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Decision Making in Life Choices

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Abstract

The project stems from the desire to better understand how decisions are made in “real life contexts”, with the aim of focusing on health and mainly on how cancer patients and survivors decide to participate in psychological interventions that aim to improve the quality of life.

Three studies have been designed to understand how decisions are made, changed and maintained in “real life” and the factors that may influence the decision to take part in psychological interventions, as well as to maintain commitment to them.

The project identifies that there are several factors that come into play when we find ourselves having to make "real" decisions that can have effects and repercussions on the entire life ahead, for example the context in which the decision is made, social interactions and individual differences. Focusing on participation in psychological interventions aimed at improving well-being and quality of life in cancer patients, we have seen how the issue of participation, engagement and adherence is paramount.

The studies highlight the importance for patients that their needs are taken into consideration during both the design and the implementation of health interventions. Another aspect that emerges from the studies is that patients' motivation may fluctuate and change during an intervention experience, with possibly unpredictable consequences on the maintenance of positive change.

In order to reduce the risk of non-participation or drop out it is important that the activities of interventions take into consideration patients' daily life, future plans and obligations, and the subjective representation of illness.

Chapter 1: Introduction

1.1 Decision-Making process

Decision-making is studied by multiple disciplines, from statistics (Stine et al., 2011) to psychology (Beach & Connolly, 2005) to economics (Stolyarov et al., 2019). The application impact of these studies is of enormous importance since decision-making processes are transversal to multiple and various contexts, including, for example, the medical, political-economic, organizational, and business fields. At the theoretical level, decision-making is a process of making a choice from a number of alternatives to achieve a desired result (Eisenfuhr, 2011). This definition has three key elements. First, decision making involves performing a choice from a number of options, resources, opportunities; second, decision making is dynamic, involves a number of factors and sub-processes; thirdly, the “desired result” involves a purpose or target emerging from the mental activity that the decision maker engages in to perform the choice. Two approaches can analyze decision-making: normative and descriptive. The first, which is typical of economic analysis, presupposes that the decision maker has made a rational choice by considering preferences that do not depend on the specific methods to elicit them or on the particular description of the options. This can be a good explanation of how decisions should be made rather than how decisions are actually made. The descriptive approach, on the other hand, assumes that people’s choices are often in contrast with each other, suggesting some empirical generalizations that characterize people’s decisions (Shafr et al., 2002). Therefore, decision making usually requires evaluating at least two options that differ one from another in one or more respects. The selection of one option at the expense of another requires an individual to put in place an overall assessment of the alternatives, using specific methods of reasoning and information processing (Bailo et al., 2019; Kondylakis et al., 2017; Kou et al., 2014). In most cases, decision-making means thinking in conditions of uncertainty: we cannot predict with certainty the future outcome of the available alternatives, but in the best of cases, we can only estimate the probability of these outcomes. Researchers in the fields of psychology and economics generally agree on the importance of two fundamental human motivations, namely the desire to reduce uncertainty and the desire to gain advantage (Bentham, 1970). Contrary to the first theories, which saw decision-making linked to rational choice, today we know that human decisions are based both on emotional motivations and on rational motivations (Cabanac, 1992). Choice behavior should be considered the result of two motivational processes, one more deliberate and focused on wider objectives and the other more instinctive, heavily influenced by emotions (Loewenstein et al., 2015; Lucchiari et al., 2016; Mazzocco et al., 2019). Several studies have referred to the distinction between two main “faces” of cognition, since Paivio (1990) who distinguished between nonverbal and verbal processes, to type I and type II processes (Kahneman & Frederick, 2002) to the reflexive system

against reflective used by Lieberman et al. (2002) to experiential and rational system (Epstein, 1994, 2003). In other words, multiple theories in cognition highlight that decision-making may be based on more immediate or elaborated cognitive processes. In this project we will refer primarily to the widespread theory by Kahneman & Tversky (1979, 2013), which describes the process of decision making in a context of uncertainty. According to the two authors, in a risky condition, a given solution can be reached in a probabilistic way based on empirical evidence violating the principles of economic rationality, which, until now, were the basis of the study of the decision-making processes.

1.2 Decision Making in Real Life context

Although decision-making is a widely studied process, we still know little about how this occurs in “natural” contexts. From the literature, we know that when a person has to make a decision, they put in place heuristic strategies (Kahneman & Tversky, 1974, 1981), but do these also apply when decision-making takes place in real life? (Galotti, 1989, 2005, 2007; Pomytkina et al., 2020). Most literature on people’s decision making concerns decision by experts (Fortin-Guichard et al., 2020; Klein, 2017), in which important decisions are made by a group of decision makers who seek consensus (Palomares et al., 2012) or decisions are made in simulations and within non-ecological contexts such as the laboratory (Hepler & Feltz, 2012; Koehler et al., 2015). Typically, in laboratory studies participants receive a series of self-contained, hypothetical decision scenarios, often gambling or games, and are asked to choose from a set of options (Tversky & Kahneman, 1974, 1981) excluding activities central to life choices such as clarifying goals, gathering information, weighting the relative importance of multiple criteria and without a real impact (Galotti & Umscheid, 2019; Galotti, 2017; Wiswall & Zafar, 2015). Life choices are influenced by numerous factors, such as context, social interaction (Sanfey, 2007), and individual differences (Galotti, 2005; Levin et al., 2002) and can have effects and repercussions on the entire life ahead. The decision-making literature is relatively limited for what regards the study of real life choices due to their complexity and difficulty of measurement (Sanfey, 2007; Rozin & Hormes, 2010; Beach & Lipshitz, 2017). First, it is difficult for the experimenter to obtain control over all the variables involved in the decision-making process. In a simulated context, the experimenter could control the main variables and reduce the decision’s field to a pseudo-mathematical problem, while partiality and uncertainty characterize decisions taken in everyday life. Secondly, life choices are important decisions for the subject. Notable attention is put in evaluating the choices in order to make the best one and many factors come into play such as the context in which the decision is taken, the presence and influence of significant others, etc. This cannot happen in the laboratory or within simulations, where subjects deal with abstract scenarios that can be very far from their daily life (e.g., “imagine you are the chief of an important

company....”). When others are involved in simulated/experimental decisions, it is hardly proven that such simulation would be an acceptable modelization of their real-life behavior (Presnilla-Espada, 2014; Bell et al., 2008). Moreover, people will attach different priorities to different goals at different times in their lives, which is why, in most real-life cases; there is not one “absolutely correct” choice to make (Galotti, 2005). On the contrary, some options may be blurred or unknown, and not all the possible consequences of the choice alternatives are available to the individual when it is the time to choose (Barclay & Raihani, 2016).

The literature on decision making in life choices often focuses on the outcome of the decision and on how the type of choice is linked to some specific individual factors, such as personality, level of stress and anxiety, etc. For example, Lauriola and Levin (2001) demonstrated that people high in openness to experience take more risks than neurotics do. Also, neurotics perform worse in decision making especially when they have to decide under pressure (Byrne et al., 2015), while extraverted people may be too confident in their choices (Schaefer et al., 2004) but also more cooperative and altruistic (Hirsh & Peterson, 2009; Tao et al., 2020). Hartley and Phelps (2012) stressed how anxious individuals’ daily decision-making is influenced by excessive fear and concern. However, there is a lack of literature on how the decision making process takes place, that is, on the cognitive resources that people put into play when they elaborate a certain decision and when they select the course of action to be implemented. This is related to the difficulty inherent to reproducing a complex life context in the laboratory simulation, as well as to the inadequacy of observational tools to capture fine-grained processes such as the cognitive ones involved in decisions.

1.2.1 Affect Vs Reasoning in Life choices

As said above, psychological literature often represented decision making as a process influenced by two “forces” or “systems”, one more rational and deliberative, that, following Kahneman and Frederick (2002), we will call System 2 and the other emotional and intuitive that we will call System 1 (Sloman, 1996; Stanovich & West, 2000; Pacheco-Barrios & Fregni, 2020). System 2 is rule-based, operates willfully and is effortful most of the time. It tends to be controllable, conscious and slow (Evans & Stanovich, 2013; Stamos et al., 2018). System 2 makes decisions based on liking and is more reactive and long-term goal-oriented (Loewenstein et al., 2015).

System 1 is quick and heuristic-based (Stamos et al., 2018); it works automatically and operates mainly through the components of the associative memory; therefore different associations tend to emerge spontaneously and influence behavior (Evans & Stanovich, 2013). System 1 makes decisions based on wanting and is influenced by emotions and short-term drives (Loewenstein et al., 2015). Despite their differences, the two systems do not operate in isolation, but simultaneously. Sometimes

intuition will have more weight in the decision, other times rationality will be more responsible for the choice (Dhar & Gorlin, 2013; Levine, 2019; Khatri et al., 2018). In addition, the influence of the stimulus could be similar or different for the two systems. For example, if there are similar motivational tendencies “during a break at a conference, the availability of a snack might create a surge of hunger in the affective system and be perceived by the deliberative system as a welcome opportunity to recharge before the next session” (Loewenstein et al., 2015, p. 58). In other cases, in which the effect of the stimuli is different “if the conferee is on a diet, for example, the availability of the snack might also remind her of that fact, leading to a divergence of affective and deliberative motivation” (Loewenstein et al., 2015, p. 58). Different studies on the use of System 1 and System 2 during the decision making evidenced that people tend to choose an option that is somewhere in between the deliberative optimum and the affective optimum. In addition, emotions play a pervasive and predictable role in decision-making and satisfaction (Côté & Morgan, 2002). A recent review (Lerner et al., 2015) showed that emotions are the dominant driver of most meaningful decisions in life (Loewenstein et al., 2001; Ekman & Yamey, 2004; Oatley et al., 2006) leading the individual to focus on information congruent with the felt emotion, and consequently to a biased interpretation of the stimulus or the event producing a distortion in risk perception and, consequently, suboptimal decisions (Finucane et al., 2000).

Researches have shown that emotions are a fundamental element for the decision-making process in its natural functioning. Historically, Zajonc (1982) was the first to criticize the idea that emotions emerge as a result of cognitive-computational activity; on the contrary, the affective responses that often appear first are not under voluntary control and necessarily influence information processing. The way this happens can be associated with the construct of affective heuristics. The term heuristics in cognitive psychology refers to problem solving strategies that aim to optimize/accelerate the process, simplifying the problematic area. An affective heuristic is used when an emotional reaction associated in memory with a certain stimulus is "recalled" (perhaps a property of a previously addressed problem, common to the problem under consideration), and is used as the main criterion for making a decision in the present moment (an important concept that, in neuropsychology, partly overlaps with that of affective heuristics, is that of the “somatic marker” of the neurologist Antonio Damasio) (Bechara & Damasio, 2005). For example, a doctor might decide against a certain treatment that is risky for his patient because of the insecurity of shame he felt following a recent mistake in the context of another completely different clinical decision. In other words, whether we fully realize it or not, we all also use our emotions as information to make decisions. Affective heuristics

undoubtedly act in the activities of System 1 but, subtly, they can also influence the complex analyses of System 2.

After having deepened the characteristics of the DM in life choices, we will focus on a particular context: the decision by chronic patients. We know that patients often find themselves having to make important decisions about therapy, screening, end of life, etc. Over the years with patient-centered care, the patient increasingly plays an active role in his or her care process in which one must make decisions together with their own doctor. In the following paragraphs, we will focus on how cancer patients faced this type of decisions.

Chapter 2: An example of real and complex decision: the chronic patients

2.1 Decision Making in healthcare: Shared Decision Making

Today, most health professionals would agree that their patients are not passive recipients of care, but persons with their own representation of diseases and health, and needs and expectations towards treatment. This evolution in the representation of patients, along with improvements in care practices, could be associated with patient-centered medicine, as opposed to a disease-centered approach that would disregard patients' characteristics in favor of mere anatomical symptoms and the physiological response to treatment (Chan & Samoutis, 2020). In this context, healthcare disciplines adopted new methods to improve the *shared decision making* (SDM) or the patient-doctor-caregiver's ability to identify the best treatment solutions together, taking into account both the disease and the patient experience (Huang et al., 2020; Chichua et al., 2022; Renzi et al., 2016).

The shared decision-making is different from the just "giving consent" on the part of the patient. In fact, in addition to presenting the procedure, the SDM is a process by which doctor and patient consider together all the information available on the problem in question, including treatment options and their consequences, considering how these adapt to the patient's preferences for health status and results. Once all options have been considered, a therapeutic decision based on mutual agreement is made (Charles, Gafni, & Whelan, 1997). For this to happen, several conditions must be met: firstly, the atmosphere must foster the active participation of patients. The physician should consider and feel important the problems raised patients. Patients in turn must be clear about their preferences and goals for treatment. This way, the physician helps the patient to determine how these goals and preferences fit the treatment options available, in order to reach a shared decision (Brody, 2980).

Kon (2010), considers shared decision making as a 5-point continuum at the extremes of which we find patient-led decision-making and physician-led decision-making, and in between the many possible approaches (fig 1).

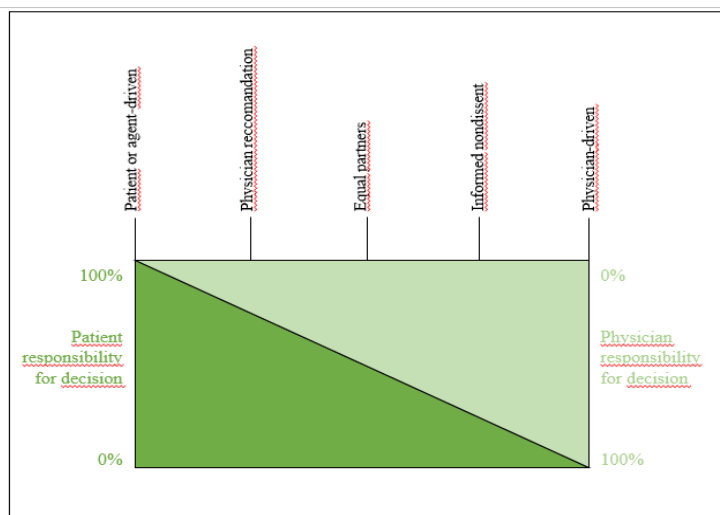


Figure 1 Shared Decision Making continuum

In *patient-driven decision making*, the doctor presents all possible options, using his specialist knowledge, without providing a recommendation, and the patient makes his/her choice.

In *physician recommendation decision making*, the doctor explains all the options and makes a recommendation. This is based on the patient's values rather than hers, which often requires time and advanced communication skills (Kon, 2006).

In *equal partners decision making*, patient and doctor work together to reach a mutual decision. To make this happen, a long-standing relationship based on respect and understanding is required. Both sides must understand the other's values and prejudices, and the physician must ensure that the patient's values guide the decision-making process instead of his/her own.

There are instances where it may be necessary and appropriate for the physician to take charge of the greater burden of decision-making (Kon, 2009). With *informed nondissent decision-making*, the physician, guided by the patient's values, identifies the best action strategy and informs the patient. This can either consent to the doctor's decision, or veto it. In this approach, the patient should have a full understanding of all relevant information (as in any decision-making method) and should understand that you still have a role to play in accepting or not the doctor's decision.

At the other end of the decision-making continuum is *physician-driven decision making*. In general, physicians should only make decisions on their own that are of no value to the patient (e.g. the size of the endotracheal tube to use), although even then some patients may have strong feelings about this type of problem. For example, a patient may prefer a conventional ventilation mode even when

high-frequency ventilation might be more effective, because the former requires less sedation and would allow him to interact with family members. Therefore, even in the case of decisions that may seem neutral, clinicians should still be aware that patients might have preferences, thus including them in the decision-making process when appropriate.

The patient's preferences should always guide the approach used and doctors should understand that each patient has their own individuality with different preferences at different times and for different types of decisions. Some physicians tend to use specific approaches for certain types of decisions, however, patients' preferences for decision approaches vary widely depending on the decision to be made. For example, in end-of-life decision making, some patients simply want the doctor to decide, when they usually tend to use the patient / agent-directed approach. (Jhonson et al., 2000; Mazur et al.; 2005). The types of decisions that require different approaches cannot be classified because every patient is different and it is the patient, not the decision under consideration, who drives the process.

While this decision-making approach has focused on the doctor-patient dyad, the doctor may also include other family members (e.g. patients' family, friends, or other health professionals) in the decision-making team. Even in this case, however, all team members have to understand the process, the objectives and consider the primacy of the patient's values.

The goal of shared decision-making is to make decisions that are consistent with the patient's wishes. It is always the patient who guides the process. Identifying where on the shared decision continuum the patient is most comfortable requires a stable relationship and clear communication (Légaré et al., 2018; Resnicow et al., 2022). Active listening skills are essential for the doctor to be able to maintain a "marginal" role without taking control or forcing the patient to bear more weight than he wishes.

To date, therefore, patients have the opportunity to participate in decisions regarding their health. However, since these are decisions made in a real life context and not in the laboratory, several aspects influenced them, which must be taken into consideration. In particular, cognitive process of chronic patients could be affected by cognitive distortion influencing information processing about the disease and consequently decision making (DM), affecting the health and quality of life.

2.2 The thinking associated with decisions: Cognitive Biases in chronic illness

DM in chronic illness is complex because patients find themselves in a state of uncertainty (Reyna et al., 2015), and have to take life-relevant decisions in an emotionally-charged situation (Szekely &

Miu, 2015; Mazzocco et al., 2019). People are averse to the unknown and risk (Tversky & Kahneman, 1986), and this may lead them to choose suboptimal treatments because they are perceived as less risky. For example, a patient may decide to refuse a treatment as it involves unlikely yet feared risks, this way failing to consider the benefits (Fraenkel et al., 2012; Pravettoni et al., 2016). The biases most frequently highlighted in the literature on chronic illness are attentional (Bar-Haim et al., 2007; Chan et al., 2011), interpretation (Ouimet et al., 2009; Lichtenthal et al., 2017), and recall biases (Karimi et al., 2016). Schoth et al. (2012) define attentional bias as the selective attention to specific information, failing to consider the alternatives because of the interference of pre-existing sensitivity. Interpretation bias is the patients' tendency to interpret an ambiguous information in an illness-related fashion and to catastrophize (Crombez et al., 2013; Khatibi et al., 2015). Recall bias consists in distortions in the accuracy of the recollections retrieved ("recalled") about events or experiences from the past (Last, 2000).

These biases have, in common, the tendency to prioritize information connected to the disease/illness experience, at any level of information processing and DM. For example, individuals tend to selectively-focus on threat or pain-related words or pictures (Bar-Haim et al., 2007; Crombez et al., 2013). Attention to threatening stimuli and illness-related interpretation can lead to biased decisions in terms of treatment and lifestyle. Subjects with chronic pain will tend to focus on pain-related information and consequent preoccupation (Bar-Haim et al., 2007; Hakamata et al., 2010; Schoth et al., 2012), this way preferring healthcare options that are less likely to cause pain, independently of their overall effectiveness or value. Similarly, they would avoid certain activities they feel potentially pain-inducing, with the consequence of social isolation and reduced social support (McCracken, 2008; Schoth et al., 2012). Negative interpretation of information influenced by interpretation bias could promote a greater pessimism about the potential control of a disease and, therefore, lower the implementation of control behaviors, which are considered ineffective (Miles et al., 2009; Everaert et al., 2017). Studies in psycho-oncology have shown that biases play a role in the fear of recurrence (FOR) (Miles et al., 2009; DiBonaventura et al., 2010). The fear that cancer may return, an important aspect to monitor in cancer survivors (Marzorati et al., 2017; Tsay et al., 2020), features a cognitive component related to the survivor's difficulty in processing disease-related information, thus, reducing the understanding of pathology and treatment. Patients with FOR tend to focus on the negative aspects within the doctors' explanation (Wenzel & Lystad, 2005; Davey et al., 2006; Han et al., 2006). Possible consequences entail detriment to the patient-doctor alliance (Ha & Longnecker, 2010), patient's inability to take into account all aspects of medical information to take good decisions (Kee et al., 2018), and, in the long run, the tendency to resort to options alternative to traditional medicine patients feel reassuring (Dobrina et al., 2020). For what regards recall bias, people with past

experience of pain or suffering create memory traces that distort the memory of a stimuli associated with those sensations (Karimi et al., 2016). Some studies on patients with chronic pain have shown propensity to recall pain-related information (Pincus & Morley, 2001; Rusu et al., 2012). Studies have demonstrated a recall bias for somatic symptoms showing a retrospective overestimation of symptom severity (Broderick et al., 2008; Walentynowicz et al., 2015). Lindberg et al. (2017) showed that breast cancer survivors' perception of past quality of life is significantly worse than it actually was (physical and cognitive functioning, fatigue, and pain). Patients with depression and pain recalled negative health-related information to a greater extent than the non-depressed controls and patients with depression or pain only, showing that the recall bias is exacerbated both by the psychopathological and physical condition (Rusu et al., 2012). While there is less information on the direct influence of recall bias on health management, the propensity to recall negative information may affect the patients' self-efficacy or their belief to be able to manage their own health, in that memory of successful management ("mastery") is crucial to the maintenance of motivation (Hiltunen et al., 2005). In other words, it would hinder the perception of an effective self-agency, which is necessary to implement healthy behaviors and treatment adherence, especially when it requests effort on the patient's side.

Full consideration of biases within the chronic illness context requires taking into consideration those related to social cognition. DM rarely occurs in isolation. Indeed, the decisions in a chronic illness are often influenced by others (Ellickson et al., 2005; Germar et al., 2014). Others' influence on decisions can often lead to a wrong evaluation of the choices with a tendency to take a greater risk (Gardner & Steinberg, 2005; Muchnik et al., 2013). Social biases can occur within the social context. Several studies have dealt with the study of group psychology (Bar-Tal, 2012; Hogg, 2012; Thibaut, 2017); for example, the classic experiment by Asch (1951) showed that a subject will tend to conform his opinion, even when clearly untrue, to that of the other members of the group he feels part of because of social pressure. Groups may exert an influence on the cognitive processes and decisions just by a conformity effect. Certainly, such classic experiments may be criticized today, for example because they rely on abstract tasks and artificial settings and have a low ecological validity (Arjoon, 2008). Yet, it is well known that groups belonging could promote biases in reasoning. Caregivers, family, and close friends, who often have different preferences regarding the treatment (Laryionava et al., 2018), influence chronic patients. Furthermore, health and medicine have now become an increasingly shared context online; patients have access to information that is not always reliable and evidence-based, and they may join groups more easily, often with the aim to share experiences, receive advice, and empathic support. The well-known example of anti-vaccine groups and related studies (Jolley & Douglas, 2014) show that the exposure to conspiracy theories within groups may

sensitively affect the patients' health decisions. Even in the case of chronic patients, a social bias can, therefore, lead the patients to change their attitudes and opinions in favor of those shared by relevant groups.

Biases can influence the DM process in chronic illness (Gorini & Pravettoni, 2011; Lucchiari & Pravettoni, 2013). Some cognitive biases in chronic illness could enhance attention to and the salience of symptoms which tend to be perceived as uncontrollable and incurable (Moss-Morris & Petrie, 2003), so that they negatively influence the patients' decisions regarding treatment and health management. Furthermore, patients affected by biases in self-perception may find themselves in a situation of perceived helplessness and self-derogation, which affects their ability to manage their own health and possibly augments the risk of mental health issues, such as anxiety. Psychologically vulnerable chronic patients could also refer to others and groups to make health decisions, which is a risky strategy especially when unprofessional opinions are involved. It is possible that biases in chronic illness could influence DM and the formation of effective motivation to engage in healthy behaviors. Many psychological interventions are conducted to help patients manage their own health, as well as to recover a sense of authority and control over their life, this way addressing the biases' effects (Kondylakis et al., 2017). However, the patients' decision to take part in such interventions could be influenced by biases as well. Among the multiple possible mechanisms, we hypothesize that this happens because of three main processes (Figure 2). The first involves fatigue as psychological process directly related to biases. Recent studies have underlined that a reason to decline participating in a psychological intervention or resorting to psychological support is feeling tired or weak (Bernard-Davila et al., 2015; Aycinena et al., 2017). Indeed, it exists as a reciprocal interaction between the systematic biases and perception of fatigue: on the one hand, fatigue (physical and cognitive) leads to a careless information processing which augments the likelihood of biased reasoning (Boksem & Tops, 2008; Howard et al., 2015); on the other hand, symptom focusing and the way chronic patients interpret disease-related information are demonstrated to augment their perception of fatigue (Wiborg et al., 2011; Hughes et al., 2016). Another relevant process regards the perception of helplessness as a self-perception component. Helplessness leads subjects to perceive symptoms like chronic pain as uncontrollable, unpredictable, and immutable, and to generalize these to daily functioning (Abramson et al., 1978; Evers et al., 2001). Along with passive coping (activity avoidance and persistent worrying), this contributes to perceiving the disease as uncontrollable and invincible, reducing self-efficacy, and the motivation to react to it (Samwel et al., 2006; Verhoof et al., 2014). Finally, it is possible that the influence of systematic biases is pervasive to the point that it influences motivation formation. While motivation is often conceptualized as a dynamic force or pull (e.g., drive, instinct, intention), it could be structured as the declarative, explicit course of actions and

outcomes to achieve, namely objectives or goals (Ryan, 2012; Triberti & Riva, 2016). Goal setting is a fundamental component of any care plan (Vaughn et al., 2016). Goal setting allows patients to identify the short- and long-term objectives to achieve, taking into account the patient’s needs and lifestyle (Wade, 2009; Levack et al., 2015; Smit et al., 2019). Biases and, in particular, the tendency to focus on the negative factors may lead the patients to formulate goals to avoid the negative symptoms (e.g., pain), instead of pursuing the long-term personal growth objectives (e.g., “I will not participate in the intervention because it’s tiring: I just need to rest”). On this basis, it is possible that systematic cognitive biases in chronic illness do not only influence the treatment decisions but also the motivation to resort to interventions that could help in reduce their detrimental effects. In other words, the repeated influence of the cognitive biases may be associated with a “vicious circle” that reduces the patients’ motivation to recognize and address the same mental health issues that influence their DM.

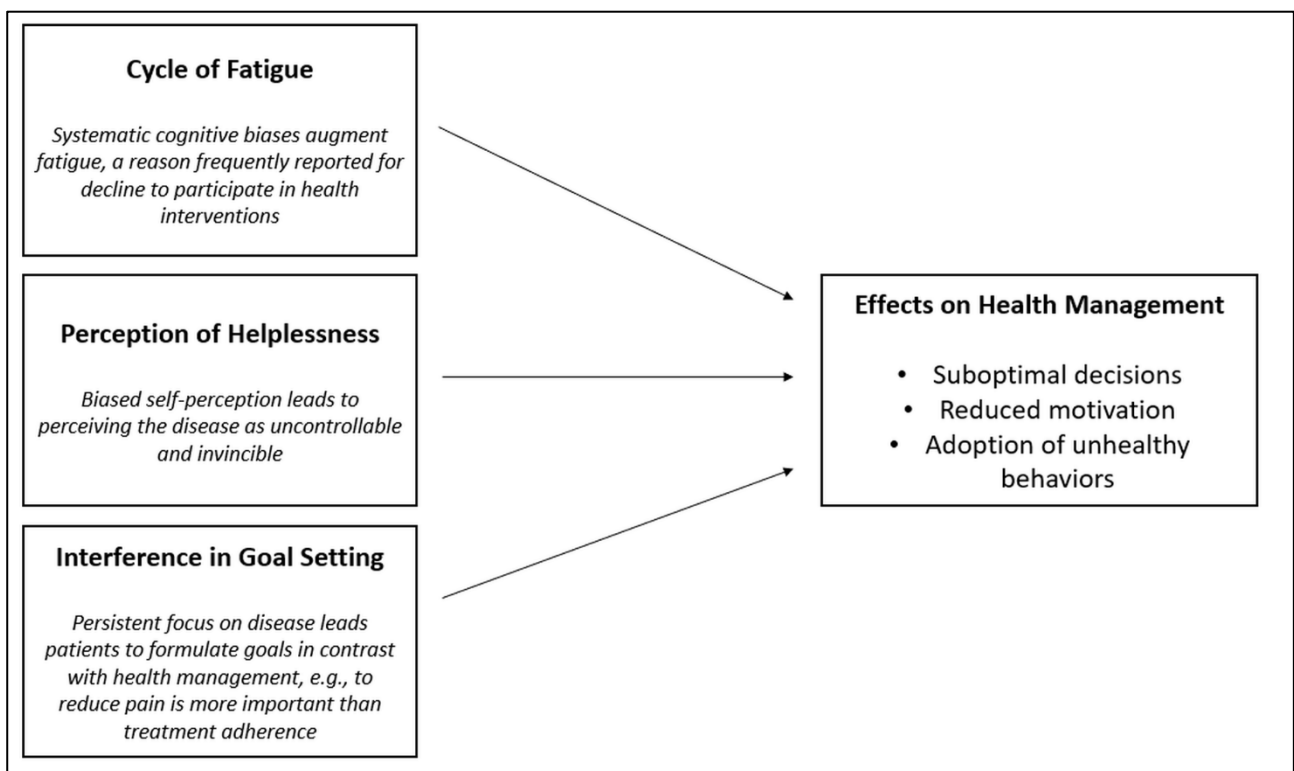


Figure 2 Three main processes by which cognitive and social biases influence patients’ health management

In the following paragraphs, we will focus on some decisions that cancer patients have to face. One of these is the decision on the therapy to be undertaken.

2.3 The decision about therapy

Cancer treatments can have physical and psychological repercussions with a huge impact on the quality of life. For this reason, it is of fundamental importance that the patient's goals and wishes are taken into account when deciding on the treatments available. In fact, due to the increase in treatment options for cancer patients, patients and doctors must face the challenge of choosing which treatment is most suitable, considering the risks and benefits, in line with the concept of shared decision-making. The consideration of the patient's personal values is a central aspect that contributes to the increase of satisfaction with the treatment and to the reduction of regret (Lam et al., 2014). There are three points to take into consideration when deciding on cancer treatment:

1. Adequate understanding of treatment options - it is important to have enough information about treatments to establish expectations, but at the same time, exposure to too much information can be misleading and overwhelming (Schulman-Green et al., 2020). A strongly correlation appears between Regret about treatment choice and early discussion of treatment options and good information (Check et al., 2020). Healthcare professionals must accurately describe the risks and benefits of proposed therapeutic alternatives in order to create realistic expectations about the post-treatment period. In addition, it may be useful to assess information needs and understanding in the pre-treatment rather than in the post-treatment phase, to avoid distortions in memory. The presentation of information as well as the quantity should not be neglected. Medical information is often complex and intimidating and therefore difficult for patients to understand. For this reason, decision aids (ADs) are developed to provide explanations about healthcare options to patients.
2. *Congruence between preferred and experienced patient roles* – Several studies show that a significantly lower level of regret is associated with greater patient involvement in decision-making (Wilding et al., 2020; Wollersheim et al., 2020). However, it is necessary to contextualize the active and passive roles. Although the active participation of patients in the decision allows the creation of realistic expectations (Wollersheim et al., 2020) and the expression of their preferences, the health literacy of patients should be considered. It has been shown that perceived excessive responsibility is associated with less knowledge of treatment and more regrets in decisions (Livaudais, Franco, Fei, & Bickell, 2013). The risk is that patients, without adequate clinical support and recommendations, assume more responsibility than desired, resulting in decision regret rather than prevention (Wagland et al., 2019). Another factor to consider is the culture of belonging and the influence it can have on control preferences and information disclosure. Wang and colleagues has shown (2018) that

decision regret is associated with the discrepancy between the role they prefer and the one they actually play. The involuntary passive role (Mancini et al., 2012) as well as an involuntary active role (Wagland et al., 2019), predicts greater decision regret. According to this thinking, an assessment of patients' decision-making capacity and engagement preferences should be considered.

3. *Attitudes and trust they have for one another* - Problems with healthcare professionals are among the most common aspects identified by patients who regret the treatment received (Fernandes & Bloom, 2011). Patients who trust their doctors perceive treatment choice as a shared experience and show lower levels of regret related to the decision (Hasak et al., 2017). Even in the event of a disagreement, patients are more confident in the final decision when these disagreements are handled with kindness, providing sufficient explanation and time availability (Hasak et al., 2017). Good patient confidence in oncologists' consideration of their personal values (Mack, Fasciano, & Block, 2019) predicts significantly lower levels of decision regret. Being recognized and understood as an individual is critical not only to the outcome of the medical decision, but also as a process.

Finally, another peculiar decision is to participate in psychological interventions aimed at improving the quality of life.

2.5 The decision to participate

The transformation of cancer into a chronic disease has made necessary to take into consideration the effects that this diagnosis has on the lives of patients, many of whom report great difficulty in returning to their everyday lives (Vonk Noordegraaf, et al., 2014; Sebri et al., 2019). Following this, various interventions have been performed over the years with the aim of improving the quality of life and well-being of cancer patients (Durosini et al., 2021).

The decision to take part in these interventions is also very important and peculiar, as it considers various aspects that are often overlooked, focusing only on the effectiveness of the intervention itself. Several studies have shown that patients often do not adhere to these interventions or drop once started. As we will see later, the aspects that underlie this type of decision are varied and complex (e.g. compatibility of the intervention with one's daily life, the effective taking into account of the patient's real needs, etc.) (Savioni et al., 2022)

In particular, an important construct that underlies the decision to participate or not in interventions for the improvement of the quality of life is motivation.

2.5.1 Motivation

Often, in everyday life we wonder why a person behaves in a certain way or why he or she has made that choice. Our behavior is not accidental, but motivated ("explained") by a series of causes and is oriented towards the realization of certain purposes, as well as the satisfaction of specific needs (desires, needs, etc.). We are also often interested in "motivating" a person to do what otherwise, alone, she would not do. We are therefore in the perspective of actively influencing her and directing her resources in one direction rather than another. Motivation (from the Latin *motus* = "movement") is a drive to carry out a certain activity and can be defined as a process of activation of the organism aimed at achieving a given purpose in relation to environmental conditions. This process involves the initiation, direction, intensity, duration and termination of a conduct by the subject.

The motivation foresees the presence of very different levels of complexity, ordered in a hierarchical way: from simple automatic responses and elementary pushes, we reach very articulated and elaborate behaviors (Kleinginna, & Kleinginna, 1981).

The reflexions. They represent the simplest system of response of the organism as a reaction to external or internal stimuli. They are innate, automatic and involuntary mechanisms determined and regulated by genetically based neurophysiological devices. They perform a defense function (need for protection) towards noxious stimuli or a regulatory function that has the purpose of restoring the organism to its equilibrium.

The instincts. At a higher level, we find the instincts, which constitute congenital, fixed and stereotyped sequences of genetically based species-specific behaviors in relation to given environmental stresses. The notion of "instinct" was strongly valued in the early days of experimental psychology as a fundamental concept for describing and explaining the intensity, variety and direction of behavior.

Needs and drives. The concept of instinct has come under criticism, as it is deterministic and unable to account for the motivational variety of humans. Our inclinations are subject to the pressures and influences of the environment, as well as our constant learning. In the 1950s, the concepts of need and drive were developed in psychology. The first indicates a condition physiological deficiency and need (hunger, thirst, sex, etc.). The second expresses a state of unease and internal tension that the individual tends to eliminate or, at least, to reduce, if needs are not satisfied.

Primary and secondary motivations. The motivations connected with the physiological needs have been called primary motivations, while the motivations that mainly refer to the processes of learning and social influence are called secondary motivations.

2.5.1.1 The main theories

Behaviorist conception

In an attempt to explain human behavior in its various aspects, Behaviorism proposed an explanatory model of the needs of individuals based on the interaction between drive and habit. The drive, which arises from a condition of deficiency due to the appearance of a need, provides the propulsive thrust and determines a condition of activation in the organism. The latter maintain an optimal level of stimulation to respond efficiently to stimuli. In particular, it serves to reach a certain goal (object of need) or to avoid a frustrating condition (source of unpleasantness). The elaboration of the secondary drives takes place by learning, thanks to the association, according to the principles of classical and operative conditioning. If we place rats in a white cage with a metal bottom and pass the electric current to the bottom, we observe that the animals immediately take refuge in an adjacent black cage. After a few times, the rats exhibit white cage avoidance behavior, even though it is no longer electrified. This new drive, which can be defined as "fear of white", is learned and acquired on the basis of a process of secondary reinforcement. The repeated association between drive and response creates in the individual a habit that serves to give direction to behavior and makes predictable proper conduct to satisfy or reduce the need in question. With reference to motivations, behaviorism aims to identify the conditions for establishing and maintaining an optimal relationship between the individual and the environment through processes of learning and association in the connections between stimulus and response. Certain environmental situations become incentives thanks the recurring association with one's own gratifying (pleasantness) or dissatisfaction (unpleasantness) experiences. From the earliest years, the natural incentives that establish physiological connections between needs, stimuli and responses, intertwine with each other and give rise to new social incentives, of a learned nature.

Cognitivist perspective

Cognitivism overturns the behaviorist point of view, immediately underlining that motivation and needs change in relation to the quantity and quality of information coming from the environment that the organism is able to process. With equal strength, cognitivism highlights the individual's ability to set goals and pursue the set goals. Motivation consists of a goal (or value) to be achieved, capable of creating expectations and to guide conduct. In this way, the motivational sphere is effectively removed from the biological sphere. In the cognitivist conception (MacKay, 1956; Miller, Galanter, & Pribram, 1960), attention is focused on the cognitive processes underlying the identification and definition of the goals to be achieved, the assessment of the probabilities of success (success) or failure (failure), the progressive modification of the aims according to the information available at

that time, the evaluation of the results of their conduct, as well as the adoption of a temporal perspective anchored to the future rather than the past. According to cognitivism, individuals tend to achieve success and avoid failure (Atkinson, 1974). Success is given by the interaction between the motivation, the incentive represented by its achievement and the probability of obtaining it. In this process, speaking in terms of probability and on the basis of the subject's level of aspiration, the tendency to avoid failure (fear of failure) also becomes relevant. The individual with a high motivation to avoid bankruptcy thus orientates himself or herself towards highly probable goals (perfectly understandable condition) or towards goals, whose pursuit is highly improbable (paradoxical condition). In fact, failure in very difficult tasks is less frustrating and somewhat justified as an experience shared by many other individuals. In anticipation and perception of success (or failure), the level of motivation is significantly influenced by the perceived difficulties of the task, the skills the subject believes they possess, the commitment that the task is thought to require, as well as the perception of the task role to be assigned to the case. Likewise, the temporal dimension plays an important role in attributing value to a goal. Past and future describe the motivational horizon of who I am. Conducts that in the past have been associated with successful (or unsuccessful) experiences become fundamental elements for defining the goals of the present and the future with respect to one's expectations. The success and failure of the past and present constitute a significant mortgage for the construction plans for the future. Both experiences and plans influence the choices of the present.

Interactionist point of view

According to the interactionist point of view, interactions with others arise, nurture and regulate motivations. Even at the level of primary motivations (hunger, sexuality, etc.), interpersonal relationships play a fundamental role in orienting their manifestation and their satisfaction. For instance, we pay attention to the aspects of conviviality, sociability and friendship underlying the fact of consuming food together. In the various cultures of the world, it is common practice to celebrate the signing of an important contract, or to signal a significant social change, with a banquet or, in any case, with the consumption of food (from marriage to graduation party, to farewell for retirement). In fact, food confirms the psychological (and often institutional) value of the new understanding and the new relational pact. Likewise, secondary motivations (affiliation and attachment, power, competition, success, etc.) are supported and governed by the relational games that are created within a given community. In the continuous exchange of moves and counter-moves between individuals, some conducts are strengthened and valued as worthy of interest, while others are discouraged or even openly rejected. Each individual, therefore, acts in a certain way rather than another according to the

relational network in which he or she is inserted. Within these psychological games, each of us can become a form of reward, support, obstacle or frustration towards others based on the culture of belonging. In Western societies, individual affirmation represents a fundamental and obvious motivation for one's choices; for against, in Eastern societies individual affirmation is strongly discouraged, as a sign of selfishness and social immaturity (Anolli et al., 2005; Anolli, & Mantovani, 2011). The reasons therefore indicate the type and sequence of interactions that occur between two or more subjects. Rather than being a reality strictly pertinent to the single individual, they belong to the relational model that regulates the exchanges between them in a given culture. For example, the motivation to obtain protection involves acts of dependence towards another perceived as dominant. Conversely, the motivation for leadership is expressed in struggle and competition.

We have seen that, from the multiple approaches of psychology, what moves the behavior can be called in many ways. In light of this, it is important to understand that motivations, in addition to their nature, can be differentiated in terms of those characteristics that make them able to influence behavior. One of these differentiations between intrinsic and extrinsic motivation proposed by Ryan and Deci (2000). The first is to carry out an activity because it is self-rewarding; the second is to perform the same activity to achieve something else (to receive a reward). As a rule, intrinsic motivation turns out to be longer and more effective than extrinsic motivation and is closely associated with a sense of self-efficacy. For example, with respect to the activity of drawing, children who did not receive a reward have many more drawings than those who are explicitly anticipated that their drawings will be awarded. Rewards, which are extrinsic motivations, can in certain circumstances reduce (rather than increase) the original intrinsic motivation. Rewards are a shift in people's attention and interest and can become misleading.

It is important to consider how the motivations transformed; many behaviors are in fact linked to the achievement of “nutriments” linked to fundamental areas. Self-Determination Theory (Ryan & Deci, 2017) individualized three of these:

- Competence, defined as feeling effective in one's ongoing interactions within the social environment and experiencing an adequate number of opportunities to express one's abilities;
- Relatedness, that refers to feeling connected to others, caring and being cared, having a sense of belongingness towards individuals and community;
- Autonomy, which relates to the perceived origin/source of one's own behavior. Specifically, humans pursue the need of experiencing their own activity as rooted in personal interests and integrated values.

Another aspect to consider is how motivation can change and transform itself from extrinsic to intrinsic. For example, if a patient is involved in an intervention that includes tasks / activities that

respond to his/her real needs, his motivation, which initially could be extrinsic, therefore linked only to the result, can turn into intrinsic.

This is the important point consider in my PhD project which have the aim, firstly to study the decision to participate in intervention for quality of life, secondly to understand the characteristic that are important for a psychological intervention in order to have a high participation rate and a low dropout rate.

Chapter 3: Empirical contribution

3.1 Introduction to the research studies

In order to study the decision-making process in real life decision and specifically in the decision to take part in psychological intervention to improve quality of life in chronic patients, 2 studies and a scoping review have been conducted with the following aims:

1. To investigate how decisions are made, changed and maintained in “real life”;
2. To translate the decision making in real life in health care context, in order to provide useful knowledge for health care, with a focus on psycho-oncology;
3. To provide practical guidelines to promote health interventions taking into account decision making in oncological patients.

Paragraph 3.2 (study 1) will show a primary look for a way to study decisions in the real life context in order to understand how decisions are made. Paragraph 3.3 (study 2) will report a scoping review with the aim to identify the factors that may influence the decision by cancer patients and cancer survivors to take part in psychological interventions, as well as to maintain commitment to them.

Finally, paragraph 3.4 (study 3) will show a qualitative study on the motivations that orient the decision to participate in psychological intervention for oncological patients.

3.2 Study 1: How to make big decisions: A cross-sectional study on the decision making process in life choices

The Role of context in choices

Often, Choices are not made in isolation, but decisions occur within the family, peer groups and in wider social contexts (Ben-Akiva et al., 2012; Chao et al., 2021). Especially, when decision regards important life paths, they are influenced by the “realm” in which they happen; if I have to take a decision regarding my work or my degree program, I know this could affect my self-realization and possibly my future wealth; if I have to take a decision regarding love and family, I know this would affect my future relational and social well-being. Obviously, paths chosen in life intertwine and influence one another, for example pursuing some career will have an impact on one’s family life and vice versa. Yet, it is possible that people would first consider the possible consequences more salient in a certain life area, and this could have an influence on the decisional process as a whole

(e.g., taking emotions more or less into consideration to orient the choice). Career research and college selection, for example, show that deciding which type of job or which type of degree program is tied to the best use of your talent and ability, job security and high income, good social status, etc. (Ngambeki et al., 2008). This suggests that career or university choices can be made with a greater use of the deliberative system (System 2). Of course, this does not mean that the more intuitive, emotional System 1 is not involved in career choices. Indeed, if we would accept the “homo oeconomicus” approach to motivation and decision to work (i.e., workers are motivated by earnings only), it would be impossible to explain motivation’s components such as enthusiasm and interest (Bojanić, 2014). Work and career often hold important emotional and identity value, which act as motivators to pursue it (Meijers et al., 2013; Yang, 2019). Yet, many studies in career choice and job orientation emphasize that a career choice should be made based on rational and careful evaluation of alternatives and possible consequences, rather than instinctively. For instance, university degree choice appear to be influenced by a mixture of interest towards the subject, high or low worry for one’s own future, attitude towards helping others and the preference for easy choices (Skatova & Ferguson, 2014), which tend to be investigated by dedicated questionnaires and point towards attentive and explicit evaluation of alternatives before taking a decision. Also the extensive research from the person-environment fit theory (Van Vianen, 2018; Guan et al., 2021; Riedo et al., 2019), which tenets that decisions are optimal when personal attributes (e.g., needs) and environmental attributes (e.g., supplies) are compatible, emphasizes that career choices are based primarily on careful evaluation of one’s own and the organization’s characteristics. Research on love and relationships shows that people decide for a relationship taking into account aspects such as eros and commitment, satisfaction and the previous relationships experiences (Hammock & Richardson, 2011). It is possible that life decisions about loved ones and relationships would imply a greater use of the intuitive system (System 1), especially in virtue of System 1’s intrinsically emotional component and instinctive nature, at least when compared with career choices. Since in the present research participants will be asked to report on their recollection of significant life choices, it is possible they will be keen to find a more prominent role of emotions, intuition and instinct in their own life choices related to love and affection. An interesting example is the work by Dailey and colleagues (Dailey et al., 2009), who employed a qualitative research methodology to describe reasons for break ups or renewals of romantic relationships. Their results show a number of themes that could be considered “irrational” and impulsive, such as decisions based on feelings independent of reasoning (e.g., “I just didn’t feel like marrying anymore”) or cognitive dissonances related to one’s own behavior (e.g., cheating after having decided not to, and feeling guilty after). Such a line of reasoning may certainly appear as an oversimplification. One could marry with the

aim to achieve specific advantages, e.g. governmental incentives, access to wealth or international citizenship (Ash & Badgett, 2006; Wray, 2006; Maskens, 2015; Hatch, 2017; Pilgeram & Amos, 2015), deciding on the sentimental life area in a cold/rational fashion. On the contrary, one could be driven towards the selection of a job by the necessity to regulate emotions and stress (Firth et al., 2004) or also by authentic passion for it (Smith & Manna, 2005). We will hypothesize that Systems 1 and 2 will be associated to a greater extent respectively to the sentimental and the work-related life choices, at least in terms of recollection, taking into account the literature outlined above but also the complexity of life choices as they develop in real life scenarios.

The Role of Individual differences

Several constructs can be interesting for investigating decision making in different life choices' contexts. Many studies in applied psychology show that individuals' attitudes and choices are influenced by personal tendencies or personality traits (Lauriola & Levin, 2001; Byrne et al., 2015). For example, when people make school or career choices, high levels of neuroticism are associated with a less experience of difficulties in making decisions (Gati et al., 2011; Di Fabio & Palazzeschi, 2009). The studies of partner' choice are focused on the personality traits that could be helpful in mate searching. For example, Back and colleagues (Back et al., 2011), found that extraversion is associated with a more active flirting behavior and therefore a greater possibility of finding a partner, as opposed to shyness. The literature about perceived social support highlights that people who experienced decision in a supportive context have a higher decisional competence and lower decisional conflict (Lawson & Pierson, 2007). For example, Chen et al. (2018) evidence that, in women who have to decide whether to undergo prenatal screening or not, social pressure decreases the satisfaction of the choice while they tend to experience greater confidence and satisfaction in the choice made if it occurred in a context of social support. It is widely acknowledged that high perceived social support is positively related to career satisfaction and expectations (Franco et al., 2019; Roxburgh, 1999; Isik, 2013), as well as to close relationships' success and marital quality (Dehle et al., 2001; Lin et al., 2017), as it acts as a buffer against stress and negative emotions. In this sense, it is possible that people experiencing a desirable level of social support would be more confident in their choices in life and even more satisfied, as they are reinforced and supported by their loved ones. Wray and Stone (2005) have studied the role of anxiety in decision-making. In their studies, they found that subjects who show higher anxiety levels tended to make risk averse personal choices, but not in others' decisions. According to literature, anxiety affects decision because its makes risks and possible negative outcomes of choices more salient in the decision maker's perception (Sebri et al., 2021; Noël et al., 2013; Cavanagh et al., 2014; Herman et al.,

2018), so that final decisions may be conservative and/or orientated to avoid risks and punishments more than obtaining distant positive outcomes.

As mentioned above, all life choices are influenced by the context and relationships with others, as the choices are made within a society and for this reason, they can influence both one's own and others' lives. Some theories argue that the way we approach relationships is influenced by how we build relationships during the first few years of life (Hamarta, 2004). According to attachment theory, (Bowlby, 1973, 1982) people develop internal behavior patterns related to the relationships they have experienced with reference figures during infancy, childhood and adulthood. According to Bowlby (1973), an individual's initial attachment is established from the beginning of his development through the relationship with his primary caregiver(s), and this provides a cognitive framework for his subsequent social relationships. Since attachment is a precursor to our future relationships, this could also influence how we make decisions in multiple life areas, since those hold important consequences for the quality of present and future social life (e.g., building a family, collaborating with new coworkers, etc.). A study on 567 students found that attachment style significantly predicts decision-making style. In particular, the authors have seen that the secure attachment style is the most significant predictor of procrastination, buck-passing and vigilance decision-making styles and decision self-esteem; while fearful attachment style was found to be the most significant predictor of hypervigilance decision-making style (Deniz, 2011). Furthermore, a study (Hazan & Shaver, 1990) demonstrated that attachment style was related to decisions and behavior in the "love and work" life areas as adults. Specifically, secure-attached adults approach their work with more confidence but attribute more importance to affective relationships. Ambivalent-attached respondents were more preoccupied that love concerns would interfere with their work performance, and feared the consequences of poor work performance the most. Finally, avoidant-attached persons were found to value their career as they use it to reduce social interactions, and were also the less satisfied by it.

Objectives

The present study (Savioni et al., 2022) aims to explore the cognitive mechanisms involved in important life choices that are identified by the participants themselves. Specifically, we will ask participants to recall significant choices they made in their lifetime, specifically two types of choices: sentimental (e.g., "Should I get married?"; "Should I break up with my partner?") and work (e.g., "Should I move abroad for work?"; "Should I accept that job offer?"). It should be noted that while a processual analysis of decision (Abbey & Valsiner, 2005; Fossa et al., 2016) in life choices is probably impossible to carry out (i.e., a step-by-step analysis of micro-components of

decisions would require collecting data on the life-relevant decision the moment/period they are taken, and with very complex tools), it is still feasible to collect information on people's recollection of decisions and the factors involved in them. This considered, the first aim of this study is to evaluate the differences in terms of System 1 and System 2 usage within life-relevant decisions taken regarding different life areas (i.e., Love/relationships and Work/career). The second objective of the study is to explore the relations between employment of System 1 and 2 in life choices and personality traits or personal tendencies. The third objective of the study is to analyze whether some characteristics of the recalled life choices (namely difficulty in taking the decision, pleasantness of the decision process, current memory ("clarity") of the decision process, final satisfaction) differ between life areas. Fourth objective of the study, as related to the outcome of the choice, would be to analyze the predictive relationships between personality traits and utilization of System 1 and 2 as predictors, and final satisfaction for the life choice in the two areas. Research hypotheses and research questions are as follow:

Hp1: People will tend to make more use of rational and deliberative system (System 2) in career choices, while for choices in the emotional sphere, they will tend to make more use of the more emotional and intuitive system (System 1).

Rq1: We will explore the differences between sentimental and work choices in terms of clarity of the decision recollection; difficulty to take the decision; pleasantness of the decision process; and satisfaction regarding the final choice.

Rq2: We will explore whether individual characteristics of participants and the utilization of System 1 and 2 predicted satisfaction with the decisions in the two life areas.

Methods

A total of 188 Italian adults were included in this study. 24.5% were male (n=46; female: n=142) and ages from 19 to 63 years old (Mage=31; SDage=8.21). The majority of them were employed and were bachelor or maiden. All the participants consented to participate voluntarily and did not receive incentives for their participation.

Participants were invited via social media and mailing list to take part in this study. We used snowball sampling based on respondents and researcher networks (Biernacki & Waldorf, 1981): "Snowball sampling yields a study sample through referrals made among people with important characteristics for the research question. It is particularly applicable when the focus of study is on a sensitive issue, and thus requires the knowledge of insiders to locate people for study." Data were collected from October 2019 to April 2020. Informed consent was obtained prior to the questionnaire completion and the anonymity was protected for all participants. The survey was set on a Google Moduli

platform. After having provided socio-demographic information, participants thought about autobiographical memories, and specifically to (a) one specific relevant choice pertaining to the professional area, and (b) one specific relevant choice pertaining to the sentimental area. Specifically, participants identified “an event or a specific experience of your life in which you had to make an important decision. In particular, think of an event experienced in your life regarding the affective sphere (e.g., Should I get married? Now or later? Should I leave my partner? Should we go to live together?)” and “a specific event or experience of your life in which you had to make an important decision. In particular, think of an event experienced in your life concerning the professional area (e.g., Should I study or work? Should I move for work? Which job/university should I choose?)”. After each request, participants were asked to indicate the clarity (e.g., How clear is the episode?) and pleasantness (e.g., How enjoyable was this episode?) of the evoked episode, the difficulty (e.g., It was difficult to decide) experienced when making the choice, the personal satisfaction (e.g., As of today, I am satisfied with my choice) related to the final choice on a 7-point Likert scale, and the days that participants spent to make a decision. Participants were also invited to indicate if they used System 1 or System 2 to make their choices on a 7-point Likert scale (from strongly disagree to strongly agree). The use of System 1 was assessed through two items: “To decide, I relied on intuition, inspiration” and “To decide, I let my emotions guide me”. While the use of System 2 was explored with these two items: “To decide, I relied on reasoning” and “To decide, I documented on all the possible options”. These questions were selected based on literature, to represent the distinctive characteristics of Systems 1 and 2 when solving problems and taking decisions: an example of similar questions could be found in trait-based questionnaires that measure individual’s tendency to rely more on rational or experiential processes, such as the REI (Pacini & Epstein, 1999; Richards et al., 2018). Lastly, we administered the following self-report questionnaires in order to assess participants’ psychological states and traits:

- State-Trait Anxiety Inventory (STAI-Y-2; Metzger, 1976; Spielberger et al., 1983; Italian validation: Pedrabissi & Santinello, 1989): STAI-Y-2 is a self-report instrument commonly used for the measure of trait and state anxiety. In this study, we administered only the 20-items related to the trait anxiety (4-point Likert scale from “for nothing” to “very much”). STAI-Y-2 can be used in clinical settings to diagnose anxiety in adults and distinguish it from depressive syndromes. The scale showed a good reliability equal to .86 (Spielberger et al., 1983). In this study, the scale showed a good reliability equal to .92.
- Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965, 2015; Italian validation: Prezza et al., 1997): RSES is a 10-item self-report scale to measure self-esteem. It is a Guttman scale rated on a 4-point Likert scale from “strongly disagree” to “strongly agree”. The items explore the individual’s

satisfaction with himself/herself, positive, and negative feelings. The scale showed a reliability equal to .84 (Prezza et al., 1997) and in this study, the reliability is equal to .87.

- Big Five Inventory (BFI; John et al., 1991; Italian validation: Ubbiali et al., 2013): BFI is a self-report questionnaire that assesses personality traits through 44-items. It explores five dimensions of personality: Openness to experience, such as curious, imaginative, and artistic people; Conscientiousness, such as efficient, organized, and thorough people; Energy or Extraversion such as sociable, energetic, and enthusiastic people; Agreeableness, such as forgiving, warm and sympathetic people; and Neuroticism, such as tense, irritable, and moody people. Items are assessed on a 5-point scale ranging from “strongly disagree” to “strongly agree”. In the present study, the scale revealed an acceptable internal validity (extraversion: $\alpha = .86$; agreeableness: $\alpha = .68$; neuroticism: $\alpha = .83$; conscientiousness: $\alpha = .82$; openness to experience: $\alpha = .85$).
- Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988; Italian validation: Prezza & Principato, 2002): MSPSS is a self-report questionnaire that explores the perceived social support. The scale is composed of 12 items on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The instrument measures support from family, friends, and significant others. The scale showed a good reliability equal to .88 (Zimet et al., 1988) and, in this study, the reliability was equal to .91.
- Measure of Attachment Questionnaire (MAQ; Carver, 1997; Italian validation: Roccato & Tartaglia, 2003): MAQ is a 14-item each rated on 4-points Likert scale (ranging from “strongly disagree” to “strongly agree”). The questionnaire identifies four dimensions, which correspond to the four styles of attachment identified by Carver: Avoidant (anxiety and anger relationships, tendency to seek emotional distance from others), Ambivalent-Worry (fears of abandoned or relationship betrayal; positive view of self, negative view of other), Ambivalent (desire for closeness, preoccupation; negative view of self, positive view of other), and Secure attachment (confidence in others and capacity for intimacy). The scale showed a good reliability of the scales between .69 and .76 (Carver, 1997). In the present study, the scale revealed a good internal validity (Avoidant $\alpha = .81$; Ambivalent_Worry $\alpha = .73$; Ambivalent $\alpha = .71$; Secure $\alpha = .84$).

Data Analysis

First of all, a factor analysis will be performed in order to determine that the items used to investigate utilization of System 1 (related to intuition and emotion) and System 2 (related to rationality and attentive consideration of available options) show internal consistency over two different factors. This analysis would corroborate the hypothesis that the ad-hoc items actually address two different categories of cognitive processes, based on the theoretical description of rationality vs. intuition. A

Principal Component Analysis with Varimax rotation will be conducted with SPSS software (Version 20.0). Principal components analysis (PCA) is one of a family of techniques for taking high-dimensional data, and using the dependencies between the variables to represent it in a more tractable, lower dimensional form, without losing too much information. PCA is one of the simplest and most robust ways of doing such dimensionality reduction. In PCA, the variables under consideration are transformed into a new set of variables, which are linear combination of the original variables (Frey & Pimentel, 1978). In the present study, we will perform two separate PCAs for the items pertaining to the “work” and the “sentimental” areas as the resulting variables will be used in subsequent analyses specific for responses to these areas. Additionally, we will carry out three analyses. First of all, the Analysis of Variance (2×2 design) will be conducted to identify whether intuition and emotion (System 1) and rationality and attentive consideration of available options (System 2) had been preferentially involved across the explored life choices. This will allow us to compare the involvement of System 1 and System 2 across the life choices in the sentimental vs. work life areas. The Analysis of Variance is a statistical technique for analyzing measurement depending on several kinds of effects operating simultaneously, to decide which kind of effects are important and to estimate the effects (Scheffe, 1999). Secondly, we will conduct

A within-subjects t-test analysis to assess the differences between sentimental and work choices in terms of clarity of the decision memory, difficulty to take the decision, pleasantness of the decision process, and satisfaction regarding the final choice. This analysis is widely used to compare groups' means for particular variables (Kim, 2015). We deemed it interesting to compare the characteristics of the participants' decisional processes when confronting one specific relevant choice pertaining to the sentimental and work life area. Indeed, the understanding of life choices requires to study the effects of contexts and specific personal aims on multiple components of the decisional process as decision makers are able to recall it.

Finally, a regression analysis will be performed to analyze whether individual differences and the utilization of System 1/2 influenced final satisfaction with the choice in the two life areas. Satisfaction can be regarded as an important information about the final outcome of the choice which, in the context of relevant life choices, needs to be evaluated ultimately by considering their impact on the decision maker's life at a later time. Regression allows us to examine the relationship between variables, providing information both at a predictive and descriptive level (Porter, 1999). Individual differences chosen as predictors were based on researchers' hypothesis and literature review. Specifically, to predict satisfaction in the sentimental choice, besides the utilization of System 1 and 2, we tested the subscales of MAQ, because the literature reported that attachment style relates to

affective relationship quality (Feeney & Noller, 1992; Meyer et al., 2015; Smith & Klases, 2016; Rafagnino & Puddu, 2018). Differently to predict satisfaction in the work choice, besides the utilization of System 1 and 2, we tested trait anxiety and self-esteem, because these individual traits have been frequently associated with subjective and objective success in the workplace (Mughal et al., 1996; Baumeister et al., 2003; Judge & Bono, 2001; Liu et al., 2017; Rogante, et al., 2019). We performed further regression models to explore the possible role of personality traits as predictors of satisfaction with the decisions.

Results

The present study explored the cognitive processes involved in life-relevant decisions. Participants reported on characteristics of their own decisional processes when confronting one specific relevant choice pertaining to the sentimental or work life area. Initially, we performed a factorial analysis in order to determine if items used to investigate the use of System 1 and System 2 showed an internal consistency over the two different factors. For sentimental area, the two-factor solution accounted for 69% of the total variance. The first factor (defined by two items) refers to intuition and emotion in relationship (System 1) and explains the 40% of the variance. The second factor (defined by 2 items) refers to rationality and attentive consideration of available options in relationship (System 2) and explains the 29% of the total variance. In a similar way, for the professional area, the two-factor solution accounted for 75% of the total variance. The first factor is composed by two items and explains the 45% of the variance. Items included in this factor were related to the intuition and emotion used to make decisions in professional context (System 1). The second factor is composed by two items and explains the 30% of the variance. It refers to the tendency to use rationality and attentive consideration of available options during decision making at work (System 2; Table 1).

	Sentimental area		Professional area	
Item	System1	System2	System1	System2
To decide, I relied on intuition, inspiration	.845	.136	.868	-.020
To decide, I let my emotions guide me	.757	-.300	.887	-.129

To decide, I relied on reasoning	.008	.801	.070	.861
To decide, I documented on all the possible options	-.119	.846	-.239	.810

Table 1 Factor loadings from Principal Component Analysis with varimax rotation.

To respond to the first objective of the research, ANOVA was performed to identify whether System 1 (reference to intuition and emotion) and System 2 (reference to rationality and attentive consideration of available options) had been preferentially involved across the life choices in the sentimental vs. work life areas. Results highlighted a statistically significant interaction effect between variables ($F(1,2687)=69.768$, $p < .001$, $\eta^2 = .272$). Data also showed that System 1 is significantly more involved in the sentimental area ($M = 5.3$; $SD = 1.46$) than in the work area ($M = 4.7$; $SD = 1.53$), while System 2 is significantly more involved in the work area ($M = 5.3$; $SD = 1.28$) than in the sentimental area ($M = 4$; $SD = 1.75$; Fig. 3).

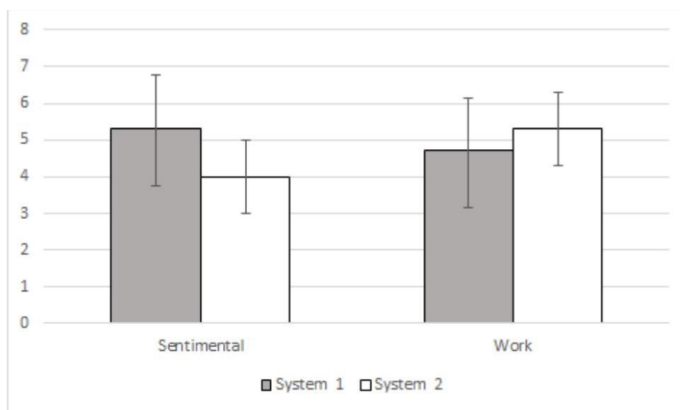


Figure 3 The use of System 1 and 2 in sentimental and work area

To respond to the second objective of the study, the two areas were compared, by performing a paired samples t-test analysis. No significant differences emerged between sentimental/work choices in terms of clarity of the episode in memory, difficulty to take the decision, satisfaction regarding the final choice. A significant difference emerged regarding pleasantness of the decisional process, with work choices being recalled as more pleasant than sentimental choices (see Table 2 for results).

	Sentimental (<i>M</i> , <i>SD</i>)	Work (<i>M</i> , <i>SD</i>)	<i>t</i>	<i>p</i>	<i>Cohen's d</i>
Clarity of the episode	6.11, 1.1	5.93, 1	-1.692	.09	.17
Difficulty to take decision	5.07, 1.9	4.74, 1.6	-1.782	.07	.18
Satisfaction with final choice	5.88, 1.6	5.62, 1.7	-1.572	.11	.15
Pleasantness of decisional process	3.4, 2.3	4.18, 1.8	3.705	.00**	.37
System 1	5.37, 1.4	4.75, 1.5	-4.255	.00**	.41
System 2	4.01, 1.7	5.38, 1.2	9.215	.00**	.89

Table 2 *t*-tests on decisional processes across sentimental/work life choices

The third objective of the research was to analyze predictors of the outcome of the choice (e.g., satisfaction with the choice) among personality traits and the utilization of System 1 and System 2 cognitive processes. The first regression analysis focused on satisfaction in the sentimental area. Satisfaction was predicted by secure attachment (positively) and by ambivalent attachment (negatively), with an explained variance of 14%. The second regression analysis focused on satisfaction in the work area. Satisfaction was predicted positively by both System 1 and System 2, and negatively by trait anxiety, with an explained variance of 15% (see Table 4 and Fig. 4 for results). Satisfaction in both sentimental and work areas was not predicted by the Big Five personality traits.

	LOVE_System2	LOVE_System1
MAQ Security	-.054	.058
MAQ Avoidance	.034	.019
MAQ Worry	.059	.177*
MAQ Ambivalent	.001	.168*
LOVE_System2	1	-.143
LOVE_System1	-.143	1

	WORK_System1	WORK_System2
Anxiety_Trait	.003	.092
Self esteem	.025	.072
WORK_System1	1	-.175*
WORK_System2	-.175*	1

** p<.001

*p>.05

Table 3 Correlation analysis on sentimental and work choice satisfaction

DV: Sentimental choice satisfaction	<i>B</i>	<i>SE(B)</i>	<i>Beta</i>	<i>t</i>	<i>p</i>
System 1	.065	.065	.058	.821	.412
System 2	.089	.079	.095	1.371	.172
Secure Attachment	.611	.187	.252	3.260	.001
Avoidant Attachment	.120	.187	.051	.640	.523
Worried Attachment	-.246	.149	-.124	-1.644	.102
Ambivalent Attachment	-.206	.180	-.258	-3.365	.001

$F = 5.203; p < .001;$

$R^2 = .14; N = 188$

DV: Work choice satisfaction

System 1	.205	.079	.178	2.582	.011
System 2	.260	.095	.190	2.744	.007
Trait Anxiety	-.049	.016	-.320	-3.109	.002
Self Esteem	-.007	.031	-.023	-.226	.822

$F = 8.568; p < .001;$

$R^2 = .15; N = 188$

Table 4 Regression analyses on sentimental and work choice satisfaction

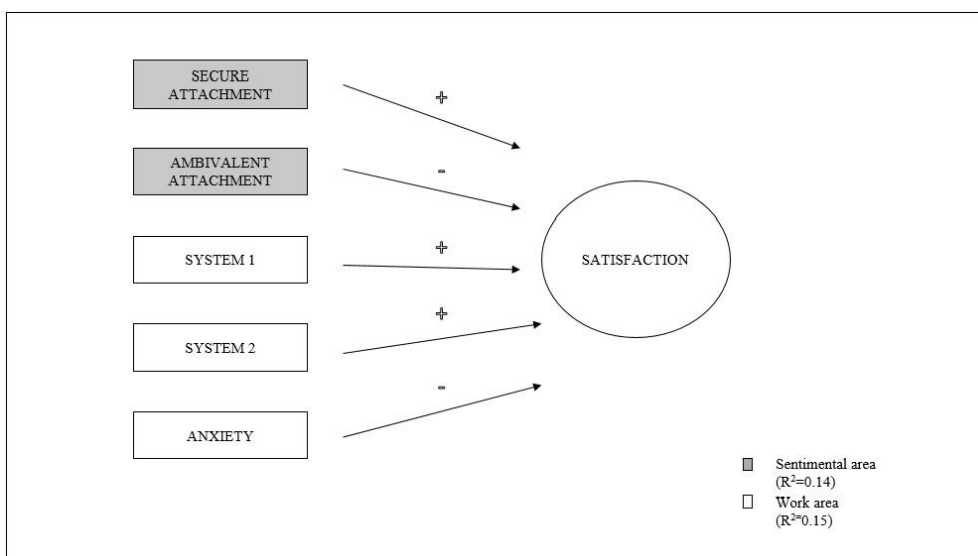


Figure 4 A graphic representation of the regression models on life choices' satisfaction

Discussion

This study aims to explore the cognitive mechanisms involved in important life choices. We explored the cognitive processes involved in life-relevant decisions asking participants to report the characteristics of their own decisional process when they had to make an important choice in two life areas. Specifically, we assessed the use of an intuitive (System 1) and rational (System 2) decisional process in sentimental and work life areas. The factor analysis showed an internal consistency over the two factors in each area, supporting the existence of two different cognitive decision-making systems in the explored life contexts.

Our results showed that people tend to use System 1 (reference to intuition and emotion) more when they have to make a decision in the sentimental area. When people have to make decisions in love, they tend to listen more to their feelings than to use rationality; for example, in the decision whether to marry the partner one has been with for several years and has built a solid relationship with, feelings and emotions come into play at a stronger extent (Franco & Sanches, 2016; Lee & Selart, 2012). When, instead, one has to make a decision regarding job and employment, analytical reasoning appears to be involved more. In this context, the subject tends to evaluate carefully situations and the pros and cons of the decision outcome. While this does not mean people exclude careful reasoning when dealing with sentimental matter or stop listening to emotions and insight when it comes to work-related choices, results clearly show that individuals have a specific *recalling* of the characteristics of cognitive processes involved in important life choices, which can be described in terms of System 1 or System 2 processes (Hertwig & Erev, 2009; Ludvig & Spetch, 2011).

The analysis of some characteristics of recalled life choices in the different life areas showed a difference only regarding pleasantness: decisions in the work area are remembered as more pleasant than sentimental decisions. This result alone is not easy to interpret. On the one side, it is possible that life choices in the sentimental area involve a wider variety of emotions and they underwent more dramatic elaboration and emotion regulation efforts. An alternative interpretation may regard a memory bias that leads subjects to remember extreme results sooner and more frequently (Madan, Ludvig, & Spetch, 2014; Wagoner, Brescó de Luna, & Zadeh, 2020). We can therefore assume that career choices involve a higher level of risk for one's own future than sentimental ones, because they may potentially lead to outcomes more difficult to change later (e.g., moving abroad). This characteristic leads career choices to be remembered more pleasantly, because the decision process involved more risk, and the participants are today happier to have overcome such obstacles.

From the correlation analyses (Table 3), we can notice that the correlation between system 1 and system 2 is small, negative, and occurs only in one of two cases. This result would be considered a problem if it led us to believe that the two measures we created with our items actually measured the same thing. This would happen if there was a positive correlation and very close to 1). On the other hand, a contained correlation between the two variables is acceptable/plausible as they are effectively questions about the "same thing", as the interest is on which cognitive processes the subject used to make a choice.

Using more intuitive or rational criteria to approach a decision does not necessarily lead to the exclusion of others.

Individual characteristics as well as the recourse to rational vs. intuitive cognitive processes proved to play a role in the final satisfaction about the outcome of the choice. Despite explained variances being relatively low, regression analyses provided some interesting information. On the one hand, satisfaction with sentimental life choices is predicted by attachment style. This supports existing literature (Akpan & Ottu, 2011; Bradford, et al., 2019; Jones & Cunningham, 1996; Kirkpatrick & Davis, 1994) as well as the idea that intimate relationships are influenced by affective experiences that could be traced back to early life development. Apparently, in sentimental life choices these preexisting dispositions are more relevant in influencing final satisfaction than the cognitive processes utilized to decide. On the other hand, satisfaction with choices in the work area is predicted negatively by trait anxiety, which again is consistent with previous literature that shows that anxious people are more vulnerable to work related stress and dissatisfaction (Extremera, et al., 2020; Saquib et al., 2019), and also positively by the usage of both System 1 and System 2 cognitive processes when taking the choice. This last result shows that, despite the possibility to utilize more one system or the other when deciding, the final outcome of a life-relevant decision may be determined by a complex decision process, which features both careful assessment of options and intuitive/emotional influences.

This research, with all its limitations, could represent a first step towards a new methodology that allows us to address the issue of uncertainty, as this is reduced, or is reintegrated, when we talk about important life choices made a long time ago. Recalling and analyzing the cognitive components of a choice made a long time ago requires analyzing the process and the outcome and then reintegrating the uncertainty. These processes put in place by these people to recall the choices made (beyond the fact that they are reliable) constitute ways of thinking or an approach to the question that can help to reconsider the uncertainty. It is an important concept in health care, in particular regarding chronic diseases, such as cancer, as they involve multiple uncertainties both existential and practical.

Han and colleagues (2011) developed a model of uncertainty in health considering a three-dimensional taxonomy. Uncertainty about the issues can have different form:

- personal or patient-centred (e.g. uncertainty about psychosocial or existential problems);
- process-based or system-centric (e.g., uncertainty about care structures or care processes);
- scientific or data-driven (e.g., uncertainty about diagnoses, prognoses, causal explanations, and treatment options),

Finally, the perception of uncertainty is multiple and can be different from one situation to another (e.g., treatment for cancer versus a skin wound) and from one person to another (for example, doctor and patient) and can involve a complex elaboration of fundamental characteristics to identify the hope of some desired outcome.

Decision making (DM) in medical practice can be conceptualized according to three models developed by Charles (Charles et al., 1997) : the paternalistic model, in which the physician is motivated by the principle of benevolence and decides what is best for the patient; the consumerist informative model, in which the autonomous patient makes a decision without direct physician involvement once she/he has been informed; and the shared decision making (SDM) model, in which decisions are made through an interactive, deliberative process wherein the patient may express him/herself and discuss treatment preferences with the physician. The obligations to inform patients about their medical conditions and treatment options and to obtain patients' informed consent for any treatment or information sharing are parts of a shift from the paternalistic model toward one in which physician–patient partnerships are founded on the principle of patient autonomy. This is in line with the patient centered care, which is defined as “a philosophy of care that encourages: (a) shared control of the consultation, decisions about interventions or management of the health problems with the patient, and/or (b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts (in contrast to a focus in the consultation on a body part or disease) (Lewin et al., 2009).

The classic models of decision making show how reasoning is also involved in important life choices and their use is predicted by individual characteristics (Hunt et al., 201). Patient centered medicine tells us that decisions are not strictly economic, but they are influenced by various factors (e.g. emotional elements, personal characteristics, etc.).

The studies on decision-making are often focused on abstract dilemmas, leaving out its study in the "natural" contexts of life choices. This research can contribute to this field. Findings show that the decision-making process changes in relation to various variables, both personal (e.g., personality characteristics, anxiety traits, attachment style, etc.) and the type of choice that one has to make (e.g., sentimental or work-related).

In this research, we have pointed out the complexity of important life decisions (not in cancer oncology). The information provided in this study can be a starting point for future research on decision making in life choices. In fact, there are several aspects that can be investigated and that can be useful for greater knowledge of “naturalistic”/life-relevant decision-making, which have not been taken into consideration in the present study. For example, the recourse to cognitive strategies more or less influenced by emotions may be influenced by emotion regulation strategies. Moreover, contextual factors deserve recognition in this area, for example the advice or influence of significant others may affect both decision outcomes and the process to reach them. At the same time, this study also has some limitations. The questionnaire-based method we employed allowed us to recognize and analyze some aspects of life-relevant choices, but these could not be studied in detail in the laboratory

(maybe only simulated); for this reason, this study lacks the controllability that could be guaranteed by experimental settings. Furthermore, we did not compare specific life choices but let participants focus on the recollection of personal examples across life areas; so what was studied is the recollection of the decision, which leaves out the analysis of contingent factors such as emotions felt at the time of decision-making. This may have led to uncontrollable variability in the sample choices, but it allowed us to study the authentic life-relevant decisions as any individual person recollected to make them. Secondly, it could be noticed that *recollection* of a choice, especially an important one like those investigated in the present study, may be a partially distorted representation of the actual decision process, as it was plausibly modified through narration and introspection over time. Further research would be needed to analyze how much recollection of a life decision could be considered a faithful representation of the original decision process. Future research may explore further the adequacy of such a methodology to similar research aims. Another limitation may be found in how the study questions were formulated, as we asked participants to report whether reasoning or emotions were a dominant factor in important life choices. Admitting that one decided to marry for merely rational/strategic reasons could be considered antisocial and morally despicable, as well as admitting that one has chosen a given career due to emotions only may be considered impulsive and foolish. This could drive some participants to alter their responses to put themselves in a positive light and/or to not experience cognitive dissonance, so we cannot rule out that demand characteristics partially influenced participants' responses. Future research may employ questions formulated differently, e.g. just asking participants to think of a moment in life where they evaluated what they wanted in a partner/job, prior to decisions. Furthermore, the sample size is limited. Similar methods could be employed with larger samples, balanced by gender and other relevant demographic characteristics, to capture additional information on how people take important choices in their everyday life.

3.3 Study 2: Cancer patients' participation and commitment to psychological interventions: a scoping review

Background

In recent years, advancements in oncological medicine have led cancer to be a treatable disease. This is due to a greater adherence to screening campaigns, an early identification of the disease, as well as improvements in treatment effectiveness (Akram, Iqbal, Daniyal, & Khan, 2017; Holt, Kozuch, & Mewar, 2009; Primrose et al., 2014). However, these developments turn cancer into a *chronic* disease, bringing along the necessity to consider its effects on patients' lives, both from the physical and psychological sides (Muzzatti & Annunziata, 2013; Triberti, Savioni, Sebri, & Pravettoni, 2019; McCorkle et al., 2011). On the physical side, there are a number of adverse-effects related to treatments (e.g., fatigue, pain), that impact on patients' physical comfort and quality of life and personal well-being (Gorini, Marzorati, Casiraghi, Spaggiari, & Pravettoni, 2015; Reich, Lesur, & Perdrizet-Chevallier, 2008). On the psychological side, the diagnosis and the treatment of cancer may lead to emotional distress, anxiety, depression, and adjustment disorder, generating impairment in different areas of life functions (e.g., work; Park, Chun, Jung, & Bae, 2017; Arnaboldi, Lucchiari, Santoro, Sangalli, Luini, & Pravettoni, 2014), treatment efficacy, and adherence to the interventions (Arrieta et al., 2013; DiMatteo, & Haskard-Zolnierrek, 2010). More, cancer diagnosis could be experienced by the patients as an actual trauma causing stress, anxiety, and depression (Arnaboldi, Riva, Crico, & Pravettoni, 2017; Oliveri et al., 2019; Shelby, Golden-Kreutz, & Andersen, 2008). Most patients report having difficulty returning to their everyday lives after being diagnosed (Renzi et al., 2017; Rowland et al., 2009), and facing specific health challenges even after successful treatment (Fioretti, Mazzocco, & Pravettoni, 2017).

Following the great impact of chronic diseases on patients' lives, there are several interventions that aim to empower self-illness management, to help patients to maintain an active role in their own care, to manage medical choices and their emotions, as well as to recover a sense of authority and control over their everyday life (Sebri et al., 2020). For example, numerous collaborative and therapeutic interventions were performed to help patients to better understand and cope with their symptoms, thereby reducing duration, frequency, intensity, and to improve patients' well-being (Fawzy, Fawzy, Arndt, & Pasnau, 1995; Durosini, Tarocchi, & Aschieri, 2017; Aschieri, de Saeger, & Durosini, 2015).

Over the years, several types of interventions have been carried out (Jassim, Whitford, Hickey, & Carter, 2015): group interventions (a type of psychotherapy in which one or more therapists treat a small group of clients and the group itself is used as a resource for therapy and empowerment; e.g.,

Montgomery, 2002), individual interventions (an intentional interpersonal relationship used by trained psychotherapists to aid a client or patient to develop functional strategies to deal with distress; Barsevick, Sweeney, Haney, & Chung, 2002), or psycho-educational interventions (where education resources are offered to people who live with a psychological disturbance, or to health professionals who have to assist them; Bäuml, Froböse, Kraemer, Rentrop, & Pitschel-Walz, 2006). Additionally, other interventions aim at allowing cancer patients to achieve better self-efficacy as well as improving their quality of life through engagement in activities that help to create social relationships and improve well-being (Graves, 2003; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

The literature dealing with psychological interventions is usually focused on their effectiveness towards specific aims (for example, are psychological intervention effective in improving patients' quality of life?; Andrykowski & Manne, 2006; Manne & Andrykowski, 2006; Williams & Dale, 2006). However, less structured information is available on factors that may influence cancer patients/survivors' *decision to participate* in psychological interventions, both at subjective (e.g., intentions and needs) and contingent levels (e.g., factors that influence participation/non participation and facilitators), as well as factors orienting the maintenance of such a decision over time (i.e., adherence to intervention). In 2016, Beatty and Binnion published a systematic review focused on predictors of adherence to online psychological interventions. Authors identified that females showed higher treatment expectancy, available time, therapist support/guidance and personalization in the interventions' materials compared with males. In the same year, Brebach and colleagues (2016) identified trial characteristics (the possibility of being randomized in a no-treatment condition), intervention type, timing, and level of a patient's distress as predictors of adherence to treatment. Moreover, a systematic review by Wakefield and colleagues (2017) highlighted the role of study type (lower participation for randomized trial; higher for longitudinal studies), type of participant invitation (lower for studies that recruited via letter than for studies that recruited face to face), total number of questionnaires and followed up studies as negative predictors of participation.

Similarly to these approaches, the aim of the present review (Savioni et al., 2022) is to identify the factors that may influence the decision of cancer patients and cancer survivors to take part in psychological interventions, as well as to maintain commitment to them. We decided to not limit the analysis to a single construct (i.e., adherence), because relevant decisional factors would not be captured by such definitions. Indeed, these include subjective factors (e.g., motivation, intentions, needs, and preferences) as well as contingent facilitating factors (e.g., demographics, monetary compensation for participation, logistics, patient's required effort); in addition, attrition analysis and adherence monitoring will be considered of interest because they are related to maintain one's own decision and modify behavioral conduct accordingly. A better understanding of these factors could

(1) help healthcare professionals to conduct interventions tailored to patients' characteristics; (2) improve patients' engagement to psychological interventions; and (3) understand factors that lead patients to dropout or withdraw from interventions, improving costs for the healthcare system.

Since the choice to participate in psychological interventions by patients is a complex process, we decided to conduct a scoping review to maintain an exploratory approach. The aim of a scoping review is to summarize research findings and draw conclusions from the existing literature regarding the state of research activity (Arksey & O'Malley, 2005). This methodology is useful when a research area is complex, not previously reviewed in full, and to identify some gap in the literature (Pham, Rajić, Greig, Sargeant, Papadopoulos, & Mcewen, 2014). Moreover, while systematic reviews are to be preferred when the objective is to analyze the effectiveness of a treatment and/or addressing a specific hypothesis, scoping reviews are useful to map a field and identify issues, possibly making the way for future, more rigorous review efforts (Armstrong, Hall, Doyle, & Waters, 2011).

Methods

With the aim to identify factors that could impact cancer patients and cancer survivors' decision to take part in a psychological intervention, a scoping review was underpinned by the methodological recommendations described by Arksey and O'Malley (2005) and subsequently updated by Levac and colleagues (2010).

Identification of the relevant studies. Systematic literature search was conducted in September 2019 and then updated in December 2020. Relevant studies were initially identified through three search engines: CHINAL, PubMed, and PsycINFO via EBSCO, by using key search terms able to retrieve contributions on interventions for cancer patients and cancer survivors as broadly as possible: ("*cancer patients*" and/or "*cancer survivors*"), and ("*psychological intervention*" and/or "*psychosocial intervention*" and/or "*behavioral intervention*" and/or "*behavioural intervention*" and/or "*cognitive intervention*" and/or "*psychotherapeutic intervention*" and/or "*psycho-social intervention*" and/or "*psycho-therapeutic intervention*" and/or "*counseling intervention*" and/or "*alternative therapy intervention*" and/or "*cognitive-behavioral intervention*" and/or "*cognitive-behavioural intervention*" and/or "*holistic intervention*").

We considered only research papers published in English. Additional hand search of the reference list of all the selected articles as well as of relevant reviews was undertaken.

Study selection. The process of study selection followed the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement (Liberati et al., 2009; see Figure 5 for the detailed process).

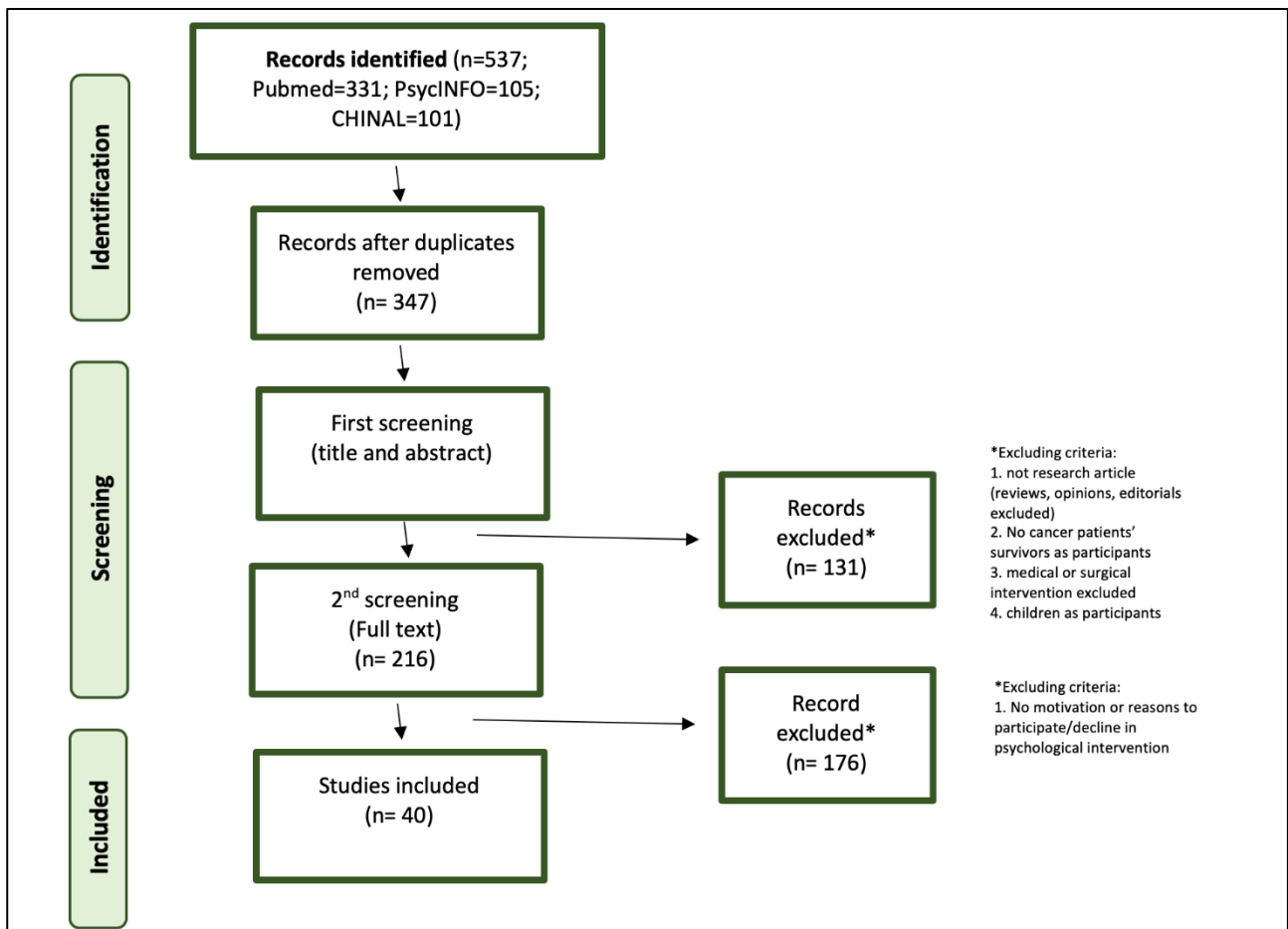


Figure 5 The systematic review flow

The search process resulted in the identification of 540 studies. The first screening was done on the title and abstracts of 540 articles, 351 after duplicates were removed; only research articles have been considered (reviews, conference paper, note, book chapter, and opinions were excluded). Moreover, only psychological interventions on cancer patients or survivors were taken into consideration, so psychological studies which analyze the effects of medical or surgical interventions were excluded; also, adults and/or elderly participants were mandatory for inclusion, because specific factors orient decisions for the participation of children (i.e., the decision is taken by parents or caregivers). Diversely, papers that do not report interventions but report research on patients' perception or preferences towards interventions (e.g., having participated in the past; or, foreseeing to participate) were included in that they are relevant to the review's aims. Indeed, while these studies are not interventions but explorative/descriptive studies on variables emerging from interventions, they are of importance for what regards the understanding of factors orienting participation. At the end of this first screening phase, 133 contributions were excluded. Subsequently, the full text of the remaining 218 articles was analyzed to identify the articles that satisfied the inclusion criteria and that provided

information on the motivations or the decision making process of cancer patients or survivors who take part in psychological interventions. In the end, there were no disagreements between evaluators to resolve by means of consensus. Three of the authors (L.S., S.T., and V.S.) who previously agreed on main factors of interest for the review's aims and updated the list while reviewing the retrieved articles multiple times independently conducted the second screening phase.

The factors identified by the authors are:

- *Needs, preferences, reasons to agree*: health needs or preferences for the intervention explicitly reported by patients, and/or the explicit reasons they gave to accept to participate (anecdotally or collected by specific research tools; e.g., questionnaire);
- *Reasons to decline*: motives explicitly reported by patients (anecdotally or collected by specific research tools; e.g., questionnaire) about why they declined to participate, or they dropped out.
- *Factors related to participation/non participation*: non-explicit factors related to the decision to participate or not in interventions, identified by means of data analysis (e.g., demographic variables);
- *“User Centered Design” and/or patient centered approach*: whether any kind of preliminary research on patients was conducted in order to identify indications to design the intervention itself (and the information that was collected);
- *Satisfaction*: participants' opinions collected after the intervention; these were considered of interest not as an outcome measure, but because they are possibly associated with the reasons why patients participated and maintained their commitment;
- *Compensation*: whether participants received monetary compensation (or equivalent) for participating;
- *Adherence*: participants' involvement in the intervention (e.g., whether they participated in any phase, used the intervention technologies, performed the required exercises or activities, etc.), which is important in order to assess maintenance of the decision to participate over time;
- *Attrition and retention analysis*: whether and why patients/survivors were no longer available after the first phases of the studies. In other words, while “reasons to decline” category featured motives subjectively reported by participants about why they declined participation, attrition/retention focuses on the results of analyses that explored the characteristics of portions of samples who dropped out from the intervention, independently of participants' subjective testimony.

At the end of the second screening process, 176 articles were removed, and 42 articles were retrieved as the final sample.

The selected studies were published between 2008 and 2019, with the studies being conducted mainly in the United States (60%), Europe (12,5%), Canada (12,5%), Australia (10%) and Asia (5%).

Results

The aim of this scoping review was to identify relevant factors that may influence the decision by cancer patients or cancer survivors to take part in psychological interventions, and to maintain commitment to them. Given the complexity of this topic, a broad approach was used by systematically searching for psychological interventions-related studies (this includes interventions, studies on their feasibility/design, and cross-sectional studies on factors relevant to participation). Analysis of relevant results led to the identification of eight categories (see table 5 for the summary of the reviewed studies and table 6 for a schematization of the categories present in the individual articles):

Author	Study design	Sample	Study description	Outcomes of interest
Akechi et al., 2014 [44]	Cross-sectional research	317 hospitalized breast cancer patients	Correlational study to assess the association between patients' problem solving skills and fear of recurrence, anxiety and depression	Needs: 63% of patients reported the need for help to alleviate fear of cancer spread
Andersen et al., 2010 [64]	Randomized controlled trial; intervention and control group tested at recurrence diagnosis and at 4, 8 and 12 months after	41 breast cancer patients who recurred cancer + analyses are made comparing patients participating and not participating to the follow up	To test the effect of intervention based on relaxation training, social support improves and health behaviors in order to have biobehavioral advantages	Adherence, Attrition, Barriers/Facilitators: patients not participating to follow up do not differ in terms of socio-demographics, prognostics, treatment received, disease-free interval variables, with the exception of age (participating patients are older)
Arch et al., 2017 [51]	Cross-sectional research	345 cancer survivors	Online survey study to assess cancer survivors' preference for types of psychological intervention, and their relation with anxiety and depression	Satisfaction: survivors feel their support and counseling needs are less likely to be met than cancer information needs Needs: - individual counseling with a professional is the preferred form of psychological support (over supports groups, counseling with a peer, psychiatric and medication); - doctors are the preferred source for recommendation of psychological support resources (over other patients, nurses, surgeon, friends and flyers), and the source of recommendations more likely to be followed; Barriers/Facilitators: correlations show positive relationship between sources of recommendation and perceived likelihood to follow them
Ashing e Miller, 2016 [81]	Mixed design (2x3 designed)	123 african american breast cancer survivors	The intervention group received 4 calls and a survivorship booklet providing both basic cancer information and psychological skills for health management	Compensation: US\$20 and a US\$25 gift card upon completion of each questionnaire, respectively
Ashing et al., 2014 [79]	Mixed design	468 breast cancer patients agreed to participate; 320 completed the full study	Longitudinal research which examines characteristics of enrollers and non-enrollees in behavioral intervention	Compensation: participant obtain US\$20 grocery store gift card for completing T1 measure and US\$40 gift card for completing T2 measure Attrition and Adherence: - Latina women were less likely to participate than African American;

				<ul style="list-style-type: none"> - enrolled participant reported more comorbidities and psychological difficulties than those did not - completers reported higher education levels than non-completers
Ashing-Giwa, 2008 [78]	A randomized controlled trial with a long term follow-up	23 survivors diagnosed with stages 1–3 invasive cervical cancer who were 1–3 years post diagnosis and disease (15 intervention and 8 control participants)	The intervention was based on a cognitive-behavioral framework to implement a skills-based culturally sensitive telephone counseling intervention to enhance coping strategies and knowledge about cervical cancer and awareness of cancer related resources	Compensation: Participants received a \$40 grocery gift certificate
Aycinena et al., 2017 [57]	Mixed design	112 breast cancer survivors identified as eligible; 66 consented; 42 were enrolled	Descriptive study to assess factors related to recruitment and adherence to a pilot weight loss intervention	<p>Adherence: Adherence was assessed using the attendance for the education session or telephone make-up sessions; higher scores of task self-efficacy, tangible support, general level of activity, mood and the belief on health (“without health there is nothing”) were strong predictors</p> <p>Reasons to decline: fatigue, family and work responsibilities, transportation, illness, cost and negative perceptions of exercise/diet were self-reported obstacles to adherence</p> <p>Barriers/Facilitators: early stage at diagnosis, treatment type and negative beliefs on exercise/diet were negatively associated with enrolment</p>
Badger et al., 2011 [86]	Mixed design	71 prostate cancer survivors, each one with a partner who were supporting them in their recovery	To test the effectiveness of two telephone-delivered psychosocial interventions for maintaining and improving quality of life	<p>Adherence: measured as the number of sessions each participant completed; data not associated to other variables</p> <p>Compensation: After each assessment, participants were sent a \$10 gift card from a local retail merchant</p>
Bail et al., 2020 [82]	Mixed methods research	30 breast cancer survivors (15 interviewed later)	A self-reported questionnaire data and a follow-up semi-structured interviews explored the relationship between selected cancer-related symptoms and adherence to the cognitive training (CT) intervention	<p>Adherence: measured as attendance to training sessions;</p> <ul style="list-style-type: none"> - a small inverse correlation occurred with sleep quality; -according to interviews the non adherent participants viewed the training as frustrating <p>Compensation: at the end of interview, participant received a \$25 gift card</p>

Becker et al., 2017 [66]	A quasi-experimental, repeated measures design	20 breast cancer	To test combining a group intervention to build self-efficacy by using compensatory strategies and lifestyle adjustments with brain-training practice to improve cognitive performance	Satisfaction: -combination of classes and brain-training homework; -presence of the groups and the facilitator helped them to persist with the homework Barriers/Facilitators: authors claim that survivors' scarce contact with health provider after treatment, low perceived utility and demand of time and energy may be the reasons for refusal to participate
Bernard-Davila et al., 2015 [56]	Research on participation to a trial (between-subjects design)	102 breast cancer survivors completed the screening interview	To understand factors related to recruitment to behavioral intervention trials among Spanish-speaking urban Hispanic breast cancer (BC) survivors	Reasons to decline: lack of interest in dietary change, being too sick, moving out of country, travel and work constraints Barriers/Facilitators: the perception that research is costly to participants. Non-enrolled participant more frequently identified as being of mixed ethnicity; unemployed women were less likely to enroll
Brotto et al., 2012 [55]	Mixed design (pre-, one month post-, and 6-months following treatment)	38 survivors agreed to participate; 34 women provided written consent; 31 completed all three sessions	To evaluate a mindfulness-based cognitive behavioral intervention for sexual dysfunction in gynecologic cancer survivors compared to a wait-list control group	Reasons to decline: not being willing/able to travel to the research center, time constraints, discomfort about the sexual arousal assessment, and difficulties talking about sexuality
Cleary, 2015 [80]	Within subjects intervention	88 breast cancer	To examine theoretically and empirically grounded mediators of an Internet-based psychosocial intervention to promote psychosocial adjustment in women with breast cancer	Compensation: Participants were compensated \$50 for each returned questionnaire
Eaton et al., 2011 [67]	Randomized controlled trial	123 breast cancer survivors	A web-based intervention was tested, analyzing treatment fidelity	Adherence: measured by completion of the web-based workbook's chapters; not associated with others measures; Barriers/Facilitators: chapters completed more often were those deemed more useful by participants User centered design: usability test and small-group feasibility testing
Grunfeld et al., 2016 [77]	Qualitative research	20 recruited from the treatment arm of another study	A semi-structured interview (ranged in duration between 10 and 52 min) exploring acceptability of the intervention, factors affecting engagement and perceived usefulness of the intervention	Adherence and Satisfaction: adherence to materials and practice of relaxation exercise was satisfying; factors that affected engagement (positively and negatively) are:

				connotation of mental health issues, perceived greater benefit for coping with hot flashes; men acknowledged the usefulness of intervention and increasing in understanding of their own condition
Heiniger et al., 2017 [50]	Mixed methods research	25 completed the intervention; 6 also completed a qualitative interview to provide detailed feedback on their experience	To test an online intervention to reduce anxiety, depression and fear of cancer recurrence by providing evidence-based information and psychological intervention	<p>Satisfaction:</p> <ul style="list-style-type: none"> -mean satisfaction ratings for the overall programme were fairly high; -men found e-TC acceptable, useful, comprehensive, relevant and easy to use; -intervention was slightly too long <p>Needs: the need to develop interventions both accessible and acceptable to men (i.e. masculinity issues, stigma on requesting help for mental health)</p> <p>Barriers/Facilitators: lack of time and recent diagnosis with higher distress</p> <p>Adherence: low need may have contributed to poor engagement</p>
Juarez et al., 2013 [47]	Qualitative study	8 breast cancer survivors from another study were interviewed	To evaluate the English and Spanish educational intervention (Nueva Luz), a quality of life (QOL) intervention developed to address the educational needs of Latina breast cancer survivors and provide strategies to assist in their transition into survivorship	<p>Satisfaction: Participants were satisfied of having tailored one on one education sessions with the opportunity to ask questions discuss any concerns. English and Spanish printed material with relevant and easy to understand information was also appreciated</p> <p>Needs: Patients need understandable information about post-treatment survivorship issues and concerns and ways to respond to these</p> <p>Compensation: After the interview, each participant was given a \$25 gift card for their participation</p>
Karageorge et al., 2017 [58]	Qualitative research	11 cancer survivors and 4 patients in active treatment	To explore the acceptability of a eight-lesson internet-delivered (CBT) program targeting anxiety and depression	<p>Satisfaction: Participants considered the program as acceptable and potentially useful from the time of cancer diagnosis, to post-treatment and expressed positive views of the use of the multi-modal presentation of the materials</p>

				<p>Needs: participants indicated that a separate course would be needed for advanced stage patients</p> <p>Barriers/Facilitators: time restraints and participants' anxiety</p> <p>User centered Design:</p>
Kim et al., 2018 [45]	one-group pretest and posttest design	19 cancer survivors completed the program, 5 were interviewed for understanding patients' need	To explore the impact of the KOCHI program on HRQOL, sleep disturbances, and depression in cancer survivors	<p>Satisfaction: overall satisfaction score was high; the cooking class had the highest satisfaction score followed by exercise and the healing meditation program; 84.2% of the participants indicated they would be willing to pay a participation fee for the program</p> <p>Attrition and Barriers/Facilitators: 7 patients were lost to follow-up in the middle of the program due to lack of time, loss of interest</p> <p>Needs:</p> <ul style="list-style-type: none"> -participants gave the highest priority to learn how to exercise without placing a burden on themselves; - the intervention was culturally tailored (e.g., traditional foods were embedded in cooking activities)
Lu et al., 2014 [71]	Mixed design	14 chinese American breast cancer survivor's post-treatment and 8 breast cancer peer mentors	To evaluate a social support intervention that was culturally tailored for Chinese Americans who face many challenges because of cultural and linguistic barriers; two focus groups were also conducted	<p>Satisfaction: Participants highly valued the interventions due to its cultural and linguistic sensitiveness. In addition, patients highly appreciated the empathetic and caring interaction with presenters and peers</p> <p>Barriers/Facilitators: Other people were interested in the program, but they could not participate because they were undergoing treatment</p>
Lucas et al., 2018 [68]	Cross sectional survey and randomized intervention study	150–200 postmenopausal women who were diagnosed with type I endometrial cancer (EC). Target accrual for the intervention study was 60 (20 per group)	To examine lifestyle behaviors in the context of psychosocial theory and mindfulness which would then guide the design and delivery of an intervention by targeting specific correlates of physical activity and diet and evaluate the recruitment process	<p>Barriers/Facilitators: Patients were particularly difficult to recruit because they do not see their condition as especially threatening and are therefore not motivated to change their behaviors. The presence of a favorable prognosis made them less motivated to participate.</p> <p>-patients' understanding of the importance of lifestyle behaviors and</p>

				<p>competing concerns associated with treatment;</p> <ul style="list-style-type: none"> -significant association between the type of approach used (Mailout vs. In-clinic) and whether patients responded “yes” to the offer of the survey; -favorable prognosis; -apathy towards change; -obesity and difficulties in physical activity; -stigma
Lynch et al., 2008 [59]	A prospective survey	1822 colorectal cancer patients	To describe the prevalence of psychological distress among a population-based sample of colorectal cancer survivors, and second to identify sociodemographic, medical, psychological, and lifestyle predictors of this distress	Barriers/Facilitators: More distressed patients declined to participate
Martin et al., 2015 [46]	Pilot study; two intervention groups tested at baseline and post-intervention	31 survivors	To underline the psychosocial aspects of participating in the program	<p>Adherence, Satisfaction and Needs:</p> <ul style="list-style-type: none"> -being given the opportunity to explore and redefine self-identity - provision of ongoing support to succeed, despite prior failures - importance of exercise variety and maintaining exercise behaviors - value of the combined exercise and counseling model - importance of being a group <p>User centered design: it is a pilot study collecting information for a larger trial</p> <p>Attrition and Reasons to decline:</p> <ul style="list-style-type: none"> - adverse health conditions - lack of motivation - sense of stigma surrounding mental health services - not need of counseling
Martin et al., 2016 [69]	Cross-sectional survey	1053 breast cancer survivors	To determine the factors that predict cancer survivors’ interest in new technology-based health behavior intervention modalities versus traditional modalities	<p>Needs:</p> <ul style="list-style-type: none"> - health behavior intervention <p>Barriers/Facilitators:</p> <ul style="list-style-type: none"> - interest in exercise interventions and telephone-based programs; - physical activity, fruit and vegetable consumption and interest in weight management interventions

Moran et al., 2017 [75]	Cross-sectional research	10 breast cancer patients	To present novel clinical treatment for fear of cancer recurrence (FCR) and to examine whether at-home repeated exposure to the worst-case scenarios (WCS) was related to pre- and post- therapy FCR levels	Adherence: Higher adherence to homework was significantly related to lower post-therapy FCR but not to pre-therapy scores User centered design: it is an exploratory study of the worst-case scenario exercise
Morasso et al., 2010 [83]	Cross-sectional research	339 cancer patients	To evaluating the feasibility of a screening procedure for psychological distress in cancer survivors	Attrition and Reason to decline: -work and family issues -distrust of the psychological support -not to suffer from emotional problems or able to cope -low social support Adherence: -minimal impact of cancer diagnosis on distress level
Naumann et al., 2011 [63]	Randomized controlled trial; 4 intervention are tested at baseline and post-intervention (8 weeks)	43 breast cancer survivors,	To examine the feasibility of delivering an exercise and counseling intervention to determine if counseling can add value to an exercise intervention for improving quality of life (QOL)	Adherence: - exercise program adherence averaging 80% - the psychological counseling intervention averaging 83% adherence. Satisfaction: - participants particularly liked the individual nature of the program - physical and emotional benefits Attrition and Barriers/Facilitators: 3 women dropped out after randomization, but their baseline data were included in the intention-to-treat analysis. -a significant baseline difference in Piper Fatigue Scale (PFS) total score
Offidani et al., 2017 [72]	Pilot study	106 breast cancer survivors; 50 completed the baseline questionnaires; 19 lost follow-up	To evaluate whether a 4-week version of Contemplative Self-Healing program would have different effects in reducing PTSD symptoms between breast cancer survivors with or without chronic stress at baseline	Attrition and Barriers/Facilitators: work issues and distance
Osann et al., 2014 [65]	Within subjects intervention	204 cervical cancer survivors	To identify factors associated with compromised quality of life for cervical cancer survivors subsequent to definitive cancer treatment	Barriers/Facilitators: patients enrolled were significantly more likely to have early stage disease be of non-Hispanic white ethnicity, and have a younger age at diagnosis compared to decliners
Paterson et al., 2015 [52]	Within subjects intervention	74 prostate cancer patients	To test the effects of coping and social support on HRQoL and emotional outcome and assessed the self- management	Satisfaction: satisfaction with social support, an element of the intervention,

			behaviours of men affected by prostate cancer overtime	was linked to improvement in quality of life Attrition: n=1 deceased and n=5 did not return the postal survey
Reese et al., 2018 [48]	Randomized controlled pilot trial	91 survivors + analyses are made comparing patients participating and not participating to intervention	To examine the reasons for declining and intervention preferences of study-eligible breast cancer survivors declining a trial of a four-session couple-based Intimacy Enhancement intervention (refusers) and explore whether refusers differed from participants on key characteristics	Needs: - partner' inclusion - be engage in a study of a potentially helpful behavioral intervention addressing sexual concerns; - informational websites (45%); - meeting one-on-one with a professional (gynecologist and psychologist firstly) (26%). Compensation: patients received \$10 gift card in the mail for participating Reasons to decline and Barriers/Facilitators: - time commitment (74%) - partner noninterest (32%) - topic too personal - uncertainty about the study or its usefulness
Robertson et al., 2017 [53]	Qualitative study; patients participated in 2 focus groups	35 cancer survivors	Two focus groups to asses cancer survivors' preference for the features and messages of an app to increase PA	Needs and Barriers/Facilitators: - informal interface that could facilitate engagement and goal achievement; - more private and highly individualized experience Compensation: participant obtained US\$15 gift card after completion of each session (US\$300 max) User centered design: - tone preferences - tools for personal goal attainment - prescription for physical activity; - a tailored experience
Siddiqi et al., 2008 [62]	Randomized controlled trial (secondary analysis)	885 patients agreed to participate; 713 completed the baseline	To identify predictors of attrition during two early phases: from consent to screening (Phase-1), and from screening to intake interview (Phase-2) in two clinical trials	Attrition: -time interval from consent to first screening call is significant associated with likelihood of attrition - duration of screening increases the chance of patients' attrition prior to the intake interview - screening duration affected minority patients differently than it affected white patients

				- patients reported higher interference with enjoyment of life more likely to drop out of the study than those reporting lower interference
Thomas et al., 2017 [49]	Interpretive description design	12 breast cancer survivors	Explored women's experiences in a community-based workshop	Needs: - opportunity to meet with other women who had the same experience - speak about the negative and the positive of the experience - express emotions
Valle et al., 2015 [54]	Randomized controlled trial; intervention groups tested at baseline and after 12 weeks	86 survivors; 66 completed the post intervention questionnaire	To assess the self-efficacy, social support, and self-monitoring of a Facebook-based intervention (FITNET) for increasing moderate-to-vigorous intensity PA	Adherence: the observed decreases in self-efficacy may reflect low adherence to the study website Needs: interventions offering social support from other young adult cancer survivors and/or friends
Vallerand et al., 2018 [70]	Randomized controlled trial; intervention groups tested at week 0 and week 13	51 hematologic cancer survivors	To test the effect of telephone counseling exercise intervention on aerobic exercise behavior	Adherence: adherence to telephone counseling was 93% Barriers/Facilitators: between the intervention groups were found some differences in coping planning confidence interval, instrumental attitude, affective attitude and perceived opportunity. Changes in coping planning, perceived opportunity, exercise identity and habit
Vallerand et al., 2018 [76]	Randomized controlled trial; intervention groups tested at baseline and post-intervention (12 weeks)	51 hematological cancer survivors	To assess the feasibility and preliminary efficacy of a M-PAC-based TCE intervention for increasing aerobic exercise behavior in hematologic cancer survivors (HCS)	Adherence and Retention: Adherence to the TCE intervention was 93% and retention was 100%. Participants receiving TCE increased their weekly aerobic exercise compared to SDE group. Satisfaction: participants were highly satisfied with the utility of the program, how interesting the sessions were, their clarity, the topics covered.
Van der Donk et al., 2018 [60]	Observational study	1923 survivors agreed to participate; 25 participated in the trial	Observational study which examines characteristics of participation and non-participation in psychological intervention	Attrition, Reason to decline, Barriers/Facilitators: Four reasons for non participation were: nonresponse to screening, low levels of depressive symptoms, no need, or already receiving care
Wurtzen et al., 2012 [61]	Cross-sectional research	336 breast cancer patients; analyses are made comparing	Correlational study in order to compare differences in demographic, distress, anxiety, depression, well-being and	Adherence and Barriers/Facilitators: participants were found to be younger and have a less recent diagnosis at

		patients participating and decliners	symptom burden between participants and decliners	invitation than decliners; significant differences were found in level of education, distress, anxiety, depression, well-being and symptom burden. No differences were observed with regard to marital status, children living at home, affiliation to the work market, psychiatric caseness or any lifestyle measure
Zhang and Fu, 2016 [73]	Randomized, controlled longitudinal clinical trial, cost-effectiveness study	336 (267 intervention-participating and 69 intervention-nonparticipating) prostate cancer survivors with incontinence symptoms	The two intervention groups received biofeedback training for incontinence symptoms and six groups meeting/six telephone sessions – the study is performed to evaluate cost-effectiveness of intervention	Barriers/Facilitators: according to authors, estimate of cost-effectiveness helps healthcare providers to integrate the intervention into routine standard care, and possibly the patients on the financial value of the study interventions, which may attenuate of their belief that participation is costly

Table 5 Characteristics of the reviewed studies

Article	Adherence	Satisfaction	Needs or preferences	Compensation	User centered design	Attrition Analysis	Reasons to decline	Barriers and Facilitators
Akechi et al., 2014 [44]			x					
Andersen et al., 2010 [64]	x					x		x
Arch et al., 2017 [51]		x	x					
Ashing e Miller, 2016 [81]				x				
Ashing et al., 2014 [79]	x			x			x	x
Ashing-Giwa, 2008 [78]				x				
Aycinena et al., 2017 [57]	x						x	x
Badger et al., 2011 [86]			x	x				
Bail et al., 2020 [82]	x			x				
Becker et al., 2017 [66]		x						

Bernard-Davila et al., 2015 [56]								x	x
Brotto et al., 2012 [55]								x	
Cleary, 2015 [80]				x					
Eaton et al., 2011 [67]	x								x
Grunfeld et al., 2016 [77]	x								x
Heiniger et al., 2017 [50]		x	x						x
Juarez et al., 2013 [47]		x	x	x	x				x
Karageorge et al., 2017 [58]		x	x			x			
Kim et al., 2018 [45]		x					x		x
Lu et al., 2014 [71]		x							x
Lucas et al., 2018 [68]									x
Lynch et al., 2008 [59]									x
Martin et al., 2015 [46]	x	x	x		x	x	x		
Martin et al., 2016 [69]			x						x
Moran et al., 2017 [75]	x				x				
Morasso et al., 2010 [83]	x					x	x		
Naumann et al., 2011 [63]	x	x				x			x
Offidani et al., 2017 [72]						x			x
Osann et al., 2014 [65]									x
Paterson et al., 2015 [52]		x				x			
Reese et al., 2018 [48]			x	x				x	x
Robertson et al., 2017 [53]			x	x	x				x

Siddiqi et al., 2008 [62]					x	
Thomas et al., 2017 [49]				x		
Valle et al., 2015 [54]	x			x		
Vallerand et al., 2018 [70]	x					x
Vallerand et al., 2018 [76]	x	x			x	
Van der Donk et al., 2018 [60]					x	x
Wurtzen et al., 2012 [61]	x					x
Zhang and Fu, 2016 [73]						x

Table 6 Relevant factors per articles

Needs and Preferences: this category refers to studies in which cancer patients' explicit desires or evaluations were reported in the article. A first analysis of the retrieved contributions shows that patients' needs are often conceptualized starting from researchers' assumptions, not on measurement of actual patients' perceptions. Some important elements emerged from this scoping review:

1. Considering the retrieved contributions, 12 articles reported this information. It is interesting to note that patients' explicit needs rarely regard the desire to alleviate symptoms or negative psychological experience. In only 4 of the retrieved studies, patients reported needs to reduce negative emotions related to cancer. For example, in one article, patients expressed their need to alleviate fear of cancer recurrence (Akechi et al., 2014) and in 3 studies patients highlighted their necessity to obtain information on how to improve their well-being and redefine their self-identity (Kim, Chang, Lee, & Lee, 2018; Martin, Bulsara, Battaglini, Hands, & Naumann, 2015; Juarez, Mayorga, Hurria, & Ferrell, 2013). Other studies reported that patients looked for opportunities to express their emotions and share their concerns (Reese et al., 2018; Thomas, Gifford, & Hammond, 2017).
2. Additionally, the majority of studies that report information on patients' needs seem to show that patients are able to make quite specific requests regarding the nature of the psychological intervention and the necessity to develop accessible and culturally tailored interventions (Kim, Chang, Lee, & Lee, 2018; Heiniger et al., 2017). For example, participants declared that they are interested in counseling more than in other psychological support modalities (Reese et al., 2018; Arch, Vanderkruik, Kirk, & Carr, 2018) and in private, highly-individualized experiences in general (Reese et al., 2018; Paterson, Robertson, & Nabi, 2015; Robertson et al., 2017). When external social support is envisaged in the intervention, patients express preferences on who should be involved to help them depending on specific issues, for example young adult cancer survivors would like to hear from their peers with similar experiences (Valle, Tate, Mayer, Allicock, & Cai, 2015), while women who survived breast cancer restated the importance of partner inclusion in an intervention for intimacy enhancement (Reese et al., 2018). Doctors are the preferred source of recommendation of psychological support resources (Arch, Vanderkruik, Kirk, & Carr, 2018).

Reasons to decline: 6 of the reviewed papers reported explicit reasons to decline participation by patients and cancer survivors who decided not to be involved in the interventions. Often reasons appear to be quite of subjective concerns, such as lack of motivation or interest in conducting the psychological interventions (3,2% of the total sample, Martin, Bulsara, Battaglini, Hands, & Naumann, 2015; 15% of the total sample, Teo et al., 2020); participants' physical problems (e.g.,

heart attack and back injury; 6,4% of the total sample, Martin, Bulsara, Battaglini, Hands, & Naumann, 2015), and quite specific ones such as partner's non-interest in intimacy-based interventions and time commitment (these two main reasons taking 34% of the total sample, Reese et al., 2018). In other cases, authors did not report the specific range of percentage related to each reason. For example, in Bernard-Davila (2015) the 31,3% of the total sample decline to participate due to lack of interest in the intervention, be too sick, move out of the country, travel, work constraints; in Aycinema and colleagues (2017) the 26,3% of the total sample declined to participate because rarely or never engaging in regular physical activities and involvement in treatment that affected the possibility to participate (e.g., later stage of diagnosis, chemotherapy, and surgery); finally, in Brotto and colleagues (2012) the 8,8% of the total sample decline to participate due to not willing or able to travel to the research center, discomfort about the content of the intervention (e.g., sexuality), and time constraints.

Factors related to participation/non participation: differently from the reasons to decline, which reflected participants' explicit statements, factors related to participation/non participation are characteristics of non-participating patients identified by means of analysis. In other words, these are characteristics significantly different between participating and non-participating patients. 23 among the reviewed studies provided such information. 6 studies (e.g., Karageorge et al., 2017; Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008; van der Donk et al., 2019; Wurtzen et al., 2013) indicated as a barrier/facilitator the level of stress and anxiety reported at the time of enrollment; in one case, stress is associated with the intervention's interference with patients' lives (Siddiqi, Sikorskii, Given, & Given, 2008). Naumann and colleagues (Naumann, Martin, Philpott, Smith, Groff, & Battaglini, 2012) did not find significant differences in depressive symptoms and quality of life, but a significant difference was found in patients' fatigue. In some cases, demographic differences such as age (Wurtzen et al., 2013; Andersen et al., 2010), ethnicity (Bernard-Davila et al., 2015; Osann et al., 2014), socio-economic status (Bernard-Davila et al., 2015), and level of education (Wurtzen et al., 2013) emerged as factors differing between participants and non-participants. Specifically, Wurtzen and colleagues (2013) point out that participants are younger and have higher education, in contrast with Andersen and colleagues' study (Andersen et al., 2010), in which participants are older. It should be noted however that Andersen and colleagues compared participants/non participants *to the follow up*, so it is possible that younger participants just became less committed over time while they manifested interest in the intervention in the initial phases. Other studies revealed that unemployed women were less likely to enroll in psychological interventions (Bernard-Davila et al., 2015) and that non-enrolled participants are more frequently identified as

being of mixed ethnicity (Bernard-Davila et al., 2015) or Hispanic white ethnicity (Osann et al., 2014). However, significant differences in participants' demographic characteristics are not confirmed in Naumann and colleagues (Naumann, Martin, Philpott, Smith, Groff, & Battaglini, 2012). However, such differences in ethnicity were not emphasized in other studies; it is possible they are related to specific populations reached by the research institutions involved. 11 of the reviewed studies (Kim, Chang, Lee, & Lee, 2018; Reese et al., 2018; Arch, Vanderkruik, Kirk, & Carr, 2018; Aycinena et al., 2017; van der Donk et al., 2019; Becker, Henneghan, Volker, & Mikan, 2017; Eaton, Doorenbos, Schmitz, Carpenter, & McGregor, 2011; Lucas, Focht, Cohn, Klatt, & Buckworth, 2018; Martin et al., 2016; Vallerand, Rhodes, Walker, & Courneya, 2018) reported that having an interest or considering the intervention useful is a predictor of participation or not in an intervention.

The health conditions (e.g., disease status and treatment phase) have been identified by 7 studies as a barrier (Heiniger et al., 2017; Aycinena et al., 2017; Wurtzen et al., 2013; Naumann, Martin, Philpott, Smith, Groff, & Battaglini, 2012; Osann et al., 2014; Lucas, Focht, Cohn, Klatt, & Buckworth, 2018; Lu, You, Man, Loh, & Young, 2014); participants in the intervention have an early stage diagnosis or have a favorable prognosis (Heiniger et al., 2017; Aycinena et al., 2017; Wurtzen et al., 2013; Osann et al., 2014; Lucas, Focht, Cohn, Klatt, & Buckworth, 2018; Lu, You, Man, Loh, & Young, 2014); non-participants are undergoing treatment (Lu, You, Man, Loh, & Young, 2014). Naumann and colleagues (2012) did not find differences in cancer stage and cancer treatment. Other factors emerging from the analysis of the selected studies are (1) lack of time or time constraints (Reese et al., 2018; Heiniger et al., 2017; Bernard-Davila et al., 2015; Karageorge et al., 2017; Siddiqi, Sikorskii, Given, & Given, 2008; Becker, Henneghan, Volker, & Mikan, 2017; Vallerand, Rhodes, Walker, & Courneya, 2018; Offidani, Peterson, Loizzo, Moore, & Charlson, 2017), (2) cost effectiveness (Zhang & Fu, 2016) and (3) characteristics of intervention (i.e., brevity and the telephone conduction mode that eliminates the burden of travel; Reese et al., 2018).

“User Centered Design (UCD)”: this expression comes from the world of user experience, where it identifies any design (of products or services) in which the final users take an important role; in other words, user feedback is integrated in product development, sometimes even before the development initiates. User Centered Design has been found consistent with a patient centered approach to medicine (Triberti & Barelo, 2016; Triberti & Liberati, 2015), meaning that health interventions should be designed and planned taking into consideration patients' needs and feedback, which are identified by means of preliminary research. Among the reviewed studies, 4 were pilots to test effectiveness, feasibility, or acceptability of an intervention (Martin, Bulsara, Battaglini, Hands, &

Naumann, 2015; Robertson et al., 2017; Karageorge et al., 2017; Moran, Tomei, Lefebvre, Harris, Maheu, & Lebel, 2017) and 1 included a usability test to inform redesign of a mobile application (Eaton, Doorenbos, Schmitz, Carpenter, & McGregor, 2011). Giving the origins of the UCD mindset, it is not surprising that four of these studies featured a web-based or mobile technology for patients. Anyway, users' feedback allow the authors to identify useful information on how to modify interventions in order to inform future implementation or larger trials, such as collecting specific preferences of patients on the materials' content (Robertson et al., 2017), for example clarifying parts of the program to avoid guilt associated with slow progression and inclusion of ad-hoc material to help patients to flexibly adapt intervention activities to their daily schedules (Karageorge et al., 2017).

Satisfaction: in 11 of the selected articles, patients highlighted their satisfaction with the psychological intervention in which they were involved. This information was considered of interest not as an outcome measure but because, especially when involving qualitative data, it could be related to participants' expectations and motivations before engaging in the interventions. In most of the articles (Kim, Chang, Lee, & Lee, 2018; Heiniger et al., 2017; Paterson, Robertson, & Nabi, 2015; Karageorge et al., 2017; Becker, Henneghan, Volker, & Mikan, 2017; Vallerand, Rhodes, Walker, & Courneya, 2019), patients' satisfaction is related to the typology and features of the intervention rather than the outcomes of the process, that is, patients do not express satisfaction for the outcomes they obtained, but for the aspects of the intervention experience they appreciated. For example, patients reported satisfaction with the class/group organization (Juarez, Mayorga, Hurria, & Ferrell, 2013; Becker, Henneghan, Volker, & Mikan, 2017) and for the usefulness of the intervention materials for their health management and coping (Heiniger et al., 2017; Grunfeld, Hunter, & Yousaf, 2017).

In few of the selected studies, participants highlighted that their satisfaction is related to the perceived support and help (Martin, Bulsara, Battaglini, Hands, & Naumann, 2015; Arch, Vanderkruik, Kirk, & Carr, 2018), or with the empathetic and caring interaction with other patients and peers (Lu, You, Man, Loh, & Young, 2014).

Compensation: One factor that could influence the decision of cancer patients or survivors to take part in psychological interventions is the kind of compensation that they receive for their participation in the study (Ashing-Giwa, 2008; Ashing, Rosales, & Fernandez, 2015). In 9 of the selected articles, researchers offer to participants a form of extrinsic compensation for their participation. Two different forms of compensation were identified: in one study cancer patients received a monetary compensation (\$50 for each returned questionnaire; Cleary & Stanton, 2015), whereas in 8 studies

participants received gift cards with a value ranging from \$10 to \$60 (e.g., Robertson et al., 2017; Ashing & Miller, 2016).

Adherence: The category “Adherence” refers to patients’ tendency to be involved in all phases of the psychological intervention (Bail, Ivankova, Heaton, Vance, Triebel, & Meneses, 2020), assessing the maintenance of cancer patients/survivors’ decision to be engaged in the intervention over time. The reviewed studies revealed that a greater adherence to psychological interventions could lead patients to lower post-treatment illness-related-symptoms (Moran, Tomei, Lefebvre, Harris, Maheu, & Lebel, 2017). Discovering which factors could have an impact on treatment adherence could improve cancer patients’ well-being.

In 3 of the selected studies participants showed a higher adherence to psychological interventions, with values ranging between 80% (adherence to exercise program; 83% for counseling intervention;⁶³) and 93% (adherence to TCE intervention and telephone counseling; Vallerand, Rhodes, Walker, & Courneya, 2018; Vallerand, Rhodes, Walker, & Courneya, 2019). Despite the very high percentage, 15 of the selected studies showed that four factors could have an impact on adherence to treatment:

1. *Participants’ socio-demographic characteristics:* Participants’ socio-demographic characteristics seem to be a relevant variable for involvement in the intervention. Studies revealed that younger patients with a less recent diagnosis when invited (Wurtzen et al., 2013; Morasso et al., 2010), and higher level of education (Wurtzen et al., 2013; Ashing, Rosales, & Fernandez, 2015; Morasso et al., 2010) are more prone to adhere to the whole process than other participants. On the contrary, Andersen and colleagues (2010) highlighted that participants who received the diagnosis at an older age ($M_{age}= 53$ -years old) are more prone to be engaged in the treatment compared to other patients. Additionally, the presence of tangible social support can be a predictor of a greater adherence to the treatment (Aycinena et al., 2017). In addition, participants with low social support are more prone to participate in the intervention (Morasso et al., 2010). Marital status, children living at home, affiliation to the work market were not significantly related to the adherence to the intervention (Wurtzen et al., 2013).
2. *Intervention:* Another factor that stands out significantly is the emotional burden associated with the psychological path. Bail and colleagues (2020) highlighted that participants who considered the training as non-frustrating could be more adherent to the process compared to other patients. Additionally, the sense of stigma surrounding mental health services was considered by Martin and colleagues (2015) as a limiting factor that can reduce patients’

engagement to the treatment. Lastly, the perception of being in a group leads participants to be more motivated to attend the scheduled intervention sessions.

3. *Health condition of participants*: Cancer patients and survivors with low psychological needs may have a lower engagement in psychological intervention (Heiniger et al., 2017) compared to other participants. Additionally, higher self-efficacy, belief in health, general mood (in terms of anxiety and depression), and lower perception of their body image are predictors to the adherence to the psychological treatment. Also, sleep quality is positively related to adherence and participants with higher levels of psychological distress, difficulties or comorbidities are more engaged in the intervention than the controls (Valle, Tate, Mayer, Allicock, & Cai, 2015; Aycinena et al., 2017; Ashing, Rosales, & Fernandez, 2015; Bail, Ivankova, Heaton, Vance, Triebel, & Meneses, 2020; Morasso et al., 2010). Some patients reported that “without health there is nothing” (Aycinena et al., 2017; p. 124), and this belief could lead people to be more adherent to the treatment compared to other patients.

Generally, participants referred that their engagement in the intervention could be affected by the direct perceived benefits, such as:

- learning to perceive mental health issues in a less negative way;
- perceived greater benefits for coping with symptoms (involving participants in dedicated exercise/activity, and promoting a reflection on lifestyle matters such as general eating habits);
- increased understanding of their own conditions, through the collection of informational components of the intervention (i.e., health booklet, CD; Grunfeld, Hunter, & Yousaf, 2017).

Attrition: This category explores the reasons for attrition or patients’ decision to abandon the intervention after the first phases of the process. 6 of the selected studies highlighted that four factors could have a negative impact on patients' engagement in the intervention over time:

1. *Psychological and physical condition of participants*: People who reported higher levels of psychological impairment may show a greater predisposition to dropout from the study compared to other participants. For example, authors highlighted that enrolled participants showed more comorbidities and psychological difficulties than those who did not (Ashing et al., 2015; Martin et al., 2015; Naumann et al., 2012). Also, Siddiqi and colleagues (2008) revealed that patients who showed a higher interference with the enjoyment of life are more likely to drop out of the study than those reporting lower level of interference.

On the contrary, people who experienced low levels of depressive disorders, no needs, who are already receiving other care, or are unable to cope with emotional problems are more prone to non-respond to the screening compared to other patients (van der Donk et al., 2019; Morasso et al., 2010).

2. *Perceived value and utility of the intervention:* Cancer patients and cancer survivors' perception of the utility of the intervention could have an impact on their engagement in the process. Studies highlighted that the lack of perception of value and utility of the intervention may affect patients decision to continue the study. In addition, a relevant reason for attrition for participants that clearly emerges in the studies selected by this scoping review is the value associated with the proposed psychological pathway. Participants can show a greater attrition to the treatment and interrupt the intervention. For example, studies revealed that the lack of motivation or interest, the sense of stigma surrounding mental health services, belief of having no needs, and the distrust of the psychological support can be a source of attrition to treatment for participants (Kim, Chang, Lee, & Lee, 2018; Martin, Bulsara, Battaglini, Hands, & Naumann, 2015; Morasso et al., 2010);
3. *Characteristics of the intervention:* Some characteristics of the psychological intervention could lead to a dropout. Logistical problems and temporal organization can lead to patients' attrition and can negatively influence the decision to stay in the intervention process (Kim, Chang, Lee, & Lee, 2018). Siddiqi and colleagues (2008) recognize that the length of time from consenting to participate in the study and the first screening call is significant and associated with likelihood of attrition. The duration of screening can also increase the chance of patients' attrition prior to the intake interview. Additionally, work and family issues and distance from the home to the place of the intervention can increase the level of attrition of the patients (Offidani, Peterson, Loizzo, Moore, & Charlson, 2017; Morasso et al., 2010);
4. *Participants' socio-demographic characteristics:* Lastly, socio-demographic characteristics may impact cancer patients and cancer survivors' engagement in the process. Indeed, Andersen and colleagues (2010) and Ashing and colleagues (2015) highlighted that patients who received the diagnosis at an older age are less prone to participate in the psychological intervention than other participants. Participants with a lower level of education are more likely to drop out (Siddiqi, Sikorskii, Given, & Given, 2008). Additionally, Latina women were less likely to participate than African American counterparts (Ashing et al., 2015) and patients with formal or informal support when dealing with emotional suffering are more prone to refuse to be engaged in a psychological intervention than other patients.

Discussion

Most of the literature focuses on effectiveness of psychological interventions, while there is limited information on the factors underlying the decision to participate in a psychological intervention. Furthermore, the literature shows that most of the studies do not take into account and do not evaluate the effect of the factors that influence participation in the interventions. In this sense, the invitation

to future research giving more consideration to factors affecting participation or refusal/attrition is the first contribution of the present review.

This review aims to identify factors influencing the decision to participate in psychological interventions and those that allow the maintenance of the decision over time. For this reason, not only articles reporting results of psychological interventions but also explorative/descriptive research on relevant variables emerging from interventions have been included. This approach allowed the review to report on a notable heterogeneity of factors influencing participation in interventions. Importantly, those factors emerge both from participants' subjective testimony and personal perception of the intervention (e.g., in terms of needs or reasons to decline) and from analyses of participants, intervention or context's characteristics that are independent of respondents' opinion. This echoes important models in the study of healthcare services access. For example, the Andersen behavioral model of health services utilization (Andersen, 1968, 1995), one of the most employed models on the topic, originally divided factors orienting services utilization among *predisposing*, *enabling*, and *need* related to access to medical care in the general population. Predisposing factors exist prior to the perception of illness and determine the initial conditions for people to interact with health services (e.g., demographics such as age); enabling factors pertain to resources that facilitate or impede utilization (e.g., health insurance, physical accessibility and distance); finally, the last factor regards either the need perceived by the health consumer or that evaluated by the providers, and it has been considered the most direct and important factor impacting health service utilization (Zhang, et al. 2019). Consistently with the model, the present review highlights the role of multiple factors in the participation within psychological interventions, a very specific and emergent health resource that is proposed to patients in the attempt to understand and to anticipate their demand for care. Indeed, the first relevant aspect emerging from the retrieved articles is the *commitment* and dedication patients have to put into participation. When patients/survivors decline to participate or drop out (attrition), this seems related to the difficulty in following the intervention and to continually perform the necessary activities. Even across very different interventions, participants drop out because of geographical distances, incompatibility of the intervention with their daily lives, work constraints, personal costs; often it is overlooked that participation in psychological interventions is expensive in terms of time and constraints for patients, because researchers tend to focus on the positive outcomes that the intervention may bring to participants and consider such outcomes as sufficient elements to encourage participation and adherence. Again, in accordance with the Andersen behavioral model, participants recognize the limitations in enabling factors as a burden for their participation independent of the desirability of possible positive outcomes. This considered how it is possible to promote participation.

The most straightforward solution is providing compensation. The review shows that monetary compensation is still widely employed to encourage participation in interventions, but of course, it constitutes a controversial approach. Although several researchers argued that rewarding people for their activities can have a detrimental effect on performance because it destroys participants' internal motivations, a meta-analytical study shows that, in some conditions, rewards increase people's motivation and performance (Pierce, Cameron, Banko, & So, 2003). However, such an incentive is not available to all researchers, and it may sometimes bring more problems than solutions, for example when demographics who are more difficult to involve expect higher compensation than originally planned (Webb, Khubchandani, Striley, & Cottler, 2019). Anyway, even if internal motivation is not disrupted by compensation, there is a risk patients would drop out, especially when multiple compensation tranches are envisaged for specific phases or tasks (e.g., patients leave the study after receiving part of compensation; Ashing, Rosales, & Fernandez, 2015; Ashing & Miller, 2016; Badger et al., 2011). Last but not least, compensation is available for *research* on innovative interventions, but it could not be envisaged for any possible implementation of a given effective intervention.

It is important to notice that factors orienting participation to psychological intervention may have different degrees of relevance for what regards the implementation of interventions in the “real world” of patient engagement. For example, monetary compensation helps to understand the reason to participate in an intervention research, but of course, it is not available when an intervention with no research is proposed. Similarly, in our experience, a patient may agree to participate in a pilot intervention because of fidelity or affection towards the institution or the researchers involved, but this would not be a factor relevant to promote engagement in other intervention contexts. For this reason, it is more and more important to understand which factors could be used to promote positive commitment by participants, this way improving the likeliness of positive outcomes too.

Patients certainly may find *value* in health and psychological interventions (Grunfeld, Hunter, & Yousaf, 2017; Silberbogen, Ulloa, Janke, & Mori, 2009; Huang, Lu, Alizadeh, & Mostaghimi, 2016), and this is the main factor reinforcing participation and adherence. At the same time, what exactly such “value” is for one patient is an evanescent concept. Those who design psychological interventions should take into account that the prefigured outcomes (e.g., “you will feel better, you will be able to manage your stress, your life will be easier”) may be meaningless for patients because they are not sure they will actually achieve these outcomes in the end; also, patients may not have a clear representation of these outcomes (e.g., what does it mean “to manage stress”?) so they would not consider them sufficient reasons for the effort to put into an intervention. On the contrary, patients may be concerned that the intervention will be a sustainable and possibly pleasant experience. Indeed,

they express satisfaction for intervention features more than for the expected outcomes (Kim, Chang, Lee, & Lee, 2018; Paterson, Robertson, & Nabi, 2015; Karageorge et al., 2017; Naumann, Martin, Philpott, Smith, Groff, & Battaglini, 2012; Vallerand, Rhodes, Walker, & Courneya, 2019) and they are able to manifest preferences and desires regarding the interventions' features as they do with any service they use (Reese et al., 2018; Thomas, Gifford, & Hammond, 2017; Robertson et al., 2017; Valle, Tate, Mayer, Allicock, & Cai, 2015). As highlighted by the Andersen behavioral model and related research, patients have a representation of their illness, which manifest within the need factors and actively orient their care demand and utilization of the health resources proposed by providers.

An interesting result emerging from the comparative analysis of the reviewed contributions regards the role of anxiety, stress and cancer-specific emotional issues (e.g. fear of recurrence). On the one hand, the need to alleviate/manage those issues is reported by patients as reasons to participate in the intervention, on the other hand emotional issues also emerge as reasons to decline participation. This is consistent with many psycho-cognitive studies identifying chronic illness specific cognitive and decisional biases (Savioni & Triberti, 2020): those biases are related to continued attention and rumination on the disease, and to the perception of the malady as uncontrollable and invincible. They could certainly affect negatively one's commitment to health management and motivation to participate in a psychological intervention, so that exactly those patients who may need psychological interventions the most, in the end are those refusing to participate due to exhausted or apathetic emotional state. Interventionists should take into account this specific issue, possibly adapting communication of the intervention to possible participants' emotional state.

Moreover, the value perceived in the intervention is related to patients' specific needs as well as to the lived experience of illness. A good suggestion is to maintain flexibility about techniques and contents of the intervention, to adapt them to patients if resistance arises (Grunfeld, Hunter, & Yousaf, 2017): for example, some prostate cancer patients showed negative attitudes towards the intervention when it was framed as psychological and centered on emotional issues, because this threatened their adherence to masculine social norms; in this case, the intervention was modified by incorporating a strong informational support component, which was more positively received by men. Consistently, an intervention on cognitive empowerment for breast cancer patients included a study with qualitative research (Bail, Ivankova, Heaton, Vance, Triebel, & Meneses, 2020) which helped showing how the personal representation of cognitive decline and chemo-brain effects, as well as the subjective perception of the efficacy of cognitive empowerment, were factors orienting participation. Cognitive decline was not a mere performance issue for patients, but a set of practical limitations for their everyday life activities, which put at risk important features of their identity (e.g., a passionate reader can read no more because she doesn't remember names and characters); for this reason authors stress

the value of educational resources for symptoms and issues self-management. Another study (Arch, Vanderkruik, Kirk, & Carr, 2018) found that survivors would like to receive individual professional counseling instead of psychiatric medications (the type of psychological help they were more likely to receive), yet their emotional issues were only moderately related to cancer: this could be related to the necessity for patients to collect strategies, techniques and resources to manage their own experiential issues (Grunfeld, Hunter, & Yousaf, 2017), not only to fight a specific mental health diagnosis. Such need for active listening, support and self-management could be taken into consideration when designing interventions, this way offering patients intervention features that actually meet their aspirations.

In conclusion, it is possible to resume some important indications to improve chances of participation in psychological interventions:

- Interventionists should take into account practical issues potentially affecting participation (e.g., distances, costs, commitment to activities) since the first steps of the intervention design. These information should be attributed the same importance of scientific rigor when guiding the development of intervention activities; taking into consideration the Andersen behavioral model, enabling factors should not be underestimated in favor of intervention content that is identified to respond to patients' needs;
- Reward (not necessarily monetary compensation) could be used effectively to improve participation. However, it should not replace a consideration of participants' needs, because the latter pertains to the strongest motivation to participate in and adhere to psychological interventions;
- In this sense, pre-intervention research focused on understanding potential participants' needs and life-contexts may be valuable to address risks of refusal or low adherence in advance.

Study Limitations

Despite these interesting results, it is important to acknowledge limitations in this scoping review. First of all scoping reviews *per se* are more influenced by subjective interpretation; while the search process is performed systematically, some relevant information may have escaped the final qualitative synthesis. The second limitation concerns the inclusion of all the psychological interventions generally used with cancer patients and survivors: this was done to broaden the reach of the search and include multiple factors affecting the decision to participate, which was deemed adequate for the scoping review approach, yet more specific focus on individual areas may lead to field-specific information. Consistently, while a broad search string was employed in this study in order to find relevant information that was not explicitly categorized as pertaining to participation or

commitment, future more systematic review efforts may employ specific search strings (e.g., focused on attrition) to provide meta-analysis of consistent measures. For example, it would be interesting to analyze differences in adherence, uptake, or even reasons to decline across individual vs. group-based interventions for specific patient populations, to see whether a given intervention design is more appealing or engaging for patients and survivors. Again future systematic reviews should assess quality of evidence of the reviewed studies by employing appropriate analysis methods: while assessment of quality is considered improper for the explorative/descriptive aims of scoping reviews such as the present one (Arksey & O'Malley, 2007), it is possible to say that the notable heterogeneity emerged from this very review highlight the need for reporting on study quality when trying to confirm or disconfirm specific hypotheses by means of review efforts.

Clinical Implications

Most of the literature focuses on the results that psychological treatments bring to the patient regardless of the patient's needs and motivation at that time. From our review, it emerged that there are some factors that underlie cancer patients' decisions to take part in psychological interventions and maintain commitment to them. These factors are subjective (e.g., motivations, intentions, needs and preferences) and contingent (e.g., demographic data, monetary compensation for participation, logistics, effort required by the patient). Intervention design should take in account all these factors and explore them by means of preliminary research (e.g., "user-centered"), in order to adapt the intervention features to patients' needs and improve participation.

Conclusion

Although the factors influencing the decision-making process to participate in psychological interventions by cancer patients and survivors have emerged in the reviewed articles, there remains a large knowledge gap in the study of these factors. Future studies may include more systematic review efforts, for example the assessment of participants' motivation's effects on the final outcomes. Moreover, qualitative research methods proved particularly useful to understand cancer patients' motivation and needs, as dynamic and grounded in the context of their everyday life (Durosini et al., 2021), so future research should be encouraged to adopt such in-depth exploration of the lived experience of potential participants to psychological interventions.

3.4 Study 3: The Motivation Journey: A Grounded Theory Study on Female Cancer Survivors' Experience of a Psychological Intervention for Quality of Life

Introduction

Cancer patients' journey does not end with successful treatment. Cancer survivors have to deal with the emotional trauma of the diagnosis, lifestyle changes that affect the quality of life and social relationships, and the anxiogenic possibility that cancer may return (fear of recurrence) (Lebel et al., 2016; Bower et al., 2000). Moreover, cancer treatments have secondary effects on survivors' health and quality of life. For example, chemotherapy, surgery, radiotherapy could cause negative physical long-term side effects (such as vomiting, nausea, and heart failure) (National Institute for Health and Clinical Excellence [NICE] 2009) and other undesirable appearance-related side effects that alter their perception of body image (such as hair loss, alopecia, skin discoloration; Parker et al., 2017; Triberti et al., 2019). Additionally, the diagnosis and the treatment of cancer may lead to major psychological effects such as depression, emotional distress, fatigue, and poor well-being that affect several areas of life (e.g., family, work ; Watanabe et al., 2019; Park, Chun, Jung, & Bae, 2017; Arnaboldi, Lucchiari, Santoro, Sangalli, Luini, & Pravettoni, 2014). Side effects can persist for a long time and greatly reduce patients' ability to "restart their life after cancer" (Triberti et al., 2019; Tighe et al., 2011). Patients may experience difficulty returning to their everyday lives (Renzi et al., 2017; Rowland et al., 2009) and face specific health challenges even after treatment (Fioretti, Mazzocco, & Pravettoni, 2017). It is also important to maintain a gender-informed approach to the specific experience of the lived illness: women who are dealing or have dealt with cancer in the past must face specific challenges. For example, body alterations (e.g., mastectomy) generated by cancer treatments could be particularly disruptive for women in that they affect body parts more visible and connected to the expression of their own femininity (e.g., the breast); moreover, female cancer such as uterine and ovarian put directly at risk their generativity and notably influences their personal identity and "sense of womanhood" (Ferrari et al., 2018; Faccio et al., 2020). For these reasons, it is paramount to support cancer survivors' quality of life, helping them to promote personal strength, interrupt the cycle of distress, and improve well-being. Over time, several psychological interventions aimed to empower the management of emotions during care (at the time of diagnosis, during treatment), promote problem-solving methods and redefine personal resources have been proposed (Oliveri et al., 2020; Gudenkauf, & Ehlers, 2018; Han et al., 2019). For example, collaborative and therapeutic interventions were performed to promote a deeper understanding of patients' illness and to improve personal well-being (Aschieri, De Saeger, & Durosini, 2015; Durosini, Tarocchi, & Aschieri, 2017; Fawzy et al., 1995; Sebri et al., 2020). Generally, psychological interventions should be carried out

at individual or group levels. In the first scenario, patient-therapist alliance is established by psychologists to improve patients' functional strategies to deal with their emotional burden and distress (Barsevick et al., 2002). For example, in counseling/individual psychological support, the psychologist evaluates patients' level of distress and its related causes and promotes personal resources and meaning in lives through reorienting individual priorities. Instead, in-group interventions, one or more psychologists treat a group of patients and the group itself is used as a resource for therapy and personal empowerment (Montgomery, 2002). Over the years, group therapy has been recommended as a component of standard treatment for female cancer (Spiegel, & Bloom, 1983). The groups enhance patients' social support and the expression of their disease-related emotions, encouraging them to face their problems directly, strengthen their relationships with one another and find new meaning in their lives. Additionally, other psychological interventions often require patient engagement and commitment to activities that could be more or less demanding in terms of lifestyle change, such as sports or group physical activities that lead to an improvement in personal wellbeing and the creation of new social bonds (Lorig et al., 2001; Benton, Schlairet, & Gibson, 2014). The use of mixed interventions could lead to some beneficial effects on a variety of domains related to the quality of life (Bail et al., 2020), including improved physical functioning (Mock et al., 1997; Segal et al., 2001) and cancer-related fatigue (Mock et al., 1997; Dimeo et al., 1999; Segal et al., 2003). An example of a short psychological intervention for quality of life that combines physical and psychological aspects is the "Pink is Good" project, promoted by Fondazione Umberto Veronesi. In this project, women with a history of cancer voluntarily take part in a group intervention program that combines physical exercises with psychological support. During the intervention, women strengthen their bodies through a running group-training program with a professional trainer and receive advice from a nutritionist. At the same time, women receive group psychological support from psychologists in which they talk about themselves and their experiences. In these psychological sessions, the participants define their personal goals, focus on their emotions and body sensations, and work with psychologists to overcome the "sense of limit" imposed by the cancer experience. Psychologists also help women to share in the group their personal achievements obtained along the "Pink is Good" project and to acquire greater awareness of their own psychological and physical resources. The involvement of cancer survivors in this kind of psychological intervention often requires a notable intrinsic motivation. According to the theory of planned behavior (Ajzen, & Madden, 1986), participation and adherence to interventions are directly predicted by individual intention, which in turn is predicted by attitude toward behavior, subjective norm, and perceived behavioral control. Additionally, many clinicians consider patients' motivation for psychological interventions as a crucial predictor for successful treatment (Ricou et al., 2019; Ryan

et al., 2011; Philips, & Wennberg, 2014). Generally, patient motivation facilitates better adherence, retention, and the final outcome of therapy (Clarkin, & Levy, 2004; Sharf, 2008). Thus, analyzing participants' internal motivation (personal aims, expectations, and needs) prior to participation in the intervention is useful to predict their engagement and success in treatment (Teixeira, et al., 2012). Many studies on psychological interventions analyze participant motivations to take part in them, finding that the lack of motivation at the beginning of intervention can be a source of attrition (Martin, et al., 2015; Bernard-Davila et al., 2015). Motivation is a broad term referring to a variety of cognitive processes that share the capacity to represent desired behavioral outcomes and to promote behavior initiation, maintenance, and fulfillment. Broadly speaking, motivation includes many constructs coming from different approaches to psychological research, such as needs, drives, objectives and goals. Motivations may be characterized by varied intensity or effectiveness in guiding behavior; for example, they could be intrinsic or extrinsic (Deci, & Ryan, 1985). Indeed, several studies (Elfhag, & Rössner, 2005) have shown that intrinsic motivation is associated with greater results and a long-term change compared to extrinsic motivation. Specifically, the literature divides motivation into intrinsic, extrinsic, amotivation, and identified regulation (Deci, & Ryan, 1985). Intrinsic motivation refers to carrying out an activity for the sole purpose of deriving pleasure and satisfaction from it for oneself. When people engage in activities that generate psychologically satisfying experiences, they experience intrinsic motivation, which is associated with a wide range of indicators of positive functioning, including engagement, learning, creativity, performance, vitality, and well-being (Chen, et al., 2015; Jang, Kim, & Reeve, 2012; Reis, et al., 2018; Taylor, & Lonsdale, 2010; Vansteenkiste, et al., 2004). On the other hand, extrinsic motivation belongs to a wide variety of behaviors in which the objectives of the action go beyond those inherent to the activity itself (Deci, & Ryan, 1985); for example, one may engage in some activity to please others without having a strong personal drive. Amotivation is defined as a complete lack of intention to engage in a certain behavior, as opposed to any form of intrinsic or extrinsic motivation (Deci, & Ryan, 2000); for example, one engages in some activity because he or she is obliged to by external forces. Finally, individuals who experience identified regulation find the behavior to be significant and important, so they pursue it voluntarily and actively, without relying on external or internal coercive forces. Identified regulation has been shown to be a strong predictor of variables such as vitality and positive affect (Ng, et al., 2012) and has sometimes been shown to be an even more effective predictor of positive outcomes than intrinsic motivation (Ng, et al., 2012; Losier, & Koestner, 1999). Behavior guided by identified regulation is likely to be maintained for a longer period than less autonomous regulations, given the more internalized nature of the rewards pursued (Deci, Koestner, & Ryan, 1999; Deci, Koestner, & Ryan, 2001). According to self-determination theory, these types of motivation are related differently to

various types of outcomes: intrinsic motivation would be expected to be mostly associated with positive outcomes (e.g., persistence) followed by an identified regulation, which is also associated with longer maintenance of the associated behavior. Conversely, the most negative outcomes (e.g., depressive states) will result from motivation followed by external regulation (Deci, & Ryan, 1985). Perceived positive outcomes and success attributed to personal control may lead people to foster expectations of success and positive reactions to an exercise program. This is clearly explained by the attribution theory (Weiner, 1985) that posits that the individual attributions made to explain outcomes will influence future behavior. Several reviews highlighted that motivations are monitored or analyzed in the context of multiple types of psychological interventions, almost in any area where activities and psychological support are implemented to promote attitudinal or behavioral changes (Pereira, & Barros, 2019; Sondell, et al., 2018; Hughes-Morley, et al., 2015; Paige, Stelfox, & Singh, 2016; Hyde, et al., 2014; Kane, et al., 2015). However, such analyses may not appreciate that human motivation is of a dynamic nature (Soliman, & Tuunainen, 2015). Whether conceived as drives or impulses, declarative aims or objectives, motivation may change over time based on lived experience while one is actively engaged in an activity.

What exactly is “change” is of course a question for philosophy. As Wasserman (2006) says, to understand change one should aim for a definition that could conciliate sameness and difference: how can something remain the same, even if some of its aspects are different? The most ancient description of the problem is the Ship of Theseus, early described by Plutarch (Rea, 2015): in virtue of what is the ship *the same ship* after all of its parts are progressively replaced over time? One possible response is that the ship is identified as such by some properties, which are substantially independent of its physical components (e.g., it can sail; it belongs to Theseus).

The ancient example is adequate for human motivation as well. People *do things* because they are motivated, but when a given activity extends over time, motivations for carrying it on may transform. A motivation may change in strength, personal relevance, clarity and awareness and even in its fundamental content (e.g., from extrinsic to intrinsic, like when someone says: “I used to do this for others, now I’m doing it for myself”). However, those motivations still belong to the same agent, and they persist in promoting and guiding behavior.

It may be relevant to study the motivation change process to understand how decisions are made and maintained over time, because they are considered predictors of outcomes of patients’ healthcare journey.

On these bases, the present study aimed at understanding and describing the process of motivation change during female cancer survivors’ participation in a psychological intervention featuring

psychological support and physical activity (the “Pink is Good” project) to promote quality of life by employing a grounded theory approach.

Materials and Methods

All the in-depth interviews were conducted in an online form by two researchers with experience in qualitative research methods. The decision to use qualitative interviews instead of other qualitative methods (e.g. survey and observational) is because the focus of the research is on the experience of disease and intervention from the participants. The use of the survey would have produced overly structured responses that left out specificities; observational methods would have placed the focus on how the psychological intervention was developed, leaving out the experiential aspect.

Furthermore, we were interested in exploring the motivation change process. According to the epistemology of quantitative research, in order to measure change or difference one should assess a given variable at two points in time or more, allowing for “repeated measures” analyses (Looney & Stanley, 1989). However, adopting a quantitative approach would have been improper as we did not know what specific aspects of motivation would have changed over the intervention experience. Asking participants specific questions would have limited their possibilities to report on the experience of change as they possibly lived it.

Participants included in this study were selected from a larger pool of women who voluntarily adhere to an Italian group intervention featuring psychological support and physical activity to promote quality of life (the “Pink is Good” project). All of them met the following inclusion criteria: (a) to be actively enrolled in the group intervention program for at least three months, (b) have a history of female cancer, (c) have at least 18 years old, and (d) speak and understand Italian. Participants were informed by the first author of this manuscript about the study, were reassured that the participation was voluntary and asked for a written and verbal informed consent. Sampling stopped when no new themes emerged from interview data, according to data saturation (Mills, Bonner, & Francis, 2006; Bennett, et al., 2002). Although it is impossible to predict the sample size needed to saturate this theory, some authors stated that typical grounded theory studies included sample sizes ranging from 10 to 60 participants (Starks, & Brown Trinidad, 2007).

Ethical approval was granted by the European Institute of Oncology, IRCCS (IEO, Milan: IEO1313). The semi-structured interviews lasted on average for 30 min and were conducted online in September 2020. All the interviews were audio-recorded with participants’ permission and then transcribed verbatim. Memos were also written throughout the process to orient and support data analysis. All the interviews included demographic (e.g., age, marital status), clinical (type of tumor), and open questions with accompanying prompts and probes to elicit extended narratives in participants about

their experience about the intervention, personal goals and motivations about it (Table 7). The first questions were designed to act as icebreakers to ease the participants into the interview. The suitability and effectiveness of the interview schedule were considered after each interview, and questions were adapted to follow-up on emerging concepts and themes. This iterative process also informed the sampling strategy and the evolving themes that emerged from the data. Data collection continued until each category was saturated and no new data emerged (O'reilly, & Parker, 2013; Noble, H., & Mitchell, 2016). We acknowledge the potential for further research to expand, develop or modify the grounded theory described in this manuscript, and recognize that our sample may not be representative of all cancer survivors or fully explanatory to all domains of psychological interventions to quality of life.

Content areas	Questions and Probes
Motivations/factors affecting the decision to participate in the intervention (<i>Original motivations</i>)	<ul style="list-style-type: none"> • What motivated you to participate? How did you decide? What aspects did you take into consideration to decide? (Cosa l'ha spinto a decidere di partecipare? Come ha deciso? Quali aspetti ha preso in considerazione?) • What objectives did you set for yourself within this training experience? (Quali obiettivi si è posta con la partecipazione a questo percorso di allenamento?) • How much (how) do these objectives orient your motivation to train? (Quanto questi obiettivi orientano la sua motivazione ad allenarsi?) • <i>Are there other factors that influenced your decision to participate in this intervention? (Ci sono altri aspetti che hanno influenzato la sua decisione di partecipare a questo programma?)</i>
Motivations/factor affecting engagement in the intervention after first months (<i>Evolved motivations</i>)	<ul style="list-style-type: none"> • What personal benefit do you expect from participating in this intervention? (Quale vantaggio personale si aspetta dalla partecipazione al programma?) • What are the most common feelings towards the intervention? (quali sentimenti più comuni nei confronti del progetto?) • How do you imagine the organization of this intervention in the coming months? (Come si immagina l'organizzazione di questa attività nei prossimi mesi?) • <i>What additional personal benefits do you see from participating in this intervention? (Quale ulteriore vantaggio personale vede dalla partecipazione a questo programma di allenamento?)</i> • <i>What additional features should this intervention have? (Quali ulteriori caratteristiche dovrebbe avere questo programma?)</i>
Intervention experience and outcomes	<ul style="list-style-type: none"> • Were your expectations met (to this point in time) (Le sue aspettative sono state soddisfatte finora?) • How was your experience until now? (Come è andata finora l'esperienza?) • <i>Do you want to give us any other information on your personal experience of the intervention? (Vuole darci qualche altra informazione sulla sua esperienza personale dell'intervento?)</i>

Table 7 Interview guide

All stages of the research process, from study design to data analysis and the resulting grounded theory, followed guidelines from a constructivist grounded theory approach ([66–68] and data analysis was independently conducted by three researchers alongside data collection. This allows a progressive focusing of interviews with female cancer survivors and testing of tentative hypotheses. The constructivist grounded theory allows researchers to develop a theoretical understanding of the motivation journey during psychological intervention for quality of life. In addition, we analyzed the possible positive outcomes of this motivational change in participants. The grounded theory aims at generating concepts and theory from data rather than testing hypotheses based on existing theory. In-depth individual interviews could provide a deeper understanding of the motivations under the decision to participate in psychological intervention, allowing participants to describe their experiences, insights, and the context of their experiences.

Other qualitative methods such as narrative and phenomenological methods would also have been useful, as they allow access to representation and personal experience, but upstream of listening to women's experience, the interest of the study was not only to describe the uniqueness of what participants in the intervention felt, but to construct a theory of how the change in motivation that led them to decide to take part in the intervention occurred. The grounded theory allows this, as it focuses on the process.

Interviews were audiotaped and transcribed verbatim. Transcripts were analyzed according to the grounded theory's procedure (Charmaz, 2000; Charmaz, 2005; Charmaz, 2014). In the first step, data were organized in order to facilitate the coding phases. Coding was carried out by three researchers following procedures outlined by Charmaz (2014). First, the authors used "open coding" in order to identify key actions and concepts between the texts and to develop labels representing their meaning. Subsequently, the researchers used "axial coding" in order to compare and grouped the codes into broader categories. As each interview was coded, some data were included in existing codes and new codes and categories were created to accommodate emerging concepts. Constant comparison methods (Charmaz, 2000) were used at all stages of analysis to establish bounds and contexts from codes and categories. Data were compared within and between interviews. As data collection and analysis progressed, the researchers compared codes and data from the final interviews with codes and data from the early interviews to check the relevance and applicability of interpretation of the data. These connections guided "selective coding", whereby categories were arranged to develop a conceptual model that linked to the existing literature in the field (Henwood, & Pidgeon, 2003). Thoughts, ideas, and interpretations of the data were recorded by memos written along with data collection and

analyzed according to grounded theory principles. These helped to reflect on the data collection process and to form the emerging theory. The authors had several meetings to discuss their interpretations and insights from data, and after an iterative discussion over many weeks, a consensus on themes was reached.

Results

Fourteen women with an experience of tumor agreed to participate in this study. The majority of participants had a history of breast cancer (78.6%), and all of them had undergone multiple treatments for female tumors, including surgery, chemotherapy, radiotherapy and hormone therapy. Participants' age ranged from 36 to 62 years ($M_{age} = 50.50$, $SD_{age} = 7.43$) and all of them lived in Italy alone or with their partners (see Table 8 for a detailed account of the sample). The women involved in this study were previously enrolled in a psychological group intervention to promote quality of life (the "Pink is Good" project). One of the potential participants declined participation in the research.

ID (Hypothetical Name)	Age	Education Level Reached	Marital Status	Type of Cancer Diagnosed in the Past
#1 (Rose)	36	High School	Maiden	Breast
#2 (Mary)	38	University degree or higher	Maiden	Breast
#3 (Catrine)	55	High School	Domestic partnership	Ovarian
#4 (Olivia)	56	Secondary degree	Married	Ovarian
#5 (Victoria)	50	University degree or higher	Married	Breast
#6 (Emily)	55	Secondary degree	Married	Breast
#7 (Charlotte)	47	University degree or higher	Married	Breast
#8 (Margaret)	54	High school	Married	Breast
#9 (Susan)	59	University degree or higher	Married	Breast
#10 (Sarah)	48	Secondary degree	Married	Uterine
#11 (Elizabeth)	46	University degree or higher	Married	Breast
#12 (Joanne)	54	University degree or higher	Maiden	Breast
#13 (Tracy)	47	High school	Maiden	Breast
#14 (Patricia)	62	High school	Married	Breast

Table 8 Participant characteristics

Among 14 women interviewed, 13 reported changing their motivation to participate in the psychological intervention during the months of involvement. These changes are characterized by different aspects and emotional dynamics that contribute to shaping the process of motivation change during female cancer survivors' participation in the "Pink is Good" project. Our study revealed the crucial role of the group in motivation change. Table 9 showed participants' changing. The interviews evidenced the evolution from individualistic to group-related motivations (i.e., friendship with other participants and enriching group membership), or from physical to psychological growth (i.e., being

not only healthy but a better person too). Some aspects involved in the intervention promoted the motivation journey. The engagement in the experience, the group sharing connections, the novelty, and the active mentoring emerged as important aspects for some participants and promoted changes in the initial motivation, and as such, is included in the grounded theory. The preliminary results of this study and the grounded theory of the process of motivation journey are presented in Figure 6, and aim to deeper understand the findings presented below. We also included in the text representative quotations of women involved in this study with hypothetical names.

ID (Hypothetical Name)	From intrinsic to extrinsic Motivation	From Ego to Alter	From no/unclear expectation to clear expectetation	Motivation change
#1 (Rose)		X (ego-alter)		X
#2 (Mary)		X (alter-ego)		X
#3 (Citrine)			X	X
#4 (Olivia)				
#5 (Victoria)				X
#6 (Emily)				X
#7 (Charlotte)		X (ego-alter)	X	X
#8 (Margaret)	X	X		X
#9 (Susan)		X		X
#10 (Sarah)		X		X
#11 (Elizabeth)		X (ego-alter)		X
#12 (Joanne)		X (ego-alter)		X
#13 (Tracy)	X	X	X	X
#14 (Patricia)				X

Table 9 Motivation changes in participants

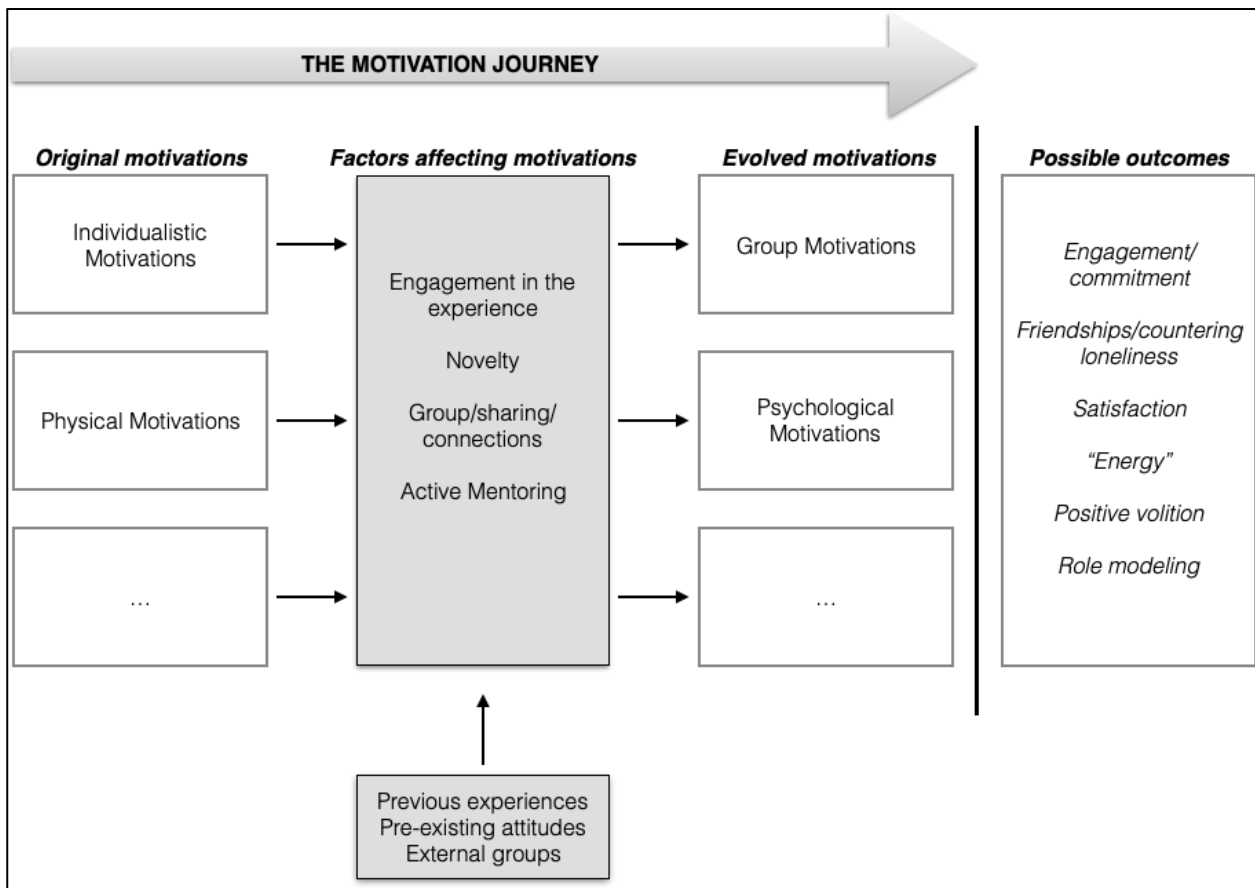


Figure 6 Grounded theory of how motivations change in a psychological intervention to promote quality of life

When responding to the interview questions on initial motivations to participate in the intervention, participants reported individualistic motivations to a stronger extent. Specifically, it emerged that one of the main initial motivations was **“to do something for themselves”** and to **“find a way to go beyond” their experience of cancer** and take their life back in hand. For example, a young woman with a history of breast cancer stated that “I decided to join the intervention also to make sense of what had happened to me, because I don't know if I can accept cancer. Surely, I learned to live with what happened to me, but I also needed to give a sense to my disease (cancer) and therefore participate in this intervention. However, (it was meant to be) also a rebirth for me; because initially it is not so simple to explain ... but there is a need to be reborn, to get cancer out of the shadows” (36-years-old woman - ID # 1). Additionally, a 46 years old woman declare that: "I had the hope that this project would extend because it had given me an element of hope also in recovering in my normal active life; I saw it as a stage to aim for, a goal to aim for" (ID #11).

In other cases, women started the psychological intervention featuring psychological support and physical activity with the desire to test themselves. Most of them were not athletes, but they viewed this intervention as a personal challenge and a way to **overcome personal limits (e.g., improve their**

physical endurance) and feel “healthier” after cancer.. For example, a 54-years old woman with a history of breast cancer stated that: “for me it is a new challenge. It is a challenge because it is a desire to achieve my personal results (...) it is not that I aspire to who knows what ... but (my personal objectives) are important to me, even just running half an hour just like I did the other day was a great satisfaction ... I feel that I would never have being able to do something like this a few years ago” (ID #8). Also another 47-year old woman said that “Initially it was a challenge with myself; I said to myself: "Will I ever be able to run 10km without stopping?"”(ID #7).

Additionally, at the beginning of the intervention participants consider this program as an **opportunity to share their experience of illness**. Some women explained that, in their community, stigma and shame about cancer still exist (Zorogastua et al., 2017) and patients try to hide cancer-related feelings within social life for a long time. Women included in this program reported that their initial motivation to participate was to **"take off their mask"** to get rid of the burden of hiding the disease and make their voices heard. A woman with a history of breast cancer declared: “By becoming a Pink Ambassador I "come out" as a cancer survivor. After that, many people told me "but I didn't know (about your cancer)!" "How did you do it? Your face was always the same!" yes ... but it was a mask! ... And I was hiding something different. And it was nice and right because at some point (of your life) that mask has to fall down! I had been wearing it for too long. It was probably not a very conscious choice, but it was what I needed to get myself out of the situation. I thought it had to be done for me and my little daughter” (#ID 7)”

After engaging in the intervention for three months, when responding to questions on expectations from the future and their current experience, participants reported that the **experience of the group** of patients was important and motivating to continue in itself. Participants underline that group-related aspects became a catalyst for their motivation to continue to take part in the intervention. Women recognized a unique **“sense of cohesion” (ID #12) in the group that they never experienced in their life**. For example, a 46 years old woman stated that: “I insist a lot on this aspect: for me ... the element that I have emphasized several times ... for me the team has become a really important aspect, the experience of the group ... because even in moments of heated conflict, (the team) is an element of strength” (ID #11). Furthermore, building bonds of new social support was an important factor in maintaining motivation. Participants stated that they found **new meaning in their lives by strengthening relationships with one another and feeling themselves more energetic and "strong" in their life**. For example, a 54 years old woman stated that: “This new group ... this feeling of being part of a group ... we feel considered in this project... (it is important) to present ourselves to others with a certain energy” (ID #8).

Finally, it emerged that transmitting a positive message of “hope after cancer” is a motivational aspect for many of the participants. After the diagnosis of cancer, it is possible that people show a tendency to exaggerate and focus on the illness outcome and to negatively evaluate one's ability to deal with cancer (Lai et al., 2003). Women included in this study are strongly motivated to be a "**spokesperson for life after cancer**", helping patients to “open their eyes beyond the diagnosis”. It was also very motivating for participants to spread this message within a group, making them feel "not alone" as well and useful for others. For example, a 59 years old woman declared that: “to make others understand that “the head matters” (the psychological aspects are important) a lot so as to believe in a possibility of normal life is a very important goal for me. (I would like to) be a spokesperson for life after cancer ... like, if you do not abandon yourself to the fatality of the tumor there is an “after”: it is not like after the disease you are a porcelain doll, like, oh my God I can't do this I can't do that!” (ID #9). In the same line, a 47 years old woman stated that: “I could have been an example of how to deal with this thing even alone, while understanding that we are not alone; because now that I am “exposed” (I shared my experience) I am no longer alone, I am no longer alone because I have a group ... I am no longer alone because people know it ... I am no longer alone because I do not ... anymore” (ID #7).

Considering these examples, it is important to underlie that the “group motivation” (i.e., maintaining commitment to the intervention in order to cultivate relationships; acting as a “spokeperson” to help others) emerged, within participants’ responses, only as a factor strictly related to the ongoing experience of the intervention, while it was absent when the intervention just started.

Some patients were aware already from the start that engaging in sports within the intervention context was a “tool” to improve their psychological well-being and quality of life. They knew that the sport-focused experience was not meant to improve their strength and thinness nor their physical health only, but also to promote psychological growth. However, after engaging in the intervention participants explicitly reported a shift of their attention and interest from the sport aspects to the psychological ones. For example, some participants highlighted, initially, a motivation to engage in sports to **become healthier, physically dashing, or more thin/good looking** for personal gratification or to face upcoming treatment. A 50 years-old woman stated that "Above all, I need to tone my abdomen to do a future reconstruction surgery and the running and training they make us do will help me in this" (ID #5). Also, a 54-years-old "Not necessarily to take this path of sport in my opinion, but in understanding that you can do things anyway and there are more resources that this path is giving me, resources that maybe someone can take as an example and make them their own and be motivated to also deal with the disease differently." (ID #7). A woman with a history of breast

cancer highlighted that she wants to "Become aware of my body ..." ... "see that my body responds and that in reality I can do what I thought I could not do ..." (ID #12).

After engaging in the intervention for three months, the motivations changed and respondents reported that they are now more **focused on achieving personal growth** than at the beginning of the intervention. From the words of some participants, it emerges the importance in finally being able to speak freely about their illness, taking off that "mask" they had been wearing for some time. This aspect has very often contributed to a personal and psychological change. For example, a 55 years old woman stated that: "I thought if this could be the connection that maybe makes me come back to live, to smile sincerely, not to have the mask I had put on. Because I never wanted to show others what I had inside. I always tried to have this mask, and I wanted to take it off, I wanted to be myself, joking, that never stops" (# ID6) . Additionally, a 47 years old woman highlighted that: "Very nice for me it was the moment when I came out, declaring myself a cancer patient. How many people came to tell me they didn't know, because my face was always the same ... yes, but it was a mask! Because that face wasn't there behind it. And it was beautiful and right, because at a certain point that mask had to collapse, it was too long that I had worn it on me, and it was important, it was what I had needed to get me out of the situation" (#ID7).

The renewed motivation for psychological growth appeared often tied to the testimony activity part of the project, namely the possibility for the participants to become positive ambassadors of the project and their enriching experience. Now, the motivation to be an "example" for other patients has become an important drive for participation. For example, a 54 years old woman stated that: "Give the opportunity to those who have lived this experience to testify that it can be done and that maybe other people (other women who are in this situation at this moment) by seeing us, they can gain strength, courage, and tell them they did. They were sick as I am sick and they did it ..." pride and pride to be able to be really helpful with my testimony to those who are going through a bad time at this moment " (ID #12). Additionally, a 56 years old declared that she: "try to sensitize more people to prevention and self-care, and to that healthy selfishness. But it's nothing more than thinking a little more about oneself in its entirety, there is not only home, work, family, sport, but doing what makes you feel good. This is a lesson that I learned from the disease, from this experience, because I could have been gone" (ID #4)

At this point of the study, it was important to try to understand what factors could contribute to modify personal motivation over time. The current research did not include questions investigating this aspect specifically, especially because asking what influenced motivations directly was considered an

influencing question. However, in some participants the process of the motivation journey was clearer in that they autonomously identified characteristics of their experience that helped them to reconfigure the motivational structure orienting participation and adherence. **Active involvement** in the intervention (e.g., strict adherence to the activities proposed and personal initiative) was deemed important to really understanding what the intervention was about and, consequently, to reflect on one's own motivation beyond initial expectations. Similarly, a “**novelty**” factor in the intervention, expressed by participants' surprise, was reported as a reason to elaborate one's own personal aims under a new light and can lead people to feel themselves more engaged and stimulated to renovate participation in the intervention. Finally, as clearly reported in many excerpts, social relationships within the project demonstrated an intrinsic motivational force. The **experience of the positive in-group**, as well as favorable memories of the **interaction with the health professionals** (the psychologist and the physical trainers especially), were associated with the possibility to reframe one's own view of the intervention as a whole, including the main drives for participation. The changes in personal motivations helped to bring out some aspects in the participants. In particular, we found that the evolution of the initial motivation could lead women to a greater **engagement/commitment** in the process. People felt themselves more involved in all activities and requests of the intervention. Similarly, after the motivation journey, people perceived greater **friendships, which countered the sense of loneliness**. By changing their personal motivation, participants perceived an involvement within the group and a greater sense of closeness and support. This process also promoted **satisfaction** in participants, and consequently a greater engagement in the path and a positive word of mouth. People lived the intervention with a greater physical and psychological “**energy**” that helped women to cope with their lives after cancer and face life with a **positive volition**. Finally, the motivation journey could lead women to position themselves as a “**role model**” for people facing cancer, sharing their experiences and thoughts. Being able to talk about their own experience and being an example for women who are now having to face cancer is often a source of pride and greater involvement in the project.

Discussion

Many studies on psychological interventions analyze participants' motivations to take part in them. According to reviews, this is done across multiple types of psychological interventions, almost in any area where activities and psychological support are implemented to promote attitudinal or behavioral change (Pereira, & Barros, 2019; Sondell et al., 2018; Hughes-Morley, Young, Waheed, Small, & Bower, 2015; Paige, Stellefson, & Singh, 2016; Hyde, Dunn, Scuffham, & Chambers, 2014; Kane et al., 2015). Patient motivation analyzed prior to enrolment may be important to predict subsequent

adherence (Thøgersen-Ntoumani, Shepherd, Ntoumanis, Wagenmakers, & Shaw, 2016; Mascaro, Wehrmeyer, Mahatre, & Darcher, 2020) as well as the quality of final outcomes (Weman-Josefsson, Jognson, & Lindwall, 2018). However, such analyses may not appreciate that human motivation is of a dynamic nature (Ryan, 2012). Whether conceived as drives or impulses, declarative aims or objectives, motivation could change over time while one is actively engaged in an activity. In the context of a psychological intervention for improving female cancer patients' quality of life by organized physical activity and psychological support ("Pink is Good" Project), it appeared that patients' motivations to persist in the project activity evolved based on the ongoing experience of the intervention. We deemed important to explore how motivations change during a complex intervention experience, because this could improve our ability to predict the outcomes of psychological interventions and healthcare management processes. As shown in table 6, we did not explicitly ask participants to report on "what changed in your motivation", rather we used open questions (e.g. "what motivated you to participate in the intervention" and "what benefits do you find in the intervention now") in order to capture variations in motivational representations. In the present study, interviews data revealed that changes in motivations regarded especially individuality/group (i.e., participants experienced enriching group membership within the intervention and valued sharing and others' well-being as emerging motivational factors) and physical/psychological growth (i.e., participants had the occasion to elaborate on the sports-related activities and then expressed more personal, existential aims to achieve). Such changes in motivations are consistent with self-determination theory (Deci & Ryan, 1985), which posits that human activity in the context of social life is implicitly directed to the fulfillment of three fundamental "nutriments":

- Competence, defined as feeling effective in one's ongoing interactions within the social environment and experiencing an adequate number of opportunities to express one's abilities;
- Relatedness, that refers to feeling connected to others, caring and being cared, having a sense of belongingness towards individuals and community;
- Autonomy, which relates to the perceived origin/source of one's own behavior. Specifically, humans pursue the need of experiencing their own activity as rooted in personal interests and integrated values.

Patients in the present study lived the intervention as the opportunity to reflect on their own motivational drives so that they let emerge deep sources of quality of life and well-being as their reason to actively participate in the intervention and, more importantly, to foster their own commitment and adherence. This highlights that psychological interventions could be able to "raise"

and to respond to motivations fundamental for participants' subjective well-being and life needs, even beyond the empowerment of health management alone.

It appeared that such evolution in motivations was tied with the experience of the ongoing intervention, especially in terms of some factors that emerged from the interviews. Social aspects have an inner capacity to influence one's goals, as the experience of a group and the possibility to share experiences with others promotes deeper reflections on one's own motive to be there (Chiaburu, Marinova, & Lim, 2007; Novick et al., 2011). Furthermore, a number of patients emphasized the novelty of the overall experience, especially if compared with initial preconceptions and expectations. Psychological interventions could be unexpected and thought-provoking experiences, which help participants to explore their own goals and expectations for the future.

We argue that the “motivation journey” (namely the qualitative, content variations of motivation within an intervention experience) could affect outcomes important for any kind of psychological intervention. In other words, when an evolution in initial motivations is envisaged, it could be correlated to health engagement and final satisfaction, in that participants adapt their own aims to involving experiences. Indeed, when reporting on renovated motivations participants in the present study often referred to “a new energy” guiding their actions within the project and active participation as a whole. When patients decide to participate in a psychological intervention that is supposed to improve their quality of life, their motivations may be partial, unclear, or biased by the painful and tiring experience of illness (Savioni & Triberti, 2020). However, it is possible that an evolution in the representation of *what they could actually achieve* from the intervention will influence their agency perception, promoting a positive volition or the tendency to aim for personal actualization beyond mere illness management.

As a limitation of the present study, it is important to notice that we did not implement any specific measurement of outcomes, also because the intervention analyzed here was not finished at the time of data collection. Also, it may be considered controversial that, in order to analyze “change”, we did not implement any multiple times (repeated measure) data collection; this was related to our intention to gather information on how motivations had been conceptualized and perceived by participants without influencing them with pre-determined questions. Future research may explore alternative methods to capture changes in motivation and the process of motivation journey in more detail. Anyway, we reported and analyzed patient testimony that, albeit at an anecdotal level, shows that participants were having a positive and enriching experience of the intervention, strictly related to a deep personal elaboration of their own motivations.

Future research should be aimed at deepening the results by studying the motivation journey of other chronic patients involved in psychological interventions. It is possible that these results may depend on the nature of the psychological intervention based on groups psychological support and physical activity. This point suggests the need to further investigate the motivation journey to test the transferability of this dynamic process to other interventions, as well as its possible effects on final outcomes. Additionally, a more articulated exploration of the factors affecting motivations and outcomes, especially in their dynamics, would be worthwhile in order to inform the development of methods and tools to improve participation and adherence. Finally, future research could use a more specific method, for example IPA, to understand how motivation is actually experienced by participants in the intervention.

Conclusion

This qualitative study aimed to obtain a preliminary understanding of the motivation journey in female cancer survivors who took part in a psychological intervention. Results of this study revealed that participants' motivations to persist in the project activity evolved based on the ongoing experience of the psychological intervention. Different aspects and emotional dynamics characterize these changes. Data highlighted the evolution from individualistic to group-related motivations (i.e., friendship with other participants and enriching group membership), or from physical to psychological growth (i.e., being not only healthy but a better person too). The engagement in the experience, the novelty, the group sharing connections, and the active mentoring emerged as important aspects for some participants and promoted changes in the initial motivation. This result is important for the implementation of a health intervention in that, while it is well-known that motivation influence adherence and final outcomes, it is less understood that patients' goals and objectives may change or evolve during the intervention experience, exactly because involving activities move them to reflect on their own needs, priorities and ultimately their identity as patients or survivors. Future studies may focus on developing innovative assessment measures that take into account the complexity and dynamic nature of motivations in order to allow researchers to fully comprehend the "motivation journey" and how it affects health management and personal growth.

Chapter 4: General discussion

We have seen earlier from the introduction to this dissertation that decision-making in real life is a very different process from decision-making in the laboratory. There are in fact several aspects and factors that come into play when we find ourselves having to make "real" decisions that can have effects and repercussions on the entire life ahead, for example the context in which the decision is made, social interactions and individual differences. Precisely the complexity and difficulty in measurement made it difficult to study this type of decision-making, creating a lack of literature on how the decision-making process takes place, that is, on the cognitive resources that people put into play when they elaborate a certain decision and when they select the course of action to be implemented. This relates to the difficulty inherent to reproducing a complex life context in the laboratory simulation, as well as to the inadequacy of observational tools to capture fine-grained processes such as the cognitive ones involved in decisions.

In particular, focusing on participation in psychological interventions aimed at improving well-being and quality of life in cancer patients, we have seen how the issue of participation, engagement and adherence is paramount. As we saw, many health interventions and initiatives still encounter notable rates of refusal or attrition lead to different aspect of intervention itself or patients. This is mainly because it does not only concern the decision itself, but it is necessary to consider that people can often change their minds.

When health professionals propose a psychological intervention, it is important to consider that patients' motivation may fluctuate and change during an intervention experience, with possibly unpredictable consequences on the maintenance of positive change. For example, intervention participants may discover intrinsic pleasure within an activity, or develop authentic passion for it; or, within group-based activities, they may develop significant peer relationship and find new resources for social support that would hold specific motivational value for continual engagement (Tezci et al., 2015; Sebri et al., 2021; Sebri et al., 2020). If motivation should be considered a predictor for engagement/adherence and final outcomes, it deserves continual and adaptable data collection that would keep trace of its evolutions and dynamics. Also Hankonen (2021), while exploring the factors that support individuals' enactment of behavior change techniques in the context of health interventions, evidenced that an updated conception of the role of motivation is more and more needed. As she says, motivation is considered important for what regards the initiation of goal pursuit

behavior, but its role in maintaining such behavior after the enactment (the “volitional” phase) is scarcely recognized and researched.

These studies highlight the importance for patients that their needs are taken into consideration during both the very design and the implementation of health interventions.

On these bases, the present dissertation provided three studies to identify the factors that can affect the decision to participate in psychological interventions aimed at improving the well-being and quality of life of cancer patients.

Figure 7 presents a schema useful to resume the experimental studies along with their respective objectives and results:

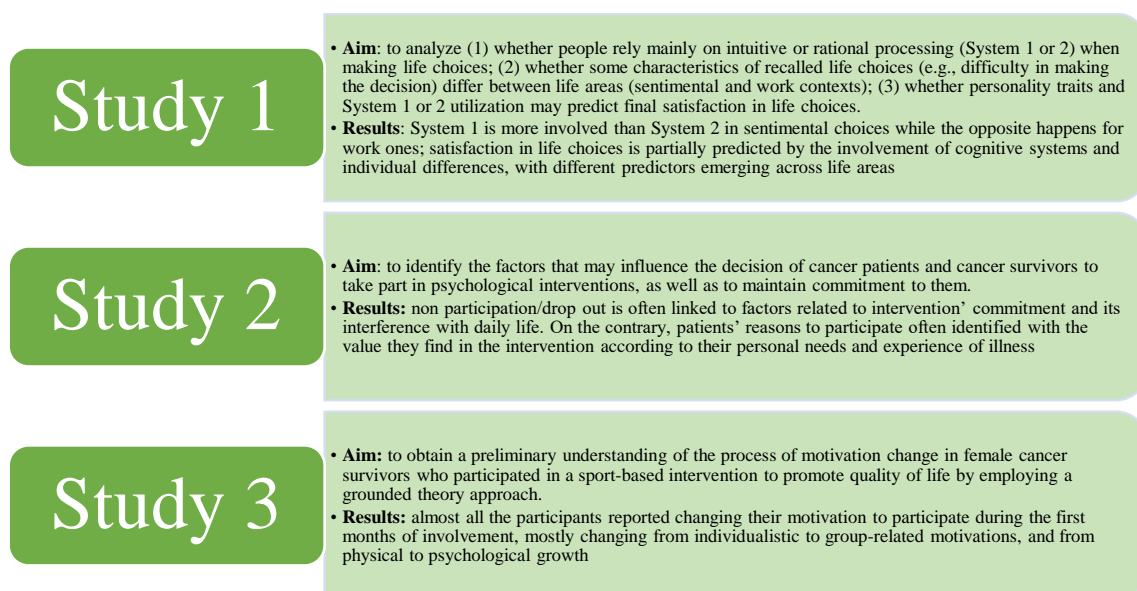


Figure 7 a schema resuming aims and main results of the three experimental studies

The general objective of the research project was to provide guidelines for psychological interventions for quality of life in order to respond to the authentic needs of the patient reducing the risk of non-participation or drop out.

The first study, focused on the study of decision making in real life context and the influence of cognitive and personality aspect of people on its process, allowed us to develop a method to study decision in real life context based on the memory of cognitive processes involved. By a cross sectional

research, we were able to identify that when people think about an important choice, they can remember that a given system (intuitive – system 1 or rational – system 2) was more active in a given area of choice and that this involvement is related to personality traits. For example, when people have to decide in sentimental area. System 1 is significantly more involved and the preferred involvement of this system appears correlated to neuroticism (i.e., the tendency to experience negative emotions) independently of life area. Finally, also the attachment styles have a role in the satisfaction about the decision. This first study does not aim to exhaust all the possible factors influencing real-life decision, but it underlies the necessity to develop research designs and tools able to capture the complexity of choices beyond the simplification of laboratory simulations. While the study did not focus on the issues typical of health psychology and psycho-oncology, its role in the present research thesis path was to recognize the impossibility to reduce “real life” decision making to abstract tasks. While preliminary in nature, the study helps to prefigure ways to investigate decisions taken “in the wild”, along with their motivational factors, conceptualization and late consequences. It is possible that cross-sectional studies and qualitative research are the most promising methodological resources to analyze “real life” people’s decisions in multiple fields, healthcare included.

In this line, the second study aimed to identify the factors that may influence the decision of cancer patients and cancer survivors to take part in psychological interventions, as well as to maintain commitment to them. What we could highlight from the scoping review is that patients’ context of life could interfere with the participation and that when patients have a positive motivation towards intervention it is because they see in it answers to their personal needs (sometimes more complex than we think). This study allowed us to understand the importance of motivation that patients have when participate in psychological intervention. In particular, what the study highlight is the dynamic nature of motivation, which can change during the intervention itself. For example, when patients decide to participate in a psychological intervention, at first, the motivation could be linked to the objectives that the intervention sets (e.g. improvement of the quality of life, physical performance, etc. – extrinsic motivation). during the intervention, patients' motivation can change, and participation can lead to an evolution in the representation of what the participants could actually achieve from the intervention by influencing their perception of agency, promoting a positive will or tendency to aim for personal actualization beyond the simple management of the disease (intrinsic motivation).

However, in the field of health interventions, participant’s motivation is often considered a predictor for both adherence and final outcomes (Foley et al., 2021; Fin et al., 2017). This view is consistent with the idea that motivation can be quantified and measured, typically by using dedicated self-report

measurements based on Likert scales. However, these approaches seem not to appreciate that motivation, and especially the attitudes or beliefs towards health intervention activities, could qualitatively change during the experience of an intervention itself. For this reason, the aim of the third study is to use an intervention that mixed physical activity and psychological support to understand how motivation evolves. The participants' interviews evidenced that in this type of intervention patients' motivations to persist evolved based on the ongoing experience of the intervention. Indeed, when patients decide to participate in a psychological intervention that is supposed to improve their quality of life, their motivations may be partial, unclear, or biased by the painful and tiring experience of illness. However, it is possible that an evolution in the representation of *what they could actually achieve* from the intervention will influence their agency perception, promoting a positive volition or the tendency to aim for personal actualization beyond mere illness management.

In the end, considering the results of the presented studies we can conclude that often the interventions do not take into account the authentic needs of patients, which are complex and stratified. Patients decide to participate and to adhere to activities taking into account their daily life, future plans and obligations, and the irreducible subjective representation of illness. To develop interventions that respond to the authentic needs of the patient makes it possible to reduce the risk of non-participation or drop out.

Future directions

Based on the results of the multiple research efforts described above, as well as on their limitations, it is possible to identify some interesting avenues for future research.

First, it might be useful to conduct qualitative research that investigates the experience psychological interventions. For example, researchers would employ tools such as structured interviews to assess practical aspects of the interventions (e.g. the daily travel to access the activities; the time taken from other personal obligations; etc.). By clarifying aspects of the *experience* of an intervention, it is possible to avoid patients' guilt associated with slow progression and to include ad-hoc material to help patients to flexibly adapt activities to their daily schedules (Karageorge et al., 2017). Moreover, qualitative researchers may consider methodological approaches such as IPA (Shaw, 2011) or narrative (Sools, 2013) in order to gather information about patients' lived experience of the intervention: this would allow researchers to explore the interventions beyond the indicators of mere effectiveness, grasping the subjective meaning of activities for the patients and how they affect the overall healthcare journey.

Another step in this direction is to use research methods that are “user centered” (a concept from the design field), meaning that health interventions should be planned and designed taking into consideration patients’ needs and feedback since the first steps (Triberti & Barello, 2016; Triberti & Liberati, 2015; Karpathakis et al., 2021) in line with a patient centered approach to medicine. Studies demonstrated that users’ feedback allows the researcher to identify useful information on how to modify interventions for future implementation or larger studies (Robertson et al., 2017). For example, when a health intervention features experiences mediated by technology (eHealth), it is known that flexible materials and user-adapted interfaces are preferable to any “one-size-fits-all” approach (Pizzoli et al., 2019; Biancardi, Dermouche, & Pelachaud, 2021). Studies utilizing preliminary research to inform design show that the interventions and their main contents could be adapted to patients’ emerging needs with positive results in terms of engagement and perceived quality of the experience (Rivera et al., 2018; Schields, 2022). Indeed, these methods do not only produce data, but also design tools that support the creation and implementation of interventions (e.g., *personas* or data-based descriptions of prototypical participants, including specific needs that the intervention should satisfy; Triberti & Brivio, 2017).

According to a scoping review on interventions for the mental health of college students (Oti & Pitt, 2021), while definitive evidence is still needed about the effects of user centered design approaches on the final intervention outcomes, it is possible to identify a number of important features of such design processes, including for example stakeholder engagement, peer involvement, and the continual access to health professionals.

Apart from relying on solid theory and previous evidence, intervention designers may implement preliminary studies - focus groups or interviews with patients; online questionnaires - focused on patients’ life contexts and the subjective priorities associated with health management. The results of these studies could be used to inform the design of the interventions before any implementation action, by adapting activities to real-life needs and situations.

The main limitations of the experimental efforts described here can be found in the lack of controllability due to the questionnaire-based method used (study 1) and that, in study 2, no specific measurements were implemented. Therefore, future research may explore further the adequacy of such a methodology to similar research aims and deepen the results by studying the motivation journey of other chronic patients involved in psychological interventions. While the study described here adopted a qualitative approach in order to capture the dynamics of motivation during the experience of a psychological intervention, it is possible that future studies focused on similar intervention may use the factors outlined in the present study to create ad-hoc quantitative tools to analyze the variation of motivations and goals. For example, given that the study described here found

that individual motivations (e.g., improve one's own physical well-being) evolved over time towards group-based motivations (e.g., cultivate and maintain social relationships within the intervention), future studies may analyze these specific variables to investigate possible differences in motivations across multiple phases of the intervention experience.

Anyway, all the results highlight that there is a renovated understanding of the "healthcare journey", meaning that finding an effective treatment for a disease could not be considered the sole objective, or even the main one, for any care process. Healthcare evolution is connected to two main discoveries: first, treatment effectiveness is irrelevant if the patient does not actively participate in his/her own care (e.g., taking medications, adopting a healthy lifestyle, etc.) (Hankonen, 2021; Graffigna, Barelo, & Triberti, 2016). Second, some diseases are actually treatable but not curable, so they are considered chronic and the patient has to learn how to live with their long-term effects, continually accessing health services (Epping-Jordan et al., 2004; Lall et al., 2018). In other words, the healthcare system should learn how to make patients responsible protagonists in their own healthcare journey ("patient engagement").

Another important aspect to take into consideration is that patients are often more focused on the characteristics of the intervention (e.g., commitment required in terms of time and effort) and whether or not it responds to their needs. Failing to consider these aspects, along with the underlying complex and dynamic motivation, may lead to poor engagement and drop out. Studies that would investigate the real needs and motivations underlying the decision to participate in an intervention can be valid resources to create targeted interventions and to improve authentic patient engagement. Indeed, the construct of motivation could be considered the most elusive among the main theoretical constructs in general psychology, in that it is still described in terms of multiple and partially inconsistent conceptions (e.g., needs, impulses, goals/objectives, etc.) (Shah & Gardner, 2008). Research focused on the lived experience of complex decisions and activities, such as committing to a health intervention to manage one's own chronic illness, could provide important information to understand how motivations work in the "real world" of human decisions. The concept of "motivation journey" proposed in this dissertation could be a useful guide for research aimed at capturing the complexity of human activity, and to improve our capacity to support positive conducts from a patient-centered approach to healthcare and medicine.

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