and he is not involved. He refuses care at the moment.
Mario	M	51	II IR	no	Backer, he is struggling with long working hours and stress. Not connected with Adico.
Malika	F	57	II	yes	Recently joined, she talks about her sense of being alone in that context which develops discussions on that topic. Office worker.
Marina	F	41	II	no	She reports isolation, she has a background of migration from South. Not connected with Adico. Unemployed.
Marianna	F	71	II	yes	Organizational role in Adico, expert patient, she is involved in many political activities and she is in other social organizations. Very active in support. Former headmaster, now retired.
Nora	F	67	II	yes	Expert patient, organizational role in Adico, she is involved in many other local voluntary organizations, she is now working at merging the ones devoted on health. Very active in support.
Pietro	M	65	II	yes	Organizational role in Adico and active in other voluntary organizations with Nora. He is part of network of parents who lost their children. Farmer, now retired.
Rosa	F	66	II	no	Not connected with Adico, she does not feel to socialize with other diabetics. Retired.
Tano	M	64	II IR	yes	Organizational role in Adico, he is long friend with Pietro and Nora. Sales representative.
Tina	F	70	II IR	yes	Recently joined Adico.

ANALYSIS

The process of data analysis has started during fieldwork, simultaneously to development of a set of analytic categories, or concepts, that captured relevant aspects of the data. These concepts helped in making sense of fieldwork experiences. Among the concepts that I decided to focus on, several ones were recurrently emerging during therapeutic education and other activities, for instance concepts of lifestyle and self-care, which have been also explored taking into account their origin and uses. Other categories instead have been observer-identified, developed by my-self during the fieldwork. Examples of the formers are the dichotomies: "control/pleasure" (which informs on narratives that describes learning experiences, senses, taste, but also narratives of self-control, stigma, victim blaming); "knowledge" (experiential/biomedical). Dichotomies have been treated as opposite points of a continuum instead of polar categories. Examples of categories that I have developed there are the identification of: "care practices" (food and eating; cooking; walking and sport; measuring; treatment); "types of work" (care work, biographical work, chronic illness work; identity/gender work; emotion work). Additionally, since I wanted to let tensions emerge, I decided to employ the concept of "trajectory" which gives light to narratives of balance of types of works and moments of crisis. Sensitizing concepts have been particularly employed during fieldwork as a starting point and as guide to further data collection. Among these sensitizing concepts, I have been using those who better grasp the data on social practices, by giving strength to interactions and cooperation such as "logics" (of care/choice), "intra-action" (to grasp the presence of human actors, instruments and places).

Considering the huge amount of fieldwork's notes and the limited number of interviews, I decided not to employ a software. After the transcription of all interviews I identified the recurrent themes across the interviews (coding), by selecting sections of the text based on their content, and I finally looked for relations between the codes attributed to the segments of content (Cardano 2011). I have also used schemes and memos which I also employed and developed throughout the year of fieldwork. Every time a shift occurred, I kept track of the changes, the conceptual insights, which I borrowed mainly by the sociological literature.

A second stage of analysis has been to clarify their meaning, giving the data, and exploring their relations with other categories. The strategy in this phase has been the continuous comparative method, examining each item or data coded in terms of a particular category, noting its similarities with and differences from other data that have been categorized in the same way, to let other categories and subcategories to emerge. The work of Adele Clarke's has been particularly influential in this phase, by employing the "situational analysis" in which the situation is taken in all its social complexity as unit of analysis. Situational analysis has had the advantage of grasping multiple discursive constructions, or logics, that circulates at the same time. Different maps therefore can inform on this complexity. "Situational maps" articulate elements (human, non-human, discursive, objects) and the relations among them; "social worlds/arenas maps", lays out collective actors, as cartographies of collective commitments, negotiations and sites of action. Finally, "positional maps", are used to lay out the major positions taken, or not, around conflicts, controversies and so on. This method has been employed to highlight the systems of relations between the elements, and that cooperation can be achieved without consensus (Clarke and Star 2008).

On being allergic to onions

I am allergic to onions that are raw or partially cooked. When I eat even a small amount, I suffer stomach pain and nausea that can last for several hours. In the grand scheme of things this is a very minor disability. However, precisely because it is so minor and yet so pervasive in my life, it is a good vehicle for understanding some of the small, distributed costs and overheads associated with the ways in which individuals, organizations and standarized technologies meet.

Susan Leigh Star

"Power, technologies and the phenomenology of conventions: on being allergic to onions". In J. Law (Ed.), A sociology of monsters: Essays on power, technology and domination. London: Routledge

CHAPTER 6 – CITIZENS IN HEALTH CARE

As we have seen in the previous chapters, one of the most significant transformation in the organization of health care over the last few decades has been the shift towards primary care and patient-centred models; as part of this patients are being involved more and more in processes of decision making and evidence-based medicine (Moreira 2014; Rabeharisoa, Moreira, and Akrich 2014). In the background, health care policies driven by neoliberal ideals of choice and citizen-consumer seem to combine with democratic claims-making around participation based on citizenship (Newman and Clarke 2009). In this context, individuals' responsibility for their own health has also been reinforced by narratives of health promotion and risk (Nettleton and Bunton 1995; Lupton 2013), with individual responsibility being adapted to both of these narratives.

It has been argued that forms of public involvement in healthcare decision-making ensure services are more responsive to patients' needs while addressing issues of accountability in health care institutions and producing forms of co-production between professionals and patients. Yet there is still relatively little known about this involvement and participation in practice: who are the patients involved? To what purpose? And what kind of visible and invisible work are they supposed to do? These questions can be addressed, I argue, by looking at the care work and knowledge embedded in care practices. If there is a type of patient who has been given the role of engaging with the institutional space of health care, then what are these patients expected to do and what do they in fact do, in practice? What care practices does this situation give rise to, along with what forms of knowledge and care work?

CITIZENS IN THE AGE OF PARTICIPATION AND EVIDENCE-BASED MEDICINE

The Emilia-Romagna (ER) Region claims to promote a model of welfare, sometimes defined "community" and sometimes "generative", in which citizens are enrolled though the third-sector and civic organizations to take on a particular role, rights and duties[49]. Third-sector and civic society organizations, for their part, are called on to be a part of welfare delivery. In keeping with this view, the region encourages local health organizations, and patient's organizations in particular, to support participatory processes. With the role of the third sector explicitly recognised, civic society organizations and patient organizations become stakeholders, players operating at the same level as the private sector in health policy and health care[50]. Moreover, in order to connect citizens to health care, CDS (Casa della Salute) have been established to act as centres of primary care and resources for communities. CDS are also focal point for chronic care and, therefore, for diabetes. But what does this mean in

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[49] See "Piano Sociale e Sanitario della Regione Emilia-Romagna 2017-2019" in which the Region declares to follow these welfare models. For generative welfare, promoted by the Zancan Foundation, see Vecchiato T. (2013) Verso un welfare generativo: da costo a investimento, in «Prospettive Sociali e Sanitarie», 3, url: http://www.welfaregenerativo.it/media/uploads/WelfareGenerativo_FondazioneZancan.pdf

[50] Corrective decree Law117/2017 in which, for the first time, voluntary organizations, mutual help, and other civic society organizations, are defined in order to be possible stakeholders of public administrations. The turn towards models of generative welfare needs new legislative frameworks that recognise patients and users as stakeholders in health policies, in project management, programming and validation.

practice? Who are the citizens they are set up to serve? And what are they asked to do, in practice? As far as chronicity is concerned, the Emilia-Romagna Region follows evidence-based medicine (EBM) programs and standards, such as the Chronic Care Model and the implementation of primary integrated care.

THE INFOSTRUCTURE OF EBM: PDTA AND GESTIONE INTEGRATA (GI)

In terms of diabetes specifically, the region has implemented a PDTA[51] Program, literally a diagnosis-therapy-assistance plan that aims to standardize diabetes care overall in ER. The plan defines the basic infostructure that a patient should encounter in terms of health care delivery from diagnosis onward and establishes personalized paths of care according to specific categories: diabetes types, age, pharmaceutical adherence, levels of complications, multimorbidity, and so on. The PDTA is a complex system of standards that prescribes the basic infostructure that will determine what a patient can ask for and receive, what he or she has the right to obtain, when and for how long, where and at what price. Furthermore, the PDTA also defines codes of behaviour for the actors involved. At the present, however, the PDTA is not uniform.

A second pillar of EBM in E.R. is Gestione Integrata (GI "Integrated care"), one the most widely-used PDTA programs addressing Type 2 diabetes patients[52]. GI has been implemented at randomly selected sites in ER since the beginning of the 2000s with the aim of decreasing the healthcare provision burden on diabetes clinics alone, given the rapidly increasing prevalence of diabetes worldwide. The guidelines are described in a document[53] produced by the ER Region. The population of patients covered by GI has grown rapidly in the last years: from 20.1/1000 patients in 2009 to 24.95/1000 patients in 2016, with high geographical variation. In the same document it is estimated that diabetes prevalence stands at 5.9%, higher for men than women (9.1% versus 7.3%), higher for people with Northern African and South Asian backgrounds, and higher for people aged over 65 as well as disadvantaged groups. The document notes that PDTA, and GI as a relevant plan for type 2 diabetes patients, allow the healthcare system to early identify patients and ensure access and care to people throughout the region in keeping with principles of equity. This takes place, according to the document, through multidisciplinary units (health care and social territorial services and hospitals) and "through the active role of the citizen and the community in the management of their health". The region's planned strategy focuses on the intervention in patient lifestyle that generally follow a diagnosis and outlining specific indications for all the actors involved in PDTA so as to re-define their roles and duties, including those of (patient-) citizens. According to the region, data regarding diabetes in ER suggest that, due in part to early diagnosis, the incidence of diabetes is growing rapidly. While on one hand mechanisms of early diagnosis raise the number of new patients, on the

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[51] "Piano Diagnostico Terapeutico Assistenziale" in Italian.

[52] This program is directed to all diabetes type 2 patients who have not developed micro-macrovascular complications and in stable metabolic balance.

[53] See "Linee di Indirizzo per la Gestione Integrata del Diabete Mellito Tipo 2 Regione ER".

other hand these mechanisms also allow healthcare providers to intervene earlier and avoid the later complications that would entail higher costs. According to this perspective, therefore, it is of paramount importance to take charge of new patients. Early identification, one of the pillars of EBM, is thus the primary goal of GI, based on the idea that earlier intervention will reduce the direct and indirect costs of diabetes. In order to achieve this early detection, diagnostic values have changed over the course of the last few decades (see chapter four).

Under the GI agenda, it is family doctors instead of diabetes specialists who are tasked with assisting individuals with a low complexity of care, a status which is defined in terms of treatment and namely the oral administration of metformin pills or single-dose insulin. The GP, and not the diabetologist, is therefore the main point of reference for a person with type 2 diabetes. Furthermore, a patient who enters GI is required to adopt, by consensual agreement, a diagnostic-therapeutic plan that all the actors involved (patient, family doctor, diabetologist and so on) agree on, because the patient will have to return the diabetes clinic every time he or she needs to. Consequently, it is not a single professional but a network of professionals who are asked to communicate with each other in order to make the program work, including by sharing (digital) documents and establishing common (care) practices. The space indicated to serve as the focal point for chronic illness care is the CDS, the preferential space for intervening proactively to practice preventive medicine and assure every kind of care is available for chronic illness.

THE RIGHTS AND DUTIES OF COMMUNITIES WITH DIABETES

The region considers the GI Program the most suitable instrument for ameliorating care assistance for people with chronic illness. As specified in the guidelines[54], the plan hopes to activate on the “collaboration of the community’s resources, such as patient’s organizations, voluntary organizations and so on, the active involvement of the family members and the patient”. “The centrality of the latter is not only decisional but also managerial towards illness and care and needs to be put in a condition to be aware of and expert about their illness” (p.6). The document presents a list of sections which define the rights and duties of all the actors involved, including individuals with diabetes[55]: the duties and rights to access care (*curarsi* in Italian). These tasks and expectations assigned to the person with diabetes include: to play a “central role in the management of the illness”; “sharing with others a care plan and an agenda of meetings and follow up”; to “participate in a structured therapeutic educational activity”; to acquire “knowledge regarding illness management”; and to “produce and access digital clinical data”. This list of expected outcomes and codes of behaviour obviously requires chronic illness and care work that is not specified, work that is not visible on paper. On the other hand,

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[54] See Linee di indirizzo per la Gestione Integrata del diabete mellito di tipo 2, Regione Emilia-Romagna, Direzione Generale per la cura della persona, salute e welfare, Servizio Assistenza Territoriale (2017) url http://salute.regione.emilia-romagna.it/cure-primarie/diabete

[55] See “Il dovere e il diritto di curarsi della persona con diabete” p. 8.

the plan does specify what must be avoided, what should not happen and what constitutes a “bad” patient: complications due to not following the plan and not being properly compliant.

> deviating from the personalized program produces a high risk of complications and of hastening the most disabling phases of the illness, creating economic and life burdens for the patient and their family (for instance in terms of working days missed, care assistance in acute care needs, economic charges for the purchase of home aids or family assistance), and high social costs, such as hospitalization, the use of medicine, disability and institutionalization. (p. 8)

Family members and care-givers have duties and codes of behaviour to follow that resemble those defined for the patient with diabetes. They are also expected to acquire specific knowledge and skills in order to support the person with diabetes, from biomedical knowledge to a general supporting role and active involvement in the reconfiguring of healthscapes. It is expected that professionals will focus their educational efforts on these actors as well. On one hand, citizens need to acquire biomedical knowledge; on the other hand, professionals need to adapt medical practices to citizens in order to take care of the patient as a person and in context.

> The patient, the family, the care-giver and the institutional subjects that enter in contact with the person with diabetes need to be adequately trained by General Practitioners, nurses and the diabetes team to understand what is their active role regarding diabetes care. The main focus of this education must be the diabetes illness and its evolution, the specific conditions of the person and the contribution that the person and his or her relationships could make in redefining health and well-being. Education needs to produce a transfer of knowledge and skills to the patient or caregivers. It needs to be verified in detail to evaluate knowledge and skills and include follow-ups and additional training from the diabetes team. Education can be facilitated through the tools of Health Literacy, especially with people with low educational levels or people who do not speak Italian. In these activities, the involvement of patient organizations could support both the education and the improvement of education tools. (p. 8)

It is not surprising, then, that the 2016 diabetes program “Assistenza integrata[56]” established by the Ferrara AUSL includes patient’s organizations in the GI network of professionals and assistance providers. They are assigned the same role, on paper (p.5). In the same document, there is also a section clarifying the patient’s duties: “the person with diabetes is his or her own case manager, an empowered patient, a self-care giver, the manager of their own lifestyle, the active protagonist of their own life and well-being (…) with responsibility for consciously managing their own condition, at the centre of GI”. To this end, the AUSL recommends “planning periodical educational activities and personalized assistance” (p. 25).

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[56] See “Protocollo per l’assistenza integrata alle persone con diabete mellito” Servizio Sanitario Regionale Emilia-Romagna, Azienda Unità Sanitaria Locale di Ferrara, 2016 url http://ferrara.fimmg.org/wp-content/uploads/2017/07/08.-PROTOCOLLO-DIABETE-GESTIONE-INTEGRATA-ALLEGATO-4.txt

TEACHING EXPERT CITIZENSHIP: RIGHTS AND DUTIES UNDER GI

It was on another occasion, however, that I had a chance to better understand the role of patients, the work and knowledge expected from them under the EBM paradigm. I had this insight thanks to Vita, the president of the Regional Federation of Diabetic Patients Associations Fe.d.ER[57]. Since assuming this role in the organization, Vita has always pushed for a recognition of patient organizations, claiming for them the same role played by other institutional actors. In her view, it is necessary for patient organizations to be part of the restructuring of health care. Together with the primary care and territorial services unit of the ER Region, in 2018-19 she organized a course entitled "The active and competent citizen"[58] directed at other patient organizations throughout the region and other professionals specialized in chronicity, mostly working with diabetes services. The course, held at the building of the ER Region in Bologna, lasted several months so as to cover topics and presentations from patient organizations, family doctors, and diabetes specialists. The course was an extraordinary occasion for observing discourses on the expert citizen, descriptions of "good" care practices, and the setting of ideal and quasi-ideal standards of care.

A presentation on PDTA and GI in particular captured my attention. The main speakers[59], doctors Di Ba and Zam who have both been involved in the development and organization of PDTA and GI since the beginning, were asked to share the achievements as well as the critical points of these programs several years after their first implementation, a process which is still not complete. I was particularly interested in the description of codes of behaviour and normative style of care that they presented. The PDTA program, says doctor Di Ba, implies a kind of patient who "moves around all the time between one or more specialists who offer them a series of solutions, like in a fun park", depending on the patient's required level of assistance, low when he or she is stable or higher, when there are complications. Patients need to be able to *orientate* themselves and know where to go, while professionals need to be *receptive and connected* with each other. When the situation changes, everyone must know what to do. But I wonder: how?

There is a list of well-defined roles that define the rights and duties of all the actors involved, presented in the form of recommendations. Again, the keywords is "network", (*rete* in Italian), meaning that people need to be engaged with each other: "they all need to be prepared to spend time with the patient and give them information, to engage the patient actively so that the patient revolves around the system, knows what to do, becomes the

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[57] Feder stands for "Federazione Diabete Emilia Romagna".

[58] "Cittadino attivo e competente" in Italian. See the program url http://www.federdiabete.emr.it/progetti/paziente-competente/

[59] The scenes that follow were recorded during the course, and participants were not asked for their consent.

main *aware and expert* person, their own primary case-manager who knows where to go". In other words, an ideal patient with ideal professionals all of whom are informed, connected, aware and in communication.

Patients, says Dr. Di Ba, needs to be *informed*, *responsible*, *educated* and understand the pathway they should follow. They need to know that, when they deviate from this pathway, their diabetes can change and become more serious. The expectation is that they will agree, gain expertise, participate and learn about access points instead of passively undergoing (*subire*) the treatment. The patient must become as *compliant* ("*aderente*" in Italian) as possible so that care services can meet his or her needs. Patients' needs must be addressed, and a PDTA does not simply unfold through a pre-established sequence of actions; rather, patients' needs are adapted to costs and resources. Patient organizations also hold a fundamental role and Dr. Zam is very specific about the need to "*stimulate* the patients as much as possible", especially those in GI, because "they often do not present complications and they easily forget that they have diabetes". He says that the process of engagement is very lengthy and difficult, especially with younger patients. The expert citizen could help to *build networks* and *help professionals be more resolutive* towards common problems.

It is clear that the focal point is the network itself: the knowledge and practices that make it possible to build a network and maintain it, to keep it operative and functioning. Networks of professionals, patients, and hybrid networks. The more tight and complex networks are, moreover, the more potential there is to monitor, for instance when someone beings having problems. A good integrated professional network, according to Dr. Di Ba, allows to check when someone is missing the appointments, from a first information round that comes from a digital infostructure, to a round in which chronicity nurses actively check on patients if something does not go well. "when we started Gi in 1997, says Dr. Di Ba, it was not done well, now we have improved the targets, because we understood we needed to differentiate them according to many variables".

However, the audience members for the course did not always agree. This extract is from a woman representing a patient organization who asked to speak:

> We, type 2 patients, are preoccupied… I don't want to offend GPs, but since there has been GI there have been lots of patients with relapses, neuropathy, eye complications… maybe they have stable glycaemia, but neuropathy works in the background. It is true that there are many patients who are not aware of complications and do not carry out self-checks, but GPs need to teach patients to do self-checks because patients cannot get the strips, so they tell you that you need to do self-checks, but in the end you have to pay for it by yourself, "I cannot give you the strips, not one a week". So then what if the patients themselves do not ask for annual check-ups and tests, like for their vision, or feet? My GP told me that he would not have known what to do if it wasn't for me! What is needed is real education to allow patients to be balanced, otherwise they go to the diabetes clinic or to the CDS with diabetes professionals once a year… Can we do something more?

The problem, according to her, is that, due to a lack of time and experience on their side, GPs are not providing information to patients that would allow them to practice self-awareness. The consequence is that patients underestimate important symptoms and have to cover the costs of self-management by themselves; they do not discover complications until it is too late, and complications arise. The entire burden rests on the shoulders of the patient, who is expected to have medical knowledge and ensure self-management at their own expense. In other words: in actual practice, the network is not connected. While Vita seems to agree with the women who spoke up, she also remarks that "we need to work as a group, otherwise we will never solve anything" and that, with this new mentality, CDS could produce results. It is not the time for complaining, according to Vita. She supports the recognition of CDS as focal points for people with type 2 diabetes and the uniformity of PDTA for everyone. It is important that all diabetic patients, regardless of where they live in the region, have the same rights and duties. As expert citizens, they are asked to be engaged and physically present in health spaces such as CDS. For instance, she suggests, during world diabetes day patient organizations could help people set up digital health records accounts instead of merely monitoring blood sugar. This is important, she says, because we as patients need to change our mentality:

> We can't expect to have everything for free. What has emerged is that is important to create collaboration and the importance of citizens' participation in order to disseminate these initiatives because people do not know about them, and secondly to make them follow, in part as a form of respect for those who are making this effort. This collaboration program is a point of departure and not of arrival, we all need to collaborate and to find solutions that are shared, taking the right steps and denouncing critical point in order to find agreement.

In her presentation, Vita underlines the key role that patients have in this landscape. It seems that the role she envisages for patients is even more intense in terms of knowledge and skills than the one conveyed by ER guidelines. For instance, she states that it is important for people in patient organizations *to understand how to argue with the local health organizatio*n (AUSL), how to *bring our claims to them and present them* properly: "Patients are called on to define what should be measured and reported in clinical practice"; such practice, she argues, has nothing to do with patients' "preferences" and everything to do with "experiences", because it is difficult to say "no" when someone asks you if you are satisfied. "Preferences follow a logic of consumerism that negates the illness". According to Vita, patients need to obtain the *knowledge to allow them to be able to take part in the various exploratory research phases, in the design of clinical programs, in the ethics committee, HTA and other regulatory processes*. Patient organizations therefore need to produce knowledge themselves, for instance by administering questionnaires within their organizations that they themselves have produced and organized.

The patient's knowledge that Vita is describing goes beyond the above-mentioned citizenship model of participation, compliancy, awareness and so on: this subject is also a knowledge producer. She talks about scientific knowledge (such as defining indicators and statistical data) so as to make patients a reliable counterpart of biomedicine and EBM in particular, cultural and experiential knowledge (communication and presentation skills, ethics, qualitative and quantitative research), and so on. Of course, in this case I maintain a distinction between scientific and cultural only for the purpose of description, to indicate the vast store of knowledge, skills, practices, and experiences that this "expert citizen" is asked to acquire. It is interesting to note the way Vita differentiates between "preferences" and "experiences", thus emphasizing her distance from a consumerist model of EBM and HTA and specifying that patient participation should improve such a model by bringing *experiential knowledge* into play.

TEACHING EXPERT CITIZENSHIP: RESTRUCTURING DIABETES SERVICES

The course also presented another case concerning the restructuring of the diabetes services run by the Modena AUSL; this restructuring began in 2016 with the involvement of the regional patient organization. The general director of the Modena AUSL, Dr. Anni, begins his intervention by expressing his hopes that health care roles, and especially those of citizens, will change. He suggests that such a shift will be of paramount importance in the next years. In the Modena AUSL case, planners have decided to calibrate the diabetes services by involving only patient organizations at the beginning, a choice that is unusual in Italy:

> Usually when we discuss the organizational set up, specialists are the first to be involved. But in this case, we first asked the organizations of patients to tell us about the local area, its problems, the barriers, the communication problems, because we know that differences between geographical areas should not exist but they do, and we want to take the good practices that exist in a few places and make them uniform throughout to the whole AUSL. Professionals came in only at the end of the process and we brought their needs into dialogue with those of the patients. In this way we have rebuilt the organizational and delivery set-up. (Dr. Anni)

The final outcome of this process is to assure that everyone has services nearby, since diabetes clinics are now present in all the districts and there is one operational unit that coordinates all the services and clinics. Patient organizations, he concludes, are important to engage in "promotion and information but also for empowerment. They told us what the problems were but also they have been available, actively involved". According to Anni, Vita's involvement in the process was fundamental and the national health system agenda must start focusing on involving citizens. However, he also remarks that "citizens can ask for services but also behave appropriately because we all have rights and duties". It is the point of view underlying health care management system that has changed:

> health care was organized on the basis of fixed and standard services, developed by the organizers of the system according to their needs, whereas now we need a system that is driven

> by patients, by some kind of patients, by their needs. Now, health care is dealing with a primary care that is capable of listening and providing orientation, guided by the users instead of the organizers (…) it is more complicated to manage activities with the users, but we need to create trust.

For a long time, the point of view and needs of patients were not taken into account, with pharmacists taking the lead role in guiding policies of therapy distribution. Professionals working in hospitals set visiting hours according to their own needs; only recently have these hours been extended to allow patients and visitors to spend more time together. In his view, it is time to introduce new actors onto the scene, actors such as expert patients. It is significant, however, that he specifies "some kind of patients", meaning that there needs to be a process of selection because not everyone has the skills that are needed. Vita and Anita are among these preferred patients. They have been participating in audits, meetings, and organized trainings for professionals, including a theatre forum.

TEACHING EXPERT CITIZENSHIP IN HEALTH TECHNOLOGY ASSESSMENT

Feder has participated in the restructuring process and, considering Anni's comments, this instance of engagement will be followed by others. Vita has been involved in the Modena AUSL process since the beginning and she talks about it with pride. She says that this case has come to represent a precedent and "we will fight for this to happen everywhere in the region. But this will only be possible everywhere if there is mutual understanding". This was not the first time Feder had become involved, however. They also had a role in the HTA to evaluate Continuous Glucose Monitors (CGM, also known as Flash). In October 2015, Emilia-Romagna issued regional guidelines for the appropriate use of medical devices in diabetes self-monitoring and management[60] after having decided on its reimbursement in keeping with patients' eligibility criteria. Eligibility criteria for the use of Flash glucose monitoring system are HbA1c over the target >64 mmol/mol, >8%, needle phobia, suspected frequent hypoglycaemic events, and unawareness of hypoglycaemic syndrome. However, it is always the diabetologist who decides whether or not any specific patient fits the criteria and makes choices accordingly, because the number of available devices remains limited.

In that case, Vita was in favour of a "care agreement", a sort of contract to be agreed on by both patients and doctors (with the latter representing the region). This agreement would regulate the distribution of the devices according to specific patient responsibility profiles: "when we wrote the protocol for the [distribution of] Flash I insisted on including the agreement because people who get the device have a responsibility to use it, otherwise it should be given back. We need to verify this". Vita's position on this issue is quite clear: you need to be

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[60] See Circolare n. 13 09/10/2015 "Linee di indirizzo regionali per un uso appropriato dei dispositivi medici per l'autocontrollo e la autogestione nel diabete mellito".

compliant because it does not make sense to only use this device to measure glycaemia four times a day. A patient who measures so few times a day could use a common glucometer; Flash would not be the correct tool. This device instead provides patients with an overview of the situation at any moment as well as the way it changes and evolves over all 24 hours: “it is like seeing a film instead of pictures”, explains Vita. It does not make sense to use Flash only to avoid pricking your fingers. It is “right that after a month its use be evaluated” and if does not match a certain standard of usage, “then it [the device] goes to someone else who needs it and who has the same right to use it”, says Anita, another expert citizen and T1 diabetes patient:

> it does not make sense to give it to someone who does not know how to count carbs. There are rules to follow and if you are not compliant then you don’t need the monitor anyway. Of course it is very appealing because it is advertised in a certain way, but you need to know how to use it, it is the doctor who needs to understand whether or not you will use it properly. For now there are very few of the devices distributed by the AUSL, but we want more people to have access to the devices in future. We are convinced that diabetes costs are decreasing, because when you monitor diabetes better than complications also decrease. In a few years we will see that hospitalization due to hypos is reduced because of this technology being used. (Anita, T1, patient organization in Bologna)

The fact that patients have duties is reiterated multiple times by Vita and Dr. Anni. I wonder, however, what kind of work Vita has done to be recognized by these health service officials, and if it is the same work that she is asking other patients to do: “this is the model on which we will work, according to the resources of voluntary organizations. Patients organizations need to have certain qualifications to work and give back to the territory”.

BECOMING EXPERT CITIZEN: KNOWLEDGE IN PRACTICE

Vita lives in the province of Ferrara. She does not have diabetes herself but first came into contact with the condition when two of her three children were diagnosed with T1 diabetes. The first to receive the diagnosis was 13 years old, the second, a few months later, was 2 years old; this was in 1999. Vita had no familiarity with diabetes at the time and she had to study and learn in the effort to understand everything. She says it took quite a while to understand what her children needed, not just to survive but also to improve their quality of life. At that point, she says, she understood that there was also a social problem that needed tackling: in schools, with services, and with other families that have children with diabetes. She thus went from being active in her province to also being active with other organizations in the region as a whole. Her main objectives were to improve the daily life of her children, so she engaged with schools, hospitals, care services and other families. She did have some skills that turned out to be useful, however. Vita has always been involved in the voluntary sector; in particular, she was part of a network of foster families. As part of that network she learned the importance of working within groups to compare and discuss experiences and build supporting relationships. It was also as part of that experience that she developed the skills to create and manage groups as a facilitator and counsellor. And she did the same with groups of parents whose children have diabetes, participating in and starting several groups. According to Vita, the knowledge that is *generated* within groups is not comparable to any other form of knowledge; it is not the same knowledge that someone can glean from therapeutic education in health care spaces, but the two forms do need to co-exist:

> I knew that mutual support is the most important tool, I knew how important counselling and communication techniques are. It is fundamental, otherwise you can't make it. There is a series of information that circulates only among people with the same condition, professionals only share clinical information, they have no clue about the strategies that people adopt to survive. Professionals only tell you something more if they have time, which never happens. (…) it was not easy to create groups, to make people understand that this is important, it takes time. I remember that, at my first group, we were asked to make a drawing about diabetes in our life. Mine was positive, it was a hand-cart full of soil to make a garden. Another person had a pressure cooker. I realized that people could have different feelings, this one was about something about to explode. My positive approach was useful not just for my family but also for others, but sometimes it was not. A woman once told me that my being sure of myself was making her feel insecure. She said, I will never be like you. I learned that, before expressing too positive of feelings, you need to bring people around to positive thinking, otherwise they are overwhelmed. So I received training as a facilitator and I started other groups. (…) I always tell the story of a father who I met in a group, he is now a friend of mine. He spent two years coming to the group, never saying a word. The day he started to talk, he never quit, he was talking non-stop like a river. But this process took two years.

However, in Vita's view the knowledge that is generated through support groups cannot act alone; it also needs biomedical knowledge and, in particular, medical care practices. She has different stories of care practices in the clinic shared with doctors, kids and their families, and one example is their work at the day-hospital. It is important for her as the representative of a patient organization to be there at the hospital and share care practices with professionals and other families:

> Doctors don't know a lot of things: things to do with families, sacrifices, these are all elements they never mention. We also had this role in the patient organization, for instance I was intercepting some things and other people they were intercepting other things, so then we did things like the day hospital with families because I felt I needed to catch, to support the families. But it is impossible to do this if you don't have the support and the complicity of the

> professionals. They do not feed these practices, but it would be very helpful [if they did]. Organizations that are strong are that way because they give this support, without interference.

For many years after the diagnosis of her children, she provided volunteer support at the hospital because she wanted to know more, and she was convinced that the hospital was the place that could teach her the most. She regularly brought her youngest child with her until he turned six, and she realized that she was creating relationships with everyone, with families and professionals alike; her son became a sort of mascot. It was at that moment that someone told her that they had done all that they could in the local area, and it was time for her go to the region.

Despite Vita's uplifting story, I understood it was not easy for her in that this work involved a great deal of emotional labour. When I asked about the process of Feder's gaining recognition from the region as a significant actor, she explained that Feder first had to show that it was independent and autonomous. The next step was bringing together 15 organizations from all over ER, a step which required 3 years of work. However, it was Feder's capacity to gather data themselves and present these data in a meaningful way that finally garnered the organization the status of a significant actor. This step occurred when Feder entered the HTA regarding Flash[61]. The organization members personally collected and presented data about patients' experiences with Flash. "It was back then", says Vita, "that they started to see us in a different way". Over the course of a few years, Vita built a network of organizations and has been holding them together and maintaining their collaborative relations while moulding their knowledge into the shapes requested by health system institutions.

She had to deal with a number of conflicts with institutions and professionals because "every institution wants to work with citizens nowadays", so "sometimes they ask you to take on a consultant role and then you have to say no: either I am part of this process since the beginning or nothing. You need to step on their feet continuously". Vita says that she had to learn to mediate and discuss without generating conflicts. She had to navigate tensions with professionals as well. As she explains, it is common for doctors to want to use patient organizations for their own purposes, but at the beginning people "do not smell it [this instrumental use]". So, when working with medical and scientific professionals, patients need to learn to avoid manipulation and conflicts.

> Sometimes they want something from you, they want to use you, so they give you their agenda. I have been very lucky because I came from volunteering where the recurrent state of mind is not about asking for something in exchange. I did not leave space for that and when they actually asked me I was able to say no. When you are vulnerable, you depend on them and it is easy for them to use you for their purposes. That is the problem. She [indicating Anita] was in

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[61] Health Technology Assessment is a tool for decision making in health care based on multidisciplinarity and the involvement of different actors as its constitutive elements. Its scope is to evaluate the properties, effects and/or impacts of health technologies and interventions. In this case, ER involved Feder in assessing of Flash (Flash CGM), and this device was made available throughout ER but with specific criteria patients have to meet in order to access it.

> an organization that was used by a doctor and, the minute she did not agree with him, he kicked her out.

The expert citizen (patient) is not just an expert patient, says Vita, because anyone will become an expert in the effort to survive. What makes a competent citizen is not only the fact of being expert in chronic illness management, but also knowing how to "move in" or "navigate" society, ("sapersi muovere nella società" in Italian) in defending the claims of the people you represent. This distinction lies in not only understanding your illness but having knowledge about chronicity as a whole and knowing also how to present such knowledge to a broader scientific community:

> I am working towards unifying all the organizations in Italy. We need to work on chronicity, not for diabetes but with a larger perspective because we are all potential chronic patients. The class we organized was not about diabetes. It is hard to study the rules, but you need to proceed down various career paths, you cannot learn only for yourself. The practical class will not be mandatory; it is on counselling because the goal was to provide this competence, to get knowledge about how it works at the regional level, where to find data and how to use them.

Vita talks openly about the difficulties of being an expert citizen, of being involved in the highest level of the organization with enormous responsibilities. As this account has shown, at various moments she has had issues with professionals and the region and, in order to resolve them, she has had to identity strategies for being accountable so as to effectively negotiate and achieve compromise. She also had to develop strategies to communicate with other parents and patients, even at the cost of working on her feeling rules, in order to successfully act as a facilitator and a resource for others. In the next fragment she talks about her experience of failure, the tension between wanting to solve problems and accepting the fact that there are some things you cannot solve:

> I need to find solutions, to solve problems, the responsibility of this keeps you from sleeping at night. It is also hard physically, you start to somatize. And even if there are good results, there is always someone who is difficult to deal with; it is tiring when you can't understand why you are not able to find a way to communicate with a person. Since you can't force people to care for themselves ("curarsi" in Italian), you cannot force them to love themselves, and so you need to accept that you have failed. I had a burn-out when I was facilitating a group that, I realized, was depending on me too much; if I didn't go, nobody went. So, I decided to close down the group because it cannot weigh on the shoulders of only one person.

Vita's experience as an expert citizen resonates in Anita's statements as well. Anita has T1diabetes; she is also an "expert citizen" and, together with Vita, has been involved in the restructuring of the Modena AUSL. She is the president of a patient association in Bologna which is also included in Feder. Vita has supported Anita in dealing with the conflicts that arose in the organization of which Anita was a part. They are also both worried about what will happen in the future, when they both "retire" from the organizations. Anita has always been very good in managing diabetes; she has a very successful career and engaged in professional-level competitive sports for most of her life. After retiring, she wanted to be more involved with volunteering and so, at the suggestion of her diabetologist, decided to join a patient association. After some time, however, she realized something was wrong. Since Bologna hosts two diabetes clinics located in two separate hospitals, she advocated for the idea of carrying out activities in both of the hospitals, for all the patients. This idea was not embraced by other members of the organization, however, especially (as she eventually realized) because a doctor was manipulating the organization to achieve his own goals. She told me how, at a certain point, she realized that the organization was aimed at serving not patients but professionals, reflecting the goals of the doctor who had the control over it. Vita reassured Anita that she was doing the right thing, that she could keep trying to unify the diabetes care in both clinics to the benefit of all patients and that it was important to maintain a presence inside the clinics as well. And yet after some time Anita was asked to leave the organization. Despite her sense of frustration, Vita managed to convince Anita to start another patient organization in 2016 specifically for and composed of T1 patients, an organization that could continue the work Anita had already begun. The patient organization that Anita founded now maintains a physical presence in both the diabetes clinics and, of course, takes part in Feder. The old organization was never part of Feder, and Vita explains that she had numerous conflicts with this particular doctor who sought to speak for patients on multiple occasions. Anita was not wholly convinced about this project at the beginning, however. She knew that the work waiting for her would not be easy, but she had the support of other Type 1 diabetes patients, and they expressed enthusiasm. By the time we spoke, however, four of them had already left:

> All were type 1 and all said that they would help me. Now, four of them are already gone. I didn't want an office far away from the hospital (…) there need to be at least two of us and we need to be where the patients are. In the other hospital there were two people, but one was coming from outside Bologna and so now she left because she needed to travel every day. Now I am both here and there. I can do that for a while, but I need help. I can't abandon it and so I am trying to make it work and looking for someone who can stay here as well. To be present is the biggest part of the work (…) what we miss here is a doctor who suggests to patients that they become a member of the organization. On one hand, because there are two organizations, doctors feel uncomfortable. But it is important, because if the doctors suggest that, then the patient will sign up and join. Now we are starting with Conversation Maps but we still don't know if nurses here are going to do them as well. And also, we don't know where. You need to have a space available to do that! Here, there are no suitable spaces. It is wonderful to do voluntary work, but people need to be willing to do it and carve out some space for it. I do it, but I am alone. The woman you met before works hard but she just told me that she can't do

> more than this because she wants her life back. Not everyone can do this. It is difficult to find people like me who spend so much energy on that. If you work during the day then you have no time, and you also need strength. People join and after a while they don't see so much change and so then they leave (…) I will stay probably for three more years, till the end of my mandate, then I will leave, I will be 70 and so, that's enough. I would like to find someone to replace me but it seems difficult. For now, we try to achieve easy goals; we'll see about the bigger ones.

In this fragment Anita very vividly describes the difficulties of being there, of being an expert citizen who has done lot of work by themselves and with others, but who does not know whether someone else will step up to take her place. The work of people in patient organizations is very intense, both physically and emotionally, and often not well supported in practice.

FINDINGS

The competent citizen model promoted by health care institutions, both regional entities and AUSL, is a "citizenship model" that operates in multiple ways: on one hand, it renders patients the bearers of rights and duties; on the other, it works to create ideal types of patients. Patients are supported not only by virtue of their being ill, but by virtue of their being citizens while, at the same time, certain citizenship characteristics are cultivated and endorsed. Even though patients may not yet possess them, these characteristics are presented as desirable or even natural traits that citizens possess. If the ideal is for patients to be recognized as citizens, the goal should be to instil these properties in them (Ootes 2012; Tonkens, Grootegoed, and Duyvendak 2013; Newman and Tonkens 2011). For the latter model, Feder seems to play an important role in cultivating the ideal competent citizen (patient) among other patient organizations. This call for citizenship might be seen as empowering as well as problematic. In processes such as these, citizenship runs the risk of becoming a means of exercising governance, by defining who has the right to provide and receive care (Pratesi 2013). Within the framework of citizenship, it becomes important to question who holds power in caring relationships, what counts as care and how, according to this framework, care should be administered. In a framework based on citizenship, who is included and who is not? Care has to do with moral visions of the world; it speaks to how we care for each other and how we would like to care. Care is entangled with politics in that, while caring for certain things and lives it also excludes others (Martin, Myers, and Viseu 2015).

Another consideration is prompted by patient organization themselves. I agree with Moreira's (2014) point that some organizations have extended their repertoire of knowledge-related activities to collaborate increasingly often across lines of expertise. Neither biomedicine or "experience", disease or illness, hold a central role here. Instead, Feder activates a process of hybridization of epistemic identities. By articulating the shaping of experiential knowledge through credentialed knowledge, Moreira argues, these organizations become part of networks of established expertise. Feder, in this case, has transformed its epistemic identity by mobilizing, extending and deepening collaborative links with clinicians, researchers and policy makers, thereby gaining the status of knowledge producer and mobilizer instead of expressing solely experiential knowledge. Some characteristics of Feder are also in line with “Evidence-based activism”, a concept which is useful for understanding how activism modes that focus on knowledge production and knowledge mobilisation in the governance of health issues have developed over time (Rabeharisoa, Moreira, and Akrich 2014). Feder’s aims, in our case, include redistributing competencies and prerogatives among patients and credentialed experts. This redistribution forms part of a process in which certain patients have become “lay experts” (Epstein 1995), the legitimate interlocutors of specialists, while other patients have collected, formalized and distributed their personal experiences as a legitimate body of knowledge. The two-fold role played by patient organisations, as both “lay experts” and “experts of experience”, has led to new forms of cooperation between patients and specialists in the production, discussion and dissemination of knowledge.

In terms of knowledge, this case challenges the dichotomy between illness and disease in uniting the spectrum of knowledge. Patient organizations, such as Feder, connect these bodies of knowledge under the common framework of citizenship, translating experiential knowledge into the language of science and biomedicine and the other way around. It is not a translation solely in the direction of biomedicine and EBM, because, through the process, patient organisations adapt the information to their own claims, for instance by opting to use “experience” instead of “preference”. They produce knowledge to address care medical practices and organizational structures that makes their situations perceptible not only to medical experts but also to themselves. They develop a micro-politics of knowledge that makes information accessible to a wider community to use in navigating health care services and institutions. They produce guidelines identifying the best possible practices through the constant effort of amassing evidence. It is precisely this evidence, in the form of data collection, analysis and presentation, that has grated Feder the position of recognized interlocutor in the institutional and medical setting. In some situations, such as the restructuring of diabetes services and the HTA for Flash, this position was maintained through practices and mutual relational labour enacted within the citizenship model. A fundamental area for further investigation is to understand in more depth when and where this position is recognized and when and where it is not, and through what practices.

The example of Feder provides an effective depiction of the issue of patient involvement in health care in the context of a generative/community welfare model which, on paper, presents itself in opposition to the neoliberal model of choice. This case involves a convergence, or an attempt at convergence, of work between health care institutions, professionals and patient organizations, all under the umbrella of citizenship. It also entails the convergence of a techno-clinical rationality (of EBM, programs and guidelines), a techno-management rationality, and patients’ knowledge. Such a convergence brings with it tensions and conflicts, on one hand, (Barnes 1999; Vicarelli 2012) as well as new practices and knowledge, on the other.

If knowledge in health care, and the collective negotiation of what counts as such, has become central to the governance of health care services, programs and systems, it is of paramount importance that we examine the multiplicity of work and knowledge that these organizations are mobilising through their involvement in technoscience. Such labour and knowledge forms include biomedical knowledge, health technology assessment, public health research or forms of judicial expertise, but also much more. From the data, I have identified the ideal skills and codes of behaviour comprising the ideal type of citizen and other relational skills that competent citizens are expected to acquire and learn, skills and codes that constitute hybrid knowledge and practices. These include: be informed, responsible, compliant, assertive, exercise your rights and duties, collect strategies for survival, attend medical practices, be capable of orienting yourself, navigating and asking for help and support, build networks, help professionals develop solutions, engage in facilitation, mediation, communication (also with scientific communities), present results and claims, conduct research design and data analysis, and also be respectful of other people's feelings and timeframes. The section above shows just how burdensome and tiring it can be to bear these responsibilities, skills and work. Furthermore, "competent citizens" are not easy to find or replace and this fact constitutes an additional weight expert citizen feel rests on their shoulders, a burden which can be emotionally difficult to manage.

Competent citizens are patients first of all; as such they also have to struggle with chronic illness work and care work which, embedded in practices, they had translated and transformed into different forms of knowledge. To be able to sit at the same table with clinicians and scientist, they had to translate this knowledge into scientific and biomedical language as well. This knowledge can still be seen through daily care practices, however. In the next chapter I focus on the care work of people with diabetes, at the intersection of medical, family and gender practices.

CHAPTER 7 – CARE PRACTICES

As we have seen in previous chapters, at the discursive level of international organizations such WHO, diabetes has become linked to concepts of epidemics, risk and certain newly emerging diseases such obesity and metabolic disorder. There has been increasing pressure to treat diabetes with the framework of prevention medicine and EBM. In this chapter we shift to the level of practices by looking at certain relational, material practices that are fundamental for diabetes care: prevention and care are grounded in nutrition, physical activity and therapy (treatment). These practices are of paramount importance for diabetes care. Since survival depends on food and medical treatments, diabetes can also improve with physical activity and can be partially caused by a lack of it. Any new diabetes patient will be confronted with a regimen of diet, physical activity and therapy.

Nutrition, exercise and therapy are not individual, easy-to-control activities; rather, they are care practices with both social and material dimensions, the outcome of the configuration of heterogeneous elements in which assemblages of affects endlessly *do* care. They are deeply intertwined with family, gender, clinical and care practices, but they also do-undo and shape-reshape gender, relatedness and care according to the use, and affect, of material and discursive relations or "material semiotics" in Haraway's phrasing (1991). Care practices are social and material relationships in action: they are gender and family relations interacting with medical practices as well as material and technological actors such as devices, app, diets, diaries, shoes and so on. As care practices, they contain the same tensions previously explored in the literature on care. Specifically, they hold multiple dimensions of power which can, in turn, develop into regulation and control. They also entail a selective mode of attention which can, in turn, exclude or invisibilize others in that care is "ambivalent, contextual, and relational" (Martin, Myers, and Viseu 2015). And, because of these tensions, pleasure or constraint are not easy to detect.

Through care practices such as nutrition, exercise and therapy, the categories of illness and disease can be brought together. Care practices, as socio-material practices, allow us to focus on a sociology of diabetes disease (Timmermans and Hass 2008) in order to examine, for instance, how diagnostic categories, a specific program of relational object, facilitate particular labours and perform actions and situated tasks. Care practices allow us to follow trajectories that are clinical, social, therapeutic, political and organizational at the same time. As we will see, the tensions that emerge in relation to care in situated practices shed light on the norms embedded in healthcare programs as well as hierarchies of care within the family and collective care, contributing to revealing the hidden work of diabetes care and its consequences.

WHAT HAPPENS WHEN WE LOOK AT DIABETES THROUGH CARE PRACTICES AND CARE WORK

BAD PATIENTS IN THE WAITING ROOM

When I entered the waiting room of the diabetology unit for the first time, I found several people waiting and chatting with each other. Most of them, probably patients, had difficulty walking and were sitting together with younger care givers; I later understood these younger companions were usually their children, daughters in law, nephews or nieces. My task was to deliver a questionnaire commissioned by Feder, the regional umbrella organization for people with diabetes, that was simultaneously being given to other patients in several diabetes clinics around the region. The aim of the questionnaire was to create a large-scale portrait of patients' perceptions of retinopathy[62], one of the most common and disabling complications of diabetes. The questionnaire was a fundamental doorway into my fieldwork on care practices, the object of this chapter. Practices of eating, walking and medical therapy are areas that all diabetics patients must tackle in order to deal with their diabetes and avoid complications. Later that year, I had also the opportunity to meet the people I had interviewed using the questionnaire once again, as part of subsequent activities by the association or later on, in the unit.

One of the questions was particularly interesting: a generic "what do you to deal with diabetes", which enabled several possible answers including eating and diet, physical activity and walking practices, and therapy. Most of the answers I received began with the confession that the interviewee was "not good", that is, too greedy or gluttonous; of course they described being careful with sugar – except when they were not – and they admitted that their eating habits were not always as they should be. What did those answers mean? I was wondering if it was a translation of being not compliant, of not following the diet that the nutritionist prescribed to them. Or was it a consequence of the sigma that frames people with diabetes as people who cannot resist food? Or were their answers emphasizing the fact that it was hard for them to follow the rule of their diets? What was behind these answers? Could it be that medical practices are out of synch with other care practices in daily life?

ENTERING CARE PRACTICES

At 2:30 pm the diabetology waiting room is empty but the staff is still working in the rooms. The nurse, Eva, starts to prepare the table: today there is a Conversation Maps™ activity[63] about food. She prepares the table

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[62] Diabetic retinopathy is composed of a characteristic group of lesions found in the retina of individuals having had diabetes mellitus for several years. Diabetic retinopathy is considered to be the result of vascular changes in the retinal circulation. In the early stages vascular occlusion and dilations occur. It progresses into a proliferative retinopathy with the growth of new blood vessels. Macular oedema (the thickening of the central part of the retina) can significantly decrease visual acuity. Medical interventions can decrease some of the risk to vision caused by diabetic retinopathy. The control of glycemia decreases the risk of the incidence and the progression of the retinopathy. If sight-threatening retinopathy is present, timely laser photocoagulation of the retina decreases the risk of a subsequent severe visual lesion. In diabetic patients, regular examination of the fundus is essential, followed by appropriate laser treatment if required. (WHO https://www.who.int/blindness/causes/priority/en/index5.html)

[63] Based on ample evidence that group diabetes education is more efficacious than individual as well as the fact that diabetes is a complex chronic disease demanding the active involvement of patients in its management, a program has been developed to pomote diabetes self-management that educates and empowers the patient. This is known as the "Diabetes Conversation Map program" consisting of conversation maps (CM), a tool

and puts a large sheet of paper on it, with the chairs arranged around it and a board on which she will write the theme of today's map and the names of the people participating in the activity. She has selected the people herself, usually because they have been diagnosed with diabetes recently or because they want to refresh their knowledge, learn something new or have answers they want to ask.

Eva is a diabetes nurse; she is specialized in diabetes treatment as well as diabetes education. She has worked with diabetes for her whole life and has attended a number of courses during her career to learn to act as a trainer and facilitator of therapeutic education. In the last few years she has led other activities besides the maps; her work was also supervised by the organization's resident psychologist, and she does education with new patients on daily basis. Eva already told me at an earlier moment that they are the only diabetes clinic in the province to do Conversation Maps™ and that have been applying this education technique for ten years. There are only two or three more cases in all of Italy. Eva has been trained to do conversation maps™ and she is the only nurse in the region who has facilitated this activity for so long time. In a few months she is going to talk about this experience at the level of the ER region, presenting the training initiative as part of a course organized by Feder and the ER region.

During the mapping, she is assisted by another person from the organization, one of the "expert patients" either Nora or Marianna. Dante, who used to be in charge of diabetes services for AUSL, is now retired, for a year now has served as president of the organization of people with diabetes. He is particularly interested in food and nutrition, so he often comes to this mapping. Dante is also Eva's husband.

A group of six women and one man slowly take seats around the table. For most of them, this is the first time they have attended a mapping, even though not all of them have been diagnosed recently. Eva says that this group is particularly heterogeneous, and they are all going to participate in three sessions: living with diabetes, how diabetes works, and healthy habits (focused on food and nutrition). This is my first map activity, and I have been given permission to attend as a non-participant observer with the request that I report my observations to them at the end.

When everyone has arrived and is ready, doctor Z comes in to introduce the map, even though she is not going to attend the activity itself. She says that the work they as patients are called on to do involves a change in lifestyle, but that it is necessary and important for everyone, not only those with diabetes. It has to do with preventing other illnesses as well, especially illnesses the probability of which increases with weight gain. It is

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created by Healthy-Interactions in collaboration with the International Diabetes Federation Europe. The program, which is currently being used in 105 countries in 34 different languages, includes two formative steps: (1) healthcare professionals' (HCP) training through continuous education in medicine (CMe) and (2) patients' education by trainers. Diabetes conversation maps comprise a simple and consistent delivery of educational therapy. This program is patient-centered and conversation-based and composes a verbal and visual learning journey. Through the active involvement of the patient, conversation maps facilitate patients' diabetes knowledge by improving their awareness about the disease, health self-management, and treatment adherence. The program consists of four maps: each CM includes images and metaphors reproduced on a card table focusing on a specific topic (living with diabetes, how diabetes works, healthy habits, and starting insulin treatment). The interactive discussion about each map facilitates group education resulting in patient empowerment. Local, certified trainers have also started educational sessions for patients using this new methodology.

important, however, to learn the logic behind eating healthy in order to make choices accordingly. This point is reiterated multiple times during the mapping: there are principles in healthy nutrition that would benefit everyone. There used to be a specific diet for diabetes, but that is not recommended anymore. The presentation emphasizes that we need to learn and understand these principles of nutrition and physical activity because, having moved beyond the initial phase that comes with a diagnosis, we need to choose over quality and quantity in dealing with daily meals. We need to make the best choices in terms of what will happen and what our possibilities are. This is the lifestyle work that is required. If we fail to do this work, the diabetes will silently gain ground and we will develop complications. We need to learn to keep it under control. There is no need to eliminate certain foods or make radical lifestyle changes, but it is necessary to know and understand how small changes can make the difference in the long term.

Everyone says their names and their objective for the day in the form of a question while Eva writes everything on the board. The initial questions were about weight, the challenge of losing weight and experiencing the new diet as not about giving things up. The language the patients use from the beginning is a language of care. They are interested in learning how they can deal with a new diet when they are sharing food with other family members, how to manage eating breakfast when they do not have any appetite in the morning (breakfast is recommended in the diet), how to deal with the stress of going out for dinner, and how to ensure meals taste good even while using less fat and salt. Besides being an expert in her field, Eva also knows all the stories of the patients, their diabetes status, and, often, their contexts and family situations. While Eva facilitates, Dante plays the role of teacher. The language he is using is that of biomedicine, and from time to time this biomedical terminology is mediated by Eva’s language. There are calories, nutritional facts, chemical elements, different types of fat, and different types of sugar. When the focus shifts to physical activity, they talk about kilometres, steps, apps, and body mass index. At the end of the mapping, participants will be asked if they feel their questioned were answered, or if they have more questions. The answers that circulate are mixing languages, with biomedical language combined with the language of suggestions among people who share the same problem, the same issues.

At the end of the session, Eva tells everyone they are welcome to attend the other events by the organization which are listed on the Facebook page, and encourages them to come to the support group. When everyone has left, Eva says that the woman who had been sitting next to her, Gianna, publicly “came out” as a diabetic only one month ago. She had never told anyone before, even though she has had diabetes for a long time and both her parents had diabetes. For Eva, Gianna has taken a big step: not only by beginning to talk about it, but also by asking to join the Map, becoming more informed and more willing to share concerns and doubts. During the mapping activity she listened to other people’s experiences without speaking. Another woman, instead, was particularly talkative, describing in detail how she finds it hard to deal with diet and exercise on a daily basis. She said the work is “hard” multiple times. For her, diabetes came as the last of a series of pathologies that she now suddenly has to combine together. Moreover, her family is not supportive. Her husband, she told the group, keeps asking for fatty and fried food. She does not want to eat this food, but she still needs to prepare it. She therefore struggles to stick to the diet, cooking twice as much as before, and to not eat what she has just prepared for others. When she complains about these issues with her family, she says, everyone tells her to be quiet. When she talks about them in the map session, she explains that she has not been successful in losing weight and talks about her suffering multiple illnesses, as well as the fact that she is frustrated at not feeling well… maybe, she says, she suffers from depression. She becomes emotional and appears to cry. There is not a lot of time to take care of her suffering during the mapping, however. Eva briefly reassures her that she needs to take small steps, that rapid changes are impossible, and we go on with the scheduled activities.

At the end of the mapping Eva says that the woman has an issue with herself: she cannot accept that she is ill; she is angry and looking for excuses. Eva has learnt that it takes time to deal with this process, that it involves multiple phases and some people find it very difficult. However, I was intrigued by an issue that the woman posed: the fact that it is so hard for her to combine, manage, resist, to find a space to complain, a space in which to say that she is angry because she has diabetes. This was an issue of care – she was talking about care work.

ONSET STORIES ARE STORIES OF CARE

The support group takes place twice a month, in the evenings, in a meeting room at the CDS. The first time I joined the support group I did not know most of the people who I would later interview and encounter several times during organization events. I promised that day that I was not going to record their conversations or write about them specifically, and I have not. However, I did feel the need to share with some of them, several times, that that meeting has had an enormous impact on the research and myself because, even if they never mentioned the word “diabetes”, every time they met and all the time they were together they talked about *care*.

Despite that initial understanding, I had to collect all the interviews together to see clearly how much care weighs on people’s health and illness stories; how onset stories, and stories of relapses, were interwoven with stories of loss, illness, and the deaths of significant others. What the respondents recounted was not the incidental merging events. Most of the time, instead, they expressed a clear awareness that all of these care events were related and intertwined. Onset and illness stories were woven into a complicated, ever-mutating web of families and relationships. In their stories, the triggering causes of their diabetes were never nutrition and lack of exercise but rather a parent being diagnosed with Alzheimer’s, being the mother of young children, a partner developing cancer, a break-up, the loss of a child, the stress of sudden unemployment. Diabetes is embedded in families’ histories, marking and defining significant events or moments of change. And after the onset, care comes with a series of costs in terms of work that must be done, meals that must be sacrificed in order to feed others, and time spent travelling to reach others instead of using that time for one’s own health. Intense care requires emotional and maintenance work, labour which is added to the chronic illness work that a person with diabetes normally needs carry out for him or herself.

This is not to suggest that emotions have an impact on the onset of diabetes, which is not in question, but rather that trajectories of diabetes are written and shaped by daily care, its (interdependent) relationships, the ethics and examples of good care we pursue in practice. What these stories drawn from my fieldnotes indicate is that care stands behind diabetes care; it holds a fundamental role. When focusing on onset, daily life, emotions, and diabetes experiences are profoundly linked to care, and the trajectories of onset are shaped by the way care circulates in daily life, by care relationships and ethics of care.

Then why does care remain hidden, rarely if ever mentioned in medical practices? Care matters, and it cuts across the boundaries between illness and disease. Is it that the conceptualizations comprising biomedicine and policy do not *see* care and relationships? Is care the missing link between disease and illness stories? By focusing on care practices rather than a collection of illness stories, I propose to place care at the centre of diabetes care, diabetes medical practices and concepts. What do I see when I look at care practices, interdependent caring relationships and situated ethics? If the course of diabetes has to do with lifestyle and exercise as much as with the care burdens and care work that are necessary for survival, instead of looking at care standards it might make more sense to explore possible ways of setting standards of care in the daily practice of caring, in order to enact good care and avoid bad care.

TRACING SELF-CARE AND LIFESTYLE: CONFLICTS IN PRACTICES

CARE PRACTICES IN TENSION

GIOIA

Gioia is unemployed; after leaving work to have children she was not able to find another job. She used to be very busy with them when they were young, but now they are teenagers they spend less time at home and need her less. Her diabetes exploded five years ago. She describes that moment as frustrating, because she did not yet have a job; she was feeling bored and food was the only relief in her daily routine. Food was comforting for her, so she ended up eating more and gaining weight. After the diagnosis, she worked hard to do everything that her therapeutic plan indicated, keeping a diary, exercising self-control, dieting and losing weight. After a few months she returned to the clinic. She had made it. Her diabetes was in balance, she felt relieved and proud of her work.

Because her tests results were good and she had proven capable of doing such great work, she was enrolled in the "gestione integrata" or GI program in which she was monitored by only her GP[64].

After one year she was began having problems with her blood sugar levels once again. She regained the weight she had lost, and she had to start all over again. As we will see, this is a very common issue for new patients. Relapses sometimes occur for no apparent reason; they are uncontainable. Gioia clearly stated in the interview that she needs help. She asks to be checked up on, monitored; she needs to be taken care of by the diabetes clinic instead her GP. She does not feel safe by herself. But why? This is how she describes the daily tensions she is dealing with at home, tensions between self-care and caring for her family:

> They say: "you need to clean up!" I know, but I am not alone at home. Not alone. Today it's a mess but sometimes I feel I want to do something other than taking care of the house, instead I want to comfort myself. (…) My husband lets me do what I want but sometimes, especially when the kids are not here, he says "today you ate too much, be careful". He puts me [back] on track. "I know I make you angry", he always says, because it bothers me when he does that. Because it means admitting and seeing that the others also notice I have crossed the line. It is bringing me back to reality and then I get angry with myself, and to have someone close who does that when it becomes necessary. (…) My son has celiac disease, so I need to cook double, lots of pans and so on. It is a continuous fight… when I make healthy food, for instance chicken breast with vegetables, my husband says okay but after a while he starts complaining: "can't you make something else?". Another one "why can't you make breaded cutlets?", "why don't you make…". And so I need to cook this for them and that for myself, in separate pans because of the celiac disease. Sometimes I get really tired of this and I make only one meal for everyone, which needs to be gluten free. My husband and the other kid don't like gluten-free food either, the taste is not the same and for me it is also not good because they take out the gluten but they compensate with sugar. Yesterday I made breaded cutlets them and grilled meat for myself, but it is not the same… you take out that nice cutlet and I have… "Mum can you make us a cake?" but then they go out and the cake stays in the kitchen. You understand? (…) the fact that I am at home implies that it is me who needs to make food.

Gioia is blaming herself for not being strong enough to resist the food that is at home, for not making food tasty enough for her children and husband, and for not making healthy food for herself. She is trapped in this dilemma between properly tasty and comforting care for her family and care for herself. Even while blaming herself,

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[64] Gestione integrata is a management system that became operative after the institution of the Diabetes National Plan in 2013 and the National Plan on Chronicity on 2016. It is based on interventions by different professionals (diabetes professionals and diabetes clinics), with the GP as the most important of these, playing a gatekeeping role. The patient has an active role in this system. Gestione integrata is a fundamental change that occurred with the reform of primary care, although this reform was not carried out everywhere in the country. Patients who enter gestione integrata are monitored not by the diabetes centre but by their own GP, and it is the GP who is supposed to intervene when needed. For instance, in the case of a relapse, the patient is encouraged to make an appointment at the diabetes clinic in order to revise his or her therapeutic plan.

however, she also recognizes that the she cannot manage to negotiate her son's allergies, her own diet, and the comfort food that they are asking for; it is too much work. For her, sticking to her own diet is just something that can happen once in a while rather than on a daily basis, despite the fact that she recognizes the importance of it, the importance of losing weight in order to care for her diabetes but also feel better.

Gioia does, however, find a compromise with self-care that helps her to spend time outside the home, to feel occupied and supported with a space to express herself and also talk about diabetes. She finds this in two groups. One is the support group of the organization, the other is a theatre group. When I asked Gioia to tell me about her experience with these groups, she repeated several times that they offer reciprocal support and care: "they are family". Regarding the support group, she says that:

> When Eva told me to come to the group after I had the relapse last year, I was like a spectator, later I began to be part of it and feeling engaged always makes me feel guilty, and the others help me a lot. Sometimes they do even if I am the one talking. In other worlds, it is me supporting someone else and I tell myself: look, Gioia is supporting this person and not herself! But I learn from other people's mistakes. I forced myself to join the group, but it was good, it makes me feel good.

As we will see, the organization is providing a space of relational care in which all of these issues and conflicts are explicated and made visible. Self-care cannot exist by itself; it only happens when conflicts around care are solved or made explicit as the result of a change. It happens when a significant other's care needs are not impeding the work required by self-care. In self-care, care presents all the unresolvable tensions of its many facets. Self-care, like taking care of the self, involves an enormous amount of work that must first be carried out. This work must happen at the expense of the care work that is enacted on a daily basis for others.

CARLO

I had the interview with Carlo in a bar that he proposed in Ferrara. He had just recently been to this specific bar with his son, Enzo, and wanted to return there because they offer smoothies and other healthy drinks. For Carlo, menu options like that are a new habit. Carlo defines himself as bad example, a bad patient. He has type 2 diabetes, insulin dependent, which means that he needs insulin injections to survive and is at risk for hypos. He has developed several complications: a diabetic foot, retinopathy causing partial vision loss, and macrovascular disease leading to a stroke. It was when he experienced temporary vision loss that he decided to "change" and adjust his diet, paying attention to insulin and taking care of himself better: "you start to think you really need to change your life". I wondered if that was the lifestyle change that is always called for and mentioned, the first point on patients to do lists.

Carlo is divorced and lives with two of his four children. Recently Lena, one of his daughters, left home. She is still very present in his daily life, however, and she is also part of the diabetics' organization, where she sits on the board and also participates in the support group. When she was living with him, he said, she took care of the meals. That task is on 17-year-old Enzo, the youngest in the family. Enzo began to attend the events held by the organization and, according to Carlo, he was particularly taken by a workshop on food and diabetes. It was at that point that he started to take care of the food shopping and cooking in the house, preparing meals for everyone but especially his father using the principles of a healthy diet. In the interview Carlo said that his son insisted on only going out to certain types of restaurants, types that he normally would have avoided such as vegetarian or vegan cuisine. To his surprise, Carlo reported, the food there is good, and lately he has been eating healthy and well. He told in the interview that he feels better; it is now rare for him to suffer deficiencies, and this is undoubtedly the result of eating better in combination with the use of a continuous glucose monitor that helps him maintain control. He "behaves better" now, he says.

A few months later we were at the campus. Carlo's family was there, as three of his four children came to the campus with him. While Lena is well-known to everyone, the other two are new faces for some people, and Enzo is definitely the youngest person there. There are several activities and workshops being held at the campus and, at the end of each activity, the participants gather together to reflect on what they have done; people give feedback about the activity and talk about how to improve programming and their time together. It is a moment that resembles the support group sessions, when everyone is free to introduce a topic and talk about their feelings and doubts. In the last session, the conversation focuses on the everyday importance of the family for people with diabetes, the way family members serve as support and a shoulder to lean on in dealing with difficult moments. Doctor Z and Eva underline the improvements that Carlo has made recently, pointing out that his attitude towards diabetes has improved enormously thanks in part to his family and that they are an example for everyone. Enzo, who is very shy and had never spoken openly within the group before that point, spoke up to say that it is very hard for him. He described how makes an effort to cook for his father, but Carlo never says anything; he never knows what to do for his father to please him or make him feel better ("non so mai cosa fare per fargli piacere" in Italian). The group takes care of this moment by giving him the space to express these feelings, but also reassuring him that what he is doing is very important, that they are a great example of what a family should do. I was not convinced by this answer, however. I had the feeling that Enzo was aware of the importance of his work, knowing that it is necessary and ensures his father survival. At the same time, however, the suffering and difficulty of talking about these experiences are a result of the fact that the work he is doing is not seen or valued. It is experienced as burdensome and bad instead of pleasurable and good. In other words, it is invisible care work.

Carlo's practices of self-care are made possible by the maintenance work carried out by his children. I found this same phenomenon in multiple stories of men with diabetes who are completely supported in their chronic illness work thanks to the hidden work done by their partners. If Carlo is becoming a "compliant" patient, a patient who practices self-care and a changed lifestyle, this transformation is thanks in part to the fact that other people have been able to do the maintenance work necessary to allow him to make this change, to teach him that self-care can be pleasurable and tasty. For Enzo, however, doing such work for his father has meant a huge change in daily practices. His father and his sisters commented that this is unusual; he is not engaged in the kinds of activities that other kids his age are busy doing. Their work is instead the maintenance of a child-father relationship hanging in a constant balance between chronic illness work, care and identities. Such work is also embedded in their family history, as Carlo is the only adult who takes care of the children. In the eyes of the organization and professionals Carlo's family is a good example, but at what cost for the people who actually do the hidden work necessary for survival? It struck me to wonder if this is a cost that must be paid in order to become a compliant patient, a cost that drags the whole family into this sense of urgency to become "compliant" as well. Manual, the psychotherapist who facilitates the support group, has said multiple times that when an individual is diagnosed with diabetes, the whole family receives the diagnosis as well. While he meant that the whole family gains awareness and needs to understand what diabetes is and how to deal with it, I found myself thinking about the broader "chronification" of society. Everyone has a chronic illness, either because that person already has one or more diagnoses, or because, under the EBM paradigm, he or she has a high probability of becoming a chronic patient in the near future and must therefore act in the present to avoid this development.

FRANK

Frank was diagnosed with type 2 diabetes when he was 27, and he has just now turned 40. After the diagnosis, he found out that diabetes was actually quite prominent in his family history: all of his family members had diabetes, but he had not been told about this history. His father died following a car accident because of complications caused by untreated diabetes. For Frank, this revelation was enough to motivate him to take a radical step and completely change his lifestyle. He started following a rigid diet and eliminated a lot of the ingredients that had been a part of his daily meals. He no longer consumed even a drop of alcohol. He describes everyone around him completely understanding what they needed to do to support him, particular in relation to food. Everyone prepared food in keeping with this diet, meals that did not put him in the position of feeling uncomfortable. Even at restaurants, it was usually friends and colleagues who interacted with the staff when it came time to order so as to prevent him from having to explain all the time that he has diabetes. His wife, his sister, his friends and colleagues were all supportive and helpful, according to Frank's account. He never had a single issue with any of them. He says that his friends are "pillars and temptations", and that they have been careful to not act as too much of the latter. The only exception is his mother. Frank becomes very angry every time he sees that she has not read the diet table he gave her, listing forbidden foods in alphabetical order. He becomes upset when she makes meals for him and demonstrates that she is not paying attention to the list. They have constant arguments and tension. He says that he knows he should not act this way with her, but “I can’t help, I can’t hold back. She makes me angry – when I see that I am not being supported I get angry”.

Frank experiences this feeling of not being seen or supported as an injustice. In a context in which he is well supported by almost everyone around him, where friends call his wife before a dinner to ask what he can eat or not and his wife goes shopping with him, someone who does not pay attention to this aspect is guilty of not being sensitive or supportive. This is not the case with Gioia; she does not think in terms of injustice. Her role as mother and wife in her family demands that she make certain types of food for the family, that she prepares different dishes every day that are tasty and appealing to everyone. If she cannot keep it up, it is her fault.

What these stories reveal is that the successful story of the adherent and compliant patient who has made a lifestyle change is embedded in the relational environment of people with diabetes. Moving far beyond the “family that supports” narrative, the stories of Carlo and Frank show that the support of family and friends in social and daily-life eating practices is a much larger sphere. These friends and family members do care work to take care of diabetes patients. They resolve possible tensions before they can even emerge, they do *maintenance* work, they make survival possible. These fragments show the complexities characterising the intersection of care, gender and family practices. Food, a key pillar of diabetes care, is not actually only food; it is embedded in family practices of cooking, sharing, and being together. Food is also an affective practice and involves relational care work such as the maintenance of relationships and expressions of affection. It stands for identities and affective ties. It defines what it is *good* care as opposed to bad care.

The intersections of gender, illness and class have a cumulative effect in producing care, emotion and chronic illness work. The tension is particularly severe for people with diabetes such as Gioia, who do chronic illness work for themselves by themselves because they do not receive support from the people with whom they share food. The fact that Gioia has the role of care-giver in her family means that she is not able to make any changes without causing a violent rapture that would affect her identity and role and indeed the identity of her whole family. Because care-giving keeps family, kin and relatedness bonds safe, a change in caring practices puts these bonds in danger. Her chronic illness work and her relational care work are unable to find points of converge; at best, there are only occasional compromises. The other two examples instead show what happens when chronic illness work is carried out by someone else in the family, such as with Carlo, or shared, as in the case of Frank. In Carlo’s case, the fact that work is done by another family member allows him to improve his health and feel better, but at the cost of increasing the burden of work that falls to Enzo. Just as in Gioia’s case, this work is invisible and Enzo finds it hard to talk about it, to find a space to share his feelings. Frank’s health has also improved because the work is shared among family, friends, kin, and significant others. Frank is wrapped in a safety net, and the tension only emerges when there is a gap in this net of sharing. Frank views this gap as an injustice. The interdependency of care implies that lifestyle maintenance and self-care for people with diabetes depends on the maintenance of care and chronic illness work done by a vast web of people. The more this work is shared among many people rather than falling entirely on the person with diabetes, the more the person will be able to navigate tensions. It is therefore important to consider the position of the person with diabetes within their relationship web, and in particular what type of relational maintenance work they do in everyday life.

Intersecting practices are particularly difficult for the working-class women I interviewed. It is not by chance that most of the conflicts I found in the interviews were expressed by women who were required to deal with their diabetes in daily life while at the same time taking care of others, doing the maintenance work of care. This finding suggests that biomedical hierarchies of care devalue the chronic illness work of women, and more generally the person or people who carry out maintenance relational work, the most. Zivkovic et al. (2015) argue that care, through cooking and eating, is entrenched in cultural understandings of women's roles and class, understood as material circumstances of life. They note that public health notions of careful eating actually clash with differing paradigms of care in which gender and class have a paramount role. In the case they explored, they suggest that sweetening, understood for instance as the consumption of sugar-based food, should be understood in its local context, as embedded in the bodies and social lives of those who "sweeten in order to cope and to care when one's place in the world diminishes possibilities for other securities". Care practices of eating therefore have powerful connections with kinship, gender relations and class. In contrast with the mediatic tendency to blame working-class mothers' "poor tastes", unhealthy diet and lifestyle choices, they show that people care through sweetening[65].

This point is particularly pressing when looking at concepts such as lifestyle and self-care. Commercialized by biomedicine as acts of individual choice, these concepts involve a rational way of thinking about behaviours directed towards the self that improve the person's physical and mental health, what Mol would call the "logic of choice". Self-care and lifestyle can be translated into a set of specific tasks and affective investments towards oneself. These stories suggest, however, that such tasks and investments are blind to caring relationships. Directed towards individuals, they fail to consider the conflicts that can be triggered by changing daily practices. Incorporating these concepts, or attempting to do so, inevitably gives rise to ruptures and conflicts which are never visible in clinical practices. We need to recognize these forms of work without blaming either the individual or relatedness as a whole.

As soon as we focus on practices, tensions float to the surface. Tensions say something about what is legitimate care and what is not, about when the conflict can be made visible and when it has to stay hidden, about which rules of caring for the significant other in a family can be broken, and which cannot. On the other hand, these stories suggest that practices are multiple and potentially infinite, driven by practices of good care and the desire to be useful and acknowledged. The feeling of anger and injustice that emerge from Frank's story show that what he considers "good care" is relational care, care work that is shared, with other people in his life also

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[65] See also Fox and Smith 2011; Gillies 2007.

responsible for caring for him. This same point emerges in Gioia’s story as well when she talks about her feeling of “being family” when she is with the theatre group and the patient organization. These are relationships that nurture her and make her feel good:

> When you do something that you like with others with whom you have fun it is almost like a family, and you do it ten times better, you can’t wait to go. Even though I did many things during the day… laundry, going around with the kids, family and stuff… I am tired in the evening, but I need to go out because I have rehearsal. My husband suggests that I stay home because I am tired… never! (…) Our director is [like] a sister to me; every day she calls me to tell me goodnight and good morning, my sister does not do that. (…) we really are a family. If someone has a problem, it becomes everybody’s problem. We need to find a solution but keep our own place. When my father got sick my role in the play was that of a daughter with a dying father. I had to leave that role. The others did everything to support me and someone else took that part, I was behind the scene (…) I told them I have diabetes and that I find it difficult to talk about it, they respect that. (Gioia)

We will see with other interview extracts as well that healthy behaviour, healthy food and practices are not always considered comforting and loving towards the person in question. People are constantly making decisions on the basis of what makes them feel good instead of rationally choosing on the basis of the sugar level of a meal or the risk they may incur in the long run. Ethics of self-care are often negotiated within relationships and involve feeling-based rules that are not easily to merge with the ethics of family and gender practices.

GUILT AND ABANDONMENT

MARINA AND GIANNA

Marina is 42 and has had type 2 diabetes for two years. While she says that she has never been very careful about nutrition and exercise in her life, everything became even worse after she lost her job two years ago. She started to gain weight and went through depression. That is when she received the diagnosis, but she seized on that moment as a change, as a second chance. She started to “work hard” to follow the diet, engaging in physical activity, losing weight and recovering from depression. She was able to do it all and at the next medical check-up and the following appointment at the diabetes clinic her results were good; the doctor told her she could stop using insulin, and she switched to only taking metformin pills. While she was feeling better physically and succeeding in reaching her objectives, she was also feeling better mentally. She felt full of energy. When she reached her goals, however, she was told she could not come to the clinic anymore. Like Gioia she enrolled in GI, and from that moment on she was in the hand of her GP. This is how she describes it:

> I was very sorry because I was left alone too early (…) never supported anymore. My family doctor gave me the prescriptions, but I never went to fill them.

At that point Marina's mother was diagnosed with cancer and ended up dying a few months before we had the interview. Marina took care of her mother a great deal when she went sick, and to do so she had to travel often because Marina is the only one of her family of origin who lives in the area; all of her sisters and her mother live in the south of Italy. When her mother's condition worsened and she died, Marina again began suffering from depression and once again she "lost control" of herself. She explains that she still had the desire to "go back to that lifestyle"; she knew that it made her feel better, but she could not manage it anymore. She told me that she needs the support of someone else:

> I let myself go, neglect myself. For a while now I have found it hard to get out of bed in the morning and get ready, it takes the whole day. I behave wrongly; I find comfort in food when I am stressed, when I am disappointed, I can't find the end of it. Emotions push me towards the wrong things (…) I need to get my health back again, changing my lifestyle as I did before. I want to do that but I can't. I need someone to help me to keep on track. I only have my husband because I am from the south, all my family is there (…) when I came here I changed my lifestyle, before I never ate fruit and vegetables, but after I started to look for it, I learned. (…) I really need support, someone who pushes me. Just the fact that after few months you need to come back here for a check-up makes you keen to not transgress, to maintain certain rules. If nobody is checking up on you, telling you which way to go, you tend to transgress, once, twice, and then you get lost and back to the initial point.

Marina's story and this interview extract describe an experience that is very common among respondents. There is a diagnosis that forces a change in lifestyles, elements that patients used to consider and experience as daily life, as fixed in terms of daily practices of care for themselves and the people around them. After the diagnosis, daily life must be examined, scrutinized, revisited and often dismantled. However, after a first phase in which people try to reach their goals, they often experience life events that make it difficult to manage to maintain what they had previously achieved in the short term. For new patients, this timeframe covers the period from diagnosis until the next check-up at the diabetes clinic. Daily practices have their roots in the period before the diagnosis, however, when life was reproduced without thinking in terms of good and wrong. In the "after the diagnosis" time, people find themselves needing to deal with other issues that had never been problematized previously, issues such as emotions, sadness and loss. The result is a sense of abandonment, the feeling of being left alone.

Gianna is 55 and also has type 2 diabetes. Like Marina, she recently lost her mother. They both had a difficult time dealing with the loss of their mothers and Gianna, like Marina, had to think about her lifestyle and self-care. Gianna has known the diabetology staff for 40 years because both her parents had diabetes as well, but she never told anyone that she had it too. It was only recently that she made the decision to "come out" when, after joining the support group, she started to talk about it openly. Gianna never told anyone because she feels the stigma of having diabetes:

> No one knew about me since I came to the support group. I feel ashamed, even now, I still can't talk about it at work. I find it hard because when people see you are fat they associate fatness with diabetes, they say it is normal. I can't stand this, I listen to what people say "well she is fat she eats everything she can't control herself, she only eats sweet stuff!" (…) I always ignored it, only now am I becoming aware of what it really means to have diabetes and I walk, I try to eat well… but I have some moments in which food is therapy for me. When I walk, I come home and I find myself thinking about eating less. At lunch, we eat at work, everyone brings something, so I eat well… vegetables, rice, pasta or salad. But when I come back home, everything I find… I eat. When I come home from work, I say… let's have a snack… and I start with yogurt, then chips, coca cola, bread. Manuel says we should do something different than usual to keep our mind's busy, but when I switch on the tv I want to eat, I can't manage to not do it, even if I have diabetes. I know it is wrong. I just can't do it.

The stories of Marina and Gianna are particularly relevant because they are alone in doing care work. They are in the position of doing self-directed work that is deep, long-term and has to do with pain and loss. There is no tension stemming from conflicts and negotiations, but rather feelings of isolation, abandonment and loss. The issue at stake here is how to take care of that loss, identifying what work is needed to take care of that. And again, who needs to do it. Abandonment and guilt once again emerge when there is no collectivisation of responsibility.

Their stories show how different relationships and settings make a difference. The care work to be done might be effective for part of the day, at the office, but not effective during the other part of the day, when they are at home. Places are highly significant. A lifestyle change is never linear and the work of pursuing it never ends. As in the stories presented above, in Gianna's story as well it was the patient organization that allowed the patient to discover relational care. Together with the support group, she is working on the feelings of guilt and self-blaming that had previously prevented her as a "stigmatized person" from dealing with diabetes. This is how the reciprocal support of the group contains such widespread stigma:

> I feel like family when I go there, I feel I have no secrets. Finally, I can be myself, talk about what I really have, because, I told you, I could never go and talk with a colleague, despite everything I never talk about it. There, instead, I felt I could talk and describe what I feel about diabetes, how I was feeling, why I could not stay well and stay like that. It gave me the chance to talk, I found it very nice… people who listen to you in silence, never judging you…it is beautiful. My mother-in-law always says that I deserve it, that I need to lose weight and then

> the diabetes will go away. She was 136 kg and had diabetes. She got surgery and now she seems to not have it anymore. She lost fifty kilos and says “why don’t you do that?”

In all of these extracts, the respondents defined themselves as somehow guilty of not being able to resist, which is one of the most long-standing illness metaphors in the case of diabetes. This “victim blaming ideology” (Crawford 1977) resembles the kind of biomedical frames in which an unhealthy diet, being overweight and failing to engage in physical activity constitute the main causes of diabetes; they are cast as people’s bad choices and habits. What we can see here is that biomedical readings that view these patients as non-compliant serve to flatten loss and pain. Instead, loss as care circulates and drives diabetes back and forth in family histories. These passages from Malika’s interview provide a particularly clear illustration of the connection between diabetes, loss, and abandonment when stigma and a victim-blaming ideology are taken out of the picture

> Diabetes entered my life when my mother received a diagnosis of Alzheimer’s (…) my mother also had type 2diabetes, at that time they said it was due to nutrition, which is something that is confusing because it seems that it is your fault, if you don’t eat properly it’s your business. Instead, my diabetes came, I am also overweight, but after a moment of stress, combined with the prolongated stress I have suffered in the last eighteen years, because of my mother’s illness (…). I am the only family member she has, and she is the only one I have. I am the only one who can take care of her (…) when I understood I was alone, it was 2010, high blood pressure came first (…) in my family it was troubles that brought these types of illness (…) high blood pressure came because of emotions. Then it became better when I lost weight and I was reassured by her going to a residence but at the same time I felt lost, I felt the ground [under my feet] was missing and I have gained back forty kilos since then. My attention shifted from me to her (…) and when she moved to the residency, I had a breakdown, I gave up.

The next story instead provides an example of loss that is cured with food, at the cost of diabetes. In this case the tension arises because caring for the loss clashes with diabetes care standards. Arturo opted for the former.

ARTURO

Arturo is dealing with the loss of his son, who died only a few months before we had the interview. Arturo’s wife cooks every evening for many people: Arturo and herself, their son’s partner and two 5-year-old grandchildren. Arturo says in the interview that this is a way of supporting them but also of feeling the loss of their son less sharply. However, it is difficult for him to deal with diet during family dinners as these often include dessert and food that everyone likes. He does not want to put stress on his wife because she is the only person taking care of food in the house, from shopping to cooking and cleaning, and he recognizes that she does a lot of work to make dinner every day. Food goes beyond calories, quantities and sugar intake; it is something that offers warm feelings and quietness after a painful moment in life. He does not blame himself for having chosen comfort over a sugar balance.

> Yesterday I had something high [in sugar]… but what can I do, after my son died the kids have been coming over for dinner. My wife wants to have their company, when the kids are around there is a nice atmosphere, and we eat more than usual. (…) I should not eat the fruit either, I know, but it is satisfying, if I had to eat only things that make me feel sad, I would not like it. Maybe the fruit at dinner gives me some higher glycaemia, but emotionally I feel calm, better.

Focusing on caring practices and on the intersection of practices brings care work and the of doing care to the surface. We have seen through the stories presented here that there are different types of works that need to be carried out, recognized and shared in order to follow the diabetes care tasks that biomedicine and policy-oriented concepts define as lifestyle and self-care. The stories point out that it is important to look at the position of the diabetes patient within significant relationships and to explore the work that the person performs to maintain and sustain these relationships in different spaces. The search for good care, the sense of feeling good, sometimes clashes with diabetes care when there is no room in such case for feelings of loss and suffering. These feelings need to be recognized because they are fundamental drivers of diabetes onset and relapses, constituting links between family histories and diabetes.

In other words, a focus on family practices reveals the way that changes in relationships, for instance an illness or loss, constitutes a disruption with enormous consequences for a person who has or is at risk of developing diabetes. A feeling of abandonment arises in this context because the care work required to deal with the loss is not shared with institutions and significant others. Under the agenda of EMB programs and models reinforced by ideal types of citizen-patient, health institutions might instead set standards that are too high to be realistically achieved by someone who is in a vulnerable position, thereby reinforcing feelings of guilt and abandonment.

While in the first sets of stories it was noted that biomedical concepts are blind to relationships practices and care work that is needed to keep relationships stable, with these last stories I argue that biomedical concepts are blind to feelings of loss and abandonment and the related care work that needs to be done to deal with them. They are also blind to the emotional work associated with care burdens, work that is often closely linked to diabetes in the accounts of my respondents. In this context, by failing to acknowledge such feelings, concepts of self-care reinforce stigmas and the diabetes metaphors. Caring relationships and caring relational practices seem to have an important role in these stories, figuring highly in the search for good relational care that supports, balances and nurtures. It is this is what we are going to ding into in the next section.

FOOD AND EATERS: CARING FOOD AND EATING PRACTICES

Central to both physical survival and social relations, food is laden with meaning while also being a physical object. Food is a wonderful portal for entering into social practices (Harbers, Mol, and Stollmeyer 2002). Food and eating hold the tensions that arise between food as therapy and food as control, food as pleasure and food as poison, food as sociality and food as isolation, food as care and food as obligation. Eating and caring are inherently bound together. Caring is enacted and experienced both around and through eating, sometimes in conflicting ways: while the seeming benevolence of care is deeply embedded in governing processes of normativity, regulation and control, at the same time cultivating pleasure, indulging the senses and enacting practices of good care find unexpected ways of evading such regulation. Food is an arena for creating and evoking joys, anxieties and regrets; as a comfort it can often be discomforting and its associated closeness claustrophobic, what Holtzman has labelled the ethnography of tasty things (Holtzman 2006). Resting on this tension-laden terrain, from the only therapy available to the most sophisticated forms of contemporary diet, the topics of food and eating are central for people with diabetes. In contemporary diabetes care, food is a central focus of therapeutic education and nutritionists are present and involved to a degree comparable with the more obvious figure of the diabetologist. Food is also a central social practice for people who share, buy and prepare food with, or for, people with diabetes.

As Bennett has noted, when the social sciences and humanities take up the question of food, they tend to focus on human acts; they investigate, for example, the sociocultural rituals through which meaningful food objects are produced, the rhetoric of culinary self-expression, or the aesthetic-commercial techniques through which advertisers seek to kindle the desire for a new food product. A relational materialist perspective, however, considers food as an “ontologically real and lived presence”[66]. As Harbers et al argue:

> By showing how food matters, we hope to make a convincing argument about the importance of ethnographies of daily care. Ethnographies that describe care as socio-material practice and that, thereby, transgresses the divide between ethical and biomedical versions of the good. (Harbers, Mol, and Stollmeyer 2002, 208)

In their volume, Abbots et al. ask whether discourses of “good” and “proper” food and eating utilize the concept of care to promote certain ideologies, to govern and regulate individual bodies and the way in which individuals respond to such governance. They question the way care, in the context of food and eating, may quite often be a political mechanism through which the self/the other are (re)produced and social hierarchies constructed. Eating and caring can therefore be further understood not only as performances of reproduction, but also of production: ones that constitute Others and (re)establish relations between those Others and selves (Abbots, Lavis, and Attala 2016).

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[66] See also Goodman, D (2008), “Ontology Matters: The Relational Materiality of Nature and Agro-Food Studies,” 183.

A NEVER-ENDING STRUGGLE

The metaphor of struggle or battle is probably the one most commonly used by people with diabetes when asked to talk about their daily labour of lifestyle maintenance, especially in relation to food. As we saw earlier, for instance in the account by Gioia that references her "continuous battle", struggle involves care work and relational care work, forms of emotional labour that are often invisible but nonetheless entail consequences in terms of diabetes care practices and feelings.

The lifestyle struggle has one main goal, that of maintaining a balance in terms of glucose levels. In other words, to avoid having any blood glucose peaks or troughs, with levels neither too high nor too low. This translates into avoiding slipping into a coma, or the effects of high levels which do not involve a sudden lethal threat but do carry the risk of developing complications in the near or distant future. People who are successfully winning the battle are proud of this fact, because the struggle takes place every day and at every moment. *Lifestyle* can therefore be translated as a list of tasks and work which enables them to reach the specified goal for some period of time; it involves a strategy of defence and attack and the result, winning, is a list of achievements: stable blood tests, a therapeutic plan that will remain the same – or change for the better, for instance lower doses of medicine – enrolling in GI, the idea of being allowed to take breaks from the diet, especially if combined with physical exercise: patients often say "Con il diabete ci convivo"; literally: I live with diabetes. It is not always easy and it does require strength, but it is possible.

CALORIES, DIET AND INSTRUMENTS

The first moment a newly patient hears the word "diet" is in the clinic, after having received his or her diagnosis. The next step is an appointment with the nutritionist, whose consultation room is located next to diabetology. The nutritionist drafts a personalized diet for each patient according to the objectives suggested by that person's specific clinical situation: the main objective may be to balance blood sugar, lose weight, reduce fat intake and so on, or a combination of all the above. Doctor P, the nutritionist, asks questions about the person's family, habits, physical activities, types of work and everyday routine. After collecting this information, she makes a table in which food is expressed in calories. The table is later revised if a patient returns to her because his or her levels are unbalanced, and something has gone wrong. Otherwise, this table will be the rule for the patient to follow.

Diet is an individual system based on the measurements of an established number of calories. Doses and calories can be counted by using instruments such as a scale and nutrition facts labels. Dietary practices, as Mol has noted, turn the kitchen into laboratory, positioning the mind over the body. But how this is done, in practice? Calories are not only calories, as food is not only food. As we have seen, calories are embedded in food that is bought, cooked and (most of the time) shared with other people. Calories collide with care practices; they bring something else into the picture. A new system of eating, driven by calories instead of pleasure, memory and rituals, needs to become daily practice, a routine that challenges not only the person's usual life but also his or her role as well as the family and community practices in which the person is embedded. In medical diabetes practice, diet comes first. It is expected that people will follow this diet and lose weight, if necessary; it is likewise expected that they will give up their "bad habits", gradually change their lifestyle and become compliant with the new system. And yet, as suggested above, diets hardly ever work in the long run. How do people make diets work? How do they solve the conflicts? How does a specific diet work and how do people "work" the diet? Furthermore, a diet system is an important component of the therapeutic plan for a new patient because it grants a framework to the new daily timetable, a schedule which is also filled with other elements. There are pills or insulin that need to be taken at certain times of the day, alongside the main meals. There is a diary to fill out and blood sugar to measure in association with the main meals, the values of which need to be written down on certain days, or at certain times of the day. Everyone has a fixed therapeutic plan that they must follow.

At the first examination after a diagnosis, Doctor Z sorts out the core of the therapeutic plan, but often she does not see the patients directly. Her exams are quite long, usually more than 30 minutes, longer than the usual wait time that patients experience; indeed, it is common to hear other patients complaining in the waiting room. She also gives a list of other medical check-ups that need to be carried out in the following months and ones that will need to be scheduled once per year. These include checks for foot and eye health as well as cardiological screenings. After the visit, the nurses take time to explain everything to the patient in detail, including scheduling an appointment to have a first education session as an introduction to diabetes. This passes particularly quickly for people who need to learn how to inject insulin. There is a lot of translation work to be done by the nurses. In her daily work, Eva tries to condense individual therapeutic plans into a list of tasks that everyone can easily follow. She tells patients that fasting blood glucose should be between 90 and 130, and less than 160 mg/ml two hours after the meal. If it is higher, this means that the next step is to rethink the therapy and diet. The patient will come to the next appointment at the clinic with all this material collected; assuming, of course, that the person has followed the plan.

And a plan means therapy. As discussed above, the therapeutic landscapes of diabetes care vary to a large extent across regions and welfare systems. They are also increasingly complex as compared to a decade ago, but they still are quite homogenous by diabetes types: while type 1 diabetes is treated with insulin injections, type 2 is most commonly treated with oral medications combined with nutrition and exercise. However, insulin might be necessary for type 2 patients as well. They both need to test their blood glucose, at a frequency that is usually indicated in their therapeutic plan. Blood glucose testing is required to monitor hyperglycaemia (high blood glucose which, if untreated, leads to complications) as well as hypoglycaemia (low blood glucose, which can result in coma and death and is a direct consequence of the use of insulin). The treatment might be adjusted by the patient themselves, especially in the case of type 1, or later with the help of the diabetologist (especially in the case of type 2 patients). Because blood glucose testing is of vital importance, diabetic patients need to quickly learn how to do it by themselves, and testing is thus the first topic of education, usually carried out by nurses. Secondly, people with diabetes learn that the amount of energy in the food they absorb should balance be balanced by the amount of energy they expend, while their insulin dose should be adapted to both factors. Type 1 patients also need to quickly learn how to store insulin and syringes safely and how to count carbohydrates in order to calculate correct insulin doses. They must decide whether to use a body device, such as the insulin pump or continuous glucose monitor. The availability of such devices is a direct consequence of access to health care or health insurance, in particular when the cost is only covered by the patients themselves. There are several actors that must be considered in this scenario, especially in terms of their role and use in daily life: different sorts of instruments, calories, the diet, the treatment plan, pills, injections and so on. All these actors must co-exist peacefully in the patient's daily life; in other words, they need to find a balance. This balance requires care.

THE NUTRITIONIST DOES NOT AGREE WITH THAT!

At the Conversation Map session, it is once again time to talk about food and diabetes. Dante asks why we think it is important to have a varied diet, to eat different foods every day. "Because each food has different elements", a woman answers, and continues: "I know that. But what makes me angry is that I have always been very careful with my diet, I was even fanatic about healthy food. I ran races, I train every day with my bike, and then with menopause I had a total collapse… cholesterol, liver steatosis, and the last blow is diabetes. I have always been careful, and nonetheless this… why?". Dante answers that there are factors which are modifiable, such as diet and sport, and others which cannot be changed in that they are part of our genetic package. Lifestyle can contribute to improving health, but other factors cannot be modified. Menopause is a metabolic overturning that must be accompanied by a change in lifestyle; the person's routine cannot remain the same as before. "We are like motors who save a lot of energy, in time we need to consume less and less, despite our taste pushing us to eat". The woman does not ask any more questions and the conversation goes on.

Dante later asks if we think that, with diabetes, eating out at restaurants is forbidden. The same woman answers "no, it is not. But it is very sad when everyone orders a dessert and I can't!". Another woman chimes in: "last time a patient said that when he went out for dinner he was criticized because he did not want to eat something, so he said: be careful you who criticize, because anyone can get diabetes, especially people who eat too much!" The woman did not like the answer "I never ate too much but I have it anyway". Dante again answers that it is not necessary to always say no to dessert. "Only look at what you ate, maybe you can order it if you have only eaten one course before". The woman becomes upset: "then why did the nutritionist say no, no, no to dessert?" Dante then explains that it depends on the situation: "It is a difficult moment when someone enters into this new world, there is the need to bring things back in balance, when you enter the clinic you need to go down, maybe also to lose weight. Then you need to maintain it, but by then you have a lot more elasticity, if you only had a salad for dinner then maybe you can treat yourself to cake". The woman keeps saying: "the nutritionist won't agree with that! She told me not to eat pizza. And in the last 40 years I have always eaten pizza without mozzarella, with only vegetables. Saturday at the pizzeria I only ate grilled vegetables while everyone else was eating pizza! It was such suffering". Dante then shifts the conversation to the difficulties of eating out at restaurants and on how to maintain a balance in terms of calories with the help of physical activity. "I know it is difficult to measure calories, I personally use an app. I use it because then I am aware of what I have eaten during the day. But a solution to pizza", says Dante, "might be to eat only half of it, or to eat a salad first, because with the salad I slow down my digestion and change my glycemic index. Then there are also different types of pizza, whole wheat, with sourdough starter…" The woman interrupts at this point: "so a whole wheat pizza allows me to eat without worries?"

THE EATER (CITIZEN): LEARNING TASTE AND (GOOD) NORMS

Dieting techniques (Mol 2012) and training practices (Vogel and Mol 2014) are important sites to explore in order to understand how different eating and care practices enact disease and health, pleasure, control and norms. In good taste, Mol (2009) is interested in the way the "consumer citizen" normativity is literally incorporated into food packaging[67]. Packaging suggests that it is impossible to combine public good and private pleasure: people must choose between tasty and healthy or tasty and fair. Food packages can be seen as heterotopias: they conceptually teach us something about combining the common good with pleasure by addressing a consumer-citizen with a body that is not torn between natural wildness and civic society; instead, this body is sensitive and well-attuned to its surroundings through tasting. Appreciating good taste requires a body that is able to taste it, Mol argues; tasting does not come naturally but rather improves with training and requires effort. Tasting is mediated in that nature and culture are intertwined in this skill.

The "tasting body" is socially embedded and may learn from others, from what it drinks and eats. In politics and eating, good taste depends on variously shared practices of daily life. This view follows Sutton's insight into the other meaning of "taste", the one that evokes cultivation and learning. Cooking is a process of learning skills as habit memories, pointing to processes of enculturation and enskillment through which taste is learned, mobilized and repeatedly practiced. In fact, states Mol, people with diabetes who regularly measure their blood sugar levels may learn to intro-sense it. The body that is able to sense it, to appreciate it and be pleased, is not singular and isolated. Quite the opposite, it is linked with others and the world. Acquiring good taste depends on food and drink that taste good, that have been prepared and cooked in ways that taste, smell and look good. However, as Vogel and Mol have shown in the case of education, there is a very thin line between liberating the pleasures of

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[67] According to Mol, eating "healthy foods" does not figure as a potential source of pleasure in public health campaigns, but rather as civic duty. The concern is with the health of the population. With fair trade food, it is not public health on the agenda but global inequalities. A novel figure is created: a consumer citizen who remains all in one piece, with deliciousness and fair trade concerns going together.

the body and imposing yet more obligations on the caring self (Vogel and Mol 2014). This is particularly evident when eating and food preferences are positioned as integral to a seemingly virtuous self-care that enacts "good' citizenship" through responsibilized caring for both the individual and social body (Abbots, Lavis, and Attala 2016). Since with diabetes the overriding concern is with obesity, new patients are exhorted to lose body weight; through such discourses, the body emerges as central to the enactment of neoliberal citizenship. Eating becomes tangled up with neoliberal notions of individual responsibility and continuous self-improvement with the feeding of others, especially children; indeed, this latter is also an act that must be performed within disciplined parameters (Zivkovic et al. 2010; Truninger and Teixeira 2015).

Diet systems are not fun; they are painful, but in reality, it is the diet system as a whole that patients find untrustworthy. In the interviews, respondents continuously challenged the whole diet system, asserting that they do not believe in a standardized system that gives the everyone same instructions. Donatello defines diets as "un-useless" because they use a standardized system, which in his case resulted in advising him to eat more than he already did and was comfortable with. According to Dante, the more we eat different things and especially things we like, the better. Rose also criticized the diet she had just received because the standardized calories and portions would have her eating fewer vegetables than she normally eats. In the clinic, however, diet is an integral part of the therapeutic plan. It has the same weight as medicines, pills, and medical screenings. Diet is taken for granted; it lies in the background of diabetes care. However, diet is not something that people are very eager to adapt to. More than acts of resistance, it seems that diet requires too much work, overlooking the fact that food is not fuel, but affection and pleasure.

THE BATTLE ASSEMBLAGE

The struggle is composed of diet assemblages: family members, kin, friends, colleagues, different kinds of professionals, but also available time, instruments and objects. These often include scales, glucometers, portions and calories, nutrition facts labels, recipes, dogs who help their humans maintain the habit of walking every day, the environment and walking paths, the neighbourhood its and shops. The main battleground is often the home kitchen, and it frequently involves family members, kin, and friends. The battle can also take place at a restaurant, however, involving friends and the staff of the restaurant; it can also be staged at work or in any other public space. When we look at diet assemblages, we can see what is left out of the biomedical system diet: memory, identities, comfort, pleasure, affection, relatedness. This is a relational assemblage because relationships are shaped and nurtured with food, materials, smell, taste, the environment and so on. Eating practices make and sustain good and bad relationships.

A diet system based on control does not take into consideration the conflicts and work that people are called on to perform with and for others. Diet stands by itself, as if in a lab, where the person responsible for both its functioning and results is the individual. And yet there is a web of relational care around diet. How do people deal with that fact? How do people *do* diet? how do they use calories in their daily practices? In medical practices, food is translated into the elements necessary for survival, calories, weight, metabolism and so on, while in care practices food has other qualities, from taste, comfort and safety to boundaries or sweetness. It is not a means of survival and element of metabolism, but a medium for caring and expressing affection. Attending to food in all their daily life complexity is a crucial part of people's caring activities. The list of things that matter are virtually endless, as Mol has pointed out: "a whole gamut of practices, of simultaneously social and material ingredients that shape daily dealings with food" which become visible in the kind of collective practices of food and eating that we will now explore.

Relational materialism assumes that eating constitutes a series of mutual transformations between human and nonhuman materials. While arguing about the obesity epidemic in the US, Bennett noted that the scientific literature has instead supported the idea that certain lipids promote particular human moods or affective states. According to this view, therefore, particular fats are agents that take part in the eating assemblage: food as itself is an actant in an agentic assemblage the members pf which include metabolism, cognition, and moral sensibility.

> To take seriously the efficacy of nonhuman fat is, then, not only to shift one's idea about what counts as an actor but also to focus one's attention away from individuals and onto actants in assemblages. The problem of obesity would thus have to index not only the large humans and their economic-cultural prostheses (agribusiness, snack-food vending machines, insulin injections, bariatric surgery, serving sizes, systems of food marketing and distribution, microwave ovens) but also the strivings and trajectories of fats as they weaken or enhance the power of human wills, habits, and ideas. (Bennett 2009)

When looking at food practices, therefore, we need to recognize the value of different and contrasting versions of reality and the norms embedded in practices

> If realities are adaptive and multiple, if they take different shapes as they engage and are engaged in different relations, then questions of ontological politics become important. The art is rather analysing the norm embedded in practices while interfering in them through adding a novel, oblique analysis. Instead of a singular, ontology has become multiple and questions are asked about the ways in which contrasting versions of reality come to be coordinated in scientific and professional practices in which a practice is done. (Mol 2012, 381)

The food itself acts together with its components and the structures that have made that particular food available, that have produced and distributed and finally cooked it in specific ways and quantities. It is only through interactions, or intra-actions (Barad 2007), that objects relationally grant each other their essences.

This perspective of multiple interactions is evident when looking at dietary practices. In “Mind your plate” (2012), Mol seeks to explore how food and bodies are enacted in dietary advice, exploring what she calls the “ontonorms” of different diet techniques. She poses the questions: “what kind of matter is food?” What kinds of body does it feed in different techniques? And finds that different dietary practices[68] enact different versions of the food, bodies, ideals and dangers they warn against. They motivate people in different ways, and they motivate different people. Viewed in this way, food is an ensemble of calories, or a prevention technique, or a variety of nutrients to combine. The emphasis is on the food and body embedded in the advice and the norms that suggest how people ought to eat. Pleasure, desires and routines are enacted as bad in that they lead to bad behaviours. In the advice “enjoy your food” such desires and routines call for cultivation, a process in which families, friends and activities come to play an important role.

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[68] Mol analysed three different dietary techniques: “counting calories” requires discipline; food is a fuel and energy is quantified in terms of calories. The model is biophysical and the logic is that counting calories allows a rational mind to take control of a pleasure-seeking body. The kitchen is a laboratory in which everything is measured. In “lists and columns” the model is epidemiology; food is an input variable, correlated with an output variable such as long-term survival or the risk of developing complications. Fish, for instance, is not considered in terms of calories but in terms of prevention, on the basis of epidemiological studies. Some foods generate more pleasure than others. A consumer may go with her desires or alternatively overrule them as she makes her own food choices. In “disk of five”, food is divided into five categories: food is nutrients, the molecular building blocks that participate in the body’s physiological processes. The eater who freely serves herself a large portion of vegetable regardless of the available amount and what her companions are doing.

MARIANNA

Marianna is 71 years old and has had type 2 diabetes since she was 50. When she received the diagnosis, her sister supported her in every way. Marianna's sister is older and had already had diabetes for a few years. Marianna's sister was a pillar for her at the beginning, guiding her through diabetes. Although some other members of their family also had diabetes, as often happens, at the beginning Marianna's only source of support was her sister. Together, they started to attend meetings and education activities. Marianna is active in social and political groups; she is an organizer and joined the diabetics organization five years ago, as soon as she moved to the diabetology unit from another one in the region and discovered that it hosted an active patient organization. Since then, she has been very active in the organization and views it as a fundamental resource, a "gym" where she can go when she feels her fighting energy begin to wane. She sometimes participates in Conversation Maps™ and she always present at events, the campus, and the support group. Marianna is a node in a web of patients who are visible and open to discussion, to storytelling, to learning and sharing. Marianna is thus well known among her fellow patients, that is, anyone who has participated in at least one event held by the organization. Because Marianna is also busy with other groups, she also acts as a link with other worlds that she is trying to connect with the world of diabetes.

After many years of having diabetes, her sister is becoming tired: "Sometimes you get tired of fighting", she told Marianna in the interview, "because it is something that you have to do every day". Marianna says she understands that, because you can never take a break.

> It is true that you need to do it for yourself, that you need to be in control, but really… this is something I always say to others, when I'm having a discussion with someone who says: be careful! I say: you try! Because if you are in control you need to do it every day. Now I have to rebuke my sister often: why are you reacting like that! We have switched roles. But I also understand that she… if for me it has been 21 years with diabetes for her it has been 30… you import a lifestyle that goes against everyone and yourself, it is not easy.

Marianna is now the pillar for her sister as the other woman finds herself dealing with serious complications. Her sister is almost blind; she has lost vision in one eye and three years ago she risked having to amputate a leg because of diabetic foot and leg vessels infection. She is now waiting at another hospital for a vascular implant. Marianna often talks about this experience with the group. For her, participating in the medication process and going often to the centre where her sister was being treated represented a moment of awareness about the effects of complications in daily life. In the interview, she also tells me that she spends time with her sister, often eating together on Sunday when she cooks revisited versions of traditional local dishes for her sister's family. Marianna cares about doing this but she also describes these moments as tense, involving conflicts with her brother-in-law. In fact, such conflicts are a frequent occurrence in her experiences of sharing food with other people:

> The group helps. Because when you have fragility you know you are not the only one to have it, you see it in others as well, so you don't feel this form of blame on you. Because you blame yourself every time… I messed up… I am responsible for myself and so if I don't do something then I feel guilty. Sometimes I am aggressive towards people who are not ill. On Sunday I did it with my brother in law, he was complaining because he had to follow a diet for a few days, he said: I haven't drunk wine for a week. I could not help but reply: "then when you blame my sister you should keep in mind that she has been struggling with cravings every day for 30 years". When you yell at someone you blame that person! This is something that Nora often says, that people think type 2 diabetes is people's fault because they eat too much. But it is not inevitable, there are people who eat a lot and don't have diabetes, but the general opinion is that it is your fault. So it goes that every time you don't do what they tell you is right, you feel guilty and you are blamed by others, saying "you know you shouldn't [do that]!" So I say: you try! Let's do it together for a month and we'll see that the whole society goes in the opposite direction of what health should be.

Marianna says that her experience resembles many others that she has seen in the organization over the years. She herself has experienced the tension that erupts at the beginning when concepts of life style and self-care enter into people's lives, and she has learnt to negotiate with others while listening to herself and practicing self-awareness. These practices do not lead to blaming the self; instead, they lead to reflecting on broader societal structures and ways of living. It does not occur naturally but instead requires cultivation: it is an effort (Italian: sforzo), work, a sacrifice (rinuncia).

> Earlier, my lifestyle was in favour of diabetes (laughing). On one hand I made work choices that did not allow me to have control over time, eating… at the end of the day I ate a sandwich, anything I found available. It is a long story. Then after you have diabetes you try to fix it. It is a path I often see among the new people we meet. We live in a society that imposes rhythms that are not normal for people (…). I have to say that now I listen to myself more and I give priority to feeling in balance, to choosing what makes me feel better (…) every time now I ask myself, who am I doing this for? Why? Maybe because I have had public roles for a long time, I see that sometimes you do things because it is your role that imposes it on you, and you need to do it because the message you give to others is important. But now I don't care anymore. It is a matter of love for yourself, [something] that is not in line with this historical moment. Therefore, it requires effort.

The interview extract follows with Marianna vividly explaining the effort of bringing others over to her side, of sharing chronic illness and relational care work with others:

> It cost me a lot to give up, to sacrifice. When we meet with friends we go for lunch or dinner together and I often say that I won't go. They say that it is me who has to make a decision – But this is not easy! Let's do it together! – It is also indicative that every time we want to organize something with Adico we always organize lunch or dinner. For instance, every Christmas we do a lunch, and I point at that. A colleague of Adico told me not to always complain. But how can I deal with friends, family, people I know and all those people who say come over for dinner tonight… please stop always meeting up around a table! Years ago, I had friends from another city and we used to meet halfway to go out and eat fish. At some point I proposed to go to a spa instead. So then we started to meet there (…). I take care of myself better at home, that is the point. Even though I love to cook.

Marianna loves to cook. When she talks in the interview about eating practices that she has leant after years of living with diabetes, one simple practice stands out: to eat slowly, to set a nice table using different plates for different meals, to take time to chat and listen to others. And when she narrates a list of these things, she immediately starts telling me the story of dining when she was a child, with her big family full of other children, parents, uncles and grandparents all at a table, chatting and interacting with each other. Food is memory. Not just what to eat but how to eat; it is a circulation of affects, memory, and rituals.

RECIPES

At a Conversation Map about food, the discussion has already become dense while talking about breakfast. It seems impossible to find anything to put on bread that does not contain sugar. It is common for people in Italy to eat sweet things at breakfast, usually cookies or bread with jam. That is why breakfast is particularly stressful when people need to cut their sugar intake after a diabetes diagnosis. Marianna starts to talk about her homemade jam, a solution she has found to continue having the same breakfast as before but without eating sugar and at the same time gleaning the best nutrition possible from the fresh fruit available in her area. In fact, the Emilia Romagna region is particularly rich in fruit farming and Marianna herself has a huge orchard. After having explained ingredients and instructions, she says that if we want the recipe, we can ask her for it; she is happy to share it with other people. She says that homemade jam without sugar is sweet anyway thanks to the natural sugar contained in the fruit. Someone intervenes by saying that the problem is that it is not sweet enough, like with any other sugar-free jam. She says that over time it will begin to taste sweet as well, because people become accustomed to the amount of sugar they consume every day. And fruit is tastier if you use fresh produce.

What this recipe does is maintain family history and tradition as well as the food in the local environment. Food rituals strike a balance between pleasure and control by cultivating and nurturing senses and taste. Her recipe is famous among people in the organizations; some have tried to make their own and often ask her for advice. This is how she talked about her jam and food rituals when I asked her:

> I gave out the recipe for jam without sugar. Well let's not call it "jam"… you have the impression that it is jam when you spread it on bread in the morning, also the eyes want satisfaction, and you have it if you preserve the gestures. Often, I say this to the group…I believe in gestures that bring you back to your routine, your history. You don't necessarily need to be there suffering. Usually I also talk about how I set the table for myself… I put everything on the table, at the end I have four or five plates for different vegetables, a bit of pasta, fruits… this is pleasurable. It is getting in the habit of enjoying food instead of devouring it and eating it up. I always enjoyed food, even a leaf of lettuce should make us think about its coming from the earth and how we need it. Before I was always in a rush, I did not have time and I got used to eating quickly.

At the campus Nora, another expert patient who contributed to founding the diabetics organization and is very active in several local organizations, asked for help with organizing a dinner event. The help request had to do with the menu and preparing the dinner which will be part of a festival that happens every year, a local event that is always quite crowded. Usually, she says, people at this festival eat things like sausages and drink alcohol. Nora instead wants to show that the food people with diabetes are asked to eat is actually tasty and respects the cooking tradition of the local area. Although this might seem very arduous, they did the same thing the year before when they organized a lunch based on rice, a product that grows in the surroundings. At the annual Rice Festival, they also proposed a menu. In the interview she tells me why it is important to be present at food events:

> Conviviality is very important in general, but especially in Italian culture. We speak about food even when we eat. It is true and I see that also every time I eat with friends and we make up new recipes while we are eating. You share not only bread but everything that is around it because then you start talking about family, children, parents and so on… it is the best moment, we need to take it into account, we can't erase it, so I say let's do it, but in the right way. For instance, for the last dinner we organized (Adico) (…) Dante found the recipe for Pantesca salad, so we prepared it with other fresh salads, all vegetarian. It was open to everyone and the walking group also came, and I was very happy about that. We had only whole grain bread on the table, and legumes instead of meat. Then because it was summer, we had seasonal fruit, melon… I saw they enjoyed it a lot, even those who do not have diabetes. It was tasty and this is what we want people to appreciate, that you can eat well instead of thinking "that poor person with diabetes".

The exchange of recipes in different spaces is a way to disrupt the stigma of the diets and food that people with diabetes have to deal with. Food is a battle that comes on many fronts and in their private kitchens people with diabetes are left alone to grapple with the tensions that explode when self-care and lifestyle disrupt family, gender and class practices. In the public sphere, restaurants and bars are also battlefields. Since diabetes is associated with losing control over food, people with diabetes are scrutinized all the time by others and by themselves. They are guilty of having done something wrong. Restaurants are places where recipes are not shared; they just arrive on the plate. Customers are supposed to be able to eat everything on the menu, with the exception of some ingredients that are carefully highlighted. There are very few people who have no issues at all when eating at restaurants. The majority of respondents instead described restaurants as unfamiliar and uncomfortable. Interviewees emphasized the action of insulin injections in particular, for people with both type 1 and 2 diabetes. While for the former this action might be particularly stressful, going hand in hand with the stigma experienced by respondents, for type 2 diabetes this action is often mentioned when identifying a point they hope to avoid reaching. In this passage, Elena vividly describes the work she has to do in advance when she wants to go out for dinner:

> The restaurant is always a question mark, if you don't know how they make food, what they cook, who is running the restaurant. Sometimes I ask in advance… but I don't always feel like doing it … neither eating different stuff than others [are eating], nor asking them to make something just for me that maybe is not even on the menu. (Elena, T1)

The creation of recipes is a way to share the knowledge they have gained over the years of living with diabetes, of doing chronic illness and care work for others and themselves. Since recipes travels, they also reach people who have not tasted them but have heard about them; they make their way into new territories. Home kitchens and restaurants are places that describe sets of tensions, while recipes are travelling objects, created and shared, that tend to enable instead of constraining. But how do these objects do care?

COOKING LAB

Another element of Adico's yearly programming is a daily cooking laboratory held at a local cooking school. The school provides a professional kitchen for the class, which enables a maximum of thirty people to work at the same time. The trainer of the school participates as well, supervising us and helping with tools and instruments. Dante, together with others in the organization, has put together a menu featuring a five-course meal: an antipasto, a first dish, a second dish, a dessert and sangria to drink. Marianna prepared the sangria the day before, in order to serve it that Sunday. Other people bought all the fresh ingredients necessary to make the dishes. Participants have been asked to dress appropriately for working in the kitchen. At the start of the day, Dante introduces the menu, describing the ingredients and giving information about where they come from, how they were grown and under what conditions, caloric intake and macronutrients. Everything is projected onto the wall: there are pictures of the ingredients as well as the finished dishes. They are all examples of the Mediterranean diet. At the end, all the participants are assigned to work in small groups, each making one of the dishes. We are given the recipes and instructions.

The total lunch calorie count is matter of discussion: 1000 calories all together, which is equal half of the daily calorie intake. Some people are very surprised. Most of the participants are permitted less than 2000 kcal per day. The menu also includes forbidden ingredients and dishes: the cake, chocolate, sangria and particularly the alcohol in it. One participant complains about that, but the trainer says that we will clean the kitchen afterwards and that cleaning will provide us with some healthy exercise. People are laughing, the climate is fun. Dante says that it is not necessary to eat all the dishes and that after the schedule includes a walk so that the overall intake can be compensated for. This whole scene gives us the adrenaline boost of people playing with danger all together.

I am assigned to the cake, so first we need to find kitchen tools and check that everything is accounted for. There are five people in our group: Frank, Nora, Gianna, Pat and her nephew, and me. Since not everyone already knew each other, at the beginning some time was devoted to introduce ourselves and making small talk about avoiding cake, cake recipes, and general attitudes about dessert. I understand that deserts are a difficult topic. It is not clear to me if they have developed strategies to cope with dessert, but they are quite surprised to hear that we will be making a cake. We also need to decide how to proceed and who is going to do what. The trainer comes to help us. He first announces that, in a professional kitchen, nothing should happen by chance. We need to be able to measure the quantities precisely and accurately, especially when making dessert. He prepares the tools: two scales, one for dry ingredients and the other for liquids, knives and a mixer. He says that it is important to learn to use them at home as well because, especially for us diabetics, it is only possible to make dessert if we are careful about measuring; indeed, this is a basic rule for making a good desert even with less fat and sugar. Making desert is science, not something we can improvise. I was struck by the fact that science with its counting and double checking has come back into the picture once again. The second tip he gives us is about sugar. He says that we will learn to use ingredients other than sugar to give the dish its sweetness. We are listening to him carefully, but we are not convinced. “Maybe”, one says, “after a while you get used to it and everything is fine”. “Yes”, states another, “I never use it and I don’t miss it anymore, it is fine”. I am not sure if they are saying that because it is something we have often heard or if they really believe it. However, when tasting the final batter, we notice that it is not sweet at all. We do agree, however, that it is tasty: we have used lemon peel and almonds, so the chocolate taste is interesting, surprising, and new. In that moment, we are satisfied. We put it the cake in the oven despite our serious doubts that it will really rise effectively considering how little fat we have used.

A few months later when I asked Frank about that experience, the first event he had participated in with the organization, he said he was very surprised that day, especially about the menu. He was used to following a very strict diet; he did not drink alcohol except at his wedding and he has been totally sober since his diabetes onset when he was 27. He does not eat cake either, with the exception of very special occasions. That day at the cooking lab he played with calories and forbidden food, making him “drunk and happy”:

> I think it was clear to everyone that nobody has the knowledge to calculate calories so accurately, but time, experience and dedication help you to understand more or less what they mean and in an everyday kitchen you understand that calories depend on where the food comes from and what food group f it belongs to. That day I would have never thought of drinking sangria… I learned I can drink it. Same with the cake. I went home happy and a bit drunk – many years had passed since the last time I had a sip of alcohol, the day of my wedding.

Besides having learned that it is possible to have a big lunch featuring new recipes that are tasty and easy to make, Aldo, who is 63 years old and has type 1 diabetes, found out that he was able to work in the kitchen and take care of food, something he had never done before in his life. This experience challenged him; it led him to do something he would never have expected to do:

> When we prepared the lunch, I gave it a try, they put me on making fish, but I had never done it [before]. My wife always does everything in the kitchen, I never do anything. Putting myself out there… I told myself: I’ll do it! whatever it takes, I’ll put myself out there. It was a nice feeling because I felt like: I made it, I was like the others and I gave my contribution, I put myself on the line. My wife was also surprised. She said, “I’ll go in your place”. But I told her no, I’ll go, whatever I do, either more or less, I’ll do what I can. And I made it, I did it.

Aldo has no hesitation in attributing this sense of achievement to his being part of the organization. The “before” and “after” for Aldo is due not to diabetes, but to a change in self-awareness that is the result of training and spending time with other people. When we talked during the world diabetes day, he described being there that day as a voluntary with the organization and cooking lab. He said:

> If I were like I was before I would never have come here today, now I socialize more, I am more open, before I was more introverted. It is a very positive thing, now I can join in a talk, I can chime in, before I was always on the side-lines. To engage with others has helped my disposition. There were lots of things I didn’t know about diabetes, now I read, before I was stubborn. Now when I see new things, I ask about them, I get answers and I am able to understand.

Collective care practices dabble in medical, gender and family practices, playing with calories, instruments, forbidden elements and identities. The group decided to play with calories when imagining possible ways to compensate for the high caloric load of the lunch. Different options were discussed and proposed, for instance taking a walk after lunch or cleaning the kitchen which, as the trainer stressed, is a particular intense physical activity. After eating lunch, the following days, conversation revolved around glycaemic indexes, the dinner people were planning to have at home afterwards, and attempts to lower sugar levels. Collective care practices challenge gender and family practices as well: in Aldo's story, these practices brought him out of normative habits based on gender roles. In this context, the entire practice of eating is shifted into a collective space of making, from the calories in the menu to the preparation, measuring, cutting and cooking. Science also makes its way into this process, it is only necessary to become accustomed to the flavor. The repercussions of a big lunch in terms of sugar levels are shared within and around the social space, serving as a space of mutual learning and playing with things. The participants discover and experiment with new roles and intermediate roles. Lifestyle and self-care, as concepts, are not necessarily in tune with care practices; as we have seen, they might have opposing objectives. Within spaces of relational care practice, however, people can tinker with and challenge these concepts. A high caloric intake can coincide with trying out new things, actions that we have never been performed before but make the participants feel good. Measuring ingredients can fit perfectly with the act of making a cake which is not sweet but is soft and tasty. Such practices can be enacted in multiple ways, at the same time. Lifestyle in all its rational, biomedical unwieldiness can go hand in hand with the pursuit of pleasurable moments. These moment in turn may function as the steps in collective training, a collective change and reorientation that is carried out in relational care work by weaving care practices together.

NUTRITIONAL FACTS LABELS

The second day at the campus is dedicated to discussing nutritional facts and how to read labels. This is a topic that participants have specifically asked the organisers to delve into, since nutritional facts label are quite difficult to understand especially when looking for industrial products that contain low levels of sugar. The session starts by examining some products that are usually branded as healthy, as diet products or sugar-free products. Dante has prepared some examples to show how industrial products are particularly difficult to examine at a first glance. For instance, products for people with celiac disease: while gluten has been taken out, sugar has been added. It is important, therefore, to consider gluten-free products as dangerous for people with diabetes. The food industry is particularly quick to grasp the issues emerging in broader society and adapt their products to these needs, Dante says, holding up the palm oil as an example. After consumers started to raise awareness about the political issues such as deforestation involved in the massive use of palm oil, the food industry in Italy began to brand itself as palm oil-free. This is certainly an achievement, but what do these products contain instead? What has been used to replace the palm oil? The same thing happens with sugar. The general lesson is that we need to be alert and never trust products that are advertised as “free” of something. The food industry's main goal is to sell products and save money, and this goal never goes hand in hand with people's health. When something is taken out because it has begun to be considered dangerous, as in the case of sugar, it is then substituted with something else.

The example of gluten-free products struck the participants even more than other examples. Questions were raised because it is common for people to need to put together meals that are gluten-free but also low in sugar. How can that be done, in practice? Secondly, there was a question about the consumption of wheat: a woman asked whether we eat too much refined wheat in our daily diet. She said that she sometimes eats gluten-free products because she was of the opinion that it was better for her to eat less gluten. Dante answers these questions by saying that there are many products that can be used instead of refined wheat, some with gluten and some without, and we should use them all in order to eat different sources of carbohydrates, for instance integrating grains such as barley and spelt. There are also many grains which are gluten-free such as rice, millet, quinoa, and buckwheat. Basmati, whole grain, Venere and red rice, for instance, are better than other types of rice because they have a low glycaemic index. His suggestion is thus to eat a varied diet so as to better cope with these challenges.

At this point the focus returns to sugar-free and low-sugar products. Is this labelling accurate? Sometimes the nutritional facts label does not contain the word "sugar" but there are many others; what are they and which ones are better? Fructose is a word that we tend to consider harmless, but in reality, it is not. Sometimes labels list fructose, but this is not the sugar we find in fruits; instead, it might be high-fructose corn syrup, which is particularly aggressively used by the food industry and appears almost everywhere. It has a very high glycaemic index and, especially, is extremely inexpensive. Many products branded as "light" have fructose and HFCS in them; even though they do not contain refined sugar, they are nonetheless high in sugar and play a role in hindering a hormone that regulates hunger, making people crave food even if they are not actually hungry. The same is true of the whole list of sweeteners found in labels with the letter "E" plus a number. In general, they offer no nutritional advantage. The general lesson is that, if we want to eat low glycaemic index industrial products, we need to look for whole foods without simple sugars (sucrose) or added sweeteners. In reality this is almost impossible, so patients need to be on the lookout for the hidden sugar.

After the presentation and questions, we divide into groups to do an exercise. Each group is asked to read the labels of the same product under different brands, compare them and then make a decision about which one would be the best to buy. All of them are products people consume on a daily basis and are advertised as either fair-trade or authentic local products. All of them are presented as healthy, whether low in sugar or calories. Each group receives packages of different brands of jam, yogurt, cookies and pasta. After having discussed the pros and cons within the group, we share our reasoning with the others and discuss as a whole group. Examples of challenging issues are the readability of the labels, too small and lacking in sufficient information, and misleading advertising on the packaging, such as products labelled as "no sugar" that are free of simple sugar but do contain other sweeteners.

The lesson is that it is not easy to make decisions about what food to buy, even for people who are as well-informed as possible. The food industry and its advertising arm are fast and consistent in adapting to what consumers want to hear and advertising products to make buyers feel safe, but in reality the results are not safe. Patients as consumers need to be careful and sceptical. It is difficult to protect ourselves from the food industry, to eat products that do not put too much stress on the body while simultaneously being aware and respectful of environmental and political issues.

At this point the conversation focuses on the food industry and strategies to cope with it so as to do as little damage to ourselves as possible. The key point is that we need to know and become well-informed, to be aware enough to choose products that will not poison us. One woman proposes a solution, namely cooking for ourselves as much as possible in order to avoid industrial products. Dante agrees that, indeed, the only way to avoid hidden sugar and fat is to prepare food ourselves. The lesson that comes with the last exercise, the jam, is particularly compelling. The best jam we identified in our investigation is the one that, no one considered at the first glance. Although all of them were branded as sugar free, this is the only one that actually does not include any sugar components besides the sugar that is contained in the fruit itself. The issue then becomes, however, does it taste sweet? One person who has it at home says no, it is not sweet. Dante says that this is an exercise in practicing pleasure: "It is not sweet, but it has a sweet flavour".

The issue of time is particularly pressing in this conversation. Care through food does indeed require time, which is not easy to reconcile with the obligations of employment. There is a lot of work involved in making fresh food, and not only: the analysis of the different labels showed that checking each label also requires a great deal of time, usually the time people use to do grocery shopping. Shopping is also linked with food and diet and shopping itself constitutes the very first moment of contact with food. But even if we cannot make everything ourselves, Dante says, we need to know how to read nutritional facts labels to void being tricked. In this moment, I understand, we are not reading labels just to count calories, fat, and sugar; we are also producing critics who will look on the broader social and political system surrounding the food industry with a more sceptical eye. We are shifting the focus from a person with diabetes who has individual issues with food to a system that is deliberately taking advantage of the health of the population.

These stories of collective care within the organization show that relational care work is grounded in the recognition of the frustration, work, and conflict that comes with daily struggles to keep diabetes in balance even while performing all the care work that is necessary to live. As described in many interview extracts from different informants, the group is a space in which people can talk about the emotional challenges they are undergoing so as to identify possible solutions or coping strategies. But this chapter highlights the fact that it is also a space to play, to dabble in the daily issues of chronic illness work and the need to resist. Participants collectively stage these conflicts, fears and sacrifices because bringing them on stage makes them fun. In so doing, they displace previous practices, roles, and identities.

Objects have an important role on stage as well. It is the enabling character of objects such as recipes and labels that make connections; they trigger discussions and generate affinities, bonds and relational care. The "conversation" about taste is therefore a move between affinities, a move made possible by recipes and labels. These objects, moreover, indicate the orientation of these relational care practices in the making: the importance of setting boundaries and bringing others over to one's side by recognizing the work and battle that patients carry out every day, as illustrated in Marianna's story, preserving and maintaining memories and rituals, creating new objects and practices that are enabling instead of constraining, and shifting the focus from the individual to broader issues. These are collective relational caring practices and care making.

As Mol has vividly pointed out: Writing about care involves the "need to juggle with our language and adapt it" to everyday situations where care "may involve jointly drinking a hot chocolate while chatting about nothing in particular" (Mol 2010: 10). Relational material perspectives warn us that some food components are deeply linked to care and non-material sensorial elements such as memory, needs and desires. With eating, as with care, the tasting and sensing body makes contact with other elements which can be both material, such as objects and other people, or non-material, such as pleasure, company, comfort or guilt, feelings connected with family history and with the cultivation of our own senses (Sutton 2006). Memory connects the senses to skilled embodied practices through habits, what we would call family practices. Sutton is interested in an ethnography of cooking, in the making of memory, identity and meaning through the use of the body and recipes. Recipes are also embodied memory since, as Ingold has suggested (2001), they are cultural representations transmitted from one person to another by converting the instructions through bodily behaviour. As such, they operationalize skills that the individual has already acquired: melting, stirring, handling different substances, finding the relevant ingredients and tools. Taste is likewise a sense-body tool: smelling and tasting are employed to assess the progress of the dish. Recipes are therefore not mere objects at all; rather, they are materials which work through embedded actions and senses to connect food and the making of food with memory, family and identity. Sutton reminds us that the other meaning of "taste" (in English) has to do with the way in which "good taste" is turned into cultural capital in the pursuit of class distinction. Recipes and senses therefore inform and carry class identity and memory, cultural capital that is passed down from one generation to the next.

Taste is also linked with care in the context of daily care, as explored by Harbers, Mol, and Stollmeyer (2002). In the nursing home setting the taste of chocolate is a medium for care; it *does* care. They note how food and drink are granted attention in medical discourse in terms of their characteristics of importance, nutrients and vitamins. Food and drink in daily life are relevant to caring practices as well, however. Here they have additional qualities: they smell and taste certain ways, they have a texture and consistency, as with the taste of chocolate in milk that encouraged an elderly person with Alzheimer's to drink her milk instead of refusing it. This perspective places the attention on materialities in daily care, material elements such as objects, tables, chairs, plates and food itself, and the blind spots in which materialities and practicalities of care give shape to disease and its course in a way that is neither (bio)medical nor ethical. The questions to be answered are not about meeting given standards, therefore, but about which standards are forged in daily caring, what goods are practiced and bads created.

And finally, one last point. Pleasure and good taste are never taken for granted, never completed. As Mol has suggested, appreciating a good taste depends on a body that is able to taste it. It is an ability that improves with training: pleasure requires effort. Consumer-citizens with good taste do not depend on norms which are imposed on their bodies from the outside, like rules; rather, they experience good and bad from within. They do not enact the fixed identities of consumers; instead, they display relationships which learn from each other, good and tasty things assembled over time in the manner of recipes (Harbers, Mol, and Stollmeyer 2002; Mol 2012). The collective work of sharing strategies and "case studies" sheds light on invisible work, fears, and conflicts but also positive stories of happiness and fun. Building on (Pols 2014), this work can be read as a strategy that resembles ethnographic knowledge in terms of its comparative approach, unfolding through a process of learning, tinkering, playing and so on. This is what Pols refers to as knowing patients. Training in taste, for instance, is also a technique of display to recover what was lost. The collective work can proceed in any direction and in unexpected ways.

WALKING AND PHYSICAL EXERCISE: SHOES, SOCKS AND FEET

The tensions that emerged with nutrition and food are also common features of physical exercise and sport. From the moment of being diagnosed, people with diabetes are told to engage in daily physical activity to balance their blood glucose levels. However, while newly diagnosed diabetic patients are encouraged to meet with a medical expert on nutrition and undertake a certain nutritional regime as part of their treatment, there might not necessarily be a similar medical encounter focused on physical exercise; this aspect is left up to the patient's responsibility. However, given the statistical evidence about the link between daily walking and the prevention of complications, diabetes patients are recommended to engage in moderate and continuous physical activity and sport and, in the case of older patients who have already developed some complications or have a situation of multimorbidity, the recommendation is to do high speed walking. This makes walking the most common physical activity for people with diabetes. As we have seen, the physical activity guidelines of the American Diabetes Association suggest that individuals with type 2 diabetes accumulate at least 30 min of moderate-intensity physical activity on most days of the week. In this section, I want to connect up the ethnographic literature on walking, and in particular the relationship between the senses, walking, knowledge and the environment, with recent relational materialist literature focused on human/non-human assemblages, in particular daily material objects and eHealth. An ethnographic focus on walking practices grants visibility to the invisible worlds around: worlds of care expressed in motion as well as worlds of caring objects and materials, such as shoes or socks, and the environment. In the case of diabetes, walking materials are of paramount importance for the health of the foot and to avoid lower limb complications. In keeping with this view, a relational materialist approach focuses on care walking practices and approaches the people who walk as interdependent with other non-humans (plants, routes, trees, animals) and the environment by virtue of their all being actors within the same assemblage. Recently, sociological literature has also explored interaction with technologies and in particular personal health technology, body apps and devices. From a relational materialist perspective, technology and apps are considered part of human and non-human ehealth, mhealth (mobile health) and uhealth (ubiquitous technology) assemblages. In the last decade, indeed, sociologists have looked into the widespread, wearable devices and apps designed for walking and running. This literature has highlighted how the body/device assemblage brings about a biological reengineering of ways of being and sensing in space. In this regard, mhealth is gaining particular attention in analyses of the way bodies are reconstructed not in terms of their physiology, but in terms of their role, undergoing an imperceptible prosthetic expansion by wearing devices that engage with the environment and the mobile technologies focused on health problems and mobility, known as mHealth. These assemblages have been used to explore how bodies are broken down into fragments through data, a process which has been called the "quantified self": a knowledge system that remains flexible in its aims and can be used as a resource for epistemological inquiry and in the formation of alternative paradigms (Ruckenstein and Pantzar 2015). As Viseu and Suchman have argued, such paradigms operate to reproduce dominant discourses of personhood while at the same time reconfiguring them. They have the power to hold together different, heterogeneous imaginaries (Viseu and Suchman 2010).

FRIDAY FEET

On Fridays diabetology is open in the morning as it is every day, but doctor Z is never there; this is the day of the nursing clinic. It is on Friday that the nurses organize the clinic for diabetic foot screening and individualized education for new patients. The nursing clinic does not take place in any of the diabetology units; instead nurses usually take this extra time to organize the clinic and rather than making appointments and doing screenings and education. It is something they have autonomously decided to do because the staff believe it is important.

Diabetic foot is one of the most common complications of diabetes[69]. When the first patient arrives, she goes into the room and Eva goes with her to perform a foot screening. The test does not take a long time, but usually this time is devoted to the patient as well. It is an extra time in which the person can talk about daily management issues and questions. Older people in particular, says Eva, have trouble understanding the information that we are giving them, especially the information given out during doctor visits. W they come for screening, therefore,

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[69] Diabetic foot disease often leads to ulceration and subsequent limb amputation due to changes in blood vessels and nerves. It is one of the most costly complications of diabetes, especially in communities with inadequate footwear. It results from both vascular and neurological disease processes (Neuropathy). Regular inspection and good care of the foot can prevent amputation. Comprehensive foot programs can reduce amputation rates by 45-85%, states the WHO. https://www.who.int/diabetes/action_online/basics/en/index3.html

we take the time to use more simple words and be sure they understand, because a standard visit with the doctor is much shorter. It is an occasion for us, as well, to understand how things are going with them.

After 35 minutes the patient comes out and Eva comes to sit with me again, to explain what happened inside. First, she tells me, she asked a list of questions in relation to the patient's feet, translating the language of the questionnaire into simple, everyday language. The questions are about the degree of sensitivity the person is experiencing in daily life, his or her sense of cold and warm, unusual sensations, and pain or cuts. She then asked the woman to take off her shoes and socks and began the inspection. She uses her hands to perform the screening. The combination of the questions she asked and the indicators she found during the inspection come together to produce a score that tells the status of the diabetic foot. As is often the case, she says, I gave her instructions on how to take care of her feet, because often people do not know how to properly wash and cover their feet. And yet it is very important to have a good understanding of these basic tasks: although they are always taken for granted, they are fundamental to taking care of feet properly.

Friday screenings are a diagnostic and prevention medicine practice and, at the same time, a chance to take some extra time and dig into the lives of patients. During these screenings, Eva and the other nurses are performing both medical practices and care practices. Medical practices are mitigated by the use of everyday language that Eva, as translator, puts into circulation; she is a node for the exchange of different systems of knowledge. This weekly event is a space of intimacy that is created in the clinic in which hands, bodily senses and instruments are joined together.

SOCKS

At the annual Christmas lunch organized by the diabetics' organization, the end of the afternoon is dedicated to a lottery. People have donated objects as prizes, while all of the money goes to the organization and in particular the task of organizing next year's events. The atmosphere is very pleasant: some people have cooked a five-course meal whereas other are busy cleaning; Gioia and her theatre group have already done several performances during the lunch breaks and now Lena is describing the last lottery prizes. It is just before leaving that Lena announces that there is still one gift that needs to be handed out, and suddenly every person is given a Christmas gift from the organization. Inside the small package are socks: white, cotton socks with "by small steps" written in red[70]. I immediately recognize the slogan of the organization. The Adico logo is a smiley snail that leaves a slime trail spelling out the slogan. I had understood the motto as an invitation to take it slow, to make small changes in your life and not rush to much. Small changes are achievable and viable, while big changes are difficult. That was it. But might it suggest something else as well?

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[70] "A piccoli passi" in Italian.

The first day of the residential campus was devoted to diabetic foot, with Felix as the host for the day. He had been at the campus the year before and he has participated in some activities organized by the organization, the ones focused on physical exercise. Felix is a physical educator and therapist. He founded a company which carries out a number of activities including research, with a focus on training for people with chronic illnesses. The afternoon is organized into two parts: first, Eva talks about diabetic foot, complications and how to avoid them. Daily self-care is fundamental, see tells the group, as are clothing materials and shoes. Every day we should wash our feet and look at them: are they fine? What colour are they? Do they show any cuts or signs of something different? The task is simply paying attention to how our feet are doing, trying to feel if there are any differences in terms of sensitivity. Eva has a small suitcase with all the instruments she uses in the clinic. There is a plastic foot that she uses to show examples of real issues, pointing at the parts that are most vulnerable, the places where people should look to see if anything is happening. She recommends not using abrasive tools and protecting the feet as much as possible. Afterwards, Felix talks about clothing, and socks and shoes in particular. He notes multiple times that we always need to use socks, all year round, even in the summer. Moreover, diabetes patients need to use specific socks, their socks need to be chosen carefully. First the material: cotton, but natural fibres in general. Second: no stitching, because seams can hurt the foot especially when going for long walks. In between socks and shoes we need to use an orthopaedic insole, as they protect feet from the kind of abrasions a shoe can cause. And finally, shoes must be chosen on the basis of comfort. Sport-type shoes in particular need to be roomy, never tight, because the feet need room to breathe and be safe. I never realized how much care is involved in foot care for a person with diabetes. Diabetes care assembles a number of objects and materials, including the materials used to make them. At this point I understand that socks are also a way of reminding participants that materials play a role; materials are a part of diabetes care just as are the bodily sensations connected with wearing certain kinds of socks and shoes.

PRACTICING WALKING TOGETHER

After talking about shoes, Felix introduces his specialty: safe walking. Here again science appears on stage. This time Felix is no longer talking about materials, however, but rather kilometres per hour, steps, calculations and speed. Through a graph, he explains that it is possible to calculate the exact walking speed which allows a person to glean the most benefits from walking without becoming too tired. A red line highlights a specific range that is the ideal speed to sustain while walking. Everyone has a speed that must be calculated and then maintained, walking consistently within that range. Basically, any speed faster or slower than that range is not useful or effective and may even be harmful. Moving too quickly is as bad as moving too slowly. It is possible to calculate this ideal range using devices for tracking when the body begins showing signs of stress. Moreover, he says that researchers have discovered that in order to be effective physical exercise must be performed at least every two days, otherwise all the benefits are lost. A person’s total walking time should not be less than 150 minutes a week, which means 50-minute walks three times a week. Walking is fun but potentially dangerous; we will need to learn to perform a series of exercises before and after. The final list of tasks for patients, translated from the language of sport science to care practices, is simple: be careful about what you use when you walk. Acquire proper shoes and socks; understand that there is an ideal speed that everyone has to discover for themselves – you can learn to calculate, of course, but everyone can pay attention and *feel* this ideal speed; walking every day is the best, but if that is not possible walking should be done every two days. That is fine as well. Since everyone has undergone a physical test before the campus to establish their health status, Felix has decided to split the participants into two groups: a group that will walk at a speed of 3 km/h (the slow group) and a second one whose speed will be around 5.3 km/h (the fast group). He also brought walking sticks that can be used to facilitate the walking.

After breakfast, Eva monitors everyone's blood glucose levels and declares them ready to start. We first do a warm-up exercises under the supervision of Miki, another trainer: we sit on the grass with a towel, with some people who prefer not to sit on the floor using chairs instead. Sticks are also available as a support. Miki goes with the fast group, the largest one, while Felix accompanies the slow one. Miki guides the group in reaching and maintaining the right speed; she also knows the exact path we are supposed to follow. However, from the start there are some people who cannot keep up with the standard speed. One is Aldo, who cannot walk fast because of a diabetic foot. Even though he tries to sustain the ideal speed, he falls behind the group. Then there are also those who move faster. Ivan is used to walking at a higher speed every day; he takes walking very seriously and does not want to slow it down. In the middle there is the group. However, Aldo's wife walks next to him and from time to time other people pace them to chat, thereby slowing down for a while.

The path is very beautiful; everyone agrees on that. It is a natural reserve where visitors can catch sight of deer, water birds and flamingos. The path stretches out along the dunes, flanked on one side by the sea and on the other by a forest. Since the campus has been organized in the same location for several years, the environment has become very familiar and people notice small differences from one year to the next, such as sculptures on the beach or the plants and animals we encounter. People are talking a lot with each other while walking, moving from one small group or person to another. Aldo remains at the back of the group but people fall back to chat a bit with him, taking photos of the path, and then walk quickly again. That is how the group realizes that something has happened. Everyone stops. A couple of people together with Miki go back to check on Aldo. His foot is not doing well, he is in pain. What to do? The group decides that we should all go back with him. It is only when we meet the other group and Aldo and his wife decide to join that one instead that the fast group once again adopts the speed it is supposed to follow. When Aldo is safe with the other group, we go back to walking at 5.3km/h.

At the end of the walk, we again do cool-down exercises and undergo blood sugar level monitoring. After a shower, we gather together to talk about the morning. Doctor Z, who could not attend the walk but is present at the discussion, asks how walking together has changed over the years. This year is the 9th campus. Marianna starts by saying that she feels many things have changed. First of all, the group is more united now, whereas before every person was walking for themselves. The first times they also played a game that ended up turning into a sort of competition, so everyone was pushed to exert themselves more than necessary. They acted as if they were performing. That kind of competition is not the point, however, she says. Over the years they have learned how to "make a group"[71], to keep the group united and look back to see if someone has fallen behind. They have learned to respect everyone's rhythm and take care of being together. Many people agree with this observation. Ivan, who was ahead of everyone during the walk, says that this experience has taught him something that will change his daily walking routine. Before, he used to walk many kilometres per day; in reality he was over-exercising and putting too much stress on his body. Today, he understood that he can do less, thereby enjoying the maximum results with minimum effort. Now he can just walk. Marianna speaks up again by saying that she was quite sceptical at the beginning, not trusting Felix enough because she suspected him of being more interested in securing new patients. But now she has changed her mind: she often suffers pain in her body, so she does not walk very often. Today, however, with the combination of exercises before and after and the walking itself she feels much better. She is not feeling any pain in this very moment. So, she says, with the right exercises I can feel better and also walk for kilometres. These positive experiences provided the space for talking about how these tools might be used in the future, with the discussion then moving on to possible events devoted to walking and exercise.

This extract from my fieldnotes sheds light on the experience and feeling of care in practice, showing that, while care becomes sedimented over time, it gives rise to and moves into something else. It took years for collective walking to become an intra-sensing practice in which people take care of each other and sense each other's needs. As part of this process, the walking path is an important actor that enables them to walk together and to build affective memories over time. In this case we might speak of therapeutic landscapes (Doughty 2013). In the case presented here bodily objects such as socks, clothes and shoes perform and *do* care: they stimulate perception, bodily sensation and awareness, and facilitate the circulation of these feelings throughout the group. Once they have been named, such feelings find a space in daily practices and in turn transform them. By enabling caring practices (e.g. walking), they allow communication to function effectively; they are speculative, affective nodes for influencing others. The result of intra-action is the creation of something beyond the specific practice in question at the outset of this process (Barad 2007).

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[71] "Fare gruppo" in Italian.

WALKING AWAY AND WALKING BACK

For Ingold and Vergunst (2008), walking practices extend far beyond the act of walking itself, insofar as the movement of walking is itself a way of knowing, that is, an awareness of the body in movement. Walking entails moving through a world of information about the others around us. In the view of the authors, the taken-for-granted movements of walking are practices of awareness among bodies, a relational practice and social activity that cuts across the divide between humans and animals and between the pacing of two feet as opposed to four. For instance, when walking with others, people make adjustments, slowing down or moving faster. Another example is the link between walking and learning by means of a walking pathway that the person follows multiple times. Learning is embedded knowledge; it involves observational acuity and an awareness of the consequences of one's actions. Ingold and Vergunst have also emphasized that walking is a narrative and visual practice: in looking where we are going, we scan the horizon of the world around us rather than imagistic or pictorial representations of this horizon. Indeed, pedestrians who are overly engrossed in perusing images are most likely to trip or go astray (Ingold 2010), and thus give words to what they are seeing. Rebecca Solnit, taking up the same theme, argues that narrative writing is closely bound up with walking precisely because, just as with the act of following footsteps, it allows us to read the words of another person, the author, who has gone before us (Solnit 2001).

> There is far more to walking than what is registered on the ground in the monotonous tread of feet (…) just as there is more to walking than the iteration of footsteps, so there is more to narration than the concatenation of words. If the elements of narrative fall through the gaps between the walker's steps, there is a contrary tendency for the bodily experience of the storyteller or writer to fall through the intervals between words. In practice, the storyteller harnesses the power of the voice and lungs to deliver a performance no less visceral and muscular than that of walking. (Ingold and Vergunst 2008)

Doughty (2013) argues that shared walking can generate a supportive form of sociality that is embodied through movement, and that this process can give rise to a particular mobile therapeutic practice which is produced and experienced intersubjectively. “Therapeutic landscapes” are, according to this view, particular spaces which people enact together while walking. Such spaces constitute moments of collective healing from a range of traumatic experiences as well as a chance to relax from social norms while enjoying proximity. The therapeutic landscape could be understood as a sociable good, something that emerges through shared, situated practices. Doughty found that the restorative value of guided group walks in the countryside lies in the convergence of a desire for the supportive proximity of others and the body's sociable orientation towards its environment during such therapeutic self-work. The result, she argues, is the practice of “walking-with” as a temporary form of companionship and a shared orientation towards wellness. Walkers communicated with each other through body language and by maintaining or interrupting their physical movement. Walking sociability was a negotiation of movement as much as anything else, therefore, and could be characterised as a discursive journey.

FLORA

Flora is 63 years old, she has been living with diabetes type 2 for nine years now but it was in the last year that she experienced an enormous change, at the same time as losing her mother. We met for the first time at the campus. Since that moment, she began going for daily walks by herself. By the time we had the interview, she had lost quite a bit of weight as compared to a few months before, at the campus. When describing what has changed in the way she deals with diabetes in her daily life, she talks about feet, sensitivity and shoes.

> I now go to for a pedicure, I go every month, she knows how to take care of my nails. She said I am not the only client with diabetes. I'm always checking on my feet. I am always barefoot at home, with flipflops. I need to feel my feet. They say that with diabetes you lose sensitivity, like Carlo who loses toenails and does not even realize it. I need to sense them, to feel that my feet sense. When I go to the beach, I want to feel the sand, the water, where I am standing on my feet. Nora told me that I always need to wear shoes. But not for now; I even walk on rocks and stones [barefoot].

Flora takes care of her feet through paying attention to sensitivity and feelings. She is training herself to feel what is happening in her feet. However, this way of practicing sensitivity is not the one recommended at the unit. Her first priority should be to protect her feet. The biomedicine instructions collide with her need to engage in self-care, however. Paying attention to details gives her the space to be attentive to changes in her body and to play with them.

> It happened at the Campus. When I came back home, my legs felt like they were moving by themselves. I started to walk, a bit. Then when I understood that I could go some distance without getting out of breath… that was it. I was out of breath during the first walks, now I breath normally and when I go out and when I come back after ten kilometres. Soaked, for sure, but my breathing is fine. Eva told me that if I become breathless I need to slow down. But I found my speed and I don't run. And if there are other walks or hiking in the area, I go. It started with the Campus, I had also gone to the previous one but not… maybe a sort of click had to happen, or I'm crazier than I was last year? [laughing]. Last year I went from 108 to 98 kilos. But I didn't ask myself why this year and not last year, I didn't even notice until the first time it was cold and I was looking for my jeans but they did not fit me anymore. So I put leggings on but they were too big as well. People are always asking me if I am doing well... "you are so thin, are you ok?" you have no idea… I get upset, really. Now a friend is helping teach me how to dress… you see? [pointing at her shoes] boots! Before I wore only sport shoes, because I

> was sure that with my weight, they were the only thing I could wear. Now I have heels… you see the change?

Flora says that it was by "taking space from others" that she started to care for herself and her diabetes in a different way. But who are these others? When she talks about the relationships she has stepped back from, she talks about food within her family:

> I don't know if it was because of diabetes, or being closer to other people, or something that I felt again because I tend to cancel the memory of many things… is it a new life that has started? I don't know, let's say that this December I was 68 kilos. I lost so much weight but I am not feeling bad, I'm fine. At home, diabetes… my husband doesn't make things easier, he doesn't help, I need to manage it by myself. Now I do it better because I am more aware and when I say no it is no. My daughter says I have become more…uncaring. But let's say that many things I don't like, now they just slide past me and going for a walk for me is a bubble. It is my moment, every day, if it rains, I organized a space for myself at home and I do the 10,000 steps anyway. When I go out, I put music on and for two hours… because it went from 1.5 hours to 2 hours, from 7 to 10 kilometres… I have things that when I get back home, I feel the urge to walk more and I keep going (…) I now see that everything I understood before about diabetes was slipping away without sinking in and now I have reconsidered many things that I used to do, thinking they were normal. For instance, I was not paying attention to food. Then, when my mother died, I took space from others (…) it is not that I don't care about people, but about what is happening around me. If I don't feel like something, it is because I don't care. But I care more about myself, even my husband has noticed it! Before, what my husband and son wanted to eat, I ate it too, I didn't want to think about my having diabetes, even though you can manage it. (…) recently, I make less food. My son complains: so little food! I made food for them in the right quantities, but they are not normal.

Flora's story talks about the conflicts that arise when someone in the family breaks the unspoken rules of caring through food, through the time devoted to caring for others. She does not want to cook too much and go on eating in the way that all her family members used to in the past. This shift involves changing eating practices and walking, which in turn brings about a change in the way she deals with taking time for herself. Even though she continues to cook for them, now she does it according to her own rules. Her family members do not seem to understand these changes or realize that now she is worrying about their health and the fact that they might develop diabetes as well. In the interview, she says that people think she is strange. She does not know how to resolve these conflicts; in reality, she does not want to resolve or negotiate them. Feeling better and taking care of the self, for Flora, entails stepping back from others to do what makes her feel good. For her, practicing self-care is finding a balance between the right distance to maintain from both other people and biomedicine. In this way, her practices have also involved questioning normative ethics in relation to care. She vividly expresses this idea when describing her experience by referring to a “before” and a “now”. Flora has found a space in which to practice self-care at the expense of constant conflicts within her family and changing her ethics of care and maintenance work. The organization, in contrast, is the space in which all the participants are speculatively broadening their horizons towards new possibilities of self-care, in particular through the support group. Good care, in this case, is not an obligation; rather, it is about finding strategies to establish the right distance between the self and others. As part of this process, practicing walking has been an empowering strategy for cultivating indifference as the power to choose not to care.

DIEGO

Diego is 61 and has had diabetes for eight years; he was diagnosed the year he retired. He was a metalworker and says that he never had a doctor’s visit ever in his life before having the blood test that confirmed his diabetes. For a few months he underwent insulin therapy, but with a strict diet and walking therapy he was able to achieve a balance. He thus changed treatment plans, quitting insulin and enrolling in GI. He describes his life with diabetes as composed of ups and downs: there are times when he is careful about eating, walks a lot, and things are fine. There are other times when, as he says, “I let myself go”. At these moments he copes by “going back to the groups”. Diego participates in most of the organization activities and the support group in particular. He does not always attend, but he does go every time he feels the need to. Being with this group is very helpful for him because he knows he has the support of others; the group is the “strength and the incentive to get back the lifestyle”. For Diego, the work of maintaining a lifestyle is particularly difficult:

> It is hard for me to impose [something on] myself or follow something. I would prefer to have the lifestyle that I feel at that moment, without thinking that if I eat one apple more than I am allowed it will be bad for me.

The food is a “never ending fight” and his main struggle. Right after his diagnosis, he divorced his wife and moved back to live in the house where he grew up, together with his mother and nextdoor to his sister. Sharing food with them is particularly challenging because his mother wants to cook for all of them without following specific advice. For instance, she does not weigh ingredients and she does not want him to leave any food uneaten. This is frustrating for Diego, and when it becomes too much for him he goes back to the group. After receiving his diagnosis, he found a flyer in the CDS about a walking group organized by the CDS itself. He started to attend this group and it became very active in it. The walking group members gather every Monday to go for a walk in the surroundings, but Diego also participates in and organizes long hiking trips involving an entire week of walking.

> It is a group in which people struck up very good friendships because with a part of the group we did a long hiking trip and so then when you spend five or six days together with people,

> nights and days, and share efforts and discomfort, then you build a particular relationship. The first time we went for a hike it was only me who had done it before, the others had never done anything like that. It went well, we built a relationship and we continue to go hiking.

Diego tries to bring the two groups closer, but he says his efforts are not successful:

> I don't know why we never managed to bring Adico to the walking group; they don't come to walk and the walking group don't come to Adico's events. Some of them have come sometimes, but as a matter of fact I am the only person with diabetes. I would like to unite them because people with diabetes would benefit from it, it is fun and a motivation to walk. Because the group drags you along, therefore if I need to go alone a day like today… maybe not. But then after you get the message: get ready, we are going even if it rains, you get ready and you go. (…) when we prepared for the long hiking trips, my blood glucose level was at 60, I lost weight, and everything was fine.

Diego talks about the groups as a fundamental resource for moving forward, while at the same time he describes having limited the time he spends with other people:

> Groups have been very important for me. With the friends I had before things changed, we see each other less because I try to avoid…they don't know I have diabetes. I make an effort and then they say: why aren't you eating? Eat! Or they feel sorry for you. Here, it is like that. I don't know if you have noticed but people who come to the diabetes clinic are hiding themselves. Once I was sitting in a chair in front of the entrance, I saw someone I know coming but when he saw me he turned away.

It is within groups that he has the space to "come out" and feel safe in the work he is required to do.

> The group helps me to express feelings and emotions that before I kept to myself. The fact of being with others, sharing the same problems, they feel you. If I go out and say to someone that I am angry with my mother because she makes food for me, people would tell me 'you're crazy'. But there, they know what I mean. I have told them about it different times, we even joke about it, but it is the simple thing of sharing it with people who know what that means that is fundamental.

In these stories, walking practices are instruments for doing care in practice. For Flora, walking away is a practice she has learned to enact in order to take care of her diabetes but also *take her distance from* conflicts. The practice of walking has been a turning point for her and a focal point in her daily routine. It is not self-care and lifestyle that has led Flora to walk, it is the walking practice itself that has transformed the way she cares for others and herself. In this narrative, objects such as clothes and shoes are walking *with her*; sport shoes accompany her when training, bare foot or flipflops when she is training her feet to feel. In everyday life, moreover, she does not need sport shoes anymore. This shift speaks to the fact that she feels better, that she is taking care. These objects and sensations are symbols of feeling well; they communicate such well-being and share it even though they might run counter to the recommendations of biomedical practice.

In Diego’s story, in contrast, walking practices are a means of walking away from and taking his distance from friends with whom he cannot share his diabetes. At the same time, however, they are also a *walking back* towards feeling better, going back to blood glucose levels that make him feel better. They are also *walking with*, because it is within the walking group that he has experienced intimacy and close bonds of friendship. This practice creates affective and life-sustaining interdependencies with others. Both of these respondents walk to achieve a balance between diabetes and the act of making, or taking their distance from, significant relationships. These are walking practices that *do* care. They forge an ethical path which speaks to the way people want to take care of themselves and others. They describe the ethical orientation that people with diabetes adopt in relation to distance; in short, they tell *where* to care.

FINDINGS

The aim of this chapter was to present care practices in the daily lives of people with diabetes, shedding light on the different types of care and chronic illness work that they must perform in order to live as well as possible with a chronic illness. This analysis of care practices has shown the centrality of relationships, and caring relationships, in diabetes care.

The close link between diabetes outset and family stories, a link that appears not as a genetic thread but as intertwined with conflicts, stress, loss and so on, encouraged me to delve more deeply into family and gender practices and to look at tensions in relation to diabetes care in the “family” and contexts of relatedness. These conflicts often emerge as a result of a “mismatch” between chronic, care, identity and emotional work, the kind of hidden work that people have to perform on daily basis to take care of each other. Diabetes can sometimes be the cause of this mismatch; at other times it is a reason to change, to manifest anger or to feel guilty in a constant process of changing positions or configurations within caring relationships.

Family memories and the emotions associated with family living and family displays (Morgan 1996; Shove, Pantazar, and Watson 2012) are constantly worked and re-worked in rituals and ceremonies, a process that begins with the objects and instruments that become rituals, connected to memory. On one hand, the construction of family (diabetes) care is the representation of an imagined ideal: the supportive family that takes care of diabetes, sharing responsibilities in moving towards a lifestyle change. This image is energetically promoted by health care institutions and diabetics organizations, as can be seen in the 2018 “World Diabetes Day” with its focus on "the family"[72]. The tension, however, lies between the normative ideal of family care and the affective relatedness of collective practices of care in which new forms of relatedness emerge which are linked to health and illness, based on logics of care instead of logic of choice. This tension can be seen particularly clearly in the sphere in which family relations come face to face with disciplining care in relation to diabetes, for instance by performatively negotiating divergent gender roles or social norms. Such tension operates as an ambivalent desire for care in relation to diabetes, holding together heterogeneous imaginaries.

We have also seen that there are different kinds of work that can be identified, instances of labour that constitute knowledge embedded in practices and, therefore, pose another consideration having to do with care work. The literature uses the phrase *chronic illness work* (Strauss et al. 1985) to refer generically to the work that patients must perform to live with chronic illness. This includes not only the work that patients do but also the work that they are expected to do when entering the clinic. Such work requires knowledge. First, it requires biomedical knowledge, the one describing the physiology of diabetes, how insulin works, diet guidelines and how sugar and carburates can be counted and controlled. Then, however, this knowledge must engage with daily life, where it must constantly negotiate with daily care work. Chronic illness work thus becomes a negotiation among visible and invisible work (Star and Strauss 1999). Chronic illness work directed towards the self and diabetes care is in tension with care work directed toward others and relatedness. As a result, people constantly make decisions regarding care on the basis of what they think is good in a specific moment or situation, on the basis of situated ethics of care. In the socio-material care work I review here, they often merge and mix together. In my analysis, the identification of hidden care work is not aimed at granting visibility to hidden activities that deserve to be more highly valued. Rather, it is an attempt to engage with displacements in established hierarchies of value, an understanding of how divergent modes of valuing care co-exist with and co-make each-other in non-innocent ways (de la Bellacasa 2017).

Care-giving directed at significant others, such as children or elderly people who are in need of care. Food and eating often come up in these cases, because this form of care work usually takes place during mealtimes and involves other work to make it happen. Care givers often deal with care burdens, which in their stories in turn affects health and diabetes. There is a close link between care burden and diabetes, and the same is true of loss;

Material organizational work that needs to be performed to allow care work to take place. This work involves planning in advance, adjusting work and family life as well as commuting time, time for shopping and so on. This form of work in particular comes into conflict with the ideal of self-care and time set aside for exercising and doing physical activity;

Maintenance work, which refers to the practical activities involved in maintaining a life and relationships. The former includes, for instance, adjusting the spaces and times spent cooking fresh food or a certain amount of

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[72] See the world diabetes day 2019 theme "protect your family" url https://worlddiabetesday.org/about/2019-theme/

time spent looking for the right products at the supermarket, while the latter often includes holding family dinners to maintain family bonds. Even when carried out alone, therefore, this type of work is highly relational. It also involves technology and objects, for instance the work that needs to be done to adjust to a device or a new therapeutic plan. People must actively shape their relationships with their devices;

Emotional work touches on most of the categories listed above, but it is especially relevant in maintenance work because it involves the daily work that people need to perform in order to follow, or deviate from, the specific feeling rules that define their roles, identities and hopes. Of course this kind of work is a part of life for everyone, but we have seen that the intersection of chronic illness work and emotional work has important consequences for people with diabetes and their significant others.

Translation and dissemination: I have shown that patient groups are able to share this knowledge and translate it to others through the care practices that they have managed to set up over time. The first way they do so is by sharing stories and strategies, tips and suggestion; however, they also pass on this knowledge through objects, practices, stories, buildings and the environment. Moreover, they enable technology transfer when sharing knowledge about and tips for using certain instruments. Collective care practices are adaptation strategies for using objects and instruments.

From a relational perspective, there is something to be said about the biomedical concepts of *lifestyle* and *self-care*. In the case of diabetes, although this could be generalized to other chronic illnesses as well, the illness cannot be treated as isolated and detached from the person's daily life; instead, it is present in a series of practices that involve the person in relationships. Because the chronic illness is so pervasive, biomedical concepts such as lifestyle and self-care can hardly be applied to real life. People may make use of them to a certain extent, but never fully; rather, they choose when and where it is possible to use them or not. Because these concepts refer to individuals, taking for granted that individual people are able to make choices on the basis of what is best for them, these concepts are blind to people's relational lives. They fail to consider that people with diabetes are involved in care relationships with others. In their everyday lives, people with diabetes make choices not on the basis of lifestyle options, but according to what works better in terms of being a certain kind of person, with a role and identity. Choices are thus made in a constant balance between what it is good for diabetes and what is good for work, family, parents, children, friends and so on (Mol 2008). While biomedicine reads these choices as examples of compliance or non-compliance, a focus on care practices allows us to see the invisible work that people perform in everyday life, the compromises they must make to maintain a balance among diabetes and emotions, relationships and the tasks they are required to perform.

There is also a close link with citizenship. Eating and food preferences are thereby positioned as integral to a seemingly virtuous self-care that enacts "good citizenship" through responsibilized caring for both the individual and social bodies (Abbots, Lavis, and Attala 2016). Since the overriding concern with diabetes is obesity, new patients are exhorted to lose body weight. Through such discourses, the body emerges as central to the enactment of neoliberal citizenship. Eating becomes entangled in neoliberal notions of individual responsibility and continuous self-improvement through the feeding of others, especially children, which is also an act that must be performed within disciplined parameters (Zivkovic et al. 2010; Truninger and Teixeira 2015). While neoliberal and biomedical concepts are disseminated by various actors, however, people practicing care with others play with them, practicing care that is shared and performed. As suggested by Yates-Doerr (2012), diet systems cannot be read as only a devise of biopower. Rather, they must be approached as a template on which teaching and learning are set into motion, becoming transformative objects. I suggest that it is not only neoliberal ideology that permeates this process. When eating, training and the use of medicine and devices are unquestionably entangled with notions of responsibility and good citizenship, they can also turn into collective practices of avoiding waste, fighting industrial-type food and playing a role in food production and consumption. This process also involves granting attention to the environment, to other bodies and health. Logics of care and logics of choice mingle, interacting with each other and producing new objects and frames which sometimes subvert previous narratives. As Viseu and Suchman have argued, they operate to reproduce dominant discourses of personhood while at the same time reconfiguring such discourses. They have the power to hold together different, heterogeneous imaginaries (Viseu and Suchman 2010).

The last point refers to the care practices and knowledge of collectivities such as this particular patient organization, Adico. Together, organization members share practices and knowledge about all the types of work described above. Even more so, however, they actively create instruments and objects, ethics and values by being together. They embody a shift from an ethics of the individual to a collective ethics, for instance in the way they practice reading nutritional labels and making available a micro-politics of food and eating. Furthermore, they enact a shift towards aesthetic values, the set of values referring to what people find proper, tasteful, stylish or pleasant. This is what the battle assemblage brings to the surface. To live a good life with diabetes, what matters is keeping track of the kinds of materials, senses, objects and affects that biomedical knowledge-forms and practices such as diets tend to exclude. In this setting patients' knowledge is never mere experiential knowledge; that is, it encompasses invisible and invisible elements that extend far beyond chronic illness itself. The knowledge of patients, and "expert patients" in particular, is the focus of the last chapter.

CHAPTER 8 – KNOWLEDGE IN CARE PRACTICES

The findings of chapter six highlighted the link between citizen's codes and health, particularly intertwined with the figure of the patient citizen: as an abstract identity, this figure encompass the virtues of the good citizen who knows his or her rights and duties as well as how to express concerns and make claims in relation to other experts appropriately and clearly. In this vein, Mol uses the term "patientism" to refer to the establishment of citizenship as the standard of normality. The key question, according to Mol, is not how "active" patients are but what kind of activities they engage in, what treatments they demand and what they are asked not to do. How to include the treatment in your daily life without interfering too much with other things that are important to you? The point, she argues, "is not choosing between 'measuring' or 'not-measuring' but figuring out how to measure. How to go about it" (Mol 2008, 53). Chronic illness patients are active in the sense that they need to do a great deal in daily life and this effort lies not in using of choosing a treatment or service but in the care practices they perform. It follows that the logic of care has no separate moral sphere, because ethics intertwine with facts and caring itself is a moral activity. There is no such thing as an (argumentative) ethics that can be disentangled from (practical) doctoring. "You do what you can while watching out for the problems that emerge – in bodies or in daily lives, caused by the disease or by its treatment. What goes wrong, where does it hurt?" (Mol 2008, 79).

As these contributions point out, patient and lay knowledge assumes different features according to the contexts in which it is used and is often associated with biomedical knowledge, health care policies and the organizational practices of these policies. At the same time, consumer culture plays a major role and does not necessarily follow a different logic than that of biomedicine. Instead, they often appear to be integrated, sedimented alongside positions of dependence on or independence from professional biomedical knowledge. However, the focus on care practices and awareness allows us to cross the divide, integrating expertise into life strategies and daily care practices. From a relational materialist perspective, policies and organizational arrangements are of paramount importance when interacting with medical and care practices within assemblages: in doing so, they provide a logic individuals are supposed to follow in order to become good patients.

This chapter takes a closer look at patient knowledge, a form of knowledge embedded in practices. In chapter six we explored the model of the competent citizen, but what about other patients? The "expert patient" appears increasingly frequently in health care and the best way of gaining a more complete understanding of this model is to examine it as it is used. If the "competent citizen" operates as an ideal patient model that is useful for rendering certain norms and values more desirable, what about the "expert patient" in this situated context? And what kind of knowledge is displayed and used by these expert patients? In other words, what does "expert" mean and how is such expertise used in this case?

In order to look at knowledge embedded in care practices, I will focus on the device of therapeutic education. In this case study, such education is practiced at length and encompasses a variety of activities. In the previous chapter we had the chance to explore some of these activities in detail. The story of education practices at the Copparo diabetes clinic is, to some extent, the story of negotiating the care practices, ethics and values of a group of professionals working together in diabetes care. Their story also encounters the stories of various patients, bringing about new instances of transformation and revolution in terms of care practices. In this chapter I show that these education practices are not imposed from above, deriving from protocols and programs, but rather spring from care practices shared among professionals and patients, from certain ethics and values of care developed over time.

Through therapeutic education it is therefore possible to look at the expert patient subject. As an instrument, this subject is used for activities both inside the clinic, as with Conversation Maps™, and outside, for various kinds of events organized by the patient organization. Indeed, therapeutic education is an umbrella term which, in this context, includes a range of practices and techniques. In my analysis here I focus on the educational activities organized by the diabetes clinic, in particular Conversation Maps™ and foot screenings, and those organized by Adico, for instance the yearly residential campus, collective walks, the cooking lab, workshops on food, nutrition, and physical activity and events that do not specifically address these topics in terms of information but do constitute moments of collective practice, such as the making of a communal meal. As for family practices, all relational practices are also simultaneously forms of embodied knowledge such as the knowledge that is generated by the interweaving of biographies over time, possessed of a fundamental sensorial component. These educational practices involve the use, recognition and generation of such knowledge (Morgan 1996).

NODES

It is Friday morning at the diabetes clinic. I am in the waiting room talking with Nora while Eva and the other nurse are busy carrying out foot screenings in the other room. Friday is also the day when Nora comes to the clinic to interact with patients. She has previously informed Adico members that they could pay their membership fee of ten Euros that day, and that she was going to be at CDS in the morning to collect the payments. The money will go to fund the support group meetings and some other activities. All of Adico's activities are funded by its members themselves and the fundraising is done through social events. Our conversation is interrupted by patients coming and going from the clinic; people ask questions about the organization and Nora invites them to join. She takes the time to present what the organization does and why it is important to participate. Eva is the first person to mention Adico to patients, however; she is the first node. She introduces Nora and leaves them to her explanation. Nora is the other node. There are also patients who know Nora and Eva very well; they are members of Adico who have come to pay the yearly membership. They ask about the next events, but they also chat with each other about everyday topics: how it is going with work, how family members are doing, health issues and so on. With a man they strike up a conversation about politics and the new elections, with a woman they start to talk about her feelings of being sad and depressed, how she finds it difficult to leave her home. Both Nora, and later Eva, tell her to come back to the support group. I understand that the woman used to attend the group but quit at some point. “It would be great if you came back”, says Nora. The patient organization, Adico, plays a huge role in connecting and creating knowledge through practices because it enables participants to practice care together, to find ways of doing “good” care.

In order to uncover patient knowledge, this chapter follows the nodes of ecologies of knowledge embedded in medical and collective care practices. I argue that medical practices, which follow a logic of care, become relevant in the making of patient knowledge in that, while practicing care, patients facilitate the circulation of this knowledge and legitimize it in the eyes of a larger audience. To see this process unfold we need to look at nodes. It is in these spaces, through their care practices and care work, that the process becomes visible.

PRACTICING CARE IN TIMES OF RETRENCHMENT

As Annemarie Mol has argued, doctors and patients enact reality together and need each other in order to act out the reality of a disease. In this situated context, therefore, diabetes care practices are the result of shared practices, of collaboration between patients and doctors. Patient knowledge does not come spring into being on its own; it is practiced over time, and Eva and Doctor Z are nodes of patient knowledge as well. They have an important role in its circulation: they allow it to spread beginning from the patient’s first visit to the diabetes clinic. The history of the diabetes clinic, the practices and knowledge of its professional staff, unfolds together with the history of the CDS in an archive of practices. I propose to look at the daily medical practices of the diabetes clinic at the CDS by also looking at how these practices develop. I explore professionals in this situated context have decided to practice a certain form of care, why, and with whom, because, as Mol suggests, the linguistic repertoires entailed in this collaboration are part of what takes place in hospitals. For instance, I am interested in investigating what sort of relationship they set out to establish and what practices they wanted to replace: what they found “wrong” in medical practices, how they turned these into “good” practices, and how this relates to patient knowledge. As a form of relational care work, medical care is performed according to shared ethics, values, and, as Pols suggests, aesthetics. Therefore, breaking with or following certain logics and norms in diabetes care is significant in the making of doctoring practices, particularly in times of retrenchment, under the agenda of NPM and the new programs of the EBM.

The hospital of Copparo, now CDS, was first built in 1900 and later enlarged with a second floor in the 1930s and a central hall in the ‘70s. It has reached a capacity of almost 200 beds, with wards for surgery, gynaecology and internal medicine. It is the perfect example of the characteristic hospital of the 20th century, located in the centre of the town, right behind the main square, surrounded by bars, restaurants and cafes. The day I entered the CDS for the first time, Dante welcomed me to the Adico office on the first floor. He described the territory of Copparo with the eye of someone who had grown up in and always worked in that territory, viewing the transformations of health care as a whole. Though he is now retired, he worked for the AUSL Ferrara at the hospital of Copparo for his entire career, taking on different tasks and roles. The story of the CDS begins in the '90s when it was transformed from a hospital to a community hospital. This restructuring of the peripherical hospitals in the area also involved six hospitals other in the province of Ferrara, while the university hospital of Ferrara was reinforced and expanded. For some peripherical hospitals, the restructuring led to isolation while others turned into long-term wards and still others, as the one in Copparo, opted for a change in terms of care services, focusing on primary care and "integrated" social and health services in the local area. At that time the area was already displaying signs of change: the population was constantly and inexorably decreasing, with dropping birth rates and an aging population having an impact on health services. One in three local residents is now over 65 years of age. Data from the ER Region show that the dependency index of this area is very high and, beyond data on aging populations and low birth rates, there is a substantial care burden. The need for care was changing, says Dante, so health care and social services needed to change accordingly.

From 1997 to 2000, with the aim of dealing with the population's primary needs, the hospital of Copparo was turned into a "community hospital". A few years before the region's implementation of new guidelines, a 2002 document called the "community medicine project" narrates this experience of transition from the point of view of the people who pushed to make the change. The Community Medicine project was not imposed from above but was instead conceived "during a dinner around a kitchen table" by a group of people who knew each other. They included, among others, the head of Copparo, several doctors and two directors of AUSL Ferrara districts. It is clear that the authors of the document were aware that they were, to some extent, on the front line of new health care policy and organizational models. According to Marco N., the former director of Copparo and the Ferrara District, they had numerous difficulties in tackling obstacles due to the "rigidity of normative instruments that could not be adapted to change". But what precisely was their insight? In order to "save" the hospital, they decided to move beyond a hospital-centred model, to redefine clinic and diagnostic protocols in collaboration with family doctors and, finally, to improve the use of clinical and pharmaceutical data. The new organizational models linked existing units with local-area services. At that moment the district of Copparo encompassed six municipalities with approximately 40,000 inhabitants. Dante, who was director of internal medicine of the hospital at that time, wrote in the document that, even though their intuitions happened to be correct and the model was later echoed by regional policies, the hospital model continued to follow the imaginary of the community; indeed, community was a point of reference for them, the only available and viable solution. It constituted the link with all the "resources of the territory, including voluntary organizations" thanks to which the proposed change could take hold in the imaginary of the community.

That passage written by Dante came to my mind many times when I was at the diabetic clinic and I heard people repeatedly referring to the clinic as "the hospital", only rarely using its current name, *casa della salute* (CDS), literally "health home". The CDS now has a very limited number of hospital beds, but it provides primary care 24 hours a day and includes other specialized medical services and clinics, one of which is diabetology. Today, the CDS "Terre e Fiumi di Copparo" is considered one of the most successful examples of its kind in ER, at least according to the Territorial Services of the ER Region. What places the Copparo CDS in the vanguard is not the building or the particular foreground medicine practiced there, but the fact that different professionals cooperate and work together, starting with family doctors. Here, the CDS derives from care practices. It is an advanced case of integrating social services and care. What made these professionals want to work together? What are their care practices?

Eva was very happy to talk about these issues in the interview. She is set to retire in one year, just before Doctor Z with whom she has shared most of her career. Eva will be the last of the diabetes nurses to retire. Since I joined the clinic to carry out fieldwork in March 2018, two nurses have retired. Eva will leave next year. This is part of why Eva is happy to tell the story of the clinic, the hospital and what it has become. Her story is also a collective story, a story of the clinic and all the people who have been involved in it over the years. Her husband, Dante, has already retired. In a few years, none of the people who have been working at the diabetes clinic will be working there anymore. At various times I had the impression that, for them, this particular moment of fieldwork also represented an occasion to share their experiences and memories. Eva's story of her career talks about the transformations in health care that have occurred over the last 30 years. It says a lot about doctoring and the *subject nurse*, located at the intersection of medical, gender and care practices.

REPOSITIONING CARE IN MEDICAL PRACTICES

In Eva's view there is a turning point, a specific moment of change in her work, that is precisely located in time: the last decade of the 1990s and the first of the 2000s. It was the right moment for change. After becoming a specialized diabetes nurse, she started to work on education. Both of these pathways were quite rare at the time, says Eva. Before working steadily at Copparo, Eva, doctor Z and another nurse were the staff of a "mobile" clinic, moving every day to a different setting in order to cover the whole territory of the district. The professional team of the clinic shared the same vision and slowly decided to work towards common goals. It was a group of people who decided to make a break in terms of care.

> When I came to work here, in 1995, I could not understand why my colleague, when I was measuring the glycaemia of a patient, were saying: "you don't tell it [the number] to the patient, the doctor does". I wondered why. Everything I was doing, she was saying "you are a nurse you can't do that". Sure, I am a nurse, but I work together with the doctor, I am here for the patient. Why can't I tell them. It was a different way of working, also as organization. After a while my colleague told me that I was interfering with the way the work had functioned for many years. I started to be tired of working with patients getting upset because they were all supposed to come together here in the morning at 8 a.m. Some of them were waiting here for

> many hours. When we started to work together with Doctor Z we decided to try to change this, to work better for ourselves and for them, so they did not have to wait for hours. In those years I was upset with patients as well. They did not know many things but were certain they knew better. So, with the doctor, we started to think about education… but what and how? We wanted to do something more than what they usually did in clinics, which is training to learn to use instruments. We wanted to help the patients understand why they were being asked to do certain things. It was a long and huge job. (…) if you really want to make things better and you believe in what you are doing you can create an organization that makes it possible to care about those patients who really need you. So we wanted to have a diabetes clinic specialized for people with complex needs, with specialist medical and nursing activities for people who are insulin resistant or type 1, while many others go to family doctors. At the same time, Gestione Integrata was arriving in those years.

This extract describes how Eva and Doctor Z's working together allowed them to change medical practices in their situated context. Again, this was not a change initiated from above; it was instead driven by their practices and situated ethics of care. The example of the waiting room is particularly important because it has less to do with diabetes care and more to do with care ethics and the fact that Eva wanted to put these ethics at the forefront of diabetes care. Not surprisingly, there are still clinics which use this system to organize their visiting hours, a system which in turn penalizes patients. They also decided to invest in some way in what later came to be called Gestione Integrata (GI). It is interesting to note that their perspective in implementing this approach follows a quite different logic than the one we have seen in Chapter 6. While the former is led by the need to spend more time with patients with complications and use the remaining time to carry out active education, the latter was motivated by the need for early diagnosis and to reduce hospitalization costs. Eva wanted to change nursing practices by applying different ethics. We can now see what different ethics has meant in terms of the organization of care work in the clinic as well as education practices with patients.

At the beginning of the 2000s, Eva left the clinic to work as a nurse coordinator (*coordinamento infermieristico* in Italian), aiming to uniform all the diabetes clinic of the AUSL about services, practices, care and service delivery so that they could all begin following a unified clinical model. Eva describes that as a moment to become more familiar with all her colleagues around the area, to share ideas and practices. Indeed, this process is still ongoing and others have come to observe and implement it. It is similar to the process that took place at AUSL Modena years later, as we have seen in chapter 6. In the case of Copparo, however, it was not driven by policies or patients, so where did it come from?

> At some point we realized it was good to work synchronically in what we were doing, that we were united and that we wanted to know each other… before 2006 I did not quite know how diabetes services were in other places and who my colleagues were… everyone was doing their

> job and did not know the others even if we were all belonging to the same operative unit. We said it is time to know each other. From there, we started to do meetings and the audit we are still doing… we wanted to ameliorate the assistance for what concerned medical and nursing practices. so, we were helping everyone…and if I had a problem, they were trying to help to solve it. It became really a nice way in which we were all united, where everyone knew the others were there. I noticed also how much this model was taken from others, I saw it every time I was asked to present it somewhere, or people from other AUSL were coming to look at it.

When Eva talks about integrating services and restructuring, she talks about a group of people who got to know each other, started supporting each other, and then "integrated" with each other. It is a story of change towards a new model through the language of care practices. It is the practice of listening, sharing and solving problems that constituted change. She talks about care practices that were developed over time, practices that followed a logic of care.

PRACTICES OF TINKERING AND PLAY: MUTUAL LEARNING AND ALLIANCE IN DIABETES EDUCATION

Therapeutic education is a way of looking at doctoring practices: at the ways in which care practices produce hybrid knowledge from attempts to practice "good" care, mutual learning and forms of alliance. Eva and Doctor Z decided to focus on education, with both of them seeking out training so as to provide themselves education to patients. They shared the same reason for taking this step: they noticed that it was good for patients; they realized that it was good care, both in the clinic and beyond. Eva says they understood people needed to receive more information about diabetes, and the staff likewise needed to understand patients more fully. This is how the shift began. Eva and Doctor Z tried out different sorts of techniques over the years, from a theatre forum to Conversation Maps™. While giving education about diabetes, Eva was also learning from patients what worked more effectively for them. Doctor Z says that she spent nights and days thinking about how to help people understand the basic mechanisms of diabetes, to make their lives easier. For one attempt, she built cardboard boxes that patients had to open, discover and play with in order to make the process of understanding complicated things easier and more fun. However, she explained, "we finally found out the best way to do education only when we understood that we had to be silent and shut up". It was through this process of trying out and tinkering with ideas that Eva understood "good" ways to do education with patients:

> We realized what the big advantage of therapeutic education was when we started to do Conversation Maps in 2009. Before we had tried many other things out: a sort of involvement of patients in lectures, asking about the experiences of patients, or asking them which issues were more interesting for them, like complications, nutrition, control and management, diabetic

> foot and so on…and we were discussing these issues with them, or even playing with them, with them looking for surprises in boxes… and finally we got to know Conversation Maps, the doctor and I become expert trainers and we understood that it was the best way to interact with them, to involve them in a conversation where the professional becomes a facilitator and the patient becomes the expert of everything that happens in the conversation. We understood with the doctor that we needed to work in small groups, with a map of pictures that helps [facilitate] the conversation and understand things better. And so, for us, this was the approach for us to use and we still do it.

However, while education was appreciated by the patients, it was not very appealing for other professionals. Since their professional mandate at the level of the health organization was not organized to include education, the result was that there was very little space for education in diabetes services. At the Copparo diabetes clinic, however, matters were different. Eva and Doctor Z were very much involved in education and, together with Dante who was responsible for diabetes services, they decided to reconfigure the services to make room for education in terms of both time and physical space:

> We started to think that the services needed to be reorganized in order to create spaces, because if we want to make room for education, we can find it. Since the doctor was working part-time, we decided to leave one day, Fridays, for the nurse clinic, a day in which nurses can work autonomously, do education and foot screenings. We started to do these things by giving value to the work of nurses, [but] not a nurse who [only] opens the doors, while the doctor does everything, and then says goodbye to the patient. The chronic patient, we realized, needed more than a medical check-up. We needed to find ways of accompanying the patient, until, outside of this door, they are able to manage their diabetes.

In this interview extract, Eva not only describes changes in terms of organization, she also highlights the way the staff put distance between themselves and certain codes of behaviour associated with the role of nurse and certain ways of supporting patients. This shift was a result of trying things out, playing and tinkering with patients and the very activity of being a nurse. The caring relationship they were practicing with patients was of another kind, different from earlier practices, and Eva was “more than a nurse” in the sense that she was practicing other ways of nursing. She valued different ethics of work and care, not only inside the clinic but also outside of it, with the staff’s ethics and values including daily life. The result of this process is conceptualized by Eva as an achievement for both sides, touching on not only relationships but diabetes as well:

> It was a huge achievement… meeting the patients, not seeing them not only in the clinic but also in other places outside, being together and so seeing how their lives are… it helped us to understand how we needed to support them. We changed… I have to say that my change happened there, when I saw patients not only as clinical data but in daily life.

For these healthcare practitioners, therapeutic education was a fundamental component of clinical care and a turning point. It was a way of building intimacy and practicing care together. Education is not an achievement, however; it is a practice, a way of practicing diabetes care, and even more so, a constant practice of learning and sharing. Moreover, this practicing of therapeutic education later led to cooperating with a patient organization and finally, ten years ago, with a psychotherapist, Manuel, who provided training for the whole diabetes staff and trained Eva in particular to be a facilitator. For six years now Manuel has facilitated the support group twice a month, and he has also been involved in organizing the campus for many years. Eva references these developments when talking about the advantages of cooperating with the patient organization. Changes, in her story, are driven practices of *alliance* with patients, which Eva describes in this way:

> Chronic patients need to be understood in their family environment. Only in that way can you create a compliant patient, a patient who is next to you because you understand them. It is very important. So, everything you learn at school, that you as a doctor need to cure, to help… here the focal point is psychology… the chronic patient will always have the illness and so you need to help them to go hand in hand with the illness and to slip into a change… because you always ask for a change. It is not easy to support and guide them (*accompagnare* in Italian), we will never cure them, we can only support and guide them. We always tell them: we can give you some advice, but it is on you to take my hand, you just need to remember my hand is here, I can't force you. The doctor always says: look, I would need to change your treatment because of this reason, would you agree with making this change?", there are patients who say: I don't want to take insulin. Then the doctor explains the pros and cons, that we can try to do in this way and compromise, if the solution does not work, we will fix it, but for now the patient needs to help the treatment with physical exercise, nutrition and with being compliant. "Let's see what we can do together". I really appreciate that. The doctor has always been like that, but it was Manuel that made us understand what alliance with the patient is, why it is important to create it in order to have a compliant patient.

This extract suggests that the process of alliance-making is itself the objective. As a relational aim, it has no end point. It can change and develop in unexpected ways. Interestingly, it was through embracing another form of knowledge and practice, introduced by Manuel, that this process began. The making of a compliant patient subject is one of the possible consequences of the alliance, because they both move within a care relationship that is meaningful and in which they are interdependent entities. What Eva suggests in this passage, however, is that there is no possibility of making a compliant patient without alliance. Within a logic of care, the task is to create a relationship based on care in which the actors are trying to identify the best possible solutions.

The story of Eva and Doctor Z, the values they enact in care practices and the wealth of her experience is visible in the outpatient clinic. The walls in not only the waiting room but also and especially the exam room are full of images from Conversation Maps™, theatre-forums and materials they have written themselves over the course of years of work. It is not hard to recognize some of the same patients who sometimes participate in Adico events in these pictures taken more than 10 years ago. This is a community of practice with a fragile future, a community that needs to preserve the memory of what it has done and achieved.

PLAYING WITH THE WHITE COAT

At the 2008 campus, the first discussion among the group of participants revolved around the extraordinary fact that Eva and Doctor Z were there and planned to attend the campus at their own expense, as they have always done in the years the campus has been held. In the morning, several people also shared their experiences of being patients of Doctor Z, agreeing that she had made it possible for them to understand and change the course of their diabetes. When the patients compare her with other doctors, Doctor Z always comes out on top in their stories because she does not humiliate them or make them feel ashamed. In the group discussion some participants remark on this fact, and one person says that he appreciates the fact that both Doctor Z and Eva are at the campus "having taken off their white coats". I wonder whether they find this extraordinary because, without their medical coats, there is no marker of official knowledge that can prevail over others. However, this is a very energetic discussion that draws everyone in. It seems they all agree when Nora makes a final comment: the white coat is always present even they are not wearing it. Hierarchies still exist, but it is important to have spaces without them because the medical professionals' willingness to participate in a non-professional capacity indicates that they are all on the same level. It communicates that they want to go beyond their duties as professionals and "put themselves out there" (*mettersi in gioco* in Italian). Doctor Z intervenes at this point, talking about her story. At medical school and in the early part of her career she did learn that it was a good practice to tell the patients who were achieving good results that they were behaving "well". This made patients happy and led them to say "thank you", she for her part she felt gratified at their expressions of appreciation. She said, however, that her moment of change happened when she decided to do something different. She understood that, through this stance, she was placing herself at the centre of the process. She thus began to say "thank you" back, because, she said, patients help her a lot every day: "When I go to the clinic in the morning and I put my uniform on and wait for the first patient to come, I forget about bad things that happen in life. You help me every day; for me, my work is one of the most important things in life".

Being present without serving as a representative of biomedical knowledge is a way for Doctor Z to generate relatedness and relationships, something that she does by sharing in the practice of being part of the group, sharing examples of fragility and personal stories. To an external person like me, this sounds like quite an out-of-the-ordinary situation for a doctor-patient relationship. The reality is not that simple, however. In fact, at the end of the discussion, Nora feels compelled to pose a question to the group: "if things are going so well, which they are, why are we not able to get more people involved?". The conversation becomes animated again, and it is Nora once again who talks about how difficult and frustrating it is to convince people to come and join the organization.

WHAT DOES A HYPO DO TO YOU?

The day before, at the Campus, we are all sitting next to each other. After having discussed and shared information and experiences about apps and devices for exercising, Doctor Z asks Aldo how he is doing with the continuous glucose monitor he has recently started to wear. There are a few people in the room who are using it; besides Aldo, Carlo and Anna also have one. Doctor Z is not asking in general; she is actually interested in finding out about hypoglycaemia, in particular whether there have been changes since the patients started using the device, if using it enables them to avoid hypos. While they all have positive feedback to share, they all report very different experiences, sensations, feelings and moments of intuition. The feeling of a hypo is not the same for everyone; it varies a great deal from person to person. It is also never the same for the whole life. People begin to feel it less and less as they age. In their stories, however, the device has changed their perceptions of hypos. They can see and feel it coming in different ways. Also, they are able to act more quickly and thus avoid it. All of this information is very new: not a lot of data has been collected because the technology is constantly evolving, and Doctor Z wants to know everything. She asks about differences as compared to before, about body sensations, about emotions. The patients themselves are beginning to understand each other's sensations better and find the right shared words to describe them. They can make fun of them or share moments of fear and anxiety. This is a moment of co-production in which hybrid knowledge and care are co-created in more-than-human worlds. In this case Doctor Z is also operating as a node, as she is the one who will translate the knowledge that is produced here into biomedical knowledge.

ALDO

Aldo is 63 and has had type 1 diabetes for 44 years. It was only ten years ago, however, that he says he began to understand how diabetes works what makes him feel better. A huge step in this process was his moving to the diabetology unit, meeting the staff and having many of his questions answered. He reports that Doctor Z's attitude was very helpful in making him feel understood and safe. Aldo has developed several serious complications and is at constant risk of hypos. Another big step in his process was becoming part of the diabetic patients organization. Living with complications but in a safer, relational arena has put Aldo in a different position, what he describes as a "change". In one year, he has learned how to count carbohydrates so as to use the continuous glucose monitor. Through this device he keeps track of his blood sugar level and is able to calibrate the insulin he needs and keep it balanced. The tool has been very helpful in his daily life. He used to cover the expense himself, paying 120 euros a month or 1,440 euros a year out of his own pocket. It is very expensive, and since 2016 the ER Region has decided to reimburse this cost for patients who meet the eligibility criteria. As we have seen in chapter six, in order to obtain this device for free patients need to make an agreement with the diabetologist. They need to work on their diaries together with the nutritionist and diabetologist and learn to do carb counting. The doctor makes a treatment plan together with the patient. The patient is asked to follow the plan and attend a screening every three months to evaluate the treatment. Aldo is thus able to obtain everything he needs for free for three months, and then he has to go back to the clinic. If everything is fine, he will be given supplies for three more months. Aldo has done all of his homework. His daily life has improved quite a bit with the device, or in other words Aldo, by intra-acting with the instrument, has changed much of his daily life. Every time he feels something is wrong or is not sure he carries out a scan and, if his blood sugar level is unbalanced, he can immediately fix it with insulin or sugar. This is particularly helpful, he says, because it becomes difficult to feel symptoms when you get older. This is a common consideration expressed by older patients.

Together with his wife Aldo has bought a camper and they often travel. Now Aldo goes up into the mountains to an altitude of 2,500 meters and being there makes him feel better. He says that his diabetes is also better when he is in the mountains. This has become possible for him because he can both climb and check his sugar level from time to time. If it goes down, he immediately eats something before even risking a hypo. He is more aware of what is happening with his diabetes, he says, even though his senses no longer help him in the same way they did when he was younger. Aldo had to do a great deal of work to achieve this, however, performing more than forty years of chronic illness work and gathering experiential knowledge from daily practices. For a few years now he has been gleaning such knowledge from other people as well, when he joined the organization and started attending all the activities and educational events. Some knowledge comes from very far away, while other pieces of information had to be replaced by new findings; some other knowledge is very recent and derives from collective practices. His process is the same as any scientific process. The CGM is always there with Aldo and it is also present in his relationship with Doctor Z. All the data that passes through the CGM is visible from the remote. This is what happens when he goes to the diabetes clinic, every three months:

> when I go to Doctor Z I give her my CGM, she uploads it onto her pc and tells me to get a chair, sit next to her and we look together. We look at what happened day by day and she asks me “what happened here?” This is a very nice thing for a patient, to go and sit next to the doctor and explain something to her. This was never seen before. It was always like the doctor sits here and the patient over there, she writes and then you leave. Now I go to her every four, six months, when I finish the strips I will go in three months and I hope to get more, otherwise I will need to buy them. The relationship with the doctor here is different; you can tell her everything, she explains [things] to you, she talks to you… it is a relationship on the same level, with other doctors it is not like that. When I come to the clinic, I know I am not going to be

> yelled at, I am not afraid of what she might say if she finds I have higher values, no, she is like a friend, so you go gladly.

This story is not about how a continuous glucose monitor changes the life of patients and opens up a world of possibility. It is about intra-action with the CGM and how Aldo and the CGM together have changed daily practices and knowledge in a safer, relational arena. The practices founded at the clinic work well for Aldo. He has found "good" care for himself together with other people and the objects around him, including Doctor Z. For her part the doctor has also changed her medical practices, and relationships with patients in particular, through the introduction of new instruments.

LINDA

This story is quite different even though the type of diabetes Linda has is not so different from that of Aldo. Unlike Aldo, however, Linda was denied eligibility for the CGM, somehow failing to meet all the requirements set by the region.

Linda is 66 and has had type 1 diabetes for 55 years. In her interview she says that she lives with diabetes but has never been able to accept it into her life. Recently, her husband was diagnosed with cancer; at the moment of the interview he just finished chemotherapy. She said that she had been very stressed since this happened and still has a lot of emotional burdens to deal with. At the same time, she had a bike accident and had to undergo treatment herself as she was experiencing body pain. She said that the previous months had been quite tough, which of course has influenced her diabetes enormously. She often experienced blood glucose peaks and was feeling very down. Her friend Anna, who also has type 1 diabetes and has been her friend since they were children, gave her a CGM as a birthday present. For all these reasons and because she found CGM very helpful, therefore, she asked the diabetology clinic and Doctor Z if she could enter the program. She was denied entrance, however. Unlike Aldo, she did not do her homework. She never really learned how to count carbs and she did not fill out the diary, so she did not obtain approval from the nutritionist. When I met her, she had recently received this news and was very upset about it. She had been counting on the fact that the doctor was perfectly familiar with her situation and that, after all these years with diabetes, she knows how to use the device and what she needs to do. She is an expert.

The tension here is between Linda's knowledge, which she claims as expert knowledge, and the knowledge of biomedical practices driven by EBM: her knowledge does not count when there are standard requirements to meet, requirements that need to assume specific forms. The other issue is that instruments do not function by themselves: they need to come together with the practices and knowledge that allow such devices to do their work. The standards are established to ensure that the CGM will go hand in hand with knowledge and practice; they are intended to guarantee that the results will be satisfactory. This pushes Linda further away from the relationships she has built and the care such relationships have enacted up to that point. She feels safer with the instrument, because she is not afraid of doing things by herself. She explains that she is very tired of measuring her sugar levels by pricking her fingers until she cannot feel them anymore but, as we have seen, this is not considered a good reason to ask for the CGM. She was angry with the staff. The nurse told her that, if her diary had not been filled out, she would need to come back in a month with everything done and at that point the doctor would allow her to enter the program:

> And I got upset. Because they know me, I have crazy decompensations, now I fall down and my back hurts… when you have a problem your blood sugar goes up… I know because I always prick my fingers. But they told me "no". This morning I had an appointment with the nutritionist, I told her what had happened, that I could not follow the diary for fifteen days because I could not eat, I was not feeling well, I spent a night at the hospital and was taking pain killers. So because of that I didn't bring my diary with me today. I made another appointment at the end of the month. So I went to the nurse, I also told them this, and they scheduled me an appointment the same day I have the nutritionist, she says: come after with the diary, the doctor will see that you have understood everything and she will give you a CGM (…) to check my blood sugar with the CGM for me is relief. I will never stop saying that. For Anna it is the same. I don't understand why this morning the nurse told me that the doctor has her opinion and you can't change that. I am sorry because they know me, they know what happens with my diabetes, even with bad thinking I have 300.

The CGM does not grant autonomy to patients, but the use of it allows them to enter imaginaries of safety and control, helping them feel they can do ordinary things that would otherwise make them unsafe. In both cases it has transformed the relationship they have with the environment and with others such as professionals. In one case, it has helped to build intimacy with the doctor by sitting side by side and looking at the data for the last few months. For Aldo, the very materiality of the CGM and the fact of his being found eligible for it has also involved a recognition of his chronic illness work and the effort he had made, for instance in learning how to count carbs. Aldo has accomplished all that was asked him to do in order to obtain the Flash. He succeeded and he is now experiencing a different relationship with Doctor Z, a relationship that works even better for him. His life has also improved with the Flash.

Linda has a different story. For Linda the CGM has brought tension as a result of her not feeling recognized in terms of her suffering and the work that she has done, because she has been negated access to an imaginary of safety and freedom. What she did was not enough to meet the requirements set by the region, therefore she cannot access the device. This causes frustration and a sense of rejection. In her case, the protocols have brought about confusion in her care practices; they have seriously challenged them. Linda's story also raises the issue of access and meeting certain requirements. In this case as well, the invisible care as well as the emotional and chronic illness work that lies in the background would need be brought to the surface and acknowledged, including in terms of tensions and conflicts. Both Aldo and Linda are patients who have been engaging in education for many years. They are sharing patient knowledge and serve as points of reference for others, especially people with type 2 diabetes. While they might be granted a CGM or not, they nonetheless represent important nodes of knowledge because of their long-standing experiential familiarity with diabetes and chronic illness work.

THE EXPERT PATIENT AS A NODE OF KNOWLEDGE AND PRACTICE

As we saw in the previous chapter, Nora is a focal point for many relational networks in the area of Copparo. She is involved in multiple volunteer organizations and was the first one to push to create a patient organization in Copparo. She is, at the present, an expert patient. The story of Nora's diabetes is also the story of Adico, and it is linked with practices of therapeutic education and mutual learning. In the story, Nora becomes the node of different networks, communities and forms of knowledge.

Nora's father had diabetes type 1; diabetes has thus always been present in Nora's family life, and she was already familiar with the diabetes services and Doctor Z through her father. When Nora's mother died she decided to take care of her father and so began attending therapeutic education, not for herself but as a care-giver, to understand better her father's illness. At that time, there was a doctor – referred to as Doctor Z's *maestro* in various stories – who was organizing education in a way that differed from all the other diabetes clinics. It was this doctor who suggested Nora contact Doctor Z, who was working in a clinic closer to where Nora's father lived. The education Nora received was delivered in the classic format of a lecturer standing in front of the students and addressing a central theme, but she found it very inspiring. She discovered things she had not known and met other people with diabetes and care givers with whom to compare experiences. At the beginning of her career, Doctor Z was also involved in education. Nora describes in the interview how Doctor Z was inventive and always looking for new strategies to facilitate patients' understanding of medical issues and concepts. When Nora was diagnosed with type 2 diabetes a few years later, she herself became a patient of Doctor Z and Eva and realized that she wanted to become more involved. She said: "while talking with people in the waiting room everyone was saying that they (Doctor Z and the nurses) do a lot, that they should be more valued, so then why not organize ourselves as an organization?" Assuming the shape of a patient organization would allow them to enter clinical spaces. With the support of other patients, Nora decided to take the lead and founded the organization. Her contact with Vita was decisive in this process: it as Vita who suggested Nora become involved with the network of organizations that later evolved into Feder. It was 2008 and at that time Vita was the president of the young diabetes patient group in Ferrara. Nora started to attend meetings and assemblies, meeting other people, learning about other experiences and "understanding what we could and could not do". Nora served as the president of the organization Adico until two years ago; even after stepping down, however, she continues to do a lot of work in the organization and as an expert patient. It is, in Nora's view, the organization's close cooperation with the diabetes clinic that allows it to obtain results. They need to complement each other, "each within its role".

> I had lots of help with having to carry forward the organization, really, for many reasons but especially for the management of diabetes. And especially because I got so much, I would like others to become aware of that. I am sorry that only few people take advantage because I am convinced it will not last forever… as long as you have a diabetes clinic like this one we can work well, you feel you are getting better and we help each other because it is really mutual help with them. I am convinced that doctors and nurses have learned a lot from us, we learned from them, but they also did from us.

Being an expert patient has to do with care relationships with professionals and with others. There is no expert patient outside of caring relationships.

Nora is the node that allows patients' practices and knowledge to intersect with medical knowledge and other forms of knowledge, such as for instance the psychotherapy brought into the collaboration by Manuel. Nora is learning from others, and she is also supporting others even as she is being supported. We have seen in chapters six and seven that the collective space of shared knowledge and practices is constantly on the move and changing in unexpected ways. In these spaces, the knowledge in action is created over time together with new practices, objects, and discourses. Nora is the physical node that allows knowledge and practices to move back and forth. How does this take place? Through orientation practices: how to manoeuvre, what to call something, how to ask for help, how to locate the available resources, and how to survive. Through her involvement in clinical spaces, Nora translates these practices and this knowledge into biomedical knowledge. In exchange, she receives the same resources and is able to pass them.

PRACTICING ORIENTATION AS RELATIONAL CARE WORK AND KNOWLEDGE

Orientation, autonomy and knowledge are not skills that people possess on their own; rather, they come with practice, from doing and undoing, from mistakes and new attempts. They are the result of listening and asking, interactions and intra-actions. It is care in action. In her interview, Nora provided the perfect example of what constitutes orientation. She recently had the feeling that something was wrong with her diabetes, because she has noticed that over the course of two years the glycated haemoglobin count was slowly rising. She had talked with Doctor Z and Eva about it in various occasions and, at their suggestion, tried to make small adjustments in her diet and physical exercise regime. It was when they lent her a CGM for two weeks that things really changed, however, because with this device she discovered many things about her daily diabetes. It was an opportunity for her to understand little things, like what happens to her when she eats pizza, for instance, and fix these issues. Orientation is not only about having access to information, tools and technology, it is also about recognizing signs, symptoms and details, noticing that something is happening and recognizing it as a problem. This passage is very hard to accomplish because, in order to notice it, the individual must be close to a "knowledgeable" person who has expertise on the issue.

> it was a great present I got from the clinic and I found out why [things were not going well]. I feel very lucky that I had the chance to do it, because there are people who have the same problem, or worse, and don't have the same opportunity. Not that to say that I have privileges because I am in contact with them, because indeed they make themselves available to everyone… the point is that you, as a patient, need to notice that, first, there is a problem, and second, that there might be a possibility to solve it. (…) we need to work together with the clinic, when people enter they are comforted by knowing there is the support of professionals even if they are not physically present. It is a field we don't know, because I have my experience with diabetes but it is my diabetes, not necessarily good for someone else. Only someone who has this knowledge can help you understand certain mechanisms. I see that during the Maps, which I do very gladly, because while I am doing them I am speaking to myself first of all.

The capital in question is precisely that of organization, the knowledge to recognize problems and process of developing the orientation skills to effectively deal with or solve problems. Such development is possible thanks to the close relationship with the diabetes clinic and the other patients. It is common knowledge in practice. This is how people become expert patients: through *orientation* skills, *communication and translation* work with professionals, and the sharing of situated experiences of chronic illness work. The expert patient is a node for communicating and translating forms of knowledge and practices. But there is more.

Nora and Marianna, as expert patients, are nodes of these different forms of knowledge in that they enable the exchange of information and knowledge. Such exchange takes place during therapeutic education, for instance within the Conversation Maps™ that they facilitate, as in other educational activities such as the support group or campus. In these events, as we have seen in the previous chapter, people perform care for each other and practice different ways of dealing with diabetes, through therapy, eating and walking; at the same time, they also practice ways of embodying family, gender and medical norms and identities. Nora and Marianna are the people who are bring other people together by being there and through their organization skills and the care they enact. They do not simply organize events, taking care of details, infostructure, appointments, ingredients and so on, they also remind people to come, make phone calls, bring flyers to other events they participate in, send emails and so on. Nora does all this because she believes it is vital for people with diabetes to participate. These women are nodes of connection among different networks. They are *relationship makers*.

Orientation is possible when care work is recognized and valued, when ethics are discussed in practice, and when people do care for each other. When something happens, people who are part of a network know who to ask because each of them has in mind someone who can help in identifying another node and a possible solution. In this process, expert patients work as nodes allowing information to circulate because people trust each other and have built deep bonds of relatedness.

Of the fifteen interviews I carried out with people who have been involved in the organization in some way, eight mentioned Nora as someone who has improved their knowledge or skills: she is an example and inspiration for others because she has succeeded in managing diabetes using only food and physical exercise, something that is possible but difficult to achieve in practice. She is an inspiration because she has the ability to navigate biomedical knowledge to a certain extent whereas many patients find even basic diabetes terms incomprehensible. She also contributes to breaking down stigmas about diabetes, as one respondent said: “you will have noticed Nora often going against the opinion that diabetes comes from the eating too much or badly”. At the same time, however, Nora is also in relationships with people. Respondents say that she takes care of people by giving them reminders about daily care, in some cases, that she makes herself available: “she is there”. One respondent mentioned Nora when talking about relatedness: he had to deal with both his mother and his wife falling ill in the last year and, eventually, losing both of them. Nora often asked him about them. Nora is also frequently mentioned as the person who suggested the respondent join the organization, together with Eva. In one case, even a GP told the respondent to contact Nora first. As a node, Nora can enable circulation in any direction, towards biomedicine, certain practices, healing and support, and so on.

Neither Nora nor Marianna consider themselves more knowledgeable that others. This does not have to do with modesty, however. They have, in their view, the same difficulties that all other patients experience. What makes them “expert” is only the result of experience over time; it is a long path and one made possible by their taking part in the organization. Indeed, in Nora’s experience the organization is something that proceeds alongside the illness and that you can each out and access when needed. They also feel the need to be part of it. For Nora, the campus is “the moment that I need most during the year because I get better (*mi riprendo* in Italian). Over time, I let myself go”; “when I go to the campus, the support group and the events, I gain strength”. This is important because people with diabetes need strength, including the strength to navigate programs such as GI when even family doctors are not aware of their signs and symptoms. As Nora explains, patients therefore need to be aware of the signs, learning and standing up for themselves. Nonetheless, they are still patients with all the associated difficulties. In Nora’s view, the organization itself is a node:

> If I don’t remind my GP that it’s time to do tests, now he gets me to do them twice a year and says “you are fine don’t worry!”. But it doesn’t work like that! I can do everything well but still go bad… it is not that everyone who goes bad and have bad test results did something wrong, it does not work like that.

Patients such as Nora and Marianna are open to certain objects and techniques that they have acquired over the years. They reflect what has been done and uncover new possibilities while knowing how to orient themselves and sharing this knowledge with others, thus making them points of reference for the community around them. They connect people with each other, acting as network-makers.

First, therefore, we can say that in the context of Copparo expert patients are *technologies for education, orientation and knowledge transfer* both inside and outside the clinic. Second, the expert patient as an instrument has enabled experiential knowledge to access clinical spaces through therapeutic education and has enabled hybrid clinical knowledge to access other spaces. This knowledge is hybrid because, as we have seen, it is not a body of knowledge but instead a set of care practices that assess what is best in a certain situation. The third point is that the expert-patient-subject is variable, with an identity that varies according to the level on which it is employed, whether institutional, organizational, and the uses made of it, that is, what it will be asked to perform and do depending on the context and aims. For instance, we have seen that in the restructuring of AUSL Modena diabetes services expert patients have been used to provide training to clinicians, pharmacists, and the management of the local organization. They have been brought in to inform professionals about the best possible infostructure for diabetes care according to their point of view, presenting this vision and mediating the possible outcomes. They have been asked to act as nodes of different kinds of knowledge and practices, translating experiential knowledge into their language. Although the work that Nora or Marianna do is similar in general terms, it is very different in terms of the network, care practices and language being used.

At the 2019 Campus, after I had shared some questions on this topic with the group, a discussion developed about the expert-patient subject and its work. Manuel was the first to intervene, saying that if we want more people to be expert patients we need to ask less of them, because they are subject to very high expectations and asked to do a lot of work. Nora’s role, for instance, involved a great deal of responsibility. He thus suggests reducing the amount of work they do by employing two different expert-patient subjects instead of one. A first one would engage the other side of clinical knowledge. This patient would ideally know about people’s lived experiences and challenges and be able to work together with professionals. The other is a “guide” for other patients, a figure that supports others in their lifestyle changes. This is not a “good” patient but rather one who practices awareness, because this role requires a continuous effort to adapt. Since it is not only the person with diabetes but the whole family who needs to adapt, this patient would have the skills to direct the attention of the whole familial group. It is interesting that, for Manuel, the key problem is precisely the amount of work that is expected of expert patients. Manuel is also a node for a kind of knowledge, a knowledge different than that of patients’ or biomedical professionals. This knowledge has to do with emotional work and feeling rules, comprising a vocabulary of emotions and details about good and bad feelings as well as sets of questions that constantly recur and that people use to reflexively perform daily actions and make decisions. Manuel’s form of knowledge recognizes the importance of patient knowledge, granting it the character of expert. He pushes for such knowledge to be used as an instrument to obtain specific results. In order to achieve that specific result, however, we need to define the work to be done. We need to bring it to the surface and analyse it.

Manuel's proposal is not met with much enthusiasm. Nora speaks after Manuel, trying to define what the term "knowledge" means for her: "this happens always during the maps, it comes from other people, we have learned to listen to and practice the small changes that other people are already practicing, things that I think could be good for my own situation". For her, in other words, expertise is an archive of other people' experiences, a memory of practices; *being* expert is what other people have passed on through their practices and experiences. Once it has been reflexively practiced and embodied, this body of experiences becomes knowledge ready to be transferred. Marianna agrees: "at the group, for instance, we listen to experiences we do not like because they are too confrontational. It is a continuous exercise of positioning [yourself] in daily life through diabetes, it is a gym for life, you need to find the piece that you feel work better as part of the entire picture". This is a care practice that does "good" care. For them, this expertise in only linked to other people who are experiencing similar challenges. The expertise in question is not a body of knowledge, and neither can it as such be passed on to other people or institutions. Nora, for instance, is practicing the expert patient role in the context of people with diabetes and only the professionals with whom she has already worked. She does not align with the expert citizen ideal type. When she is asked to do so, tensions become visible. In this extract, Nora explains first what she does not want to do and then what it means for her to have the role of expert patient:

> I am an expert patient here, trained for our context. When we decided with Vita, years ago, to insist on the education of expert patients… it was supposed to start already a couple of years ago but it didn't happen [then], it happened this year. I did not sign up, fist because I don't feel like it anymore. I am 67 and I don't feel like going around and going to Bologna… I don't drive that often, and then I saw the program and there were things that seemed too specialized… like pharmaceutical validation (*validazione dei farmaci* in Italian) for instance… interesting but in the end… and it was also a very long course so I realized I could not make it. It was also open to nurses and doctors… I was perplexed. I had a different idea of the expert patient… people who live it on their skin. Otherwise, what are you going to implement? Professional knowledge that has already its own dignity? I didn't understand that. The role of the expert patient is to… I don't want to say convince… but to be more credible, because I have diabetes and you have it too. It is not that I am better, I make mistakes, I struggle, but if we do it together, we do better. This should be the role… competencies for sure, to not say bullshit, but what is important is your lived experience. It was an achievement to understand that bad feelings had an impact on blood sugar levels, it depends not only on eating but on a totality of things. There is no medicine for sadness, and you will need to live with it. Conflicts, fear…of losing a job, of a more severe illness, the loss of someone you love… all these things have a big impact and you can't do

> anything. So you can only learn that in the net around you there is someone who already had that experience and comforts you. This is what happens at the support group, with very heavy things. At our age there are experiences we are all going through, and we have already been through… it is life.

Nora's expert patient is grounded in the practical and emotional experiential knowledge that patients possess. It does not derive from a single experience, but requires the collective experience of many people, of networks of groups and knowledge. It is a safety net for bad times, for challenges, for information, for the creation of new knowledge and practices. It is an archive of practices, a memory of the collective practices of a living community.

THE LIMITS OF PATIENT KNOWLEDGE

We have defined what constitutes patient knowledge in this context while also establishing that it is not something which is fixed but instead something that changes according to context and use. In this case, it is attached to the embedded experience of orientation and the circulation of knowledge and practices of patients and professionals. And yet, to what extent and where is patient knowledge valued and recognized? We have seen that it is recognized and used only in certain institutions, programs or individual clinics, while the rest remains unseen. The next extract illustrates a common experience for people with diabetes, that of finding themselves outside of the network of professionals with whom have built alliances.

ELENA

Elena is 49 and received her diagnosis of type 1 diabetes two years ago. Her life has changed completely. In this short period of time she lost her job in the city, broke up with her partner, returned to live at her parents' house and began working with her father in the countryside. She is a very well-organized and compliant patient, however. She has understood how diabetes works and how she needs to feed herself; she has learned how to count carbohydrates properly so as to calculate by herself the correct amount of insulin needed to deal with hypos. She has performed a huge amount of work in order to build the best possible life for herself. When she was given the diagnosis, she had no idea what diabetes is. She arrived at the hospital having lost weight, in ketoacidosis. After a few days at the hospital, she said, she felt dead and lost. Nonetheless, she was asked to learn how to inject insulin and understand how diabetes works. She was so tired and out of it, however, that she was unable to concentrate. She said: "they want you to be confident and certain, in order to give you autonomy they take it for granted that you'll get your life back fast (…) the nutritionist was explaining everything to me in a notebook that was turned upside down so I could read it, but I could not read anything, I was exhausted, and so I asked my boyfriend to help me, but the nutritionist wanted me to learn".

She did not regain her normal life, however. She continued to have complications: a temporary loss of vision and great difficulty walking. She took a sick leave of three months from work, the amount of time that people who have received this diagnosis are normally given. For her, however, it was not enough. She could not drive herself to work and she was also still suffering frequent bouts of hypoglycaemia, which she still could not manage to avoid properly. She did not feel safe. However, because her glycate had improved, she was not eligible for an extension of the sick leave and she lost her job. After four months she was also diagnosed with hyperthyroidism, which brought her back to the hospital. Through the diabetology unit, in two years she has learned how to count carbohydrates, how to select the products that are best for her to buy and prepare, and how much insulin she needs to take for each meal. In the end, however, she has learned all of this by herself, by trying things out and seeing what works best for her and her body:

> with time I have gotten to know my body more (…) looking at how I react when eating something, how I feel, my metabolism, the season, well... listening to myself physically and looking at the interaction with the environment

She also knows how much physical activity she can perform in her daily life by combining work and sport, although this continues to be an area in which she says she is still finding the correct balance. This amount of chronic illness work allows her to maintain her diabetes in balance, to feel that she is in control and is regaining her independence. And yet chronic illness work she has had to do to save her autonomy is not enough and she is experiencing tensions and conflicts. She says that diabetes is a difficult illness to understand, especially for the people around the patient. Now she works with her father doing physical labour in the countryside. Most of her colleagues work nearby and, since she is at risk of hypos, she wanted to be sure they knew what to do. This has not proved to be an easy task, however. When she asked them to take care of her, she found herself facing people who were afraid of helping and also could not understand what was happening. She continues to feel unsafe at work most of the time and that people do not understand her.

> The others are working, I told them that if I feel unwell they could go get some sugar for me… I always have some and I have never passed out but… well, I told some women to take the sugar and put it under my tongue. They looked at me terrorized "I can't do it", "no, no, don't ask me", and then my father tells me not to stress and scare them and to go home if I don't feel good. There is no point in telling him I would not be able to go home in that situation.

She recently had some employment interviews, as she would like to be more independent, leave the countryside and return to her old job. Every time she told them that she has diabetes and will need to take time for medical check-ups sometimes, however, she never heard from them back. "Our contract does not include the possibility of asking for a day of leave", was the message she often received.

Elena tells me how she has lost friends because she does not want to go out to dinner all the time, seeing as she has left the city and does not feel like driving. She has also experienced tension every time she has a health issue other than diabetes, because she knows how to take care of herself while other professionals do not share this knowledge. Along these lines, she describes what happened in the hospital when she was hospitalized for her thyroid in the endocrinology department:

> When I was at the hospital, in endocrinology, they wanted to manage my diabetes. I had my pens, but they came with a tab, according to your age they give you X of insulin. This person tells me that the nurse calculated 2,000 calories per day. They were bringing me so much stuff to eat and of course I was not eating it… I mean… three pieces of bread like this… who eats them? I gave them to the woman next to me. And I had three plums that are not even included in my diet. Anyway, I told them not to inject me with insulin, I have my pen and I am used to doing four or five units at the most. With fifteen units I go into hypo. I die. So then she tells me that she has a tab, and she showed me. I told her "I don't care about your tab, you are not going to give me fifteen units". So she went to the head nurse and when she came she said that they are used to doing it that way, that I needed to do it that way too. I explained what I usually do, that I would do my usual units and then, a couple of hours later, I would check and if it was high I would do more units. She told me: "if you go on hypo, we're coming to get you up!" – No! So she asks me: "[Are you] self-managed then?" It seems that this is the magic word. So I repeat "self-managed", and every time they came for the treatment I repeated it. In this way I made it with my pens at the hospital.

The amount of autonomy, knowledge and awareness that is valued so much by diabetology and the patient herself is not the same amount that is requested by other specialists who are required to follow standardized procedures. It is not the same amount valued by other people who are in a relationship with her, such as colleagues, friends or family. In these interview extracts, the relational care work Elena had to do in order to maintain as much independence as possible for herself is visible despite never being recognized. The lack of recognition in turn becomes pathologization and paternalism when she is asked to provide certificates of invalidity in order to be covered by benefits. The vicious circle of normalcy leads her to depend more and more on others, while at the same time the healthcare system wants her to be more aware of herself and her body than anyone else.

> [My boyfriend] had the idea, I think, that because you are sick you have no more resources and you are like a dog. But that is not so, you are more reactive because you want to take back your autonomy, and you don't care about anything else. And so for everyone who wants to rule you by telling you what to eat – like people telling you how much you should eat… did you eat it all? – yes, I did the calculation carbohydrates, is there a problem? (…) people are like: I'm bored so I am going to take care of you in all the time I have left outside of work. – please

> don't! I take care of myself and if I want, I will ask you, for the rest please find something else to do.

The limits of patient knowledge lie in caring relationships that fail to recognize the chronic illness work done by patients every day. These limits are determined by institutions that establish standards of health in order to grant certain benefits as well as employment structures that consider autonomy a skill only in terms of competition. While on one hand certain health institutions would like to have expert patients with a vast store of skills, knowledge and competencies, on the other hand there are other health institutions, organizations or wards that do not recognize these patient knowledge and work. This is why it is important to look at care practices, ethics and aesthetics as they are shared among patients, between patients and professionals, and among professionals, instead of solely examining individual subjects as they would exist by themselves.

To conclude, these limits of expert patient knowledge are also expressed in Nora's accounts of the transformations of health care in ER:

> I think that there is a lot of theory and less practice. They say "organizations… organizations" but in the end they need to be supported. Not with money only, here in Copparo we have been welcomed by the CDS, I felt welcomed and listened to during the meetings they had organized, even though I didn't know so many things and I needed to understand how to orient myself. But I found CDS more a health organization than a social one, despite the name. The health care element prevails even though, in chronic illness, the social one is fundamental… like the family situation and so on. And I don't feel reassured by the fact that we are formally included because I have seen too many changes just because a single person left. There is no funding and resources are getting more scarce, not just economic resources but also human resources… I see that [the number of] professionals employed are decreasing, people are not replaced, and this recruitment block worries me a lot. I wonder how long it [their project] will last since it's a matter of people. If it was part of the system, I would feel safer.

While she has the privilege of being part of clinical spaces such as CDS, Nora expresses a clear awareness that patient knowledge must be grounded in care practices and the recognition of relationships in order to function and being trustworthy. With this assertion Nora claims a space that goes far beyond healthcare itself; in her view, the CDS also needs to be an archive of practices. In this situated context, expert knowledge coincides with the knowledge of communities of practice.

FINDINGS

Understanding "expert patient" knowledge and practices is of paramount importance because it has to do with the politics of lay participation. By sharing their personal experiences, patient experts (Pols 2013) contribute to developing practical knowledge and ensuring it is recognized by healthcare institutions. I thus agree with Pols (2014) that patient knowledge is a particular form of knowledge, specifically a *practical knowing in action* that develops through daily practices of knowing rather than through a body of knowledge. Patient knowledge, in this sense, is not ruled by the dichotomy between "object of knowledge" and "knowing subject", between disease and illness. Patient knowledge about the disease diabetes, for instance, is not interested in biomedical knowledge per se but in what the biomedical knowledge of diabetes consists of in daily life; how biomedical categories facilitate particular actions, transforming something into something different (Mol 2002; Timmermans and Hass 2008). This knowledge makes use of biomedical and scientific knowledge, among other forms, and plays with them to successfully make good care and to create and sustain good caring relationships. Patient knowledge can therefore be understood as a form of practical knowledge that patients use to translate biomedical knowledge into something that is useful in their daily lives and to coordinate it with other concerns and goals that have to do with conflicting but not exclusive forms of knowledge. Patient knowledge practices are thus a set of techniques that may be made useful to other people living with chronic illness.

The aim of this chapter has been to identify processes of legitimation (and, to a certain extent, institutionalization) of patient knowledge in healthcare and contribute to a better understanding of the production and circulation of complementary forms of knowledge and practices within and beyond healthcare. By focusing on practices of *collaboration*, between patients and professionals and among patients themselves, we have seen what expert patients do in this situated context, what experiences and knowledge professionals and patients exchange. We have also seen how patient knowledge is made visible and relevant to clinical practices.

Patient knowledge emerges through care practices, by trying things out and looking for the best possible solutions to daily diabetes care. In this vein we have looked at what expert patients *do*, conscious of the fact that it is not only "expert patients" who practice patient knowledge. Instead, we have seen that all the patients who are part of this community of practice *practice* patient knowledge to a certain extent. Acquiring patient knowledge, as we saw in the previous chapter, has to do with conflicts around care, chronic illness and emotional work because finding good care sometimes means striking a balance between different types of work, acquiring skills and finding ways to resolve these tensions.

Expert patients are, first and foremost, practicing skills, techniques, artefacts, communication and orientation in order to find good care. Expert patients are also practicing diagnostic skills, for instance in recognizing signs, symptoms and the appearance of problems and asking for help from professionals, other patients and significant others. When focusing on collaboration, for instance in therapeutic education, expert patients emerge as key figures who allow experiential knowledge to access clinical and other spaces and enable such experiential knowledge to be valued and recognized.

Importantly, expert patients operate as nodes of communities of practice. As nodes, they are relationship-makers when they care for fellow patients, organize and manage events and activities, share their lived experiences with others and make others feel safe enough to share theirs as well, or when they invite people with diabetes to join the support group and other activities. They are connected to, in communication with and practicing care with other nodes, such as professionals, other civic society organizations, institutions and so on. In this regard, they forge connections among different worlds of care by connecting families with professionals, care givers, voluntary organizations, social institutions, support groups and so on. Because their work is visible and recognized, it therefore becomes part of an archive of experiential practices which can be used by others.

Expert patients only exist within caring relationships and caring practices, however. Patient knowledge does not exist by itself; it is not something to acquire or a body of knowledge. Rather, it is practiced and contingent, always needing to be repositioned and shared. This form of knowledge is always in the making. Along these lines, clinical and patient knowledge are practiced together through situated ethics of care and the involvement of technology, instruments and materials which, while making *good* care, also build intimacy and relatedness. We have seen how collaboration with expert patients such as Nora was made possible in this case by the fact that there were professionals who challenged certain clinical practices, seeking out and playing with other forms of care clinical practices, sometimes hybrid practices influenced by patient knowledge as well as human sciences such as psychology. Given these premises, it is impossible to sketch a general description of what constitutes expert patients: their identity is shifting while their knowledge and practices are contingent and situated, always adapting. It is thus interesting to highlight the fact that expert patients themselves are not always eager to have their role canonized and made explicit or replicable. The subject-patient in healthcare has uses and identities which cannot be standardized but remain constantly contingent and situated. By focusing on collaboration, we have seen how the characteristics of patient knowledge and expert patients practices in this situated context are the result of shared care practices among professionals, patients and their significant others.

The last point has to do with the vulnerability of patient knowledge. As a knowledge that cannot in principle be canonized, it is always at risk of being dispersed, especially if at a certain point the community of practice which has enacted it over time is suddenly unable to practice care together. This risk is perceived and expressed in the interviews and fieldnotes, emerging either as a sense of anxiety about not being able to involve enough patients or as the fear of losing nodes without them being replaced or new professionals coming in who do not care about working together with Adico. Vulnerability also arises when patient knowledge is not valued or recognized, for instance in other hospital wards or with professionals who have never been interested in patients' experiences. In these situations, the expert patient loses the autonomy, empowerment and responsibility he or she built up over many years of chronic illness work.

CONCLUSIONS

Layers of invisibility

People with type 2 diabetes say that diabetes is dangerous because it is invisible. People can have diabetes for years without noticing it and, when they do notice it, this might occur as a result of the complications they have developed over time. Diabetes works in the background, unnoticed and unseen. Through this research I wanted to uncover the invisible worlds of diabetes care, the invisible yet highly material threads of care, relationships and bodies in the lives of people who have encountered diabetes and chronic illness.

In order to follow invisible things, I have grounded the research on care practices, understood as the mundane activities that people perform on daily basis because diabetes is pervasive in most daily practices, especially those that concern food, drinks, exercise and the daily routines that need to be adapted to treatment regimens. Care practices, as we have seen, do not have boundaries; they only have boundary objects. They cross multiple realms and, because care is interdependent, they are always shared with others. They connect up and forge relationships among people, technologies, objects. What usually remains invisible, however, is the work that needs to be done on a daily basis by people with diabetes. The sociological literature on care, chronic illness and STS has given us concepts that are useful for naming the invisible work that creates conflicts and tensions even while it nurtures care, memory, stories, and knowledge, and fosters communities of practice. In the conclusion I want to return to the work of Susan Leigh Star and Anselm Strauss, their important article on invisibility and visibility and how they operate, and Star's concept of ecologies of knowledge to point out the role care plays in the making of knowledge and science in diabetes care.

Ecologies of care

Science is a form of social practice. To underline this point and describe the complex interdependencies between the social dimensions of science and its constitutive knowledge and material practices, Susan Leigh Star has developed the concept of *ecologies of knowledge* (Star 1995). As an ecosystem, different layers of knowledge interrelate with each other within an entire ecosphere. Star used the term "ecology" in an effort to overcome the nature/social or nature/technology dichotomy and think speculatively about what the interaction of different units of analysis might accomplish. Here, I suggest, the ecological metaphor works quite well.

First and most importantly, care circulates through care practices, creating relationships and connecting up practices, ethics, objects, technologies, memories and senses. We have seen that technology does not enact care by itself, for instance, but as a result of invisible identity-related, care and chronic illness work. People learn how to use a CGM when sharing experiences with other users, when the instrument becomes a mediator between the patient and doctor, when chronic illness work is recognized and supported. Another example is that of food: diet and tabs are not useful by themselves; they become instruments when, within caring relationships, they lose their original identity and assume a new one, when they become useful for achieving something else. They become useful when they give rise to new knowledge by producing objects, shared meals, and discussions. In the end, as we have seen, collective practices within the organization enact a micro politics of food and the environment. Ecologies do not have boundaries. As such, the sharing of stories through care is also the circulation of knowledge that can take on different shapes and forms. Because care circulated fluidly in this ecosystem, so does knowledge. An ecosystem, in contrast to a network, can grow and develop by itself in infinite directions; as de la Bellacasa has pointed out, it develops not by extension but by holding together resilient relationships. Ecological thinking is attentive to the capacity of relation-creation and interdependencies, the way different beings affect each other and what they do to each other (de la Bellacasa 2016). Care practices in their collective creation can move everywhere. They can provide a space for practicing other identities and roles while also serving as archives and micro politics, archives of pleasure and taste that is experienced and shared.

The collective care practices described in this research highlight how patients reclaim their voices from a state of invisibility, thereby addressing their feelings of abandonment, their weaving together of care burdens and the invisible works that this implies. Collectively, they have emerged from a condition of disappearance to find the support they wished to obtain in the forms they asked for, through a process of “spooking, sparking and spinning”. In the words of Susan Leigh Star (Bauchspies and de la Bellacasa 2009), this is a process of understanding and accessing knowledge about the complex intersectionality of gender, age, ability, race and class. Spooking involves finding those elements that haunt forms of knowledge and representation: the absence of disability, for example, or the deletion of female agency in talking about work performed in and around the home. To spark is to creatively restore meaning, causing these absences or silences to collide, reveal irony, and creatively work together. And the last one, spinning, formulates these new meanings. By moving away from a critique of patriarchal, biomedical and ableist approaches, this approach co-develops new imaginaries and builds and weaves new ways of knowing. This methodological approach also creates communities of practice.

Ecologies are also about collision, however. The chronic illness work done by the patients who participated in this research often collide with other types of work that need to be performed on a daily basis, whether they be types of care work, identity work or emotional work. I have tried to highlight different forms of invisible work (care, identity, chronic illness) but I have also been interested in pointing out how different types of work can create tensions and conflicts. These tensions lie in the background to then produce and reinforce feelings of guilt and abandonment. Collective spaces are a sounding board for these conflicts that would otherwise give rise to isolation and suffering. Because chronic illness work is so pervasive in daily life, transforming patients into scientists, as Strauss would say, it collides with care and identity especially within familial and other significant relationships.

An intersectional analysis has shown the multiple forms of vulnerability affecting women: when chronically ill, they often need to perform multiple types of work at the same time, frequently dealing with feelings of abandonment and questioning their identities and roles. My focus on practices has revealed just how important it is to look at the position of the person with diabetes as part of caring relationships and care practices. Questions such as who is cooking, what other people like to eat, and how roles and habits at home might be changed are relevant in that they recognize the relational work performed by people with diabetes in their daily lives. Food is particularly tricky in this regard. It is a transmitter of family values, affection, memory and love, but also of anxiety and negative feelings. It encompasses multiple affective dimensions. With two exceptions, all the respondents share food with others on a daily basis. The data suggests that stigma operates differently for women than it does for men. While women feel responsible for having diabetes, this is not the case with men; the latter instead tend to describe themselves as "good eaters". This aspect also places women in a more vulnerable situation.

Because care is interdependent, we have seen through biographical accounts how people struggle to be carer and cared for at the same time. They need to be supported in order to deal with their diabetes in daily life, receiving care and medical attention. At the same time, they also care for others, whether they be older parents, sick people, or children, or seek to maintain a balance in their relationships. This involves constant identity-negotiation and work in order to function and produces vulnerabilities due to the multiple forms of care work being performed simultaneously. Maia and Malika, for example, suffered multiple relapses as a consequence of the caring work they were performing for their parents. As Malika has vividly said, intensive care for others often entails "shifting attention from me to her". The recognition of interdependent care work acknowledges the value of the forms of work that need to be carried out and that other people do for the person in question. This approach considers how people feel they occupy a certain position and where they would like to move in the spectrum of care. Men are also vulnerable, of course; in relation to gender, the question is whether men would be supported if they were to shift their care position, for instance. That is, whether they would need to perform identity work in order to act as carers as well. Thinking about care as a spectrum makes it possible to look at the different positions that people take on at the same time, what position(s) they like to move towards and what kind of work would be needed for them to do so.

Without considering care in its totality, it is impossible to address diabetes care. How would the recognition of these dimensions impact diabetes care? Could patients be recognized not only as individual ill subjects, but as people in multiple caring positions? What impact would diabetes have on them? However, and here Star and Strauss have another insight to contribute, trade-offs and politics are right around the corner. To recognize such invisible work might also mean "going backstage". This recognition cannot be aimed at "fixing" the patients, their relationships and conflicts. The intention and focus here is to not pathologize relationships but to guarantee space in which people can locate their own "good" care, a balance among forms of invisible work even if this comes at the expense of chronic illness work.

The collision that results in conflicts is never rendered visible through the perspective of biomedicine. Concepts such as "lifestyle" or "self-care" are blind to relationships, because it is precisely *relational* care and its associated work that is invisible. In this case as well, conflicts generate non-compliant patients who end up refusing to be cared for. "Definitions belong to definers, not the defined" (Star and Strauss 1999, 14). While the definition of non-compliant patient is rarely seen in practice, it is nonetheless widely used, for instance in the text of policy documents and by all the research participants in this case study who hold a healthcare position. There is a great deal of interest, at present, in understanding who non-compliant patients are and how to locate them, convincing them to become involved, engaged, and responsible. The limits of contemporary biomedical concepts are especially visible when we talk about relationships. What biomedicine reads as non-compliant, is, in many cases, a person who finds it difficult to carry out multiple types of work and care which are in tension with each other and with that person's identity. If patients are obliged to choose, they hardly ever choose self-care. Food and other care practices in diabetes care are highly relational: they involve codes of behaviour, feeling rules, identities and feelings. We have seen, for example, how loss and care burdens can reinforce feelings of abandonment and guilt. The intersection of gender, class, and illness produces effects in terms of chronic illness care and emotional work that need to be recognized. Indeed, conflicts in relation to invisible work have tangible consequences in terms of health more generally and diabetes specifically.

Care is a fundamental component of science because it fosters ecologies of knowledge through everyday care, emotional and chronic illness work, a form of labour that is mostly invisible and animated by conflicts and tensions. It is of paramount importance, I argue, to look at medical practice from a care perspective. A sociology of disease can benefit from care and in particular from recognizing the significant impact of care burdens on the lives of people and the onset of chronic illness. This recognition would mean granting prominent space to care in professional-patient encounters and more clearly recognizing the importance of psychological support in chronic illness.

A care perspective on medical practices also acknowledges the importance of the circulation of care. It shifts the attention to an analysis of who has the power to care and be cared of and who is left out of medical programs and protocols. Sometimes, invisibility means vulnerability. This is the case when a patient disappears under EBM programs and categorizations, vanishing in between the categories, into the spaces in between a person with low complexity care and a "non-compliant" patient in GI. To use the concept developed by Star and Strauss, it is a process of "creating a non-person". And like, like the example of domestic workers (Star and Strauss 1999, 18), the person is there. Since definitions belong to the definers and not the defined, domestic workers remain invisible. The same thing occurs when people with diabetes disappear in between the structures of GI. I found these stories among my respondents, most of them middle-aged women with diabetes who had to deal with loss, grief, or care burdens. These women must add chronic illness care to their daily struggle with food issues, having to perform such a vast amount of invisible work every day that they end up giving up on the chronic illness work for themselves. These women are invisible in GI; they have asked for support in a system that is under-funded and overlooks psychological support for chronic illness people. In this setting, vulnerability and marginalities are systemic consequences of sociotechnical arrangements that create new forms of exclusion. Who becomes invisible in between? The risk is that this knowledge and these experiences will end up being erased (Bowker and Star 2000). Generating questions about who and what is lost between new systems and programs allows us to think in terms of the ecological effects of a new system and its enrolment: if a system works for someone, what about the others who are lost in the spaces in between? Who are they?

Knowledge

Care practices are knowledge in action. Knowledge is embedded in practices. This point has been reiterated at various points in this work. The fact that it includes the word "care" means that care is a form of knowledge and indeed that any form of knowledge includes care in all its forms. This is the point of departure for this analysis because there is no knowledge without the act of taking care of the material basis of practice. Treating science as something that people do together brings us to question "cui bono?" or, as Star has argued, who is doing the dishes? Who owns the means of knowledge production? What are the political and relational aspects of what we call knowledge?

I have tried to point out different ways of making science and producing knowledge in diabetes care, following the steps of relational care practices. Because knowledge is practiced and disease is done (Law and Mol 1995; Mol 2002), care practices have allowed me to consider knowledge beyond the category of "experiential" knowledge or what has been called the "illness dimension", framed in opposition to the "scientific" or "biomedical" knowledge associated with the "disease" dimension. Instead of questioning what is real and what is experienced, the question, again in Star's words, becomes one of "under what conditions does this question get raised?" (p.11). It is through social material practices that science is made. Science is a form of knowledge that can have a hybrid character and, to a certain extent, challenge biomedical practices. Care makes science when it translates and transforms biomedical knowledge into other types of hybrid knowledge and practices that can be used by patients for a variety of purposes. In this research, I have tried to highlight the features of two distinctive types of knowledge which are assembled in this situated context: the *competent citizen* and the *expert patient*. Neither of these can be merely described as patient knowledge or knowledge born of experience. Although the experiential component is the most relevant component of both, they have the character of hybrid knowledge. As hybrid knowledge, they can be adapted to various uses and needs and to different interlocutors. It is not a body of knowledge or illness dimension; rather, it lends itself to exchange and represents a collection. Such knowledge is tinkering, training and learning. The competent citizen subject and expert patient are not merely devices developed and communicated from above, they also emerge as a result of shared care practices and enact different uses and identities in situated contexts. It is of paramount importance, therefore, to look at situated care practices and the intersection of practices within ecologies as well as the knowledge produced and embedded in these practices.

The Expert Patient

Despite the quite widespread use of "expert patient", this concept is an example of a travelling concept which displays different relational elements in this situated map than it does in the models which have been described for instance in literature on the UK. Expert knowledge emerges from *collaboration* (which, in our case study, is therapeutic education) and through care practices, to then circulate among patients and professionals. Expert patients in this case facilitate orientation and the translation of clinical knowledge towards other patients as well as experiential knowledge towards professionals. They practice care towards each other in different ways and constitute a point of reference for the entire community of practice. The nurse, Eva, is also a node of expert knowledge. Through collaboration, Eva facilitates the validation, circulation and legitimization of patient knowledge in the wider community of professionals. As a community of practice, patients do things together; they practice care and use and shape tools and instruments that can be used by others who might need them when something changes in their invisible work. Examples of such use are Flora and Aldo, who have employed practices of walking and cooking as tools to change their positions in the care spectrum and play with new identities. Flora has used walking training to find space from others, while Aldo has used the kitchen lab to embrace a different attitude towards cooking by playing with gender roles. Recipes are examples of boundary objects that are used to make good care, but also to interact with other people and create science and knowledge. They act in this way because recipes are the translation of a situated practice into science. They highlight forms of collaboration, practice through education, and preserve and transmit the uniqueness of a community of practice. The work that expert patients do in this ecology is of paramount importance in the making of relationships, connections, orientation and translation. Through the expert patient as node, this ecology of care is connected with other ecologies of care, for instance with biomedical care and the competent citizen. However, this ecology does not have boundaries; not because of its extension, but because it holds care relationships and communities of practice together.

The competent citizen

The ecology of competent citizen care is incredibly rich in terms of work, knowledge and practices. We have seen how it circulates and collaborates with health care institutions, for instance when entering in HTA, activating processes of the hybridization of epistemic identities and becoming part of networks of established and validated expertise. This ecology of care has merged into biomedical knowledge, health technology assessment, public health research and experiential knowledge stemming from other ecologies of care. Through nodes such as Vita or Anita, they connect different ecologies of care together. This scientific production is going to play a central role in the future. There are, however, some issues that need to be untangled and new questions that need to be posed.

Is this knowledge at risk of becoming a mechanism of accountability in times retrenchment, that is, with the increasing use of EBM and chronic illness care algorithms? While the outcomes of the intersection of these transformations in health care are still understudied, retrenchment and cuts in clinical work are already visible and having an impact on care. While the focus is shifting towards personalized medicine and programs, the reality of daily clinical work is under attack. While policies stress the importance of collaboration and networks, there are not yet the resources necessary to focus on care practices. What then is the role of the competent citizen in this picture and what role will it play in the future? Will its function be limited to the mere role of mechanism of accountability or will it act as mediator?

A second question is directly linked to the creation of an ideal type of competent citizen which is rarely seen, very difficult to achieve and, just as with other types of work and knowledge, needs to be recognized and valued in order for it to be maintained and function. What will the outcomes of the cultivation of the competent citizen and the setting of a standard of patient-citizen be? What kind of care is included in this standard and which one is left out? This is a fundamental issue today because it is connected with health literacy and inequalities and must be addressed. To do so, however, it is crucial to acknowledge the background material and relational care work that these subject-patients do in building and maintaining relationships, fostering communities of practice, producing knowledge and enabling its circulation.

And finally: are there limits to caring ecologies? There is surely a limit in relation to other types of health care and health institutions every time diabetes care walks through the door of another ward or professional. One limit is the lack of recognition. While such care is recognized and employed in some healthcare institutions, it is not in others. CDS are emblematic in this regard because of the hybrid discourses and practices they involve. On one hand, they do recognize patient organizations as stakeholders, embracing participatory discourses. On the level of practice, however, patients do not play any role in the organization level. If this does occur in some local contexts it is because someone has focused care practices on collaboration. It is of paramount importance, however, that we think about how this archive of practices can be operational and its survival ensured in the future. How can certain care practices be fostered and how can we help them survive in times of changes and retrenchment? What are the care practices we want to promote, make visible and set as standards for future health institutions? These are the questions that need to be addressed.

Oh seductive methaphor

Network flung over reality

Filaments spun from the body

Connections of magic

Extend

Extend

Extend

Who will see the spaces in between?

(Star 1995, 32)

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ANNEX A – INTERVIEW STRUCTURE

Temi: biografia e narrazione della propria malattia per capire quale ruolo ha avuto il diabete nel proprio percorso di vita, conflitti e lavoro emozionale: come si fa funzionare la propria vita con la malattia cronica, punti di svolta.

Domanda biografica per capire quando il diabete è arrivato, come si è intrecciato nella biografia della persona, come viene raccontato, con quali parole. Le sottodomande, se necessario, saranno utilizzate per andare più in profondità e per capire quali sono stati i passaggi critici e come si sono superati, con quali strategie relazionali, o come sono cambiati i punti di vista e le narrazioni della malattia e della salute. La domanda dovrebbe far luce anche sull'impatto affettivo della malattia sulle proprie capacità si controllo del diabete (emozioni, come loro stessi si percepiscono e come percepiscono la malattia)

Parlami di te e della tua esperienza con il diabete, Quando è entrato il diabete nella tua vita?

Ha avuto ripercussioni sul lavoro, il tempo libero, gli affetti e la tua sessualità? Quali sono state le difficoltà? ti invito a pensare alle difficolta che hai avuto/hai con te stess*, il personale medico, le persone che hai attorno (famiglia, comunità, amici), puoi farmi degli esempi concreti? Come hai superato le difficoltà di cui mi hai parlato? Ti chiedo di pensare a quali momenti, attività, ti hanno fatto sentire meglio col tuo diabete, sia nel presente che nel passato. Cosa ti fa sentire meglio col diabete? Cosa ha rappresentato un punto di forza? Stili di vita: tenere sotto controllo il diabete implica un cambiamento degli stili di vita, del modo in cui si mangia, si sta con gli altri, si fa attività fisica, è successa questa cosa anche a te? Che cosa ha funzionato e cosa non ha funzionato? Come è stato questo processo?

Temi: cura e relazioni, mappa relazionale della persona diabetica e definizione degli attori coinvolti. Cura e le relazioni, circolarità della cura e delle relazioni di cura, lavoro emotivo della cura di se Vs cura degli altri

In questa sezione cerchiamo di definire chi sono le persone attorno e rappresentarle visivamente con una mappa. Scendendo poi in dettaglio su alcune pratiche di cura che sono emerse dal field, andiamo a vedere se e come le pratiche di cura connesse al diabete creano e manifestano delle relazioni affettive e di supporto, e come queste vengono narrate. I confini della cura sono difficili da tracciare, e alla fine della sezione viene rivolta una domanda specifica sulla cura agli altri per rappresentare come la persona diabetica non solo riceve cura e supporto ma è anche inscritta in un circolo della cura e spesso è responsabile della cura di altre persone (ad esempio i genitori anziani o figli e nipoti, amici). Con questa domanda possiamo quindi vedere chi e come le persone si prendono cura, quali sono le tensioni che sorgono nello specifico del diabete. Alimentazione e attività fisica sono due strumenti che fanno luce su come le persone diabetiche possono adattarsi alla malattia e controllarla, e al tempo stesso, a differenza del medicinale, sono pratiche di cura sociali e relazionali. Vengono quindi proposte domande che dovrebbero far luce su come le persone con diabete percepiscono dieta, lo sport e l'attività fisica, quali sono le barriere sociali su base di genere e classe? Quali strategie si sono dovute attuare per perseguire il controllo sul proprio corpo e malattia?

Ti chiedo di pensare a tutte le persone, al di la del rapporto che hai con loro e dal ruolo che rivestono, che sono state importanti per te dal momento della diagnosi in poi, quelle persone che hanno svolto o svolgono attualmente un ruolo importante quando hai bisogno di sostegno, che sia emotivo, materiale ecc. Chi, cosa fa per te? ogni quanto tempo, come descriveresti il tipo di sostegno che ricevi e come la vostra relazione? (alla fine dell'elenco metteremo insieme i nomi e faremo una mappa).

Ho notato quanto il cucinare e il cibo in generale, sia una questione centrale non solo per il diabete, ma anche per la socialità che ci sta attorno (esempi concreti di cose a cui ho assistito). Ti chiedo di pensare a delle situazioni specifiche in cui hai dovuto risolvere delle questioni tra i fornelli o a tavola, come sei riuscit* a continuare a magiare insieme agli altri, a cucinare per altri in famiglia e fuori la famiglia? Come comunichi le cose che hai imparato agli altri? Ad esempio, chi cucina dentro le tue mura domestiche, avete adattato la cucina per gli altri? O mangiate in modo separato? Come comunichi i tuoi bisogni? (ripetere con sport e attività fisica).

Lavoro di cura (e lavoro emozionale): ho notato che spesso le persone con il diabete oltre a prendersi cura del diabete e di se stessi, devono anche prendersi cura di altre persone come ad esempio i genitori anziani e i figli, e questi obblighi di cura spesso sono molto difficili da gestire nel quotidiano. Puoi raccontarmi come fai a gestirli se ti è capitato? Ti occupi tu della cura delle persone che hai accanto? Come? Riesci ad avere spazio e supporto per il tuo diabete? Quando hai sentito che hai fatto fatica a gestire sei riuscit* a comunicarlo?

Temi: partecipazione e definizioni di partecipazione da parte delle persone diabetiche. Attenzione alle narrazioni di partecipazione e ideale partecipativo

In questa sessione vogliamo fare luce sulle pratiche partecipative dei pazienti con diabete a vari livelli, dentro la comunità, dentro l'associazione e dentro lo spazio della salute (CDS e diabetologia). Per fare luce sulle loro definizioni di comunità e di spazi della salute viene chiesto il loro punto di vista sulla CDS e sull'associazione diabetici di Copparo. Dopo aver dato spazio alle proprie esperienze di partecipazione, si vuole capire se e come alcune pratiche di cura possano essere considerate a loro volta pratiche di partecipazione, e quale sia il significato che i pazienti danno alla parola partecipazione.

Ti senti in qualche modo legato alla CDS, come descriveresti la CDS e diabetologia? che rapporto hai con A.Di.C.O? quale ruolo ha l'associazione per il tuo diabete e la tua socialità? Come descriveresti il legame che tu e la tua famiglia hai con questi soggetti? Tu partecipi in qualche modo, come paziente diabetico, a qualche tipo di attività? Associazione, spazio della salute (diabetologia)? se sì quale? Cos'è per te "partecipazione"? esempi? Pensi che sia importante partecipare come paziente diabetico? (es. paziente esperto)

Temi: definizione di salute e di buona cura

In questa sezione viene lasciato spazio alle proprie definizioni di salute per far emergere quali sono le possibili tensioni tra le proprie definizioni e quelle che vengono date dall'esterno, ad esempio dai professionisti. Così come *vogliamo far emergere invece cosa succede, se e quando, le definizioni di salute convergono e vengono riconosciute le definizioni di salute e benessere dei pazienti.*

Cos'è la "salute" per te? O cosa è diventata la "salute" per te con il tuo diabete? Puoi farmi degli esempi? Cosa potrebbe essere una "buona cura"? Quale ruoli dovrebbero avere i professionisti e quale i pazienti? Come potrebbero aiutarti a curare meglio il diabete?

Temi: specifico su educazione terapeutica (per chi ha seguito educazione terapeutica in una o più attività)

Domande specifiche sui progetti di educazione terapeutica, le domande sono rivolte a chi ha già partecipato ad uno o più attività)

Quale è stato l'apporto che hai avuto in questi anni dall'associazione diabetici e da diabetologia con l'educazione terapeutica (ad esempio le mappe di conversazione e il gruppo di ascolto)? Pensando anche a tutte le tue esperienze di educazione terapeutica nel tempo, in cosa ti sono state utili e perché? Rispetto le esperienze miste (diabetici e professionisti) come quelle del campus, in cosa sono state utili e perché?

Es: Come è cambiato per te il rapporto con i professionisti dopo queste esperienze? Hai avuto la possibilità di imparare nuovi termini, di apprendere e usare un linguaggio più vicino a te stesso? Hai avuto benefici per la tua socialità? Pensi che sia importante imparare e confrontarsi con un gruppo di persone che hanno il diabete e con i professionisti? Perché?

ANNEX B – MAP of the ground floor of the CDS “Terre e Fiumi” in Copparo (Fe) where the diabetes clinic is located (“diabetologia” in Italian) and the meeting room (“sala riunioni” in Italian) where the support group’s sessions take place.