

PhD degree in Systems Medicine (curriculum in Medical Humanities)

European School of Molecular Medicine (SEMM) and

University of Milan

**“A COMPREHENSIVE OVERVIEW OF PSYCHOLOGICAL AND
ETHICAL IMPLICATIONS ON THE ROLE OF CAREGIVER IN THE
CLINICAL PATHWAY OF PATIENTS NEWLY DIAGNOSED WITH
BREAST AND PROSTATE CANCER”**

Settore disciplinare: M-PSI/01

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Anno accademico 2022-2023

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List of Abbreviations

AS: Active Surveillance
ADQ: Adherence Determinants Questionnaire
BC: Breast Cancer
BC_p: Breast Cancer Patient
BR: Breast Reconstruction
BT: Brachytherapy
CARE: Consultation and Relational Empathy
CES-D: Center for Epidemiologic Studies Depression Scale
CPS: Control Preference Scale
CT: Chemotherapy
DM: Decision-Making
DNR: Do Not Resuscitate
EBRT: External Beam Radiation Therapy
FCR: Fear of Cancer Recurrence
HADS: Anxiety and Depression Scale
HT: Hormone Therapy
M: Mean
MBSS: Miller Behavioral Style Scale
MCS: Mental Component Summary
MSPSS: Multidimensional Scale of Perceived Social Support
PAIR: Personal Assessment of Intimacy in Relationship
PC: Prostate Cancer
PC_p: Prostate Cancer Patient
PCS: Physical Component Summary
PSA: Prostate-Specific Antigen
QoL: Quality of Life
RCT: Randomized Control Trial
RP: Radical Prostatectomy
RT: Radiation Therapy
SD: Standard Deviation
SDM: Shared Decision-Making
SDM-Q-9: 9-item Shared Decision-Making Questionnaire
STAI-Y: State Trait Anxiety Inventory – Y
SWD: Satisfaction With Decision
TDM: Treatment Decision-Making

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Abstract

In recent years, research on the caregivers' involvement in the Shared Decision-Making and cancer care has burgeoned in the psychological field; however, knowledge gaps still exist because most studies have failed to acknowledge the multidimensional nature of agreement/disagreement among dyads in the Shared Decision-Making and cancer trajectory, especially during the early phase of the disease (diagnosis and starting of treatments). My Ph.D. thesis focused on the agreement among patient-caregiver dyads along the cancer care pathway, from the diagnosis onward, and their mutual influence on the psychological adjustment to cancer in breast and prostate cancer patients and their caregivers. Along the cancer trajectory, dyads may experience episodes of conflicts, so it has been evaluated the concept of conflict from an ethical standpoint. The current projects highlighted the importance and need for a multidisciplinary approach to dyads, involving physicians, psycho-oncologists, and clinical ethicists. A holistic approach may help patients and caregivers coping with cancer, being supportive to each other and expressing their preferences, fears, and needs. Specifically, four studies addressed the dyadic agreement in the Decision-Making and the interdependence among dyads from a psychological standpoint through quantitative and qualitative methods. In particular, the first study explored the preferences of breast and prostate cancer patients and their caregivers in the Shared Decision-Making. Given the relevance of caregivers' involvement in the Decision-Making, two studies demonstrated the importance of a renovated family-centered model of cancer care and the need of structuring psychological interventions tailored on the dyads or on the single member. Specifically, although patients often have at least one caregiver by their side, who provide practical and emotional support, it is unclear whether dyads establish their roles and the level of involvement in the Decision-Making process. Indeed, two studies showed that most dyads disagree on the preferences and actual involvement in the Decision-Making. Moreover, caregivers are not just a supporter, as she experiences the disease almost as much as the patients. Dyadic members experience high distress and influence each other's adjustment to cancer. Findings from the qualitative assessment support the idea of cancer as a family disease. Dyads described the cancer diagnosis as an expected and shocking event, that needs to be addressed together as soon as possible. However, patients and caregivers experience different concerns: patients' worries refer to the cancer recurrence and the body image, while caregivers' worries about their ability to support patients. Then, in order to evaluate the caregivers' involvement at a multilevel, two studies assess the concept of conflict from an ethical standpoint. The first study proposed a taxonomy of the moral conflict that may emerge along the cancer trajectory. Finally, a case report provides the basis for future investigations about the presence of moral conflicts even in the early stage of cancer (diagnosis). In conclusion, findings of this PhD projects suggest the importance of caregivers' involvement along the cancer care pathway and the need to promote psychological interventions both for patients, caregivers, and the dyads. Finally, the present thesis gives future directions to increase breast and prostate cancer dyad well-being, reducing the Fear of Cancer Recurrence.

1. Introduction

The present PhD project aims to address the phenomenon of agreement or disagreement among patient-caregiver dyads along the cancer care pathway, from the diagnosis onward, and their mutual influence on the psychological adjustment to cancer in breast and prostate cancer patients and their caregivers. Receiving a cancer diagnosis has a strong psychological impact on patients and caregivers (Karimi Moghaddam et al., 2023; Kong & Guan, 2019; Petrocchi et al., 2022; Ștefănuț et al., 2023). For that reason, in the last decades cancer has been defined as a family disease or a “we-disease” (Chen et al., 2021; Kayser et al., 2007; Minuchin, 2018). Patients and their caregivers face the dramatic experience of cancer together, experiencing a roller coaster of emotions (Johnson & Ross, 2023; Li et al., 2020). Patients and caregivers may have a reciprocal influence on their psychological adjustment to cancer diagnosis and treatments (Coyne et al., 2020; Kong & Guan, 2019; Ștefănuț et al., 2023). Along the cancer trajectory, caregivers provide emotional and practical support (Karimi Moghaddam et al., 2023; Laryionava et al., 2018, 2021; Litzelman, 2019). Patients are almost always accompanied by at least one caregiver during the visits supporting the interaction and communication with physicians (Lamore et al., 2017; Schumm et al., 2010). By participating in medical visits, caregivers can be involved in the decision-making process, stating their opinions, preferences, and beliefs on the treatment (Dionne-Odom et al., 2019; Laidsaar-Powell et al., 2017; Trevino et al., 2019; Tulskey et al., 2022; Ullrich et al., 2020). However, patients and caregivers may have different perspective regarding the cancer trajectory, affecting the understanding of medical information, compliance with therapies and, consequently, the patient’s quality of life, and, eventually, even her relationship with the caregiver (Shin et al., 2016). To date, there is still a lack of clear knowledge about dyads’ involvement in decision-making, their agreement about their involvement in the decision-making, their mutual influence on the psychological adjustment to cancer, and which conflicts they may experience when they receive a cancer diagnosis. This research project is aimed at addressing the phenomenon of agreement and disagreement among patient and caregiver along the cancer care pathway, from the diagnosis onward, and their mutual influence on the psychological adjustment to breast and prostate cancer treatment. Specifically, this PhD thesis has the following research objectives: 1) to investigate how and to what extent patients and caregivers wish to be involved in decision-making process and the cancer care pathway (we expect that patients and caregivers want to be jointly involved by the medical team in the care pathway); 2) to explore the level of agreement within the dyad about the expected mutual involvement in decision making and the care pathway (we expect a good agreement in the dyad); 3) to investigate whether there is interdependence between patient and caregiver emotional and psychological reactions following a breast and prostate cancer diagnosis and/or in response to the initiation of treatments (we expect a mutual influence within the dyad’s members); 4) to assess whether and what conflicts patients and caregivers may experience along the course of cancer care.

To fill the aforementioned gaps in literature, we conducted a systematic review to assess the preferences of breast and prostate cancer dyads regarding their involvement in the decision-making process. Then, we structured a research protocol aimed at exploring over a period the impact of a new diagnosis of breast or prostate cancer on the patient-caregiver dyad, their mutual influence and alignment in DM (Cincidda

et al., 2022). Specifically, we evaluated: a) patients-caregivers' preferences and actual involvement in the decision-making process; b) patients-caregivers' information-seeking behaviors, anxiety, depression, perceived social support, quality of life, the shared decision-making, satisfaction with decision, and their mutual influence; c) patients' and caregivers' relationship with physicians. We started conducting a pilot study on dyads with PC, then a longitudinal study on dyads with BC. The longitudinal study was a randomized control trial, in which dyads were randomly assigned to an intervention group (one single psychological consultation) or to the control group (no consultation). Dyads were evaluated at two time points. The final aim of the longitudinal study was to assess patient' compliance/adherence to treatments and the satisfaction with the (shared) medical decisions (May a single psychological consultation improve patients' adherence to treatments, satisfaction with decisions and dyadic psychological distress?). Finally, a qualitative evaluation of the psychological consultation was performed. The psychological consultation lasted 60 minutes, in which we assess a narrative expression of the experience of the diagnosis, the dyad's preferences regarding mutual involvement in the decision-making process, mutual emotions/fears, and needs, as well as the clarity of the information received by the medical team.

The caregivers' involvement in the decision-making has been studied even by a bioethical standpoint, through the concept of relational autonomy. Indeed, patients and caregivers, as human beings, are relational beings, whose identity and interests are shaped by ties with others. However, patients and caregivers may experience episodes of conflicts during the decision-making process. To date, there is a lack of knowledge on the moral conflict emerging during the cancer care. Firstly, we performed a systematic review aimed at investigating decisional conflicts arising in cancer patients' care process, originating from caregiver's involvement, as well as their outcomes on the dyadic relationship and the care process. Then, we proposed a case study to show the presence of moral conflict during the first phase of cancer care (diagnosis).

Finally, we proposed future directions in line with our results.

2. Theoretical Background

2.1. Cancer and caregiving: a dyadic perspective

Receiving a cancer diagnosis has a strong psychological impact on patients (Petrocchi et al., 2022). Many patients initially respond with shock and disbelief. Indeed, a defense mechanism commonly used to face a reality hard to tolerate is denial. It may take time for the diagnosis to be accepted and for individuals to come to terms with it (Di Giuseppe et al., 2018). Other patients may experience anger and frustration due to a feeling of injustice and the loss of control over one's life (Pene & Kissane, 2019). From the diagnosis onward, cancer patients may often live emotional states such as fear, anxiety, and depression (Petrocchi et al., 2022; Ștefănuț et al., 2023). During the cancer care journey (from diagnosis to treatment choices, from prognosis to side effects) patients can be worried about their uncertain future. Uncertainty can cause cancer patients to have a prolonged feeling of loss of control, which has a direct negative impact on how they cope with cancer, their psychological well-being, and quality of life (QoL). Literature has shown that about 60 percent of the cancer population experienced disease-related uncertainty given the inability to predict with certainty the course of the malignancy, the perception of the future as threatening, the advanced state of the process, and/or communication barriers (Rodriguez-Gonzalez et al., 2022). During treatments, patients cope with physical changes, such as hair loss, weight changes, and surgical scars, that alter the body image and self-esteem (Sebri et al., 2021). Furthermore, they may present with adjustment disorders, posttraumatic reactions, and fear of cancer recurrence (FCR) or fear of death (Cincidda, Pizzoli, et al., 2022; Ștefănuț et al., 2023). All these aspects might result in a poor QoL (Ștefănuț et al., 2023). However, the psychological impact of a cancer diagnosis and treatments can extend beyond the patient to their family (Karimi Moghaddam et al., 2023; Kong & Guan, 2019; Petrocchi et al., 2022; Ștefănuț et al., 2023). Cancer can affect various aspect of families' lives (e.g., physical, emotional, social, and financial), and may cause a profound alteration and rearrangement of family roles (Petrocchi et al., 2022; Ștefănuț et al., 2023). For that reason, in the last decades cancer has been defined as a family disease or a "we-disease" (Chen et al., 2021; Kayser et al., 2007; Minuchin, 2018). This means that both members of the cancer couple/dyad are under cancer-related pressures (Chen et al., 2021).

Kayser and colleagues (2007) introduced the notion of cancer as a "we-disease," which encompasses the understanding that cancer extends beyond the individual diagnosed, profoundly influencing their family, friends, and support network. This perspective takes a comprehensive approach, recognizing the joint encounter with cancer and highlighting the broader impact on the emotional, psychological, and social aspects faced not only by the patient but also by their loved ones. The term underscores the interconnected nature of individuals grappling with a cancer diagnosis, emphasizing a collective experience that goes beyond the physical challenges of the patient.

Patients and their family members face the dramatic experience of cancer together by going through different stages of adjustment to cancer disease, from normal adjustment to cancer-related anxiety (Cincidda, Oliveri, et al., 2022; Li et al., 2020). Initially, family members have to “rethink their life” and to find a new psychological homeostasis (Petrocchi et al., 2022). The family may experience a roller coaster of emotions (Johnson & Ross, 2023; Woźniak & Iżycki, 2014), such as fear of the possible loss of their loved one, helplessness, and overwhelm, which are associated with anxiety, sadness, and anger (Sherman, 2019). Recent research has shown that cancer has the same impact on both patients and their family in terms of depression, changes in physical health, decline in social functioning and reduced QoL (Coyne et al., 2020). Finally, patients and their family members may have a reciprocal influence on their respective psychological well-being: social and functional aspects of patients' QoL affect their partners' QoL, whereas an increase in patients' symptomatology is followed by a decrease in their caregivers' QoL (Coyne et al., 2020; Kong & Guan, 2019; Ștefănuț et al., 2023). Adaptation to cancer disease often impact both members of the caregiving dyad as a unit, rather than as isolated individuals (Kelley et al., 2019; Varner et al., 2019), affecting QoL, psychological health, and relationship functioning (Ferraris et al., 2022; Revenson et al., 2016; Sherman, 2019; Trevino et al., 2019).

Following a cancer diagnosis, one or more family members are usually added to the role of caregiver (Petrocchi et al., 2022; Rohith & Patel, 2022; Ștefănuț et al., 2023). A caregiver is defined as the person who helps cancer patients without being paid, commonly identified in the patient's spouse/partner or adult child, sometimes close or extended family members, and in rare cases, friends may also play this role (Karimi Moghaddam et al., 2023; Kong & Guan, 2019; Petrocchi et al., 2022; Ullrich et al., 2020). Throughout the disease trajectory, patients have at least one caregiver by their side who provides practical/physical, emotional, and psychosocial support (Karimi Moghaddam et al., 2023; Laryionava et al., 2018, 2021; Litzelman, 2019). Caregivers offer emotional support to cancer patients, providing comfort, understanding, and reassurance counteracting fear, anxiety, and uncertainty (Molassiotis & Wang, 2022). They serve as a constant source of encouragement, empathy, and companionship throughout the patient's treatment and recovery (Cincidda, Oliveri, et al., 2022; Karimi Moghaddam et al., 2023). Being a caregiver means to take on new responsibilities such as managing appointments, organizing medications, handling insurance matters, accompanying patients to visits, and coordinating with other family members or support networks (Laidsaar-Powell et al., 2016; Longacre, Miller, et al., 2018; Ștefănuț et al., 2023; Ullrich et al., 2020). Caregivers assist patients with daily living activities, such as personal hygiene, mobility support, meal preparation, and medication management (Laryionava et al., 2021; Longacre, Miller, et al., 2018). They ensure that the patient's physical needs are met and try to alleviate some of the burdens associated with cancer treatment (Johnson & Ross, 2023; Woźniak & Iżycki, 2014). To go over all these activities, sometimes caregivers modify their lifestyle by restricting their leisure activities and social lives, and sometimes they might need to take time off work, affecting their

income, and families may have to dip into savings or take on debt to cover medical expenses (Johnson & Ross, 2023; Karimi Moghaddam et al., 2023; Rohith & Patel, 2022). Becoming caregiver is basically unexpected and usually caregivers do not have sufficient prior guidance and preparation, thus physical and psychological changes may occur (Karimi Moghaddam et al., 2023; Kong & Guan, 2019; Mishra et al., 2021). They can experience stress, anxiety, worry, depression, isolation, and anger, even sometimes higher than the patients themselves, from the time of cancer diagnosis to the last moment of their patient's life (Karimi Moghaddam et al., 2023; Rohith & Patel, 2022). Literature reported that this often occurs when caregivers have to maintain a balance between work and daily life activities (Karimi Moghaddam et al., 2023). Moreover, the higher is the caregiver burden, the greater is the levels of family distress experienced by caregivers. Caregiver burden is predicted by factors such as worsening functional status of cancer patients, caregiver's younger age, being female and prolonged duration of caregiving (Karimi Moghaddam et al., 2023). Recent reviews highlighted the importance of understanding the unmet needs of informal cancer caregivers and developing appropriate strategies to improve their well-being (Alam et al., 2020; Alfano et al., 2019; Given, 2019; Longacre, Applebaum, et al., 2018).

Caregiver's role, level of involvement and responsibility can vary depending on the needs of the patient and the available support network (Woźniak & Iżycki, 2014). When a patient is diagnosed with cancer, caregivers immediately show readiness to give support, information seeking behaviors about the disease, possible treatments, and survival rate (Karimi Moghaddam et al., 2023; Woźniak & Iżycki, 2014). Sometimes, however, they prefer to avoid talking about the cancer so as not to create additional stress for the patient. But almost everyone, patient and caregiver alike, wonders why cancer happened to them. The emotional, cognitive, and behavioral efforts that individuals make to manage, tolerate, or reduce the demands and challenges they face after a cancer diagnosis are referred as Coping (Lazarus & Folkman, 1984). Thus, coping strategies are acted toward stressful situations, emotions, or thoughts in order to adapt and maintain the psychological well-being. A good coping style toward the disease can promote healthy behavior or strengthen the patient's will to fight (Woźniak & Iżycki, 2014). During treatments, caregivers and families have to reorganize, taking on the roles that were previously patient's responsibility, as well as accompanying her to the hospital for chemotherapy or radiation therapy (Cincidda, Oliveri, et al., 2022; Longacre, Miller, et al., 2018). In this phase, caregivers may feel overwhelmed both physically and psychologically, and poised between fear and hope for the outcome of treatment. During the chronic phase of the disease, patients and caregivers slowly return to their routines, although some patients may not yet feel strong enough to resume full activity (Woźniak & Iżycki, 2014). In the end of life, caregivers have to deal with the impending loss of their loved one, the pain the patient is experiencing, and the lack of control over the situation (Karimi Moghaddam et al., 2023; Ullrich et al., 2020): they can offer comfort and ensuring the patient's dignity and wishes are respected. The way family members can cope with the death of their relatives depends on their psychophysical condition

and support network (Ozdemir et al., 2023; Ullrich et al., 2020). However, it is important that the caregiver's support is good and reliable to be beneficial for the physical and emotional well-being of cancer patient. Indeed, it is associated with improved patient outcomes, including better self-care and satisfaction with medical visits (Keast et al., 2020; Litzelman, 2019).

Overall, the role of caregivers is important to the well-being and QoL of cancer patients. With their support, understanding, and compassion, patients can deal with cancer more effectively. It's crucial to recognize and appreciate the dedication and sacrifices made by caregivers in these challenging circumstances. For this reason, it is essential that caregivers also take care of their own well-being to be able to provide effective care for cancer patients and avoid burnout (Alabi et al., 2021; Morgan et al., 2022).

2.1.1. The dyadic relationship: a theoretical framework

Considering the impact that cancer has on patients and caregivers' dyads and their reciprocal influence in terms of stress and uncertainties, it is not surprising that in literature authors tried to apply theories of families as a system to the field of oncology. Examining theoretical frameworks, Bowen highlighted the importance of the effects that family members have on each other since they share a history and a future (Bowen, 1993). He proposed the Family Systems Theory, a psychological framework that examines the interactions and dynamics within families. This theory focuses on understanding how family members influence each other's thoughts, emotions, behaviors, and roles, and how these patterns can affect the overall functioning of the family unit (Bowen, 1993; Johnson & Ross, 2023). Therapists often use this theory to help families identify patterns, improve communication, resolve conflicts, and promote individual and collective well-being (Guerin & Chabot, 1997; Titelman, 2014). Other researchers, such as Minuchin, began to apply this theory in research, and in practice, developing a dynamic model of family functioning (Pardeck, 1989). Although Family Systems Theory is not specific to any setting, it can be applied in cancer care to understand and support both patients and their caregivers, examining their coping style and communication patterns. By understanding family communication dynamics, healthcare providers can facilitate open and productive discussions among patients and caregivers, avoiding potential conflicts (Boelk & Kramer, 2012).

Kelley and Thibaut (1959) introduced the Interdependence Theory within social psychology, aiming to comprehend the dynamics of interpersonal relationships and behavioral patterns that arise in situations of mutual dependence (Rusbult & Van Lange, 2003; Van Lange & Balliet, 2015; Van Lange & Rusbult, 2012). Interdependence, in this context, acknowledges that outcomes and successes in social situations are shaped by the actions of others. When individuals share common goals with interdependent outcomes, their actions become interconnected, potentially leading to cooperation or conflict. At the core of this theory is the level of

reliance one partner in a relationship place on the other (Petrocchi et al., 2022). The Interdependence Theory categorizes social situations into three types: cooperative situations, where goals align and outcomes are positively interdependent; competitive situations, characterized by conflicting goals and negatively interdependent outcomes; and individualistic situations, where individuals have independent goals and outcomes are not interdependent, fostering a more individualistic approach (Van Lange & Balliet, 2015). This theory offers insights into how people navigate diverse social situations, make decisions, and engage in interactions with others, extending its applicability to the oncological setting (Petrocchi et al., 2022). In the realm of close relationships, the Interdependence Theory emphasizes the mutual influence between intimate partners, extending its application to patient-caregiver dyads where interactions shape each other's experiences (e.g., thoughts, feelings, and decisions). This dynamic is termed dyadic interdependence (Fletcher et al., 2012; Petrocchi et al., 2022). Dyadic interdependence focuses on three primary sources: communication, congruence, and reciprocal influence. Communication involves the co-creation, sharing, and co-regulation of meanings essential for the mutual support between a patient and a caregiver during cancer coping. Congruence reflects the agreement or discordance between dyad members on various aspects. Reciprocal influence signifies the mutual effects each member has on the other and how these effects impact their well-being (Fletcher et al., 2012). Research indicates that intrapersonal (e.g., psychological distress) and interpersonal (e.g., relationship processes) variables of both caregivers and patients interact, contributing to individual (emotional) and dyadic (relational) adjustments to illness (Karademas, 2022). A recent systematic review further supports the interdependence of well-being among cancer patients and their family caregivers (Ferraris et al., 2022; Northouse et al., 2012; Streck et al., 2020).

More recently, Rolland (1994) introduced the Family System Illness model (FSI), providing a psychosocial roadmap for navigating the challenges posed by cancer and facilitating the management of inevitable tensions within the family. This model views the family not only as a potential source of tension but also as a valuable resource. Adopting a systemic perspective, the FSI model recognizes cancer as a chronic disease and suggests considering it in terms of its pattern of psychosocial demands over time, with the family at the center of interaction. The FSI model takes a developmental approach, intertwining three key threads: the disease itself, individual development, and family development. It addresses three dimensions: "psychosocial types" of illness and disability, major developmental stages in their natural history, and key family system variables. Specifically, the FSI model assesses the anticipated psychosocial demands of a disorder across its stages, emphasizing family and individual development dynamics, multigenerational coping patterns with illness and loss, and belief systems, including cultural, ethnic, spiritual, and gender influences (Fig. 1).

By bridging the biological and psychological dimensions of the disease, the FSI model elucidates the connection between chronic illness and the family. Despite grouping different cancers based on biological similarities and differences, each cancer presents unique psychosocial demands on the patient and family, influenced by factors such as onset, course, outcome, incapacity, and uncertainty. Recognizing the varying impacts of illness stages on the patient and family, the FSI model underscores the importance of investigating coping modalities as dynamic variables that change in response to events. The FSI model proposes three main stages of chronic disease (crisis, chronic, and terminal) and outlines evolutionary challenges for each, summarized in Figure 2. In the context of this dissertation, it is crucial to highlight challenges related to the crisis phase, including developing family flexibility amid uncertainty and the threat of loss, adapting to symptoms and treatments, and establishing a collaborative relationship with professionals and institutions. Healthcare providers play a pivotal role in influencing the family's sense of competence and must approach interactions with extreme sensitivity. Sharing information and setting specific goals can empower families, providing a sense of control and realistic hope. This empowerment process is integral to families navigating the cancer journey. Based on this framework, structured family consultations and "psychosocial check-ups" can be implemented to consider the disease's progress. Family psychoeducation or support groups tailored to different cancer types and critical disease stages can assist families in navigating the journey with appropriate coping strategies.

Finally, a dyadic coping model has been proposed to investigate how patients and caregivers, engaging with each other, navigate everyday stress and significant life events, such as cancer (Falconier & Kuhn, 2019; Ștefănuț et al., 2023). Dyadic coping views stress as an interpersonal phenomenon, where one partner's stress influences their partner in a committed relationship. Grounded in the assumption of strong and

FAMILY SYSTEMS - ILLNESS MODEL

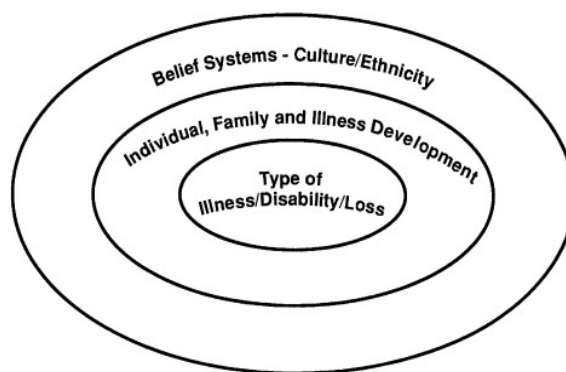


Figure 1. *The Family Systems Illness model. Adapted from Rolland JS. Families, illness, and disability: an integrative treatment model. New York: Basic Books, 1994.*

Time Phases of Illness Developmental Challenges^a

Crisis phase

1. Family members understand themselves in systems terms
2. Gain psychosocial understanding of illness
 - a) In practical and emotional terms
 - b) In longitudinal and developmental terms
3. Gain appreciation of developmental perspective (individual, family, illness life cycles)
4. Crisis reorganization
5. Create meaning that promotes family mastery and competence
6. View challenge of illness as a shared one in "We" terms
7. Accept permanence of illness/disability
8. Grieve loss of family identity before chronic disorder
9. Acknowledge possibilities of further loss while sustaining hope
10. Develop flexibility to ongoing psychosocial demands of illness
11. Learn to live with symptoms
12. Adapt to treatments and healthcare settings
13. Establish functional collaborative relationship with healthcare providers

Chronic phase

1. Maximize autonomy for all family members given constraints of illness
2. Balance connectedness and separateness
3. Minimize relationship skews
4. Mindfulness to possible impact on current and future phases of family and individual life cycles
5. Live with anticipatory loss and uncertainty
6. Balance open communication (vs. avoidance, denial) and proactive planning with need to live a "normal" life, keeping threatened loss in perspective

Terminal phase

1. Completing process of anticipatory grief and unresolved family issues
2. Support the terminally-ill member
3. Help survivors and dying member live as fully as possible with time remaining
4. Begin the family reorganization process

Figure 1. ^a Excerpted from Rolland JS. *Families, illness, and disability: an integrative treatment model*. New York: Basic Books, 1994.

frequent mutual influence across multiple domains, such as emotional experiences, dyadic coping approaches highlight the interdependence between partners (Bodemann et al., 2017). Traditionally, the study of stress and coping focused on the individual, considering the role of partner support in reducing stress without exploring reciprocal influences (Lazarus & Folkman, 1984). Over the last two decades, researchers shifted to view stressors as affecting both partners directly (e.g., facing the same stressor as financial problems) or indirectly (e.g., facing a stressor related to one partner's medical problem affecting the relationship and the other partner) (Falconier & Kuhn, 2019). Dyadic coping models emphasize how partners interact, communicate, and support each other during challenging times. These models build upon and systematically extend Lazarus and Folkman's transactional theory of stress (1984). Initial dyadic coping models include the congruence model (Revenson, 1994), the relationship-focused model (DeLongis & O'Brien, 1990; Coyne & Smith, 1991), the communal coping model (Lyons et al., 1998), and the systemic-transactional model (STM; Bodenmann, 1995, 1997; Bodenmann et al., 2016). The congruence model examines the interplay of both partners' individual coping efforts, emphasizing discrepancies between their coping strategies when facing a stressful event like a cancer diagnosis (Revenson, 1994). The relationship-focused model, based on Lazarus' transactional approach, explores the partner's contribution to the other's well-being, particularly in the context of couples coping with serious health problems (Coyne & Smith, 1991). The systemic-transactional model posits a bond between partners' stress experiences, coping efforts, and the outcomes of their stress management, indicating that one partner's stress influences both partners in a committed relationship (Bodenmann, 1995). These initial models have evolved to incorporate cultural and developmental aspects, resulting in the relational-cultural coping model (Kayser et al., 2007; Kayser & Revenson, 2016) and the developmental-contextual coping model (Berg & Upchurch, 2007). The relational-cultural coping model analyzes the couple's coping process, proposing a circular coping pattern that repeats through each phase of the cancer experience (diagnosis, treatment, and end of treatment) (Kayser, 2008). At the core of the figure are three relational qualities (relationship awareness, authenticity, and reciprocity) that facilitate the transition between stages, shaping couples' coping patterns. Two distinct patterns identified by Kayser (2008) are reciprocal responsiveness and disengaged avoidance. Couples with mutual responsiveness view cancer as a stressor affecting both partners, reinforcing the concept of cancer as a "we-disease." Expressing stress triggers a process of stress communication, leading to emotional responses and the use of various coping strategies (see Fig. 3).

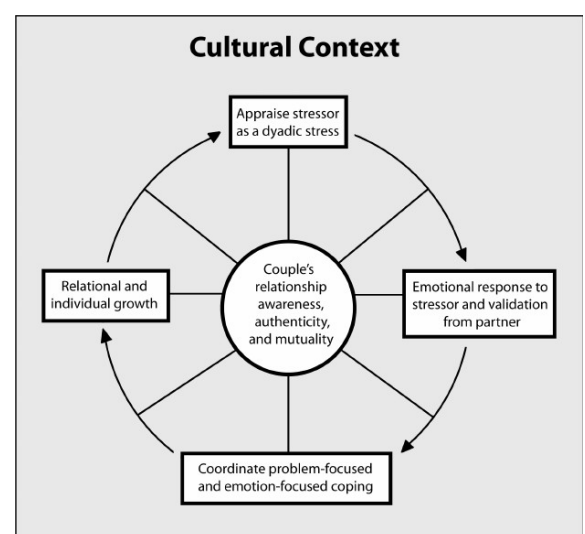


Figure 2. Relational-cultural coping model. (Copyright © 2007 by the American Psychological Association. Reprinted with permission from Kayser et al., (2007))

The developmental-contextual coping model, introduced by Berg and Upchurch (2007), shares theoretical affinity with the Systemic-Transactional Model (STM) proposed by Bodenmann (2005). This model contextualizes the coping process within a developmental and historical framework, considering distinct stages of dealing with disease across the lifespan (e.g., young couples, middle-aged couples, couples in late adulthood) and historical periods. Dyadic coping is influenced by these factors, particularly the disease stage, as well as sociocultural aspects, gender, marital quality, illness ownership, and illness severity (refer to Fig. 4). This model primarily focuses on the partner's responses, placing them on a continuum ranging from under-involvement to over-involvement. Uninvolved coping entails the perception that one's partner provides no support in dealing with stress. Supportive coping, on the other hand, involves the perception that the partner is offering emotional and/or instrumental support.

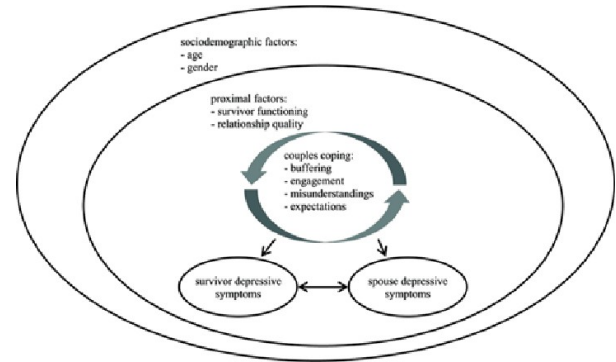


Figure 3. Adapted developmental-contextual model of coping. Source: Berg & Upchurch, 2007.

Collaborative coping characterizes joint efforts by both partners to navigate the stressful situation together. Controlling coping denotes instances where the non-stressed partner "dominates the actions of the other spouse by taking charge and telling the other person what to do".

In general, dyadic coping models recognize that stressors affecting one partner can also impact the other, and that the ways partners respond to and cope with stress can influence the well-being of both individuals and the relationship (Acquati & Kayser, 2019; Badr et al., 2010; Rusu et al., 2020; van Roij et al., 2022). The concept of dyadic coping encompasses various aspects of how couples navigate stress together, including: to provide emotional support, empathy, and understanding to each other (e.g., active listening, express affection, and validate each other's feelings); to collaborate to identify solutions and strategies to address the stressor (e.g., brainstorm ideas, make plans, and work together to implement practical steps); to feel comfortable discussing their stressors, concerns and needs in an open and honest communication, that helps prevent misunderstandings and promotes decision-making (DM); to recognize the potential effects of stress on both individuals and the relationship; to be interconnected and to recognize that one partner's coping responses can influence the other's stress levels and coping strategies (Acquati & Kayser, 2019; Falconier & Kuhn, 2019; Rusu et al., 2020). Research on dyadic coping models has highlighted their importance in predicting relationship satisfaction, adjustment to stressors, and overall relationship quality (Rusu et al., 2020). Dyads who engage in effective dyadic coping tend to experience lower levels of stress, better psychological well-being, and greater relationship satisfaction compared to those who do not (Falconier & Kuhn, 2019; Rusu et al., 2020). In the oncological setting, facing the cancer diagnosis and its subsequent treatment as a unit is a

protective factor for the quality of the dyadic relationship between patient and caregiver (Acquati & Kayser, 2019).

In conclusion, it has been shown how cancer patients and their caregivers can be conceptualized as a unit of care (Coyne et al., 2020) or, if characteristic patterns of social interactions over time are emphasized, they can be referred to as a dyad (Becker & Useem, 1942). Following dyad theoretical models, it is crucial to focus on the mutual influence dyad members have on QoL, psychological health, and relationship functioning when facing a life stressor such as cancer diagnosis (Coyne et al., 2020; Ferraris et al., 2022; Revenson et al., 2016; Sherman, 2019; Ștefănuț et al., 2023; Trevino et al., 2019).

2.2. Caregiving and Decision Making in cancer care.

The process by which people decide among available alternatives is called the Decision Making (DM) (Edwards, 1954; Thokala et al., 2016). The DM is a cognitive process that people use to make reasoning, based on assumptions of values, preferences, and beliefs of the decision-maker, to produce a final choice (Hall, 2008; Nyatanga et al., 2008; Van den Brink et al., 2019). There are different styles of DM, some people systematically weigh all the options available before deciding, others act instinctively, and still others allow themselves to be influenced by others thinking, setting aside, sometimes totally, their own will. However, there are also people who tend to avoid decisions (Parker et al., 2007; Petrocchi et al., 2022). When individuals have to decide, various factors influence their DM process, some are intrinsic to individuals (e.g., cognitive, psychological, emotional factors), others are extrinsic to the individual and depend on the situation (e.g., perception of risk and uncertainty) (Gorini & Pravettoni, 2011a). To avoid cognitive burden in complex DM, individuals often use simplifying cognitive strategies, called heuristics. These mental shortcuts reduce the time and effort that would otherwise be required to make reasonably good decisions. However, the use of heuristics, in some cases, leads to systematic cognitive errors, called biases. Heuristics and biases greatly influence DM and have been well documented in the context of all medical disciplines (Gorini & Pravettoni, 2011a). Moreover, DM plays a significant role daily by affecting everyday activities; many studies have focused on understanding DM processes by assessing why people choose one option instead of another in a set of alternatives (Nordin et al., 2021). Even in the oncological setting, the DM process has been widely explored along the cancer continuum (prevention, screening, diagnosis, treatment, survivorship, and end of life) (Cincidda, Oliveri, et al., 2022; Russo et al., 2020).

Over the past decades, there has been a shift from a paternalistic approach (the patient is a passive recipient of all the decisions) to a patient-centered paradigm (the patient is an active participant of care) that allows patients to be actively involved in the so-called shared decision-making process (SDM) along their

clinical pathway (Arnaboldi et al., 2020; Lamore et al., 2017; Pravettoni et al., 2016). The paternalistic approach is characterized by an unbalanced role between healthcare professionals and patients, where the principle of patient's autonomy and beneficence are often in conflict. Physicians who use a paternalistic approach, even if they act in the patient's best interest, do not consider the patient's point of view, preferences, wishes and desires (Gorini & Pravettoni, 2011a). To date, the principle of autonomy, according to which individuals have the right to decide by themselves and exercise self-determination regarding their own health, is the cornerstone of contemporary medical ethics (Dove et al., 2017; Gómez-Vírseda et al., 2020; Grignoli et al., 2018). Accordingly, in medical decisions it is suggested to promote the SDM among patients and physicians (Chichua et al., 2022; Kashaf & McGill, 2015; Maes-Carballo et al., 2021; Malhotra et al., 2020; Politi et al., 2012; Steffensen et al., 2018; Turcotte et al., 2019). Thanks to the SDM, the imbalance between healthcare professionals and patients should have been restored. Indeed, this approach enhances patients' individual preferences, needs, and values, which in turn, guides all clinical decisions (Marton et al., 2021; Russo et al., 2020). In the SDM, treatment decisions are taken in a collaborative way between patients and physicians with a bidirectional exchange of information and with patients playing a major role in decisions (Covvey et al., 2019; Malhotra et al., 2020; Renzi et al., 2016). Decision about cancer treatment results in a dynamic process in which patients and physicians discuss and evaluate the alternatives together until a decision is reached in agreement and patient's autonomy is maintained (Gorini & Pravettoni, 2011a; Lamore et al., 2017).

To promote patients' engagement, patients have to be informed about the uncertainty of treatments outcomes, in order to allow them to evaluate all the risk and benefits associated with treatment options and feel free to express their preferences and concerns (Grignoli et al., 2018). However, this does not imply setting aside the physicians' knowledge and preferences, but it is an interactive process between the two to decide the best option for the patient considering the concept of non-maleficence (Covvey et al., 2019; Gorini & Pravettoni, 2011a). To implement the SDM, there must be mutual trust and good effective communication between patient and health professional. In addition, it is essential to literate the general population about health-related behaviors (Covvey et al., 2019). In the oncological setting, people take different kind of decisions. When the priority is prevention, decisions are related to lifestyle, such as stop tobacco or alcohol consumption, sedentary life, etc., to maintain health status. Moreover, people can decide whether to undergo screening offered by the health care system or check their health status annually (e.g., routine blood tests) (Reyna et al., 2015). When a patient receives a cancer diagnosis, treatment options are discussed and patients are involved in cancer care decisions (Covvey et al., 2019; Turcotte et al., 2019). Often, such decisions are related to the long-term and delayed effects of treatment, such as the effect of chemotherapy on fertility, leading patients to consider procedures for fertility preservation (Reyna et al., 2015). The end-of-life is the worst period for cancer patients and decisions are burdensome: to pursue palliative or life-sustaining goals, the

place where to spend the last days, and other aspect surrounding the theme of death (Reyna et al., 2015). Recent literature showed that patients' involvement in SDM is associated with lower level of symptom distress, illness concern and psychological distress, higher satisfaction with physician, treatment decisions and care received and higher level of compliance (Gorini & Pravettoni, 2011a; Lamore et al., 2017). However, sometimes patients may experience decision conflict, that is a sense of uncertainty about what action to take (Manne et al., 2016). They may experience this state of uncertainty due to poor or no information about alternatives, benefits, and risks, lack of clarity with respect to personal values, emotional distress, perceived lack of support in making a choice or perceived pressure to choose a particular course of action (François et al., 2017; Manne et al., 2016).

Following a dyadic perspective, patients are defined by their relationship and depend on “significant others” to make decisions (Cincidda, Oliveri, et al., 2022; Del Piccolo et al., 2014; Gómez-Virseda et al., 2020; Laidsaar-Powell et al., 2016). Indeed, quite often, patients are accompanied by their caregivers during the visits to be supported in the interaction and communication with the oncologists (Lamore et al., 2017; Schumm et al., 2010). Caregivers may help patients understand information on the disease and its consequences, prescribed therapies and expected outcomes, side effects, and the best way to control them. They collaborate with healthcare professionals to understand the complexities of the disease and help the patient make informed decisions about their care (Keast et al., 2020). Providing emotional support, caregiver help patients navigate through their feelings and concerns related to the cancer diagnosis and prognosis (Laidsaar-Powell et al., 2017; Longacre, Miller, et al., 2018; Petrocchi et al., 2022). By participating in medical visits, caregivers can be involved in SDM by patients, stating their opinions, preferences, and beliefs on the treatment decisions (Dionne-Odom et al., 2019; Laidsaar-Powell et al., 2017; Trevino et al., 2019; Tulskey et al., 2022; Ullrich et al., 2020). By doing this, caregivers may assist the patient in evaluating different treatment options through a discussion of potential benefits, risks, and expected outcomes of each choice. They may help patients consider factors such as treatment effectiveness, side effects, and impact on daily life. Moreover, caregivers themselves may feel entitled to influence patients' decisions; they also inevitably bring a series of emotional reactions, interpersonal dynamics, and expectations (Blackler, 2016; Hobbs et al., 2015; Laryionava et al., 2021; Meeker & Jezewski, 2005; Reiter-Theil, 2003; Schäfer et al., 2006; Ullrich et al., 2020). However, not always caregivers contribute to the decision, letting the patient and the oncologist make the decision, and sometimes caregiver makes the decision instead of the patient (Cincidda, Oliveri, et al., 2022; Petrocchi et al., 2022). The level of involvement of the caregiver in the DM may be influenced by demographic characteristics, quality of the dyadic relationship, and disease-related factors (Petrocchi et al., 2022). Finally, the DM process is full of uncertainty and anxiety both for the patients and the caregivers (Temel et al., 2008). Caregiver involvement in the oncological examinations was associated with increased patient satisfaction with care, understanding of cancer-related information, treatment adherence, physical and

mental health (DuBenske, Chih, et al., 2010; DuBenske, Gustafson, et al., 2010; Hobbs et al., 2015; Joosten et al., 2008). Caregivers may influence patient decisions regarding medical treatments, bringing with them a range of emotional reactions, interpersonal dynamics, and expectations (Hobbs et al., 2015; Laidsaar-Powell et al., 2016, 2017; Laidsaar-Powell et al., 2013; Longacre, Applebaum, et al., 2018; Longacre, Miller, et al., 2018; Veenstra et al., 2019). However, as a downside, higher caregivers' involvement in DM was also associated with higher caregiver burden and psychological distress (Ozdemir et al., 2023). For this reason, the healthcare system should also provide support for caregivers, so that they can support patient's DM in a meaningful way.

Considerations and an expanding body of empirical literature underscore the significant role of family caregivers in medical decision-making (DM), marking a shift from the traditional patient-physician interaction to a triadic relationship involving the patient, caregiver, and physician (LeBlanc et al., 2018; Mitnick et al., 2010; Renzi et al., 2016). The extent of family caregiver involvement in DM spans a spectrum from passive to dominant, and contextual factors such as the patient's age, gender, health status, cultural background, and relationship with the caregiver can influence the form and extent of involvement. Despite the growing empirical evidence, there remains a limited conceptual description of family caregiver involvement in DM. Some authors have recently expanded dyadic DM to include family caregivers, grounding their models on the idea that decisions are embedded within and shaped by social interactions (Rapley, 19; Epstein & Street, 20; Elwyn et al., 21). The Interprofessional Shared DM model (IP-SDM) emphasizes the involvement of many members of the inter-professional team as well as family caregivers in treatment DM (Légaré et al., 2011). Additionally, two triadic process models (Dalton 2003; Wolff & Roter, 2011) propose how triadic interactions and patient outcomes (e.g., satisfaction, knowledge, and adherence) are influenced by factors such as patient/family/clinician personality, knowledge, and attitudes. However, the most comprehensive model explaining triadic involvement in DM was proposed by Laidsaar-Powell and colleagues (2001). Known as the TRiadic Interactions in Oncology or TRIO Framework, it focuses on the common scenario of one cognitively competent adult cancer patient, one key clinician, and one key adult family caregiver. The TRIO Framework is built on six key concepts: family caregiver influence over a decision varies among different groups, family caregiver influence varies within the triad over time, family caregivers are involved in various ways in the broader DM process, DM is not confined to three individuals but can occur within wider social networks, numerous factors may affect the form and extent of family caregiver involvement in DM, and family caregiver influence in DM is linked to their

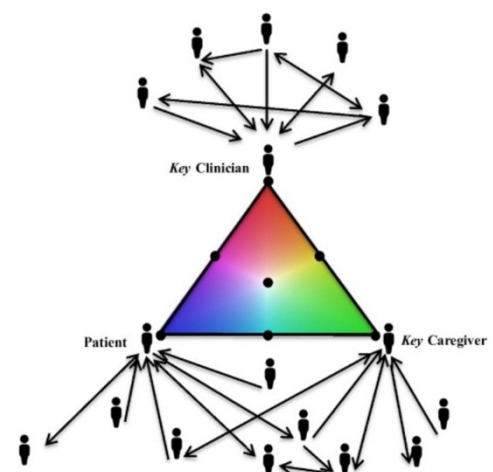


Figure 5. A hypothetical social network involved in a medical decision. Adapted from Laidsaar-Powell, R., et al., (2017).

everyday involvement in illness care and management. The model is visually represented with a triangle, emphasizing the triadic relationship (see Fig. 5).

From an ethical standpoint, it seems necessary to incorporate an interpretation of autonomy as a relational principle, namely “relational autonomy” (Baumann, 2008; Cranley et al., 2020; Gómez-Vírseda et al., 2020; Grignoli et al., 2018; Lolich & Lynch, 2017; Mackenzie & Stoljar, 2000; Wilson et al., 2014). In recent decades, the concept of autonomy has been widely criticized from various theoretical perspectives. These critiques have resulted in important philosophical works and ethical studies that have led to a reconceptualization of autonomy in relational terms (Dove et al., 2017; Gómez-Vírseda et al., 2019, 2020). A recent review of the literature found that relational autonomy, linking to a variety of ethical approaches, cannot be characterized exclusively by a single approach (Gómez-Vírseda et al., 2019). However, the concept of relational autonomy finds great acceptance in SDM, which involves not only patient and physician but also includes caregivers when necessary (Gómez-Vírseda et al., 2019; Grignoli et al., 2018). Grignoli and colleagues (2018) argued that relational autonomy constitutes the philosophical foundation of SDM. Human beings are relational beings, whose identity and interests are shaped by ties with others. Within relationships we develop a sense of identity and the ability to exercise self-determination. To some extent we are defined by our relationships (Dove et al., 2017). This concept is in line with the Interdependence Theory proposed in the previous chapter.

Recently clinicians are moving towards family-centered models of care and the need to develop a new line of research on dyadic DM in the oncological domain, considering the relationship between patients and caregivers (Krieger, 2014; Petrocchi et al., 2022), and more widely between patients, caregivers, and physicians (Laisaar-Powell et al., 2017). Ethics and bioethics have also addressed family caregiver involvement in SDM, with some authors arguing the importance of maintaining individual patient autonomy and leaving caregivers as only supporter (Blustein, 1993; Mitnick et al., 2010), and other authors highlighting the importance of caregivers’ role in the DM process (Ho, 2008; Levine & Zuckerman, 2000), since they are often affected by the treatment decision itself.

2.2.1. The importance of agreement/disagreement among dyads.

The stress of dealing with cancer can sometimes lead to strained relationships within the family. Indeed, social relations in the context of cancer and its treatment trajectory have proven to be not only supportive, but also conflictual and stressful (Hansen & Tjørnhøj-Thomsen, 2020). In other words, the presence of the caregiver may be both a facilitator and a barrier to the DM process (Blackler, 2016; Cincidda, Oliveri, et al., 2022). Patients and caregivers may have different perspectives on reporting symptom, evaluate

treatment choices, describe treatment side effects and benefits, and estimate prognosis, experiencing episodes of mutual conflicts or tensions (Benson et al., 2019a; Hansen et al., 2020; Loh et al., 2021; Longacre et al., 2018; Shin et al., 2016). In literature, it was found that many dyads disagree on whether the patient will live longer than 2 years or recover (Loh et al., 2021; Shin et al., 2016, 2018; Trevino et al., 2019). At the end of life, disagreement sometimes also arises over who should lead the DM process about routine treatment, discontinuation of therapeutic treatment, and activation of hospice care, leading dyads to experience high DM conflict over care (Longacre, Applebaum, et al., 2018; Longacre, Miller, et al., 2018). Moreover, patients (and/or their caregiver) may have to choose over life-prolonging treatment, the “do not to resuscitate” (DNR) option, palliative sedation, medically assisted nutrition and hydration. In addition to such sensitive decisions, there are a range of more practical and organizational choices to be made: on the preferred place of death, burial indications, funeral arrangements, etc. Such aspects may generate additional stress and conflicts and can be experienced as stressful and burdensome not only by patients, but also by caregivers (Ullrich et al., 2020). Sometimes, conflicts arise because of a difficulty patients and caregivers find in talking openly to each other, experiencing several dilemmas. Finally, dyads often disagree about concerns, in particular, patients are mainly concerned about the lack of energy, while caregivers worry about cancer in general (Martinez et al., 2020).

Disagreements may incur depending on personal resources (cognitive abilities, personality characteristics and interpersonal resources/quality of relationship) or to sociodemographic characteristics (e.g., age, gender, education level) or to symptoms of the disease (Longacre, Miller, et al., 2018; Tuca et al., 2021). Sometimes conflicts may have an ethical nature, so the various alternatives have different moral content, or simply people involved in the decision have different moral values, or moral discrepancies, or goals related to care and outcomes (Pavlish et al., 2014; Tuca et al., 2021; Ullrich et al., 2020). Such disagreement may negatively affect patient’s understanding of medical information, compliance with therapies and patient-caregiver’s QoL (Benson et al., 2019; François et al., 2017; Hamano et al., 2018; Hopeck & Harrison, 2017; Loh et al., 2021; Shin et al., 2016). Poor disease-related communication between cancer patients and caregivers could increase the levels of psychological distress for both parties, making the course of treatment more complex (Speice et al., 2000). On the contrary, open communication between patients and caregivers is essential to navigating these challenges and resolve disagreements as a dyad (Li et al., 2020).

Establishing constructive and open communication within the dyad can reduce caregiver burden, promote relational intimacy, and enhance dyad’s physical and mental health (Li et al., 2020). Both parties should try; 1) to understand each other's perspectives and emotions; 2) to actively and respectfully listen to each other's concerns and fears; 3) to engage in SDM; 4) to involve a healthcare professional or psychologist to provide neutral guidance; 5) to recognize the importance of mutual support.

Being on the same team can strengthen the patient-caregiver relationship, regulating coping strategies, and reduce or manage family tensions (Li et al., 2020). This leads to the need of a personalized approach, sometimes a family approach in the oncology setting. However, conflicts within a family may be somehow considered as a natural phenomenon that not necessarily ends up in a disruptive event. On the contrary, if generator of mutual dialogue and perceived as solvable, family conflict may also turn into something positive (Benson et al., 2019; Laryionava et al., 2018).

However, the literature has also addressed the level of agreement between patients and caregivers about their self-assessments of symptoms and QoL, psychological and spiritual concerns, and treatment goals (Higginson & Gao, 2008). Psychological agreement in oncology refers to the alignment of perceptions, understanding, and emotions between patients and caregivers regarding the psychological aspects of cancer care. It involves a mutual understanding of the patient's emotional well-being, coping mechanisms, and the importance of addressing psychological and emotional needs throughout the cancer journey. Psychological agreement plays a crucial role in fostering a supportive and empathetic environment, promoting effective communication, and enhancing the overall patient experience in oncology (Li et al., 2020). Dyads typically agree on the primary goal of achieving and maintaining the patient's health and well-being throughout the cancer journey, on the importance of supportive care (e.g., managing symptoms, pain relief, and emotional support, to enhance the patient's quality of life) and of having a competent and compassionate medical team that provides effective treatment and support (Coyne et al., 2020; Li et al., 2020). They also agree to engage in SDM regarding treatment options and care plans (Dionne-Odom et al., 2023; Rostoft et al., 2021). This collaborative approach allows both parties to contribute their perspectives and preferences, leading to treatment decisions that align with the patient's values and goals. When patients and their caregivers are in line with the decisions to be made and their preferences are met, the process of care is enhanced for all the parties involved (Joosten et al., 2008; Speice et al., 2000; Tulskey et al., 2022). Finally, agreement among patients and their caregivers on the decisions to be made may reduce patient's "decision regret" while improving adherence to care process (Calderon et al., 2019; Wilson et al., 2017).

In conclusion, although the gold standard in medical decisions has become the SDM among patients and physicians (Chichua et al., 2022; Kashaf & McGill, 2015; Maes-Carballo et al., 2021; Malhotra et al., 2020; Politi et al., 2012; Steffensen et al., 2018; Turcotte et al., 2019), we can argue the importance of expanding the model by including caregiver in the SDM (e.g., family-centered models of care) (Krieger, 2014; Laidsaar-Powell et al., 2017; Petrocchi et al., 2022). Define a good intervention to foster the agreement between patients and caregivers could be useful to improve patient's cancer care pathway, reduce caregiver's burden, and design effective dyadic psychological intervention. Nevertheless, to date it remains quite unclear how much patients and caregivers require their mutual involvement in the DM process, especially in the early stages of the disease (diagnosis).

2.3. Caregiving and Decision-Making in breast and prostate cancer setting.

Breast cancer, which predominantly affects women, and prostate cancer, which affects men, are two types of cancer involving families, especially spouses, in all challenges linked with diagnosis and the treatment process (Kim & Given, 2008; Northouse et al., 2007; Segrin & Badger, 2010).

Breast cancer (BC) is the most diagnosed cancer globally, accounting for a quarter of all cancer cases in women (Arnold et al., 2022; Chow et al., 2020; Fasse et al., 2017; Waks & Winer, 2019). BC is the fifth-leading cause of cancer mortality worldwide and the second most common cause of mortality, morbidity, and associated disability in women (Krok et al., 2023; Obrero-Gaitán et al., 2022). Thanks to the implementation of national screening policies, advances in the diagnosis and treatment, the number of BC survivors has been increased in the last decades (Di Giacomo et al., 2019; Obrero-Gaitán et al., 2022; Segrin et al., 2020). There are 3 main subtypes of BC: hormone receptor positive/negative for ERBB2 (most of the patients), ERBB2 positive (a small percentage of patients) and triple negative (a small percentage of patients). Almost all BCs are not metastatic at the time of diagnosis, so therapeutic goals are often tumor eradication and prevention of recurrence (Waks & Winer, 2019). When a patient receives the bad news of a BC diagnosis, a multitude of emotional reactions, including anger, fear, and a sense of guilt, are frequent and can take the form of anxious symptoms (agitation, concentration difficulties) and/or depressive symptoms (apathy, low mood tone) (Di Giacomo et al., 2019; Obrero-Gaitán et al., 2022; Saita et al., 2016, 2022). These negative feelings may impact patients' daily life (e.g., social relationships, intimacy in couples, and work life) (Obrero-Gaitán et al., 2022; Saita et al., 2022). Patients make treatment decisions, such as surgery options (e.g., mastectomy or lumpectomy) and reconstructive surgery, chemotherapy (CT), radiation therapy (RT), and hormonal therapies (HT) (Fasse et al., 2017; Waks & Winer, 2019). At early stages of disease conservative interventions, such as quadrantectomy and, where possible, mastectomy with skin and nipple preservation and breast reconstruction (BR) are preferred (Manne et al., 2016). The surgery, which preserves the aesthetic appearance of the breasts, seeks to overcome the negative emotional reactions that patients experience following breast loss (Manne et al., 2016). Surgery and other cancer treatments may impact perceived femininity (Ganz, 2008), body image, sexuality, or attractiveness, causing difficulties and uncertainty in planning the future, and also changes to the social role or adjustment in family roles (Dorros et al., 2010; Manne et al., 2004; Manne et al., 2016). For that reason, most of the patients decide to undergo BR, that can be performed immediately at the time of the mastectomy or as a second surgery (Manne et al., 2016). BC patients' body image is compromised by irreversible (e.g., scarring/amputations) or temporary (e.g., hair loss, weight, and hormonal fluctuations) changes in appearance (Saita et al., 2022). Sometimes treatments might also have significant side effects, such as pain and body image concern, which can affect cancer recovery, QoL, and long-term survival (Manne et al., 2016; Obrero-Gaitán et al., 2022; Saita et al., 2022; Segrin et al., 2005; Segrin & Badger, 2010). BC patients

may also experience stress and conflict participating in the SDM regarding treatments (Kokufu, 2012). However, being involved in the SDM seems to promote the acceptance of the disease and to be effective in adapting to pain and changes in disease conditions accompanied by treatment (Kokufu, 2012).

Regarding prostate cancer (PC), in 2020, worldwide, it is estimated to account for 7% of all cancers, although survival rates are very high (Varner et al., 2019; Yiannopoulou et al., 2020). Indeed, with early diagnosis of PC, it is increasingly being diagnosed at an early stage with more favorable survival outcomes, leading PC to be treated as a chronic disease (Maggi et al., 2019). The diagnosis of PC is made using the prostate-specific antigen test (PSA) and subsequent biopsy (Yiannopoulou et al., 2020). To date, there are several treatments for localized PC: radical prostatectomy (RP), external beam radiation therapy (EBRT), and active surveillance (AS) (Maggi et al., 2019; Scherr et al., 2022; Yiannopoulou et al., 2020). The active treatments have significant and potential side effects affecting urinary, sexual, hormonal, and bowel function (e.g., erectile dysfunction, reduced libido), affecting their QoL, body image and self-esteem (Ilie et al., 2023; Maggi et al., 2019; Northouse et al., 2007). These aspects can have further negative psychological implications, causing anxiety, depression, fatigue, stress, pain, and FCR (Cincidda, Oliveri, et al., 2022; Cincidda, Pizzoli, et al., 2022; De Sousa et al., 2012; Muzzatti et al., 2020; Yiannopoulou et al., 2020). Specifically, the sexual challenges, that PC patients may face, can impact a patient's intimate relationships and lead to feelings of frustration and loss of self-confidence (Varner et al., 2019). Changes in body image and self-esteem may result from these. On the other hand, AS allows patients with low-risk PC to avoid active treatment and thus the associated adverse effects (Ruane-McAteer et al., 2017; Yiannopoulou et al., 2020), but they undergo PSA testing and digital rectal examinations at regular intervals and annual/biannual biopsies (Ruane-McAteer et al., 2017; Yiannopoulou et al., 2020). Even patients under the AS reported high level of anxiety and depression, although they did not have the side effect of an active treatment (Ruane-McAteer 2019). The complexity of available treatment options and the potential consequences of these decisions can lead to DM anxiety; thus, it would be appropriate to provide precise information on the possible effect of treatment on the psychological variables (Yiannopoulou et al., 2020). In both cases, the best treatment for each patient depends on both medical factors and personal assessment of the risks and benefits of each choice. Finally, patients worry about treatment outcomes, potential side effects, and the impact of cancer on their overall health and QoL (Maggi et al., 2019; Yiannopoulou et al., 2020). Increased psychological distress affects treatment outcomes and men's likelihood to continue follow-up (Maggi et al., 2019; Yiannopoulou et al., 2020). It is essential to address these psychological implications and provide comprehensive support to PC patients. Psychotherapy, counseling, support groups, and other psychosocial interventions can be beneficial in helping patients cope with the emotional challenges. Following a RP or RT, patients and caregivers may experience distress and adjustment issues, and sometimes caregivers reported higher level of distress than the patients (Varner et al., 2019).

Summarizing, BC and PC diagnoses affect dyadic relationships, and in particular intimacy, dyadic communication about feelings, family management, and personal expectations about life (Di Giacomo et al., 2019; Obrero-Gaitán et al., 2022). Recent research showed a reciprocal psychological influence between patients and caregivers after breast and prostate cancer diagnosis, reporting that highly distressed patients have highly distressed caregivers, as supported by the Interdependence Theory (Varner et al., 2019; Yan et al., 2021). In such circumstances of crisis, the dyads co-create and share coping strategies to respond to the stressful event (Acquati & Kayser, 2019; Meier et al., 2019). Patient and caregiver individual coping styles may have a mutual positive or negative impact on QoL and psychological status (Acquati & Kayser, 2019; Chen et al., 2021). The common coping strategies used by dyads in this context are shared information seeking and SDM, exchanging worries, and efforts to manage their emotional reactions (Chen et al., 2021; Meier et al., 2019). However, patients and caregiver may disagree in the adoption of coping strategies, and this can have negative effects on QoL (Meier et al., 2019).

Summarizing in BC and PC treatment decision, cancer-related symptoms and treatment side effects primarily impact the intimacy of the dyads (Fasse et al., 2017; Gray et al., 1999; Schumm et al., 2010). In such condition dyads require open communication, mutual understanding, and emotional support. Caregivers must balance their own well-being while providing care, and it's essential for healthcare professionals to acknowledge the dyadic needs and promote interventions aimed at improving overall well-being and QoL for both parties.

2.4. Conclusion

To summarize, cancer can be considered a family disease, having an impact both on the patient and the caregiver, who can be conceptualized as a dyad (Kayser et al., 2007; Minuchin, 2018; Petrocchi et al., 2022; Ștefănuț et al., 2023). Indeed, following a cancer diagnosis, dyads have to “rethink their life” and to find a new psychological homeostasis, experiencing a roller coaster of emotions (Johnson & Ross, 2023; Petrocchi et al., 2022; Woźniak & Iżycki, 2014). A family member assumes the role of caregiver, who provides practical/physical, emotional, and psychosocial support (Laryionava et al., 2018, 2021; Litzelman, 2019). Through family theories, the Interdependence Theory and dyadic coping models, the theoretical basis has been provided to assess and explore the impact of cancer on the patient-caregivers’ dyad and the interdependence of dyadic members, including in DM (Coyne et al., 2020; Ștefănuț et al., 2023). Such considerations suggest that the best practice in medical DM may be a triadic relationship (patient, caregiver, and physician) (LeBlanc et al., 2018; Mitnick et al., 2010; Renzi et al., 2016). Caregiver involvement in the oncological examinations and DM is a protective factor for patient satisfaction with care, understanding of cancer-related information, treatment adherence, and physical and mental health, when patients and caregiver agree (DuBenske, Chih, et

al., 2010; DuBenske, Gustafson, et al., 2010; Hobbs et al., 2015; Joosten et al., 2008). BC and PC are two types of cancer involving families and especially spouses in challenges linked with diagnosis and the treatment process (Kim & Given, 2008; Northouse et al., 2007; Segrin & Badger, 2010). Indeed, both cancers have an impact on the intimate and sexual sphere that can have negative implications for the dyads, who has to make specific treatment decisions. A particular dyadic DM style can lead to better cancer self-management, higher quality of life, less stress, and better adherence to the medical regimen. Although caregivers' involvement in the SDM and clinical pathways of cancer patients is associated to better psychological outcome of the patients, little is known about the alignment between patients and caregivers regarding the SDM. Only Krieger (2014) proposed that aligned patient-caregiver preferences for the extent of caregiver involvement in DM are preferable (Krieger, 2014).

The present Ph.D. project aimed to assess the relevance of the caregivers' involvement in the SDM and the impact of a cancer diagnosis on the dyad. In addition, a special attention was focused on dyad agreement on treatment decisions from both psychological and bioethical perspectives to explore the impact on the psychological well-being of breast and prostate cancer patients.

3. Exploring caregiver's role in the clinical pathways of Breast and Prostate cancer patients

The first four studies involved in the present thesis focused on the caregivers' involvement in the SDM of patients with a newly diagnosis of BC and PC. Firstly, a systematic review was conducted to assess the preferences of BC and PC patients and their caregivers in the SDM (Cincidda et al., 2023). Then, starting from the results obtained, we decided to structure a research protocol aimed at exploring over a period the impact of a new diagnosis of BC or PC on the patient-caregiver dyad, their mutual influence and alignment in TDM (Cincidda et al., 2023). Specifically, a pilot study was conducted on dyads with PC and a longitudinal study on dyads with BC. Finally, a qualitative evaluation of psychological interview aimed at exploring dyadic dynamics was presented.

3.1. Study 1: A systematic review on Caregiving and Shared Decision Making in Breast and Prostate Cancer Patients

As discussed in more detail earlier in the previous chapter, caregivers play an important role in cancer care (Li et al., 2020; Petrocchi et al., 2022; Ștefănuț et al., 2023). They provide emotional support, such as listening to patients' concerns and needs, and practical support, such as accompanying them to medical appointments, helping with daily routines such as taking their medications, and often participating in decisions about treatment options (Karimi Moghaddam et al., 2023; Laryionava et al., 2018, 2021; Litzelman, 2019; Molassiotis & Wang, 2022). In this way, caregivers can help patients understand medical information and sometimes make treatment decisions (Laidsaar-Powell et al., 2017; Longacre, Miller, et al., 2018; Petrocchi et al., 2022). The DM process can be emotionally exhausting for both patients and caregivers, with a range of emotional reactions and expectations (Hobbs et al., 2015; Laryionava et al., 2021; Ullrich et al., 2020). A collaborative relationship within the dyad allows members to freely express their views and preferences, leading to SDM and improved treatment pathways (Joosten et al., 2008; Krieger, 2014; Tulskey et al., 2022). Indeed, when dyads agree on treatment, patients are less likely to regret decisions (Calderon et al., 2019; Ozdemir et al., 2023; Wilson et al., 2017). However, caregivers heavily involved in DM experienced high levels of burden and psychological distress (Ozdemir et al., 2023).

BC and PC are the most common diseases in women and men respectively, affecting the domains of intimacy and fertility (Di Giacomo et al., 2019; Ilie et al., 2023; Obrero-Gaitán et al., 2022; Varner et al., 2019). Therefore, BC and PC can have a direct impact on family caregivers to the extent that their decisions also affect them (Krok et al., 2023; Meier et al., 2019; Segrin & Badger, 2010; Stenberg et al., 2010). Indeed, these diagnoses can disrupt dyadic relationships, communication, family management and personal life expectations (Di Giacomo et al., 2019; Obrero-Gaitán et al., 2022). Adopting an effective communication style between dyads can lead to a new balance in family functioning (Yan et al., 2021). The way patients cope and react to cancer can influence the way caregivers cope and react and vice versa (Acquati & Kayser, 2019; Chen et al., 2021; Varner et al., 2019; Yan et al., 2021).

To date, several articles have provided a comprehensive overview of the role of caregivers in cancer care, but none have comprehensively addressed the involvement of caregivers in the DM process related to the treatment of newly diagnosed BC or PC patients. Systematic reviews that have already been published include caregiver engagement and support in palliative care or for elderly patients who need practical support from caregivers in their care and treatment, or psychological interventions aimed at improving three-way communication between patient, caregiver and physician, with no studies on their effectiveness (Dijkman et al., 2022; Hopkinson et al., 2012; Kraun et al., 2022; Laidsaar-Powell et al., 2013; Mulcahy Symmons et al., 2022; Northouse et al., 2010; Tulskey et al., 2022). To fill this gap in the literature, a systematic review of the psychology literature was conducted to assess the association between caregiver involvement in SDM and BC and PC patients.

3.1.1. Material and methods

Electronic searches were conducted using three main databases: MEDLINE PubMed, Embase, and PsycINFO, between August and November 2020 with no time limit for study updates. The systematic review was conducted according to PRISMA guidelines (Page et al., 2021). Original articles were in English, Italian, or Spanish and included participants aged 18 years or older. Key words searched for in titles and abstracts included terms such as DM processes, cancer treatment, PC, and BC, as well as caregiver involvement and caregiver-patient interaction. Relevant systematic reviews literature was manually searched for additional contributions that met the inclusion criteria, even if they did not focus on our topic. The reference lists of the included literature were also checked to identify additional relevant articles. The search was restricted to full-text articles. A comprehensive list of search terms was developed due to the diversity of keywords in this field (see Table 1).

Table 1. Database search terms

("role" OR "experience" OR "involvement") AND ("decision making" OR "choices" OR "decisions") AND ("caregiver" OR "partner" OR "family member" OR "spouse" OR "carer" OR "relative") AND ("cancer" OR "neoplasm") AND ("breast" OR "prostate") AND ("adult" OR "middle age" OR "very elderly" OR "young adult") AND ("English" OR "Italian" OR "Spanish")

Inclusion and Exclusion Criteria

Literature reviews, commentaries, editorials, book chapters, guidelines and conference proceedings were excluded. An eligibility checklist summarizing the inclusion and exclusion criteria for article selection

was developed (see Table 2). Studies included in this review met the following main criteria: (a) articles on BC or PC patients and their caregivers (e.g., parents, spouses, sons, other loved ones, close friends); (b) articles that included some form of psychological intervention to promote caregiver involvement in cancer treatment decisions for BC and PC patients, and studies without psychological interventions (studies that investigated/evaluated the role of caregivers in treatment DM for BC and PC patients). In terms of research methods, quantitative, qualitative and mixed-methods empirical documents assessing patient and caregiver DM related to cancer treatment were included.

Table 2. Eligibility Criteria (with exclusion criteria)

	Included	Excluded
Topic	Caregiver involvement in breast and prostate cancer patients' DM along their cancer care path.	
Research domain	Application to the specific field of clinical psychology (broadly understood).	
Population	Competent breast or prostate cancer patients and their caregivers (e.g., parents, partners/spouses, sons, other loved ones, or close friends).	Breast or prostate cancer patients and/or caregivers that are not competent due to cognitive impairment or coma. Patients with other cancers than breast and prostate.
Language	Publications in English, Italian, or Spanish.	Publications in other languages than English, Italian, and Spanish.
Types (research methodology)	Publications are one of the following types of literature: (a) qualitative literature (e.g., in-depth interview, semi-structured interview, focus group); (b) quantitative literature (e.g., survey, standardized questionnaire); (c) mixed methods literature.	Editorials, conferences, commentaries, book chapters, guidelines, and literature reviews

Screening Procedure

Initially, the search strategy yielded 1160 records that were screened for irrelevant or duplicate records by the PhD candidate. Prior to the selection process, all records were exported in EndNote X9 reference manager. The remaining records were assessed and selected by first screening the title and the abstract, followed by a full-text reading and selection according to the predefined inclusion and exclusion criteria. The entire selection process was performed by three researchers independently. In case of disagreement, the three authors tried to reach a consensus. Where needed, the co-supervisor was involved until a consensus was

reached. If the full text of an article was not available, we emailed the first or corresponding author of that article to request a PDF copy. We also used the snowball technique and citation tracking to identify additional potentially relevant publications. We selected 17 reports focused on caregiver and patient experiences and perceptions of caregiver involvement in cancer TDM. Specifically, we included 16 studies, as two reports referred to the same study. The PRISMA flowchart of the selection procedures of the studies is reported in Figure 6 (Page et al., 2021).

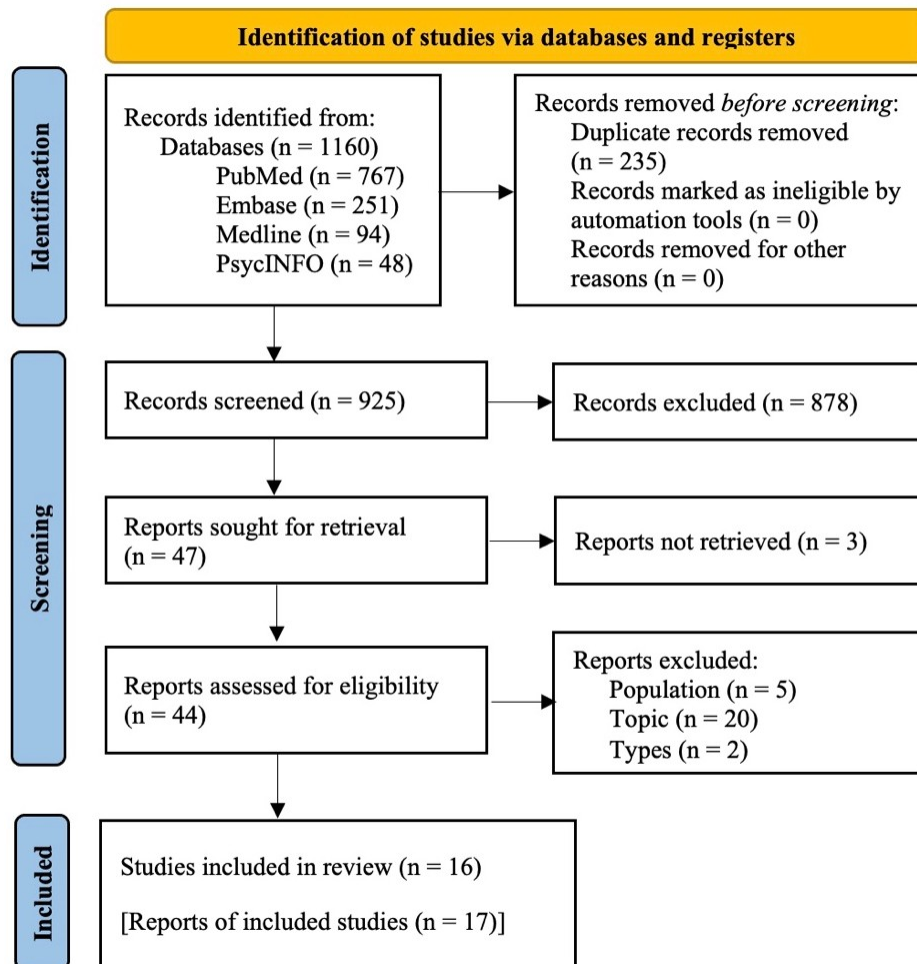


Figure 4. Preferred reporting items for systematic review and meta-analysis (PRISMA) statement flow diagram.

Data Extraction

Data were extracted from each of the included reports using a custom template: country of origin, study design, data collection technique, samples/population, measurement time-point, and significant findings. Initially, two researchers independently read and reread all the included reports, underlining the relevant parts for the purpose of the review. Subsequently, the two researchers discussed together the relevant parts underlined to reach a consensus on what to extract from the reports. Then, data were extracted by the PhD candidate and cross-checked for accuracy by the co-supervisors. Reports that were hard to decide were discussed between the researchers.

We identified 11 contributions using a qualitative method, 5 contributions using the quantitative method, and 1 contribution using the mixed method. Analyzing the significant findings from each report, we found another important aspect related to SDM, so we identified two macro themes: patient and caregiver involvement in cancer DM, and the psychological impact and its reciprocal influence on cancer in patients and caregivers.

Risk of Bias Assessment

The quality of the eligible reports was assessed using the Downs and Black's methodological quality scale (Downs & Black, 1998), a 27-item scale that provide a score on the following aspects: the reporting bias, the external validity, the internal validity, the selection bias, and the power. An overall rating of "good", "fair", or "poor" was given for each report. All the studies were independently rated by two researchers, and any disagreements were resolved through discussion with the co-supervisors. Consistently with other previous reviews, the statistical power evaluation was simplified using only two scores (1 = the sample size required to detect the significant difference was calculated; 0 = the sample size was not calculated or was insufficient to reach adequate statistical power). For qualitative studies, we considered if an analysis plan with the required sample size or quantity data for the planned analysis was included in the paper. However, the contributions included in this SR received poor scores (5–12), which means a high risk of bias due to their research methodology. Indeed, most of these contributions used a qualitative method and none of the rest were a randomized control trial (RCT). Considering the lack of adequate literature on the caregiver role in TDM, we consider it appropriate to report in this contribution the reports that have investigated the aspects with qualitative and/or exploratory methodology.

3.1.2. Results

A total of 17 reports met the inclusion criteria, among which 5 used a quantitative research method (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009; Kuo et al., 2019; Veenstra et al., 2019), 11 used a qualitative research method (Docherty et al., 2007; Fasse et al., 2017; Gray et al., 1999; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014; Rim, 2011), and 1 used a mixed-method research method (Al-Bahri et al., 2019). The characteristics of these reports are summarized in Table 3 for the quantitative documents, in Table 4 for the qualitative documents, and in Table 5 for the mixed methods documents.

Table 3. Summary of quantitative studies

Authors, Year, Country	Data Collection Technique	Samples Time Points	Measurement Time-Point and Treatment	Significant Findings
(Davison et al., 2003) Canada	Control Preferences Scale (CPS) State Anxiety Inventory (STAI-Y Form) The Center for Epidemiologic Studies Depression Scale (CES-D).	148 participants: 74 PCp ($\mu_{age} = 62.2$; 41–79) 74 Partners ($\mu_{age} = 58.1$; 29–76)	At the time of diagnosis and 4 months later Treatment = 75% radical prostatectomy	Shared decision making Most patients preferred sharing the decision with their partner or decide after consulting them and had a more active role in TDM than originally intended. Almost all the partners preferred to play either a collaborative or passive role in the TDM and assumed a more passive role in the TDM than originally preferred. Psychological interdependence Patient and caregiver levels of psychological distress did not influence the role that they assumed vs. the roles they originally had preferred in TDM.
(Davison et al., 2002) Canada	Control Preferences Scale (CPS) regarding their physician and their partner Information Survey Questionnaire.	160 participants 80 PCp ($\mu_{age} = 61.3$; 41–79) 80 caregivers (Partners) ($\mu_{age} = 57.2$; 29–76)	After their initial treatment consultation Treatment = Not yet decided	Shared decision making Most patients preferred to play either an active or a collaborative role in TDM. Partners preferred to play a collaborative role or passive role in TDM.
(Gilbar & Gilbar, 2009) Israel		114 participants n = 57 BCp ($\mu_{age} = 53$; 34–69) n = 57 (husband) ($\mu_{age} = 54.42$; 37–75)	3 to 12 months after diagnosis Treatment = under medical treatment	Shared decision making Almost all the patients preferred to decide by themselves, but their decision should be in accord with that of their husband's. Most of the patients thought that their husbands should participate in the TDM. Significant high correlation between patients and their husbands regarding participants in the DM, and who the important parties are in the DM process.
(Kuo et al., 2019) China	The Involvement in the Breast Reconstruction Decision-Making Process Scale The Body Image Scale The Decision Regret Scale	210 participants n = 105 BCp ($\mu_{age} = 48.3$; 32–64) n = 105 (Partner) ($\mu_{age} = 50.59$; 32–74)	16 months since breast reconstruction Treatment = Mastectomy	Shared decision making Patients' and partners' decision involvements were significantly correlated. The dyadic decision involvement was significantly inversely related to decision regret
(Veenstra et al., 2019) USA	Questionnaire on decision support persons concerning 3 domains of	2406 participants n = 1203 BCp ($\mu_{age} = /$)	7 months after their diagnosis	Shared decision making Partners were significantly more engaged than other types of decision support persons.

	engagement in decision making.	n = 1203 (43% Husband/Partner, 23% daughter. 23% other family members, 10% friends or other non-family members) (page = /)	Treatment = 31% CT, 50% RT, 62% lumpectomy, 38% mastectomy	Having a highly informed decision support person was associated with higher odds of greater patient-reported subjective decision quality. Having a highly aware decision support person was associated with higher odds of a more deliberative decision.
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Abbreviations: BCp = breast cancer patients; CT = chemotherapy; PCp = prostate cancer patients; RT = radiation therapy; TDM = treatment decision-making.

Table 4. Summary of qualitative studies

Authors, Year, Country	Data Collection Technique	Samples Time Points	Measurement Time-Point and Treatment	Significant Findings
(Boehmer & Babayan, 2005) USA	Face to face or telephone interview	39 participants: 21 PCp ($\mu_{age} = 59.57$; 37–70) 18 Caregiver = 14 F (12 wife, 1 partner, 1 daughter, 1 relative, 3 friends) ($\mu_{age} = 55.28$; 39–70)	Patients had decided on a treatment modality, but had not yet started Treatment = 66.7% Surgery, 19% Brachytherapy, 14.29% RT	Shared decision-making Men received from their partners emotional and informational support (emerged as being significant during the pre-treatment phase) and involved them in medical appointments. Psychological impact Spousal support depended on the diagnosed partner's willingness to accept emotional and/or informational support.
(Docherty et al., 2007) UK	Focus group	12 participants 9 PCp ($\mu_{age} = 71$; 54–79) 3 Partners ($\mu_{age} = 71$; 54–79)	Time since treatment ranged from 6 months to 5 years Treatment = RT, orchidectomy, and HT	Shared decision-making Patients made their decision using their spouse's support (often wife contacted the staff to gain information). Couples appreciated being involved in decisions and faced it as a team
(Fasse et al., 2017) France	Semi-directive interviews	18 participants $n = 9$ BCp ($\mu_{age} = 54$; 33–66) $n = 9$ Partners ($\mu_{age} = 59$; 40–76)	The time from diagnosis varied between 2 and 8 years Treatment = mastectomy	Shared decision-making The DM on BR did not entirely depend on patients' and caregivers' wishes and expectations. Some women and a few partners argued that the TDM was something decided by someone else, not necessarily causing distress or upset for the participants.
(Gray et al., 1999) Canada	Interview	68 participants $n = 34$ PCp ($\mu_{age} = 60.6$; 50–68) $n = 34$ Partners ($\mu_{age} = 57$; 42–72)	Waiting for surgery /	Shared decision-making Some couples took time to make decisions, investigating together different conventional and unconventional options along the way. Psychological impact The PC diagnosis came as a shock for all the couples, experiencing it as a shared one. It was frequently accompanied with a partial retreat from normal life. The absence of any sense of reconnection between the partners

				seemed to create dissonance in the relationship. Sometimes couples felt it was important to discuss what scared them and how they felt, and then to reassure each other
(Lamore et al., 2020) France	Semi-structured interview	18 participants $n = 9$ BCp ($\mu_{\text{age}} = 54$; 39–66) $n = 9$ Partner ($\mu_{\text{age}} = 59$; 40–76)	After mastectomy Treatment = Surgery	Shared decision-making The DM for BR seems linked to the family history of cancer, and temporality is important. Couples needed to talk together, or with other people about the mastectomy and the BR. Psychological impact Participants were concerned about treatments and their effects on their relationship.
(Le et al., 2016) USA	Semi-structured telephone interviews	30 participants $n = 15$ PCp ($\mu_{\text{age}} = 61.5$; 49–72) $n = 15$ Wife ($\mu_{\text{age}} = 59.3$; 45–71)	Within 6–18 months of the decision Treatment = 10 AS, 3 RT, 2 Surgery	Shared decision-making Most of the couples perceived the DM to be collaborative. PCp shared responsibility and partners reported that patients made the decision after considering their point of view. Men who chose AS were more likely to make the decision on their own than those who chose active treatment. Psychological impact Couples reported high dyadic adjustment, finding their marital interactions satisfying and their relationships cohesive. All couples described similar sequences of a highly emotional initial reaction and desire to be rid of the cancer, information seeking, and decision making.
(Loaring et al., 2015) UK	Interviews	8 participants $n = 4$ BCp ($\mu_{\text{age}} = /$; 37–55) $n = 4$ Partners ($\mu_{\text{age}} = /$; 37–55)	At least 6 months post treatment Treatment = Mastectomy	Shared decision-making Patients were seen by men as decision-makers. Partners wanted to be part of TDM, but they put their wives' needs or preferences first and supported whatever decision they made. Husbands were active and involved in TDM. Psychological impact There was a sense of “being together” and having a shared understanding of cancer. The diagnosis and the decisions regarding treatment could be overwhelming. Patients were concerned about their bodies and they did not believe that their husbands could find them attractive, even if partners found their wives as attractive as they did before breast cancer.

(Maliski et al., 2002) USA	Interview	40 participants $n = 20$ PCp ($\mu_{\text{age}} = 58.9$; 51–71) $n = 20$ Wife ($\mu_{\text{age}} = 54.3$; 28–70)	Between 3- and 11-months post prostatectomy Treatment = Prostatectomy	Shared decision-making Patients made their decision searching information on outcomes and complications of each treatment. The final choice of treatment was made by the PCp, even if they discussed treatment with their wives. Psychological impact The wives' goal was to support their husbands' decision, but they were concerned about their ability to do so. The diagnosis of PC represented a loss of control. Cancer was a shock, trauma, disbelief, and couples were scared.
(Nelson et al., 2019) USA	Semi-structured interviews	36 participants $n = 18$ PCp ($\mu_{\text{age}} = 11.1\%$ 50–59, 50% 60–69, 37.5% 70–70; /) $n = 18$ Partners ($\mu_{\text{age}} = 44.4\%$ 50–59, 44.4% 60–69, 11.1% 70–70; /)	At 3 time-points following diagnosis Treatment = AS 5 Radical prostatectomy 6 HT/RT 7	Shared decision-making Men on AS preferred not to discuss their cancer once treatment decisions had been made. Psychological impact Throughout the illness trajectory, partners provided emotional, instrumental, and appraisal support and they reported being happy to provide support. Partners helped patients to deal with treatment-related side effects (sexual dysfunction). Men receiving treatment spoke favorably about the support they had received from their partner. Some partners mentioned a perception that much of the support on offer was superficial and found it difficult to accept support from their wider network.
(O'Callaghan et al., 2014) Australia	Interview	35 participants $n = 21$ PCp ($\mu_{\text{age}} 4.76\%$ ≤ 50 , 28.57% 51–60, 52.38% 61–70, 14.29% > 71 ; /) $n = 14$ Partners ($\mu_{\text{age}} = 28.57\%$ ≤ 50 , 14.29% 51–60, 50% 61–70, 7.14% > 71 ; /)	/	Shared decision-making Men's TDM were informed by perspectives from medical staff and caregivers and affected by their emotional reactions, cancer-related memories, and lifestyle factors. Partners supported men's final decisions, who usually felt the support provided by caregivers. Psychological impact Men and partners' strategies for coping: positive self-talk, living as normally as possible, distraction, thinking of PC survivors, rationalizing that one could die of something else, hope for new PC treatments, denial, educating others about PC, acquiring information, continuing a healthy lifestyle, seeking reassurance, and humor.

(Rim, 2011) USA	Focus Group	433 participants <i>n</i> = 240 PCp (μ_{age} = less than 60–more than 70) <i>n</i> = 193 Caregivers (93% Wife/Partner, 5% Daughter/Son, 3% Other/Unknown) (μ_{age} = less than 60- more than 70)	At diagnosis /	Shared decision-making Some patients found partners' preference for a particular treatment “very important” Family members reported discussing treatment options with patients “very often”. Nearly all family members “strongly agreed” their role was to listen and provide emotional support, to help obtain information about cancer and treatment options, to arrange meetings with physicians and other health professionals, and to help patients make a treatment decision.
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Abbreviations: AS = Active Surveillance; BCp = breast cancer patients; BR = breast reconstruction; CT = chemotherapy; HT = hormone-therapy; PCp = prostate cancer patients; PC = prostate cancer; RT = radiation therapy.

Table 5. Summary of mixed methods studies

Authors, Year, Country	Data Collection Technique	Samples Time Points	Measurement Time- Point and Treatment	Significant Findings
(Al-Bahri et al., 2019) Oman	CanCORS questionnaires	158 participants: 79 BCp (μ age = 45; 26–75) 79 Caregiver (39.2 % spouses, 17.7% siblings, 34.2% parents, 8.9% others) (μ age = 36; 18–65)	Two years after treatment Treatment = 59.5% surgery; 40.5% other treatments	Shared decision-making More family members than the patients reported equally-shared the TDM and high levels of family control in the TDM. Most of the BC patients shared the TDM with more than one family member. Most patients reported that their families usually come together to discuss and finalize the TDM, which occurred when there was full agreement between their family members.

Characteristics of the Selected Reports

Five were carried out in the USA (Boehmer & Babayan, 2005; Le et al., 2016; Maliski et al., 2002; Rim, 2011; Veenstra et al., 2019), three in Canada (Davison et al., 2002, 2003; Gray et al., 1999), five in Europe (Docherty et al., 2007; Fasse et al., 2017; Lamore et al., 2020; Loaring et al., 2015; Nelson et al., 2019), one in Australia (O'Callaghan et al., 2014), one in Israel (Gilbar & Gilbar, 2009), one in China (Kuo et al., 2019), and one in Oman (Al-Bahri et al., 2019).

Considering the quantitative reports, a total number of 1519 adult patient–caregiver dyads were analyzed. Most of the dyads consisted of spouse–partner (54.51%; $n = 828$) or parent–son (18.24%; $n = 277$) with sons as caregivers, while the other dyads were composed of other family members (17.64%; $n = 268$, e.g., sister, cousin) or friends (8.03%; $n = 122$). The remaining 1.58% ($n = 24$) of caregivers did not provide any information about their relationship with patients. Most of the patient sample was composed of women with breast cancer under medical treatment, such as surgery, at the initial phase of their illness ($n = 1365$; 89.86%). The time frame considered in the reports started from 3 to 12 months after a breast cancer diagnosis. Most women had surgery and were enrolled in the reports after breast reconstruction. Prostate cancer patients instead were enrolled at the time of diagnosis and had not yet decided on the treatment. Moreover, four reports were cross-sectional and only one study had a quasi-experimental design (pretest/post-test).

A total sample of 737 participants were interviewed in the qualitative reports, 400 (54.27%) were patients and 337 (45.73%) were caregivers. Caregivers were predominantly spouses/partners ($n = 314$, 93.18%), followed by other relatives ($n = 16$, 4.75%), among which 10 were sons; and only 3 caregivers were friends. Finally, nine caregivers (2.67%) did not specify their type of relationship with patients. Most patients had a prostate cancer diagnosis ($n = 378$; 94.5%). The methods employed in such reports were focus groups (1 study) and interviews (10 studies, 6 interviewing patients and caregivers separately, 5 interviewing the dyads together, and 1 mixed, interviewing them separately and together). One report used both methodologies (focus group and interview). Two of the thirteen reports had a longitudinal design, while the others were cross-sectional, except for one that was a pilot study.

One last report included in our review had a mixed methodology and enrolled 79 dyads in a time range of 24 months after the beginning of the treatment and included mostly dyads with spouses (39.2%), parents (39.2%), siblings or offspring (34.2%), and other relatives, such as nephews and stepsons (8.9%).

Shared Decision-Making between Patients and Caregivers

Reviewing quantitative studies, it was found that almost all the patients preferred to have an active or collaborative role with caregivers in the TDM process (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009). Indeed, patients felt it was important to make the final medical decision by themselves, even if only after consulting their caregiver or sharing the decisions with them (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009). Moreover, many of the patients reported that it was important for them to agree with their caregivers about the decision they made (Gilbar & Gilbar, 2009). Finally, very few patients preferred to have a passive role, allowing their caregivers to decide (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009).

Regarding the caregiver role in TDM, almost all the caregivers preferred to have a collaborative or passive role in the DM process (Davison et al., 2002, 2003; Veenstra et al., 2019). However, most caregivers who took a passive role in the TDM process reported that patients decided after considering their opinion seriously (Davison et al., 2003). Very few caregivers wanted to be active in deciding for the patients (Davison et al., 2002). Another important aspect related to SDM was the agreement between patients and caregivers. Only one study explored this topic and reported that patients and caregivers had similar ideas regarding both their attitudes toward their involvement in SDM and their medical decisions (Gilbar & Gilbar, 2009). Caregiver involvement in medical SDM might have a positive influence on patients' medical decisions, since greater caregiver involvement was associated with lower patient decision regret, even if the data were not statistically significant (Kuo et al., 2019), and with an improvement of subjective decision quality and deliberation (Veenstra et al., 2019).

Regarding the results from qualitative studies, almost all the cancer patients stated that they preferred to discuss treatment options with their caregivers (e.g., partner, family members), giving importance to caregivers' preferences, and that they felt supported by them in making treatment decisions (Boehmer & Babayan, 2005; Docherty et al., 2007; Fasse et al., 2017; Gray et al., 1999; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014; Rim, 2011). Although patients involved caregivers in the DM process, feeling they were a unit/team (Docherty et al., 2007; Fasse et al., 2017; Gray et al., 1999; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; O'Callaghan et al., 2014; Rim, 2011), patients made the final treatment choice by themselves and the decision could be shared or not by caregivers (Fasse et al., 2017; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; O'Callaghan et al., 2014). Both patients and caregivers considered the DM process as personal and intimate, even if it was influenced by external factors, such as personalized care or psychological and emotional variables (Fasse et al., 2017). Moreover, it showed the importance of temporality in the DM process; some patients needed more time to decide than others (Lamore et al., 2020; Le et al., 2016). Throughout the illness trajectory, caregivers provided emotional, instrumental and appraisal support, accompanying patients to medical appointments, remembering their screening appointments, helping them to manage daily life activities at home or to manage stressful events, encouraging and reassuring them (Boehmer & Babayan, 2005; Fasse et al., 2017; Loaring et al., 2015; Nelson et al., 2019; O'Callaghan et al., 2014; Rim, 2011). In some cases, patients could perceive the caregivers' support as inappropriate or they could feel a dissonance in their relationship; these enhanced concerns and caused conflicts (Fasse et al., 2017; Gray et al., 1999).

Findings from the mixed methods study (Al-Bahri et al., 2019) reported that most breast cancer patients discussed, finalized, and shared the medical decisions with caregivers (more than one family member among partners, siblings, or parents) when there was full agreement between patients and caregivers. Even caregivers reported to be involved in the TDM process and to have the role of supporting patients (Al-Bahri et al., 2019).

Patients and caregivers consider a cancer diagnosis to be scary and severe, a true shock, trauma (Gray et al., 1999; Le et al., 2016; Maliski et al., 2002). Frequently, patients and caregivers partially retreated from normal life at the beginning of their cancer journey full of concern regarding the future (Gray et al., 1999; Maliski et al., 2002). Then, patients and caregivers started to accept this new situation and tried to deal with it actively, searching for information as much as possible (Boehmer & Babayan, 2005; Docherty et al., 2007; Gray et al., 1999; Le et al., 2016; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014). During the cancer trajectory, patients and caregivers lived with the illness experience as a shared challenge with a sense of being together and feeling it was important to discuss what scared them (Fasse et al., 2017; Gray et al., 1999; Loaring et al., 2015; Maliski et al., 2002). Patients identified a person in their family as a caregiver and received from them both emotional and instrumental support, attending and remembering medical appointments, giving reassurance, and/or hiding concern (Boehmer & Babayan, 2005; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014). Moreover, caregivers needed to tend to their own emotional needs regarding the diagnosis to be strong for patients, and sometimes they found help in other family members or friends (Boehmer & Babayan, 2005; Maliski et al., 2002; Nelson et al., 2019). Indeed, patients and caregivers felt overwhelmed by the cancer diagnosis, the medical DM, treatments, and about their role (Boehmer & Babayan, 2005; Loaring et al., 2015; Maliski et al., 2002). However, when a treatment decision was made, some patients and caregivers tried to carry on as normal, while others continued to worry some of the time (Gray et al., 1999). During the cancer trajectory, patients faced a lot of difficulties related not only to the diagnosis but also to the treatment and side-effects of treatments that were reported (Lamore et al., 2020; Loaring et al., 2015; Nelson et al., 2019). One of the most common concerns was related to sexuality or sexual intimacy, as well as who to tell about the cancer (Gray et al., 1999; Lamore et al., 2020; Loaring et al., 2015). Due to the surgery and treatment, breast cancer patients had to face a change in their body, resulting in a loss of confidence in their nakedness (Fasse et al., 2017; Loaring et al., 2015). However, male caregivers asserted that they did find their wives as attractive as before the cancer diagnosis (Loaring et al., 2015). Sometimes, patients and caregivers could disagree about whom to tell about the cancer or about seeking a second opinion or because patients perceived the support provided by caregivers as inappropriate, causing tension or conflict (Fasse et al., 2017; Gray et al., 1999; O'Callaghan et al., 2014). After the cancer diagnosis, patients underwent a great number of medical assessments to decide the best treatment, and during this period, the patient-caregiver dyad had to cope with the waiting time, and this was very anxiety inducing, as much as when waiting for surgery (Gray et al., 1999; Maliski et al., 2002). Most of the patients and caregivers expressed a need for meeting other patients and caregivers in a similar situation to obtain psychosocial support during and after treatment (Nelson et al., 2019). Finally, the level of state-anxiety and depression that patients and caregivers experienced along the cancer trajectory decreased both in patients and caregivers over time. However, female caregiver state-anxiety levels were slightly higher than patient levels in both measurements. Finally, psychological distress did not affect the role that patients and caregivers wanted to play in medical DM vs. the role they actually assumed (Davison et al., 2003).

3.1.3. Discussion

Cancer can be considered a family disease (Chen et al., 2021; Kayser et al., 2007; Minuchin, 2018; Petrocchi et al., 2022), having an impact on both patients and caregivers, who face different challenging situations due to the cancer diagnosis (Kim & Given, 2008; Northouse et al., 2007; Segrin & Badger, 2010; Woźniak & Iżycki, 2014). Moreover, patients usually involve caregivers during the cancer consultation to be supported in the DM process, in the interaction and communication with the oncologists, and along the cancer trajectory (Del Piccolo et al., 2014; R. Laidsaar-Powell et al., 2017; R. C. Laidsaar-Powell et al., 2013; Pravettoni et al., 2016). With this contribution, we aimed to investigate breast and prostate cancer patient and caregiver involvement in the TDM processes related to the cancer care pathway, as well as their level of compliance. To date, no contributions provide an exhaustive overview of the role of caregivers in cancer care and their involvement in the DM process related to therapies.

Reviewing the studies on caregiver involvement in breast and prostate cancer patient DM, two macro themes emerged: the importance of patient and caregiver involvement in cancer DM and the psychological impact and reciprocal influence of cancer on patients and caregivers. Our review shows that most patients preferred to have an active or collaborative role with caregivers in TDM, and in both cases, patients felt the need to consult or share the decision made with their caregivers, even when caregivers did not agree with them (Al-Bahri et al., 2019; Boehmer & Babayan, 2005; Davison et al., 2002, 2003; Fasse et al., 2017; Gilbar & Gilbar, 2009; Gray et al., 1999; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014; Rim, 2011; Veenstra et al., 2019). Regarding the role of caregivers, they preferred to collaborate with patients or allow patients to decide by themselves after considering their opinions (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009; Veenstra et al., 2019). Only one study explored the agreement between patients and caregivers on their role in SDM, reporting that patients and caregivers had similar views on both their attitudes towards their involvement in SDM and their medical decisions (Gilbar & Gilbar, 2009). The involvement of caregivers in shared medical DM could have a positive influence on patient medical decisions, reducing patient decision regret and better care for the patient (Kuo et al., 2019; Veenstra et al., 2019).

From our results, it emerged that patients and caregivers experienced the cancer diagnosis as a shared shocking experience, with a sense of unity, that also negatively impacted both patients and caregivers on the psychological side (Docherty et al., 2007; Fasse et al., 2017; Gray et al., 1999; Lamore et al., 2020; Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002; O'Callaghan et al., 2014; Rim, 2011). During the cancer trajectory, patient–caregiver dyads experienced different phases: soon after the diagnosis they frequently retreated from normal life; then, they started to accept this new situation, tried to deal with it, and carried on as normal (Boehmer & Babayan, 2005; Docherty et al., 2007; Gray et al., 1999; Le et al., 2016; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014). Although family caregivers provided both emotional and instrumental support, they also had to cope with their emotional needs regarding the diagnosis to be strong for the patients (Boehmer & Babayan, 2005; Fasse et al., 2017; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014; Rim, 2011). As a result, patients sometimes reported better scores in

terms of psychological distress (e.g., anxiety and depression) than their caregiver (Davison et al., 2003). Furthermore, there was an interdependence between the psychological aspects of patients and caregivers that did not influence the role that patients and caregivers wanted to play in the shared medical DM process (Davison et al., 2003). Specifically, the cancer diagnosis and treatments overwhelmed patients and caregivers (Boehmer & Babayan, 2005; B. Edwards & Clarke, 2004; Hodges et al., 2005; Loaring et al., 2015; Maliski et al., 2002; Segrin & Badger, 2010; Stenberg et al., 2010). Breast and prostate cancer patients were worried about sexuality and their intimacy, as already reported in the literature (Dorros et al., 2010; Ganz, 2008; Gray et al., 1999; Lamore et al., 2020; Loaring et al., 2015; S. Manne et al., 2004; Northouse et al., 2007; Sandgren et al., 2004; Segrin & Badger, 2010).

Finally, our results showed that along the cancer trajectory, patients and caregivers could disagree about whom to tell about cancer or about seeking a second opinion or because patients perceived the support provided by caregivers was inappropriate, causing tension or conflict (Fasse et al., 2017; Gray et al., 1999; O'Callaghan et al., 2014).

The present systematic review had some limitations. Of the 17 studies included in this review, 9 were conducted in North America (Boehmer & Babayan, 2005; Davison et al., 2002, 2003; Gray et al., 1999; Le et al., 2016; Maliski et al., 2002; Nelson et al., 2019; Rim, 2011; Veenstra et al., 2019), 4 in Europe (Docherty et al., 2007; Fasse et al., 2017; Lamore et al., 2020; Loaring et al., 2015), 3 in Asia (Al-Bahri et al., 2019; Gilbar & Gilbar, 2009; Kuo et al., 2019), and only 1 in Oceania (O'Callaghan et al., 2014). Since most of the studies (18/2) included in this review were conducted in North America and Europe, the result may be limited in generalizability. Of the 5 longitudinal studies, with observation times ranging from 4 months to 18 months from baseline, none of the studies explored the entire trajectory of a family member's caregiving experience as a dyad from cancer diagnosis to end of treatment (survivorship). Moreover, cross-sectional studies had different time points. Furthermore, it was difficult to draw final conclusions on the dyads' psychological trends during the cancer-care pathway since the included studies used different time points of evaluation. Another limitation was the lack of balance between studies on PC and BC, so it was difficult to give a final conclusion. Finally, studies comparing the different roles and interdependence of the dyads among different cancers (lung, blood, and so on) might help in tailoring interventions according to the needs linked to the specific cancer diagnosis.

3.1.4. Conclusion

The findings of this review indicate that caregiver involvement in cancer patients' SDM is very important because caregivers provide emotional and instrumental support to patients (Boehmer & Babayan, 2005; Loaring et al., 2015; Maliski et al., 2002; Nelson et al., 2019; O'Callaghan et al., 2014). Moreover, patients and caregivers walk the path of treatment together and both may have negative psychological reactions that are interdependent (Le et al., 2016; Loaring et al., 2015; Maliski et al., 2002). Furthermore, cancer patients prefer to make medical decisions after consulting or sharing the decision made with their caregivers (Davison et al., 2002, 2003; Gilbar & Gilbar, 2009; Veenstra et al., 2019). Considering this evidence, more research is needed to examine the interdependence among cancer dyads regarding

psychological aspects, their role in the DM, and how they change over time according to different phases of care to facilitate the advancement of such a framework. Therefore, ensuring that caregivers have the same preferences as the patient on how to structure and to be involved in the DM could help improve the care pathway for both patients and caregivers. Finally, these findings highlight the importance of using a perspective that focuses on the relationship between a patient and caregivers when they receive a cancer diagnosis and must make a treatment decision. Targeting caregiver–patient dyads, rather than individuals, is important since a supported relationship could have a protective effect related to psychological distress, QOL, and relationship satisfaction. Moreover, dyads may benefit from interventions that focus on the needs of both the patient and caregiver.

3.2. Study 2: A pilot study on Decision-Making involvement of Prostate Cancer Patients and their Caregivers

As has been presented in chapter 1.3, PC accounts for 7% of all cancer worldwide with a high survive rate (Varner et al., 2019; Yiannopoulou et al., 2020). Patients who receive a PC diagnosis may suffer severe psychological consequences (Maggi et al., 2019; Yiannopoulou et al., 2020). Patients may decide between active treatments or AS, depending on the stage of the disease (Scherr et al., 2022). PC undergoing active treatments face problems in the sexual sphere, the urinary control, or the hormonal function (Northouse et al., 2007). The compromise of patient's intimate relationships cause feelings of frustration and loss of self-confidence and the dyads may experience distress and adjustment issues (Varner et al., 2019). However, the presence of caregiver during the cancer trajectory may help patients to better cope with cancer diagnosis and treatments and may help patients in the DM (Acquati & Kayser, 2019; Chen et al., 2021). A collaborative approach to cancer diagnosis may enhance patients and caregivers to open communicate each other their preferences and needs, leading to treatment decisions aligned with their values and goals (Coyne et al., 2020; Dionne-Odom et al., 2023; Li et al., 2020; Rostoft et al., 2021). Nevertheless, dyads sometimes disagree about treatment decisions or other decisions regarding the cancer care process (Benson et al., 2019; Hansen & Tjørnhøj-Thomsen, 2020; Loh et al., 2021; Longacre, Miller, et al., 2018; Shin et al., 2016). The following study aimed at investigating dyads' shared expectation/wish about mutual involvement in the cancer-related DM process, monitor the agreement in DM involvement and the mutual influence (based on interdependence theory). We started with a pilot study on a small sample of PC patients and their caregivers to test whether the protocol is appropriate and establish its feasibility.

3.2.1. Material and methods

Participants

16 PC patients and their caregivers were invited and agreed to participate in this pilot study. The recruitment took place at the European Institute of Oncology of Milan (Italy). Patients accompanied by family caregivers during their oncology visits were flagged up by oncologists as possible study participants. The lead research psychologist contacted them by telephone to explain the purpose and procedures of the study.

Inclusion criteria for patients were as follows: 1) age 18 years or older, 2) recent diagnosis of PC, 3) not currently decide the treatment to be undergone, and 4) in sufficient physical and mental health to understand and complete the study. Patients who were diagnosed with early mental disorders (before age 40) or severe neurological disorder or advanced cancer stage (e.g., palliative patients) were excluded from the study.

After patients agreed to participate in the study, adult family caregivers (age ≥ 18) were also asked to participate in the study. Caregivers with an early mental disorder (before age 40) or severe neurological disorder were excluded from the study.

The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board (or Ethics Committee) of the European Institute of Oncology, IRCCS (n. R1598/21-IEO1702). Written informed consents were obtained.

Procedure

The pilot study was conducted in November 2022. Patient/caregiver dyads, who agreed to participate in the study, completed a series of questionnaires separately that were administered electronically through the Qualtrics™ online platform. Basic medical data such as cancer diagnosis, stage, duration since diagnosis, and treatments administered were obtained from the hospital information systems of the participating facilities.

Measures

The set of questionnaires completed by patients and caregivers consisted of the following. First, patients and caregivers were asked about sociodemographic characteristics such as age, gender, education level, occupation, origin, and type of family relationships. Then, a set of psychological questionnaires were administered:

- A modified version of the Control Preference Scale questionnaire (Degner et al., 1997) assessed patients' and caregivers' DM control preference (Giordano et al., 2008; Shin et al., 2013, 2017, 2018). Responses were rated as follow: patients or caregivers preferred to be the decision maker (active), patients or caregivers preferred to be the decision-makers while considering the opinion/preferences of the caregivers or patients, respectively (semi-active), patients and caregivers preferred to share the responsibility of the decisions (collaborative), or patients or caregivers preferred not to be the decision-makers, letting the caregiver or the patient decide, respectively (passive).
- Five items from the Personal Assessment of Intimacy in Relationships scale [PAIR (Schaefer & Olson, 1981)] evaluated the degree of intimacy that each actor of the dyad currently perceives in the sphere of communication (we referred to it as the dyadic communication) (Constant et al., 2016). The response rate was on a 5-point Likert scale (from completely describing my relationship to not describing it). The difference between the two actors scores revealed the intimacy between the dyad (Schaefer & Olson, 1981).
- The Miller Behavioral Style Scale [MBSS (Miller, 1987)] determined the information-seeking behavior (a coping style) of threatened individuals and classified them as active information seekers or stressful situation avoiders. Four fictional stress-inducing situations (i.e., a dentist, hostage, redundancy, and airplane scenario) were presented and participants were asked to select one or more of the eight statements representing the monitoring coping style (e.g., paying attention, scanning, and amplifying potentially painful or harmful aspects of information and experiences related to illness) or the blunting coping style (e.g., avoiding, distracting from medical information). This psychological variable can be considered a trait variable that remains stable over time. Scoring was done by summing up the monitoring and blunting style responses. Then, the difference between the two scores was evaluated: if it was negative, the subjects were classified as blunting, if it was positive, the

subjects were as monitoring, and if there was no difference between the two scores, subjects were classified as having no preferred coping style.

- The Hospital Anxiety and Depression Scale [HADS (Zigmond & Snaith, 1983)] consisted of 14 items on a person's mood in the past week (Dunbar et al., 2000). Each item is rated on a 4-point scale for a total score ranging from 0 to 21 for each subscale. A higher score indicates higher distress and the cut-off points for establishing the presence of anxiety and depression is set at 8. This scale has been adapted and validated into Italian both for cancer patients and a community sample (Annunziata et al., 2011; Iani et al., 2014).
- The Multidimensional Scale of Perceived Social Support [MSPSS (Zimet et al., 1988)] was composed by 12 items rated on a seven-point Likert scale (1 = strongly disagree to 7 = strongly agree). Participants were asked to indicate how they feel about each statement. Scoring can be calculated in terms of a total score by summing the scores of all 12 items. The sample can be divided into groups based on the total score (12-35 = low support; 36-60 = moderate support; 61-84 = high support). The scale has been adapted and validated in Italian (Di Fabio & Palazzeschi, 2015).
- The SF-12 Health Survey is composed of 12 items, selected from the SF-36, evaluating the day they completed the questionnaire and the previous 4 weeks. The scoring provides two summary measures related to physical and mental aspect of health (PCS-12 and MCS-12). Scores range from 0 to 100, with higher scores indicating better physical and mental health functioning. The SF-12 Physical and Mental Summary Scales could be scored as follow: a score of 50 or less on the PCS-12 has been recommended as a cut-off to determine a physical condition, while a score of 42 or less on the MCS-12 may be indicative of 'clinical depression' (Ware et al., 1996). The SF-12 was assessed in various Italian settings (e.g., the general population and specific patient groups), showing that the SF-12 has good validity (Kodraliu, 2001). The mean scores reported by the authors for the general population were 47 (SD 9.61) and 46.2 (SD 10.51) for PCS and 46.5 (SD 10.6) and 44.8 (SD 11.4) for MCS. Regarding the out-patients, the mean scores were 43 (SD = 5.2) and 40.4 (SD = 9.7) for PCS and 44.1 (SD = 6.3) and 44.0 (SD = 11.2) for MCS.
- The 9-item Shared Decision-Making Questionnaire (SDM-Q-9) consisted of an open-ended question designed to explore the DM context as well as 9 multiple-choice questions rated on a six-point Likert scale (Kriston et al., 2010). The total raw score was obtained by summing all items ranging from 0 to 45. If there were one or two items missing, the average of the completed items could be used to calculate the raw score. The authors suggested multiplying the raw score by 20/9 resulting in a transformed score ranging from 0 to 100, where 0 indicates the lowest possible level of SDM and 100 indicates the highest possible level of SDM.
- The Consultation and Relational Empathy (CARE) Measure (Mercer, 2004) evaluated doctor's communication and relational empathy during the consultation. It consisted of 10 items rated on a six-point Likert scale, ranging from poor (1) to excellent (5) or does not apply (6). Scores ranged from the lowest score (10) to the highest one (50), with a higher score meaning excellent empathy shown by doctors. Mercer and Murphy (2008) assessed the CARE's performance and suitability in secondary

care showing that the mean score for the total sample of patients was 43.5 (variance 55.8, SD 7.47, N =1010) (Mercer, 2004).

Statistical Analysis

Descriptive statistics were calculated on raw data to report participants' socio-demographic characteristics (mean, standard deviation, median, minimum and maximum or reported frequencies in combination with confidence intervals). Dyadic analyses were conducted to verify the differences between patients and caregivers and their interdependence for each variable of interest. Specifically, pairwise t-tests, contingency tables and Chi-Square tests were then performed to compare patients and caregivers. Expected values and residuals in every box were calculated to verify if a specific group gave a significantly higher or lower rate of response (observed values) to certain items, compared to the percentage expected and calculated on the number of subjects recruited. Finally, correlations analyses were conducted for the sample of patients, caregivers, and dyads. Analyses were performed with SPSS (25.0, IBM, USA, 2014).

3.2.2. Results

Descriptive analysis of the sample at baseline

16 dyads were enrolled in the study composed by 16 prostate cancer patients (all male, Mage= 66.13, SD = 7.402) and their caregivers (12 females and 4 males, Mage= 57.06, SD = 10.853). 13 dyads had a marriage/partner relationship (81.3%), and 3 had a kin relationship (18.8%). Socio-demographic data are reported in Table 5. A statistically significant difference was found in the age of the dyads ($t_{(15)} = 2.91$, $p < .05$).

Table 5. Descriptive statistics for patient and caregiver demographic variables

Variable	Patient (N = 16)	Caregiver (N = 16)
Age (M ± SD, range)	66.13 ± 7.402 55-76	57.06 ± 10.853 35-74
Gender		
Male	100%	25%
Female	0%	75%
Educational level		
Primary/middle school	18.8%	18.8%
High school	50%	31.3%
Bachelor/Master's Degree	31.2%	43.8%
Post PhD	0%	6.3%
Employment		
Blue-collar	31.3%	62.5%
White-collar	25%	12.6%
Unemployed	6.3%	6.3%
Retired	37.5%	18.8%
Origin		
North of Italy	43.75%	43.75%

Center of Italy	31.25%	31.25%
South of Italy	25%	25%
Relationship		
Parent/child	18.75%	18.75%
Spouse/Partner	81.25%	81.25%
Cancer diagnosis		
Prostate cancer	100%	
Cancer stage		
Stage I	70%	
Stage II	30%	

The preferred involvement in the SDM

Half of the patients (50%) and slightly less than half of the caregiver (43.8%) preferred to share DM responsibility within the dyads, having a collaborative role. The other half of the patients preferred to have an active role in DM, although almost all the patients preferred to make decisions after taking the caregiver's opinion into account (43.8%) and only one patient preferred to decide alone. Regarding caregivers, 43.8% of the sample preferred to have a more passive role in the DM, letting the patient decided by themselves or after having considered their opinion. Only two caregivers preferred to have an active role in the DM, although considering the patients standpoint.

Considering the concordance among responses, 7 dyads agreed on the preferred DM modality, specifically 4 dyads agreed in sharing DM responsibility. For more detail, see Table 6. Contingency table and Chi-square test didn't show a significant association between patients' preferences in DM modality and caregivers' preferences. Indeed, pairwise t-test showed a statistically significant different between patients and caregivers' preferences ($t_{(15)} = -3.033$, $p < .01$)

Table 6. Contingency table among patients' and caregivers' preferences in their DM involvement

			Caregivers' preferences				
			Active Patient	Semi-active Patient	Collaborative	Semi-active Caregiver	Total
Patients' preferences	Active Patient	Count	0	1	0	0	1
		% of total	0.0%	6,3%	0,0%	0,0%	6,3%
		Adjusted residual	-.3	1,3	-.98	-,4	
	Semi-active Patient	Count	1	3	3	0	7
		% of total	6,3%	18,8%	18,8%	0,0%	43,8%
		Adjusted residual	1,2	,4	-,1	,5	
	Collaborative	Count	0	2	4	2	8
		% of total	0,0%	12,5%	50,0%	12,5%	50%
		Adjusted residual	-1,0	-1,0	.5	1,5	
Total	Count	1	6	7	2	16	
	% of total	6%	37,5%	43,8%	15,5%	100%	

Based on patients' and caregivers' concordance on their preferences regarding the involvement in the SDM, we divided the sample into those who agreed and those who disagreed (Dummy variable = Agree 1, disagree 0). However, no differences were found in all the patients' and caregivers' psychological variables (perceived social support, anxiety, depression, physical and mental health, SDM and empathy toward physicians) between dyads who agreed and who disagreed.

Patients and caregivers' communication style

Referring to the communication style, dyads reported experiencing an open and flowing exchange of ideas between them, showing high scores in the communication scale ($M_p = 4.43$, $SD = .51$; $M_{cg} = 4.11$, $SD = .84$). Table 7 shows the difference between patients' and caregivers' scores. More than half of the dyad agreed on their communication style (56.25% had same or very similar score), while within the other dyads, patients reported a better communication style than the caregivers (31.25%) or vice versa (12.5%). Indeed, no statistically significant difference was found among patients and caregivers in their responses. Patients' communication style was positively correlated with patients' perceived social support ($r = .51$, $p < .05$).

Table 7. PAIR differences between patients and caregivers

Differences	N	%
$\leq - 0.5$	2	12.5
0	9	56.25
≥ 0.5	5	31.25
Total	16	100,0

How do patients and caregivers cope with the prostate cancer diagnosis?

Most of the patients and the caregivers showed a monitoring coping style in responding to prostate cancer diagnosis (62.5% of both). This means that most of patients and caregivers tended to pay more attention to scan for and amplify threatening cues. Only one caregiver showed to have a blunting coping style (6.25%), and no one of the patients. The other didn't show a preference in the two coping styles (37.5% of the patients and 31.25% of the caregivers, respectively). No statistically significant difference was found among patients and caregivers in their responses.

After receiving the prostate cancer diagnosis, patients showed higher level of anxiety and depression than the caregiver (Anxiety: $M_p = 12.94$, $SD = 2.74$; $M_{cg} = 11.75$, $SD = 2.02$; Depression: $M_p = 11.00$, $SD = 1.59$; $M_{cg} = 9.06$, $SD = 1.06$), however a significant difference was found only in the level of depression between patients and caregivers ($t_{(15)} = 4.20$, $p < .001$). There was no significant correlation between patients and caregivers' anxiety and depression. Patients' level of anxiety was related to patients' mental health ($r = .737$, $p < .01$).

Regarding the QoL, patients and caregivers reported a mean score in the physical and mental subscale above the cut off (PCS: $M_p = 53.23$, $SD = 3.73$; $M_{cg} = 53.11$, $SD = 6.88$, MCS: $M_p = 46.37$, $SD = 12.96$; $M_{cg} = 49.07$, $SD = 9.65$). Comparing patients and caregivers' score, no significant difference was found. There was a positive correlation between patients' mental health and their age ($r = .60$, $p < .5$). Regarding caregivers, a negative correlation between their mental health and their physical health ($r = -.54$, $p < .05$) was found, while their mental health was positively related to their perceived involvement in the SDM ($r = .70$, $p < .01$).

Finally, both patients and caregivers reported high level of perceived social support ($M_p = 64.69$, $SD = 15.17$; $M_{cg} = 70.38$, $SD = 9.21$). No statistically significant difference was found among patients and caregivers in their responses. Caregivers' perceived social support was positively related to their age ($r = .63$, $p < .01$) and their mental health ($r = .56$, $p < .05$), while was negatively related to the perceived involvement in the SDM ($r = .56$, $p < .05$).

Triadic relationship: patients, caregivers, and physicians

Regarding the relationship with physicians, patients and caregivers reported to be sufficiently involved in the DM process by physicians ($M_p = 77.92$, $SD = 21.07$; $M_{cg} = 71.58$, $SD = 29.57$) and a good physicians' empathy and ability to communicate during the oncological consultation ($M_p = 40.31$, $SD = 9.80$; $M_{cg} = 46.79$, $SD = 12.22$), however, patients showed lower score than the referred sample. No significant difference was found between patients and caregivers.

Correlations between patients and caregivers

We run a bivariate correlation between the psychological variables of patients and caregivers (Table 8). We found that caregivers' communication style was positively related to patients' levels of anxiety ($r = .54$, $p < .05$), it means that when the caregivers thought to have an open and flowing exchange of ideas with the patients, it enhanced patients' level of anxiety.

Moreover, it was found that high level of caregivers' anxiety was related to lower level of patients' depression ($r = -.56$, $p < .05$). Moreover, caregivers' anxiety was positively correlated with patients' high score in physicians' empathy and communications ($r = .59$, $p < .05$). Caregivers' mental health was associated to patients' perception of physicians' empathy and communications ($r = .56$, $p < .05$). Whereas caregivers' perception of physicians' empathy and communications was negatively related to patients' perceived involvement in the SDM ($r = -.56$, $p < .05$).

Finally, patients' perceived involvement in SDM was positively related to caregivers' one ($r = .65$, $p < .05$).

Table 8. Patients and caregivers' correlations.

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1 Age_p	-																	
2 Age_{cg}	.11	-																
3 Dyadic Communication_p	.25	.12	-															
4 Dyadic Communication_{cg}	.15	.12	.06	-														
5 Anxiety_p	.30	-.34	-.11	.54*	-													
6 Anxiety_{cg}	-.11	-.45	.47	-.07	.18	-												
7 Depression_p	-.23	.29	-.33	.00	-.40	-.56*	-											
8 Depression_{cg}	.25	-.01	.05	.23	.02	-.24	.08	-										
9 Social Support_p	.18	-.12	.51*	.43	.37	.21	-.27	.25	-									
10 Social Support_{cg}	.22	.63**	.39	.06	-.28	-.08	.11	.41	.32	-								
11 Physical Health_p	.23	-.18	-.08	.05	.43	-.12	-.10	.26	-.13	-.07	-							
12 Physical Health_{cg}	.06	-.10	-.26	-.15	-.37	-.42	.32	.05	.01	-.09	-.25	-						
13 Mental Health_p	.60*	-.17	-.01	.40	.74**	.00	-.31	.43	.37	.11	.28	-.29	-					
14 Mental Health_{cg}	.12	.07	.27	-.12	.03	.38	.02	.20	.14	.56*	.29	-.54*	.18	-				
15 SDM_p	-.14	-.09	-.25	-.06	.19	.19	-.09	-.46	.10	.00	-.10	-.24	.12	.37	-			
16 SDM_{cg}	-.28	.23	-.28	.08	.20	.00	.12	-.01	-.05	.56*	.33	-.45	.20	.70**	.65*	-		
17 Empathy_p	-.35	.02	.36	-.20	-.22	.59*	-.19	-.08	.02	.22	.02	-.39	-.38	.56*	.06	.22	-	
18 Empathy_{cg}	.19	.42	-.13	-.04	-.15	-.32	.14	.38	-.16	.11	-.04	.21	-.17	-.14	-.54*	-.37	.20	-

* $p \leq .05$; ** $p \leq .01$

Abbreviations: p = patient; cg = caregiver

3.2.3. Discussion

Considering cancer as a family disease, exploring patients and caregivers' reaction to a cancer diagnosis and their alignment toward TDM is becoming increasingly important, as it is the first step to create appropriate guidelines for healthcare providers and structure dyadic psychological support intervention for patients and caregivers' dyads (Chen et al., 2021; Kayser et al., 2007; Minuchin, 2018; Ștefănuț et al., 2023). The alignment among dyads' preference in SDM may enhance the process of care for all the parties (Krieger, 2014). In this pilot study, we investigated the psychological impact of a newly diagnosed PC on patients' and caregivers' dyads and their alignment in the TDM. Some questions which guided our investigation were the following: Does the dyad really agree on how to be involved in the SDM? How patients' and caregivers' dyads react and cope to a cancer diagnosis? How the psychological reaction of patients' influences the one of the caregivers' and vice versa?

In our sample, participants were predominantly middle-aged adults, married and well-educated. The mean age of the PC patients is similar as the one reported in Europe (Yiannopoulou et al., 2020). Specifically, almost all the dyads were spouses, as reported in literature (Davison et al., 2002, 2003; Docherty et al., 2007; Gray et al., 1999; Le et al., 2016; Nelson et al., 2019; Northouse et al., 2007; Varner et al., 2019). Our study showed that only a quarter of the dyad agreed in sharing the DM responsibility, although questioned separately more patients and caregivers reported preferring to share opinions. This result suggested that patients and caregivers not always claim their preference on how to be involved in DM process, and this could lead to friction within the dyad, even if not explicit, and worsen the psychological well-being of both. This result was in line with our systematic review (Cincidda et al., 2023). Moreover, dyads mainly reported experiencing an open and flowing mutual exchange of ideas and more than half agreed on their communication style. A better communication style was related to a perceived social support in the patients' sample. This result suggested that patients in our sample talked openly to their caregivers, communicating needs, and feeling supported. Conversely, when caregivers experienced high levels of anxiety and thus failed to support patients, patients sought support from physicians, reporting higher levels of empathy and communication with them. This was in line with the literature (Karimi Moghaddam et al., 2023; Mishra et al., 2021; Park et al., 2022; Rohith & Patel, 2022) and claimed for specific psychological intervention for caregivers (Alam et al., 2020; Alfano et al., 2019; Given, 2019; Longacre, Applebaum, et al., 2018; Newell, 2002a). Finally, when caregivers freely expressed their emotions about cancer by having good dyadic communication, they made patients feel more vulnerable and may experience higher levels of anxiety, supporting the need of dyadic psychological intervention focused on reestablishing equity in the dyad and fostering acceptance of social support, developing communication skills, and changing stressful communication patterns, improving relationship quality and quality of life, and reducing depression and anxiety (Petrocchi et al., 2022).

Again, literature provided evidence of psychological distress in both patients and caregivers after a cancer diagnosis (Edwards & Clarke, 2004; Hodges et al., 2005; Krok et al., 2023; Meier et al., 2019; Segrin & Badger, 2010; Stenberg et al., 2010). Nevertheless, in our sample patients experienced markedly higher

psychological distress than caregivers, demonstrating a sort of asynchrony in their emotional state. We might infer that caregivers may not be fully aware of the significance of the diagnosis and what it will entail, at the beginning, while patients may experience more fears about the uncertainty of the future, related to fear of death or recurrence (Cincidda, Pizzoli, et al., 2022). However, our sample reported an overall good QoL, specifically, older patients had a better QoL. This could be also due to a lower concern for the sexual sphere, being a less impactful topic for older people, even if they were in couples.

Regarding the mutual influence of patients and caregivers, our results showed an interdependence between patients' and caregiver' different psychological variables (Coyne et al., 2020; Ferraris et al., 2022; Kong & Guan, 2019; Ștefănuț et al., 2023; Trevino et al., 2019). It is interesting to notice that there was a correlation between patients' and caregiver' perceived involvement in the SDM. In particular, higher perceived involvement by patients' was linked with a similar perceived involvement by the caregivers. This result supported the importance to promote the triadic SDM and to train physicians on how to communicate with dyads. In addition, patient's perception of being involved in DM by physicians led caregivers to perceive physicians as less empathetic. This result was in line with the conceptual framework proposed by Laidsaar-Powell and colleagues (2017), according to which caregivers were involved in various ways in the DM process, transforming the classic patient-physician interaction into a triadic relationship (patient, caregiver, and physician) (Laidsaar-Powell et al., 2017; LeBlanc et al., 2018; Mitnick et al., 2010; Renzi et al., 2016; Tulskey et al., 2022).

Another important finding was the negative correlation between patients' level of anxiety and caregivers' level of depression. This might suggest that highly anxious patients activate caregivers, who on their side showed low levels of depression. We might argue that patients' perceived anxiety about the uncertain future would be poorly managed by caregivers with high levels of depression, that usually exhibited low levels of activation and planning. On the other side, higher levels of caregivers' anxiety were related to patients' empathy toward physicians, suggesting that patients might feel they cannot count on an emotionally stable caregiver and search for someone they can trust and who is able to accommodate their needs and frustrations.

Another interesting aspect emerging from our results was the greater empathy showed by the study participants (dyads) toward the physicians and the level of involvement in the DM. We might speculate that health professionals have appropriately taken charge of the patient and caregiver, providing exhaustive information in a clear manner. They made the dyads feel comfortable, inspiring confidence in them. It is important to underline that patient with high level of anxiety reported higher level of physicians' empathy and communications. This might suggest that health professionals were able to accommodate patients' anxiety and that at the same time patients with a lot of anxiety needed physicians who were more empathetic and available for dialogue.

Before concluding, it is important to point out some limitations of this pilot study. As the sample was very small, this pilot study cannot guarantee the magnitude of the response rate in the main survey. Questionnaires to assess psychological variables were self-report and this may lead potential bias. Most of the sample was composed by couples, and this may limit the generalization of results for other type of dyads.

Moreover, we didn't collect information about the quality of the relationship, and this may have impact on the results. Despite lack of statistical power and these limitations, results of this study were promising and important to consider when designing future research in this area.

3.2.4. Conclusion

In conclusion, our results suggest the importance of involving both patients and caregivers in decision making, but that it is critical to know how they want to be involved to have a good degree of agreement in the dyad. Cancer certainly is a family disease that impacts both members of the dyad, and it is necessary to structure specific interventions for both individuals and dyads, considering the mutual influence they have when facing a cancer diagnosis. Finally, this pilot study provided us with the necessary information to move forward with the longitudinal study. However, because of the large time difference between prostate cancer and breast cancer, in terms of waiting time between diagnosis and treatment initiation, and because of the difficulty in enrolling patients with prostate cancer, we decided to focus only on dyads with breast cancer.

3.3. Study 3: A longitudinal study on dyadic pathways of Breast Cancer Patients and their Caregivers

As reported in the introduction section and in our systematic review results, patients commonly face the dramatic experience of cancer diagnosis with at least one caregiver at their side, who may be involved in the DM process (Fatigante et al., 2021; Laidsaar-Powell et al., 2017; Laryionava et al., 2018). In many cases, the patient and caregiver engage in SDM regarding treatment options and care plans (Cincidda et al., 2023; Laidsaar-Powell et al., 2017). Our systematic review showed that most patients and caregivers preferred a collaborative or supportive caregivers' involvement (Cincidda, Pizzoli, et al., 2022; R. Laidsaar-Powell et al., 2017). Sometimes, BC patients may also experience stress and conflict participating in the SDM regarding treatments, and dyadic members may have different perspectives regarding treatment decisions (Benson et al., 2019; Boelk & Kramer, 2012; Hansen & Tjørnhøj-Thomsen, 2020; Hauke et al., 2011; Kokufu, 2012; Kramer et al., 2010; Levine, 1999; Levine & Zuckerman, 2000; Longacre, Miller, et al., 2018; Shin et al., 2016; Vivian, 2006). Being involved in the SDM promotes the acceptance of the disease and adaptation to pain and changes in disease conditions accompanied by treatment (Kokufu, 2012), except when patients and caregivers tend to disagree on different aspects (mutual involvement, organizational aspects, treatment choices). Disagreements may also affect the understanding of medical information, compliance with therapies and, consequently, the patient's QoL, including the dyadic relationship itself (Shin et al., 2016). More broadly, caregivers' involvement in the oncological examinations was associated with both increased patients' satisfaction with respect to the care process and improved understanding of cancer-related information (DuBenske, Chih, et al., 2010; DuBenske, Gustafson, et al., 2010; Joosten et al., 2008).

Following the preliminary results of the pilot study, we decided to set up a longitudinal study on BC patients, aimed at assessing patients and caregivers' agreement regarding the involvement in the SDM, their actual involvement, their psychological reaction to cancer diagnosis and treatments, and their mutual influence. We decided to focus on BC since the European Institute of Oncology ranks first in the world for the number of BC surgeries performed each year. For such reason, we also aimed to assess patient's compliance/adherence to treatments, together with the satisfaction with the (shared) medical decisions, and dyadic psychological distress over time. Finally, we tested the efficacy of a single psychological consultation in improving patients' adherence to treatments, satisfaction with TDM and reducing dyadic psychological distress.

3.3.1. Material and methods

Participants

51 BC patients along with their caregivers were invited and agreed to participate in this longitudinal study. The recruitment took place at the European Institute of Oncology of Milan (Italy). Patients accompanied by family caregivers during their first oncology visits were flagged up by oncologists as possible study participants. The lead research psychologist contacted them by telephone to explain the purpose and procedures of the study.

Inclusion criteria for patients were as follows: 1) age 18 years or older, 2) recent diagnosis of breast cancer, 3) not currently decide the treatment to be undergone, and 4) in sufficient physical and mental health to understand and complete the study. Patients who were diagnosed with early mental disorders (before age 40) or severe neurological disorder or advanced cancer stage (e.g., palliative patients) were excluded from the study.

After patients agreed to participate in the study, adult family caregivers (age ≥ 18) were also invited to participate in the study. Caregivers with an early mental disorder (before age 40) or severe neurological disorder were excluded.

The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board (or Ethics Committee) of the European Institute of Oncology, IRCCS (n. R1598/21-IEO1702). Written informed consents were obtained.

Procedure

The present randomized longitudinal study, with a 1:1 allocation ratio, was conducted between September 2022 and April 2023. The dyads filled out a set of questionnaires separately, administered electronically via the Qualtrics TM online platform. After the completion of the questionnaires, the patient-caregiver dyads were randomly assigned to an “intervention” group (1 session of dyadic psychological support), or to the control group (no psychological support sessions). The time window in which the psychologist met the dyads was on average two weeks after the detection of a suspected cancer. For ethical reasons, the dyads in the control group were also offered the option to meet the psychologist at the end of the study for psychological support. The study did not foresee a cross sectional design. All the participants to the study filled out a second set of questionnaires separately after two months from the baseline. During this timeframe, had already started the treatments (e.g., performed surgery or neoadjuvant chemotherapy). Figure 7 shows the flowchart of the study.

The psychological support session lasted 60 minutes. The first part was dedicated to the narration of experiences related to the diagnosis of cancer, the dyad's preferences regarding mutual involvement in the subsequent treatment DM process, mutual emotions/fears and needs, as well as the clarity of the information received by the medical team. In the second part of the intervention, the psychologist, after assessing the need for psychological support, provided personalized input and feedback on the main themes that emerged during the first part of the intervention to foster the alliance between patient and caregiver. If a further need for psychological support emerged, the psychologist was available to provide it immediately and to suggest a longer period of care. Only 6 dyads needed more intensive psychological support, not only because of the impact of the cancer diagnosis, but also because of personal and/or relational problems. Basic medical data, including cancer diagnosis, stage of disease, time since diagnosis and treatments performed, were collected from the IEO hospital information systems and reports.

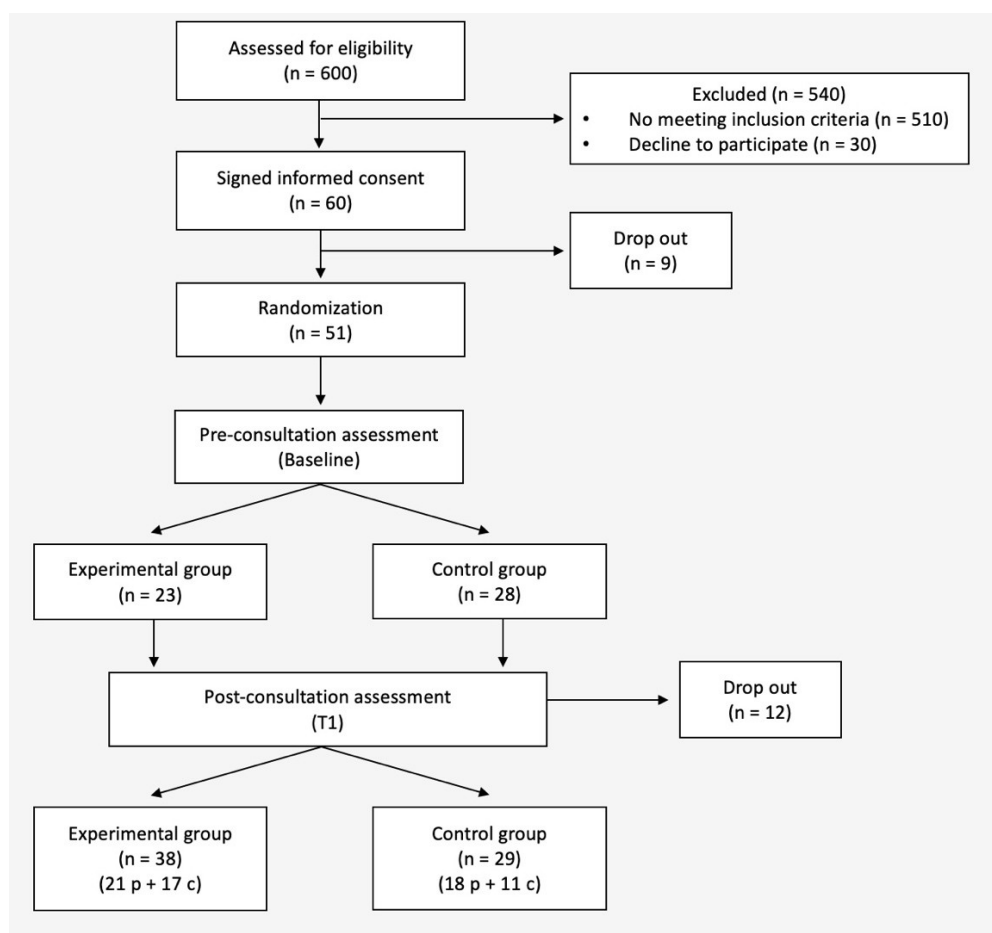


Figure 5. Study flowchart

Measures

A total number of nine questionnaires was included in the survey. The first questionnaire studied the socio-demographic characteristic of patients and caregiver, such as age, gender, educational level, employment, origins, and the type of relationship of the dyads.

The second questionnaire explored the DM preferences. A modified version of the Control Preference Scale questionnaire (Degner et al., 1997) was used to assess patients' and caregivers' decision control preference for medical decisions, as used in other studies (Giordano et al., 2008; Shin et al., 2013, 2017, 2018). One item explored patients' and caregivers' preferences about their role in medical decisions. Five answer options were proposed referring to an active (e.g., patients or caregivers preferred to be the decision maker), semi-active (e.g., patients or caregivers preferred to be the decision-makers while considering the opinion/preferences of the caregivers or patients, respectively), collaborative (e.g., patients and caregivers preferred to share the responsibility of the decisions), or passive (e.g., patients or caregivers preferred not to be the decision-makers, letting the caregiver or the patient decide, respectively) role in SDM.

The third questionnaire assessed the dyadic communication. We used five items from the Personal Assessment of Intimacy in Relationships scale (PAIR) (Schaefer and Olson, 1981), 3 items from the emotional intimacy subscale and 2 items from the intellectual intimacy subscale (Schaefer & Olson, 1981). The response rate was on a 5-point Likert scale (from 0 not describing it to 5 completely describing my relationship).

Following the theoretical conceptualization of PAIR, these items attempted to identify the degree of intimacy that each actor of the dyad currently perceives in the sphere of communication. In particular, the scores have significance in terms of the difference between the two actors (Schaefer & Olson, 1981).

The fourth questionnaire evaluated the patients and caregivers' coping style through the Miller Behavioral Style Scale [MBSS (Miller, 1987)]. The questionnaire aimed to determine the information-seeking behavior of threatened individuals, i.e., to classify participants into those who act by actively seeking information in response to a stressful event and those who react by trying to avoid the stressful situation. It consisted of four imaginary stress-evoking situations (i.e., a dentist, hostage, redundancy, and airplane scenario) and each scene is followed by eight statements representing different ways of coping with the situations. Half of the statement referred to the so-called "monitoring style" (e.g., pay attention, scan, and amplify potentially painful or harmful aspects of information and experiences related to illness), and the other half to the so-called "blunting style" (e.g., avoid or distract from medical information). Participants can choose the responses that reflect how they would act in each situation; more than one option is allowed. This psychological variable can be considered a trait variable that remains stable over time. Scoring was the sum of the responses for monitoring style and for blunting style. Then we evaluated the difference between the two scores. When the difference was negative, participants were classified as blunting, when it was positive as monitoring, and if there was no difference between the two scores, subjects were classified as having no preferred coping style.

The fifth questionnaire screened the presence of anxiety and depression. The Hospital Anxiety and Depression Scale [HADS (Zigmond & Snaith, 1983)] consisted of 14 items on a person's mood in the past week (seven items assess depression and seven items assess anxiety) (Dunbar et al., 2000). Each item is rated on a 4-point scale for a total score ranging from 0 to 21 for each subscale. A higher score indicates higher distress and the cut-off points for establishing the presence of anxiety and depression is set at 8. This scale has been adapted and validated into Italian both for cancer patients and a community sample (Annunziata et al., 2011; Iani et al., 2014).

The sixth questionnaire assessed the perceived social support. The Multidimensional Scale of Perceived Social Support [MSPSS (Zimet et al., 1988)] was composed by 12 items rated on a seven-point Likert scale (1 = strongly disagree to 7 = strongly agree). Participants were asked to indicate how they feel about each statement. Scoring can be calculated summing the scores of all 12 items. The sample can be divided into groups based on the total score (12-35 = low support; 36-60 = moderate support; 61-84 = high support). The scale has been adapted and validated in Italian language (Di Fabio & Palazzeschi, 2015).

The seventh questionnaire evaluated the quality of life. The SF-12 Health Survey is composed of 12 items, selected from the SF-36, evaluating the day they completed the questionnaire and the previous 4 weeks (Gandek et al., 1998; Jenkinson et al., 1997). The scoring provides two summary measures related to physical and mental aspect of health (PCS-12 and MCS-12). Scores range from 0 to 100, with higher scores indicating better physical and mental health functioning. The SF-12 Physical and Mental Summary Scales could be scored as follow: a score of 50 or less on the PCS-12 has been recommended as a cut-off to determine a physical condition, while a score of 42 or less on the MCS-12 may be indicative of 'clinical depression' (Ware

et al., 1996). The Italian validation reported a good validity (Kodraliu, 2001). The mean scores reported by the authors for the general population were 47 (SD 9.61) and 46.2 (SD 10.51) for PCS and 46.5 (SD 10.6) and 44.8 (SD 11.4) for MCS. Regarding the out-patients, the mean scores were 43 (SD = 5.2) and 40.4 (SD = 9.7) for PCS and 44.1 (SD = 6.3) and 44.0 (SD = 11.2) for MCS (Kodraliu, 2001).

The eighth questionnaire measured the extent to which patients and caregivers were involved in the process of DM with physicians. The 9-item Shared Decision-Making Questionnaire (SDM-Q-9) consisted of an open-ended question designed to explore the DM context as well as 9 multiple-choice questions rated on a six-point Likert scale (Kriston et al., 2010). The total raw score was obtained by summing all items ranging from 0 to 45. If there were one or two items missing, the average of the completed items could be used to calculate the raw score. The authors suggested multiplying the raw score by 20/9 resulting in a transformed score ranging from 0 to 100, where 0 indicates the lowest possible level of SDM and 100 indicates the highest possible level of SDM.

The ninth questionnaire assessed physicians' empathy perceived by patients and caregivers during the consultation. The Consultation and Relational Empathy (CARE) Measure (Mercer, 2004) evaluated doctor's communication and relational empathy during the consultation. It consisted of 10 items rated on a six-point Likert scale, ranging from poor (1) to excellent (5) or does not apply (6). Scores ranged from the lowest score (10) to the highest one (50), with a higher score meaning excellent empathy shown by doctors. Mercer and Murphy (2008) assessed the CARE's performance and suitability in secondary care showing that the mean score for the total sample of patients was 43.5 (variance 55.8, standard deviation 7.47, N = 1010) (Mercer & Murphy, 2008). The questionnaire was validated in Italian setting showing a high internal validity (Cronbach's $\alpha = 0.962$) (Natali et al., 2023).

The following set of questionnaires was administered at two months follow-up:

- An original modified version of the Control Preference Scale questionnaire (Degner et al., 1997) that estimates the actual level of patient and caregiver involvement in SDM. Specifically, the same question used to assess patients and caregivers' preferences for the SDM were modified asking for the actual involvement in the SDM. The possible answers were the same as baseline.
- An Italian translation of the original questions drafted by Shin et al. (2017) investigating the patient's perceived benefit/negative of caregiver involvement in TDM were administered only to the patients (Shin et al., 2017). Participants were asked to indicate if the caregivers' involvement was harmful, neither harmful or helpful, or helpful regarding communication, treatment decisions and psychological support. Moreover, patients were asked to rate their agreement with the following statements: a) caregivers' involvement in TDM hampers patients' autonomy, b) caregivers' involvement in TDM complicates the TDM process, c) caregivers' involvement in TDM leads to a harmonious decision, d) caregivers have the right to be involved in TDM. This questionnaire was completed only by patients.
- The Satisfaction with Decision scale (SWD) which measures satisfaction with health care decisions (Holmes-Rovner et al., 1996). It consisted of 6 items rated on a 5-point Likert scale

(from 1 = strongly disagree to 5 = strongly agree). Higher scores indicate higher satisfaction with decision. Scoring was obtained summing all the items' scores.

- The Adherence Determinants Questionnaire (ADQ) which assesses patients' self-adherence to clinical treatment for cancer, considering a set of cognitive and motivational skills, as well as social and behavioral variables, making it a multifactorial instrument (DiMatteo et al., 1993). It consisted of 38 statements rated on a 5-point Likert scale (from 1 = strongly disagree to 5 = strongly agree). Seven elements of patients' adherence to medical treatments and preventions were assessed: interpersonal aspects of care, perceived utility (benefits/costs and efficacy), perceived severity, perceived susceptibility, subjective norms, intentions to adhere, and support/barriers. Higher scores indicated higher adherence to cure. The components of the ADQ were found to be generally reliable (median alpha reliability = 0.76) (DiMatteo et al., 1993). This questionnaire was completed only by patients.

The following questionnaires were also re-administered: 5 items from the PAIR (Schaefer & Olson, 1981), the HADS (Zigmond & Snaith, 1983), the MSPSS (Zimet et al., 1988) and the SF-12 Health Survey (Ware et al., 1996).

Statistical Analysis

Statistical analyses were performed in SPSS version 25. The socio-demographic data for patients and caregivers were described in terms of mean, standard deviation, median, minimum and maximum or reported frequencies in combination with confidence intervals. Preliminary analyses were conducted for the sample of patients and caregivers in terms of correlations. Dyadic analyses were conducted to verify the differences between patients and caregivers and their interdependence for each variable of interest at the two-time evaluations. Specifically, pairwise t-tests and cross tabulations with chi-square tests were applied to compare patients and caregivers scores at the questionnaires at the two-time point. Moreover, independent group t-test and cross tabs with chi-square tests were applied to compare the two conditions (experimental and control) both in the sample of patients and caregivers at baseline and follow up. We performed repeated measures ANOVA to assess changes in each psychological variable (dyadic communication, anxiety, depression, perceived social support, physical and mental health, DM, empathy toward physicians) within each group of dyads, Experimental and control group. Independent group T-tests were then performed to compare differences between experimental and control dyads for each variable at different time-points.

3.3.2. Results

Descriptive analysis of the sample at baseline.

51 dyads were enrolled in the study composed by 51 breast cancer patients (all female, Mage= 51.55, SD = 8.939) and their caregivers (41 males, Mage= 50.29, SD = 12.749). 40 dyads had a marriage relationship (78.43%), 9 had a kin relationship (17.64%), only two were friends (3.92%). Socio-demographic data are

reported in Table 9. No statistically significant difference was found among patients and caregivers socio-demographic variables.

Table 9. Descriptive statistics for patient and caregiver demographic variables

Variable	Patient (N = 51)	Caregiver (N = 51)
Age (M ± SD, range)	51.55 ± 8.938 31-69	50.29 ± 12.749 21-78
Gender		
Male	0%	80.4%
Female	100%	19.6%
Educational level		
Primary/middle school	9.8%	13.7%
High school	52.9%	56.9%
Bachelor/master's degree	31.4%	25.5%
Post PhD	5.9%	3.9%
Employment		
Student	0%	3.9%
Blue-collar	7.84%	13.9%
White-collar	60.78%	70.6%
Unemployed	17.65%	0%
Retired	13.73%	11.8%
Origin		
North of Italy	33.3%	33.3%
Center of Italy	11.8%	11.8%
South of Italy	54.9%	54.9%
Relationship		
Parent/child	11.76%	11.76%
Sibling	3.92%	3.92%
Spouse/Partner	78.43%	78.43%
Aunt/niece	1.96%	1.96%
Friend	3.92%	3.92%
Cancer diagnosis		
Breast cancer	100%	
Cancer stage		
Stage I	15.68%	
Stage II	84.32%	

Patients and caregivers responses at the baseline

The preferred involvement in the SDM

52.9% patients and a smaller percentage of caregiver (29.4%) preferred to share DM responsibility, choosing a collaborative involvement. Slightly less than half of the patients preferred to have an active role in DM, among which 23.5% preferred to make decisions alone and 21.6% preferred to decide after taking the

caregiver's opinion into account. Regarding caregivers, 64.7% of them preferred the patient to have an active or semi-active role in the DM, although most of them (47.1%) preferred that the patients also considered their opinion (semi-active involvement). The proportion of patients and caregiver who promoted an active role of the caregiver (even if considering the patients' standpoint) was very small (patient 2%; caregiver 5.9%).

Considering the concordance among responses, 26 dyads (51%) agreed on the preferred DM modality, specifically a high degree of agreement was noted in the mode of sharing DM responsibility (25.5%; adjusted residual = 3.1). For more detail, see Table 10. The weighted kappa reflecting patient and caregiver concordance in TDM preferences was fair ($k = 0.30$), showing a modest concordance among dyads. Contingency table and Chi-square test showed a significant association between patients-caregivers preferences in DM modality [$X^2_{(9)} = 18.576$; $p = .029$].

Table 10. Contingency table among dyads' preferences in their DM involvement

				Caregivers' preferences			
				Semi-active patient	Collaborative	Semi-active caregiver	Total
Patients' preferences	Active patient	Count	5	5	1	1	12
		% of total	9,8%	9,8%	2,0%	2,0%	23,5%
		Adjusted residual	2,5	-,4	-1,8	,4	
	Semi-active patient	Count	2	8	0	1	11
		% of total	3,9%	15,7%	0,0%	2,0%	21,6%
		Adjusted residual	,1	1,9	-2,4	,5	
	Collaborative	Count	2	11	13	1	27
		% of total	3,9%	21,6%	25,5%	2,0%	52,9%
		Adjusted residual	-2,0	-1,0	3,1	-,7	
	Semi-active caregiver	Count	0	0	1	0	1
		% of total	0,0%	0,0%	2,0%	0,0%	2,0%
		Adjusted residual	-,5	-1,0	1,6	-,3	
Total		Count	9	24	15	3	51
		% of total	17,6%	47,1%	29,4%	5,9%	100,0%

We then divided the dyads into those who agreed and those who disagreed regarding preferred mutual involvement in DM (Dummy variable = Agree 1, disagree 0), but no differences were found in the two groups regarding the other psychological variables (anxiety, depression, perceived social support, mental and physical health, DM with physicians, and empathy toward physicians).

Patients and caregivers' communication style

Enrolled dyads reported experiencing an open and flowing exchange of ideas among them, showing high scores in the dyadic communication scale ($M_p = 4.33$, $SD = .66$, range 2-5; $M_{cg} = 4.26$, $SD = .82$, range 1-5), except one dyad reporting very low scores. Difference between patients' and caregivers' scores in communication style are reported in Table 11: most of the dyads agreed on their communication style, presenting close scores to the scale, 17.65% of the caregivers reported a better communication style than the patients, while 21.57% of the patients reported better scores than the caregivers. However, no statistically significant difference was found among patients and caregivers in their responses. Moreover, it was found that the communication style reported by the patients positively correlated with the one reported by caregivers ($r = .60$, $p < .001$).

Table 11. PAIR differences between patients and caregivers

Δ PAIR patients and caregivers	N	%
$\leq - 0.5$	9	17.65
$-.49 < x < .49$	31	60.78
≥ 0.5	11	21.57
Total	51	100,0

Based on the dyadic communication, we divided the sample in poor, fair and good dyadic communication style using their mean scores. A mean score below 1.99 referred to a poor dyadic communication, scores between 2 and 3.99 referred to a fair dyadic communication and scores above 4 referred to a good dyadic communication. The sample of the patients reported only fair or good dyadic communication style (23.5% and 76.5%, respectively). Caregivers reported similar results, except for a small percentage who reported poor dyadic communication style (2%). Then, we run a t test for independent patient's sample between fair vs good dyadic communication in psychological variables. We found a significant difference in the depression level ($t_{(49)} = 2.13$, $p < .05$), perceived social support ($t_{(49)} = - 2.87$, $p < .05$) and empathy toward physicians ($t_{(48)} = - 2.23$, $p < .05$). Specifically, patients with a fair dyadic communication reported higher level of depression than patients with a good dyadic communication. Indeed, a negative correlation was found between the dyadic communication and the level of depression ($r = -.285$, $p < .05$). Patients with a fair dyadic communication reported lower level of perceived social support and empathy toward physicians than patients with a good dyadic communication. Indeed, a positive correlation was found between dyadic communication and perceived social support ($r = .342$, $p < .05$). No differences were found for the caregivers' sample and only a positive correlation with the physical health was found ($r = .383$, $p < .01$).

How do dyads cope with the breast cancer diagnosis?

Most of the patients and the caregivers showed a monitoring coping style in responding to BC diagnosis (patients 74.5% and caregivers 72.5%, respectively). This means that most of patients and

caregivers tended to pay more attention to, scan for, and amplify threatening cues. The proportion of patients and caregivers who had a blunting coping style was very small (5.9% of patients and 2% of the caregivers, respectively). Remaining dyads didn't show a preference in the two coping styles (21.6% of the patients and 23.5% of the caregivers, respectively). No statistically significant difference was found among patients and caregivers in their responses.

After receiving the BC diagnosis, patients showed higher level of anxiety and depression compared to the caregivers (Anxiety: $M_p = 10.92$, $SD = 2.17$; $M_{cg} = 5.51$, $SD = 1.89$; Depression: $M_p = 10.43$, $SD = 1.90$; $M_{cg} = 4.84$, $SD = 1.61$; anxiety: $t_{(50)} = 14.08$, $p < .001$; depression: $t_{(50)} = 17.84$, $p < .001$). Nevertheless, caregivers' and patients' levels of anxiety and depression were not correlated (thus no interdependent). Negative correlation was found between anxiety and depression within the group of patients ($r = -.307$, $p < .05$). Finally, the level of anxiety was related to the mental health ($r = .427$, $p < .01$).

Regarding QoL, patients and caregivers reported a mean score in the physical subscale above the cut off, while they scored under the cut off in the mental health subscale, suggestive of clinical depression. Mental health score was significantly different between patients and caregivers ($t_{(50)} = -2.67$, $p < .01$), with patients reporting lower levels of mental health than their caregivers ($M_p = 37.02$, $SD = 11.66$; $M_{cg} = 41.82$, $SD = 11.10$). Mental health scores positively correlated between patients and caregivers ($r = .38$, $p < .01$).

Finally, both patients and caregivers reported high level of perceived social support ($M_p = 73.44$, $SD = 8.92$; $M_{cg} = 70.50$, $SD = 12.03$) and patients' perceived social support was significantly related to caregivers' perceived social support ($r = .32$, $p < .05$). No statistically significant difference was found among patients and caregivers in their responses.

Triadic relationship and DM

Dyads felt sufficiently involved in the DM process by physicians reporting an average score higher than the overall median score ($M_p = 27.39$, $SD = 11.55$, $Median_p = 27$; $M_{cg} = 24.10$, $SD = 12.51$, $Median_{cg} = 27$). The patients' perceived involvement in the DM correlated with caregivers' one ($r = .32$, $p < .05$). They also reported a good physicians' empathy during the oncological consultation, and such scores significantly mutually correlated ($r = .32$, $p < .05$). No significant differences were found for the involvement in the DM and the physicians' empathy reported by patients-caregivers.

What happens at the first follow-up?

The follow-up response rate for patients was 76.47% and only 54.90% for caregivers. The response rate was higher in the experimental group (53.85% of patients and 60.71% of caregivers). Socio-demographic data are reported in Table 12. At this time, all the patients underwent surgery, 24 of them had a quadrantectomy and the remaining underwent a mastectomy.

Table 12. Descriptive statistics for patient and caregiver demographic variables

Variable	Patient (N = 39)	Caregiver (N = 28)
Age (M ± SD, range)	50.36 ± 8.31 31-69	47.54 ± 12.01 21-70
Gender		
Male	0%	75%
Female	100%	25%
Educational level		
Primary/middle school	10.3%	10.7%
High school	51.3%	64.3%
Bachelor/Master's degree	33.3%	25%
Post PhD	5.1%	0%
Employment		
Student	0%	3.6%
Blue-collar	7.7%	7.1%
White-collar	66.7%	82.2%
Unemployed	12.8%	0%
Retired	10.3%	7.1%
Origin		
North of Italy	33.4%	44%
Center of Italy	10.3%	4%
South of Italy	56.4%	52%
Relationship		
Parent/child	5.1%	14.3%
Sibling	7.7%	7.14%
Spouse/Partner	82%	60.7%
Aunt/niece	2.6%	3.6%
Friend	2.6%	3.6%
Treatment		
Surgery	100%	
Radiotherapy	45.1%	
Chemotherapy	29.4%	
Neoadjuvant	15.4%	
Hormone Therapy	72.5%	

The actual involvement in the SDM

53.8% of patients and 25% of caregivers reported a collaborative involvement in the SDM, sharing the responsibility of the decisions. 46.1% of patients reported an active involvement in DM (46.2%), although half of them decided alone (23.1%) and the other half decided after taking the caregiver's opinion into account (23.1 %). Regarding caregivers, 50% of them let the patient make the final decision on her own, albeit having considered caregivers' opinion; 18% of them, on the other hand, let the patients decide on her own. Only few caregivers reported an active involvement in the SDM (7.15).

50% of the dyads agreed on the actual involvement they had in the DM process. In particular, the dyads who agree most about the implemented involvement are those who had a collaborative involvement,

sharing the responsibility of the decision (30.8%). Importantly, no patients let the caregivers have a semi-active involvement in DM, although 7% of caregivers reported having this type of involvement. For more details, see Table 13. Contingency table and Chi-square test did not show a significant association among dyads' actual involvement, although the weighted kappa was poor ($k = .12$, $p = .053$).

Table 13. Contingency table on patients and caregivers' agreement

			Caregivers' involvement				Total
			Active patient	Semi-active patient	Collaborative	Semi-active caregiver	
Patients' involvement	Active patient	Count	4	3	1	1	9
		% of total	15,4%	11,5%	3,8%	3,8%	34,6%
		Adjusted residual					
	Semi-active patient	Count	1	1	1	0	3
		% of total	3,8%	3,8%	3,8%	0,0%	11,5%
		Adjusted residual					
	Collaborative	Count	1	5	8	0	14
		% of total	3,8%	19,2%	30,8%	0,0%	53,8%
		Adjusted residual					
Total	Count		6	9	10	10	26
	% of total		23,1%	34,6%	38,5%	38,5%	100,0%

Based on patients' and caregivers' concordance on their actual involvement in the SDM, we divided the sample into those who agreed and those who disagreed (Dummy variable = Agree 1, disagree 0). No significant differences were found between groups in the psychological variables (anxiety, depression, perceived social support, physical and mental health, SDM with physicians and empathy toward physicians).

Did something change between preferences and actual involvement?

27 patients (69.23%) endorsed the involvement preferred at baseline (see Table 14). A high degree of agreement was noted in the mode of SDM responsibility (46.2%; adjusted residual = 3.4). The weighted kappa reflecting patients' concordance between patients' preferences and the actual involvement in the TDM was moderate ($k = 0.47$). Contingency table and Chi-square test showed a significant association between patients' preferences in DM modality and the actual involvement [$X^2(6) = 24.968$; $p < .001$]. Thus, reflecting that it is the patient's preference that drives the effective involvement in the cancer care pathway.

Table 14. Contingency table of patients' involvement in DM

			Patient's actual involvement			Total
			Active patient	Semi-active patient	Collaborative	
Patient's preferred involvement	Active patient	Count	6	2	0	8
		Total %	15,4%	5,1%	0,0%	20,5%
		Adjusted residual	3,9	,1	-3,4	
	Semi-active patient	Count	0	3	3	6
		Total %	0,0%	7,7%	7,7%	15,4%
		Adjusted residual	-1,5	1,7	-,2	
	Collaborative	Count	2	4	18	24
		Total %	5,1%	10,3%	46,2%	61,5%
		Adjusted residual	-2,8	-1,2	3,4	
	Semi-active caregiver	Count	1	0	0	1
		Total %	2,6%	0,0%	0,0%	2,6%
		Adjusted residual	1,8	-,6	-1,1	
Total	Count		9	9	21	39
	Total %		23,1%	23,1%	53,8%	100,0%

Only 40% of caregivers were actually involved in the DM reflecting their preference claimed at baseline (see Table 15). In particular, the higher link was noted between caregivers who preferred to let the patients decide after being consulted and patients who acted accordingly (20%).

Table 15. Contingency table for caregivers' involvement in DM

			Caregivers' actual involvement			Total
			Active patient	Semi-active patient	Collaborative	
Caregivers' preferred involvement	Active patient	Count	2	1	1	4
		Total %	8.0%	4,0%	4,0%	16,0%
		Adjusted residual	1,6	-,7	-,7	
	Semi-active patient	Count	2	5	6	13
		Total %	8,0%	20,0%	24,0%	52,0%
		Adjusted residual				

	Adjusted residual		-,6	-,2	,7	
	Collaborative	Count	1	2	3	6
		Total %	4,0%	8,0%	12,0%	24%
		Adjusted residual	-,2	-,4	,6	
	Semi-active caregiver	Count	0	2	0	2
		Total %	0,0%	8,0%	0,0%	8,0%
		Adjusted residual	-,7	1,8	-1,2	
Total		Count	5	10	10	25
		Total %	20,0%	40,0%	40,0%	100,0%

Finally, 87.18% of patients reported that caregivers' involvement in the SDM was useful for the communication, only 5 patients referred that caregivers' involvement was neither helpful nor harmfulness for the communication. 61.54% of the patients reported that caregivers' involvement in the SDM was useful for the decision about the treatment, while for 38.46% of patients, caregivers' involvement was neither helpful nor harmfulness. Finally, 79.49% of patients, reported that caregivers' involvement in the SDM was useful for the psychological support, while only for 17.95% of the patients was neither helpful nor harmfulness. For one patient the caregiver's involvement was harmfulness for the psychological support.

Patients and caregivers' changes in communication style

Dyads experienced an open and flowing exchange of ideas at the follow up similar as at baseline (no significant difference at different time points), showing high scores in the communication scale ($M_p = 4.35$, $SD = .68$, range 2-5; $M_{cg} = 4.41$, $SD = .84$, range 1-5) (see Table 16). Regarding patients' perspective, the dyadic communication at the follow up was interconnected to the baseline communication ($r = .530$, $p < .01$) and level of anxiety ($r = .355$, $p < .05$), but also to the perceived social support ($r = .554$, $p < .01$) and to the level of depression ($r = -.414$, $p < .05$) showed at the first follow-up. From caregivers' perspective, a better physical health at baseline was related to a better dyadic communication reported at the follow-up ($r = .51$, $p < .05$).

Table 16. Dyadic communication style

Δ PAIR patients and caregivers	N	%
≤ -0.5	1	8.3
$-.49 < x < .49$	9	75
≥ 0.5	2	16.7
Total	12	100,0

Changes in dyads' psychological state and perceived social support

Following treatment decisions and the start of treatments, patients and caregivers reported high level of anxiety and depression (Anxiety: $M_p = 11.26$, $SD = 2.55$; $M_{cg} = 11.64$, $SD = 1.97$; Depression: $M_p = 10.02$, $SD = 2.15$; $M_{cg} = 10.04$, $SD = 1.88$). Specifically, 66.7% of patients and 75% of caregivers showed severe levels of anxiety, and 38.5% of patients and 50% of caregivers severe levels of depression. No significant differences were found between patients-caregivers in such psychological condition, and the depressive status mutually correlated (positive correlation) ($r = .43$, $p < .05$).

A significant difference was found in caregivers' anxiety and depression levels between baseline and follow up (anxiety: $t_{(50)} = -17.80$, $p < .001$; depression: $t_{(50)} = -12.39$, $p < .001$). A significant correlation between baseline and first follow-up was found both in patients and caregivers sample for anxiety scores (Patients: $r = .52$, $p < .001$; Caregivers: $r = .49$, $p < .01$) and only for patients in the depression level ($r = .50$, $p < .001$). Finally, a negative correlation between anxiety and depression was found in the patients' sample ($r = -.331$, $p < .05$). In the caregivers' sample the level of anxiety was related to the perceived social support ($r = -.517$, $p < .01$). Patients' depression levels at the follow up were negatively correlated to the patient's level of anxiety at the baseline ($r = -.325$, $p < .05$). Whereas caregivers' level of anxiety at the first follow-up was related to caregivers' mental health at the baseline ($r = .541$, $p < .01$).

At the follow up patients had mean scores under the cut off both for physical and mental health ($M_{PCS} = 42.11$, $SD = 9.86$; $M_{MCS} = 41.78$, $SD = 10.13$), reflecting lower QoL. On the other hand, caregivers reported mean scores above the cut off ($M_{PCS} = 53.04$, $SD = 4.93$; $M_{MCS} = 44.12$, $SD = 10.29$), reflecting better QoL. Comparing patients and caregivers' score, it was found a significant difference only in physical health score. Patients also reported lower quality of physical health than the caregivers ($t_{(24)} = -4.47$, $p < .001$). A positive correlation between the mental health at the baseline and the mental health at the first follow-up was found both for patients and caregivers ($r = .655$, $p < .01$; $r = .435$, $p < .05$, respectively): the more mental health was good at baseline, the more resilience was confirmed at follow-up. The same trend was found for physical health among caregivers ($r = .792$, $p < .01$). Interestingly, caregivers' better mental health at the first follow-up was related with lower score in the empathy toward physicians at the baseline ($r = -.667$, $p < .01$), while a better physical health at the follow-up was related to higher level of perceived social support at baseline ($r = .444$, $p < .05$).

At this time point, high level of social support was reported by the dyads (93.2% of the patients and 82.1% of the caregivers), with no significant mean score difference compared to baseline, but positive correlation with the perceived social support perceived by the caregivers at baseline ($r = .798$, $p < .01$). Patients' perceived social support scores at the follow up were related to patient's dyadic communication ($r = .427$, $p < .01$), mental health ($r = .368$, $p < .05$) and involvement in the DM with physicians ($r = .356$, $p < .05$) reported at the baseline, and also to caregivers' perceived social support at the follow up ($r = .53$, $p < .01$), caregivers' anxiety ($r = -.517$, $p < .01$), caregivers' involvement in the SDM with physicians ($r = .475$, $p < .05$), and to the satisfaction with decisions ($r = .44$, $p < .05$).

Changes in the triadic relationship

Patients felt sufficiently involved in the DM process by physicians ($M_p = 32.56$, $SD = 11.9$; $\max = 45$). together with a good perceived physicians' empathy during the treatments ($M_p = 42.23$, $SD = 10.25$). No difference was detected for both involvement and empathy compared to the baseline, rather a positive correlation was confirmed ($r = .48$, $p < .001$ for involvement and $r = .58$, $p < .001$ for empathy with the physicians). Finally, a better physical health at baseline was related with a higher involvement in the decision-making with physicians reported at the follow up ($r = .38$, $p < .05$).

Also, caregivers reported to be sufficiently involved in the DM process by physicians ($M_{cg} = 29.88$, $SD = 13.63$), with good physicians' empathy during the treatment pathway ($M_{cg} = 49.10$, $SD = 11.88$). Nevertheless, there was a significant difference compared to the baseline for both variables ($t_{(23)} = -2.73$, $p < .05$ for involvement, and $t_{(19)} = -4.47$, $p < .001$ for empathy), with caregivers who felt to be more involved and empathizing. Also, a positive correlation over time confirmed this trend ($r = .53$, $p < .01$ for DM involvement; $r = .48$, $p < .05$ for empathy with physicians). Positive impact of the triadic relation was also reflected on caregivers' physical status ($r = .623$, $p < .01$ between empathy and physical health, and $r = .52$, $p < .01$ between good physical health at baseline and empathy with physician at follow up), and on perceived social support ($r = .481$, $p < .05$).

Finally, patients and caregivers reported high satisfaction with the decision made ($M_p = 25.95$, $SD = 4.26$; $M_{cg} = 25.52$, $SD = 4.08$). A positive correlation was found between the satisfaction with decision and the empathy toward physicians in the patients' sample ($r = .415$, $p < .05$).

Patients' adherence to therapies and cancer care pathway

At the follow-up, patients reported high level of adherence to treatment ($M = 120.39$, $SD = 8.80$). Specifically, our sample reported lower mean score than the sample of the validation study in the perceptions of the interpersonal aspects of medical care received ($M = 23.83$, $SD = 1.97$, $t_{(150)} = 13.78$, $p < .001$), in the beliefs about the perceived utility of the recommendations ($M = 23.70$, $SD = 2.12$, $t_{(150)} = 18.03$, $p < .001$), in the intentions to adhere ($M = 12.25$, $SD = 1.03$, $t_{(150)} = 15.31$, $p < .001$), and in the presence of supports and the absence of barriers to adherence ($M = 12.21$, $SD = 1.91$, $t_{(150)} = 6.14$, $p < .001$). The other factors were higher than the sample of the validation study (Beliefs about susceptibility to cancer: $M = 13.13$, $SD = 1.73$, $t_{(150)} = -4.936$, $p < .001$; Beliefs about the severity of cancer: $M = 11.46$, $SD = 1.47$, $t_{(150)} = 13.78$, $p = .35$; Subjective norms: $M = 6.25$, $SD = 6.25$, $t_{(150)} = -2.17$, $p < .05$).

Finally, the intention to adhere was positively related to the perceived susceptibility ($r = .421$, $p < .05$) and the level of anxiety ($r = -.697$, $p < .01$). A negative correlation was found between the adherence to treatment and the physical health ($r = -.578$, $p < .01$). The beliefs about the severity of cancer were related to the dyadic communication ($r = -.626$, $p < .01$). The satisfaction with decision was related to the beliefs about the perceived utility of the recommendations ($r = .488$, $p < .05$), and to the presence of supports and the absence of barriers to adherence ($r = .542$, $p < .01$).

All the correlations between baseline and the first follow-up were reported in Table 17 for patients and in Table 18 for caregiver.

Table 17. Correlations between baseline and follow up for patients

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. PAIR	-																	
2. Anxiety	,119	-																
3. Depression	-,328*	-,307	-															
4. MSPSS	,389*	,263	-,204	-														
5. PCS	-,023	-,088	,063	-,130	-													
6. MCS	,089	,426**	-,304	,333*	-,194	-												
7. SDM	,161	,086	,026	,262	,114	,177	-											
8. CARE	,129	-,056	,040	,089	,200	,143	,112	-										
9. PAIR_T0	,530**	,173	-,135	,457*	,148	,029	,006	,169	-									
10. Anxiety_T0	-,139	,520**	-,236	,142	,014	,086	-,204	,033	-,267	-								
11. Depression_T0	-,207	-,325*	,500**	-,273	,226	-,143	,071	-,119	-,414*	-,331*	-							
12. MSPSS_T0	,427**	,181	-,141	,820**	,083	,368*	,356*	,219	,554**	-,045	-,227	-						
13. PCS_T0	,102	-,037	-,257	,070	,310	-,041	,032	,090	,385	-,117	-,148	,198	-					
14. MCS_T0	-,065	,355*	,014	,396*	,040	,655**	,040	,227	-,249	,295	,245	,337	-,186	-				
15. SDM_T0	,075	,057	,157	,150	,379*	,060	,475**	,205	,156	-,170	,115	,280	,154	,184	-			
16. CARE_T0	,103	,457*	-,080	,167	,141	,304	,345	,579**	,104	,276	-,218	,226	-,008	,307	,460*	-		
17. SWD_T0	,066	-,120	-,099	,158	,276	,104	,282	,322*	-,136	-,100	,017	,143	,049	,110	,261	,415*	-	
18. ADQ	,372	-,277	,157	,326	-,144	,191	,322	,088	,134	-,294	,217	,258	-,578**	,320	-,024	-,472	,281	-

* p < .05; ** p < .01

Table 18. Correlations between baseline and follow up for caregivers

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. PAIR	-																
2. Anxiety	-.156	-															
3. Depression	-.272	.117	-														
4. MSPSS	.335	-.093	.198	-													
5. PCS	.231	.056	.320	.463*	-												
6. MCS	-.154	.248	.066	.047	-.227	-											
7. SDM	.046	.165	.178	.283	-.173	.436*	-										
8. CARE	.129	.024	-.141	-.347	.171	-.300	-.137	-									
9. PAIR_T0	.336	-.218	-.107	.294	.510*	-.357	-.008	.310	-								
10. Anxiety_T0	.069	.490**	-.094	-.287	.018	.541**	.105	.126	-.103	-							
11. Depression_T0	-.033	.199	.101	-.194	-.165	.006	.165	-.111	.357	.285	-						
12. MSPSS_T0	.070	-.247	.227	.798**	.245	.143	.294	-.283	.434	-.517**	-.118	-					
13. PCS_T0	.181	-.078	.265	.444*	.792**	.032	-.210	.088	.125	.072	-.184	.202	-				
14. MCS_T0	-.118	-.071	.055	.173	-.127	.435*	.219	-.667**	.220	.187	.356	.152	-.090	-			
15. SDM_T0	.049	-.171	.309	.481*	.028	.126	.533**	-.441*	.325	-.024	.082	.475*	-.056	.306	-		
16. CARE_T0	-.190	-.106	.157	.330	.520**	-.174	-.269	.476	.197	-.221	-.271	.291	.623**	-.400	-.010	-	
17. SWD_T0	.205	-.033	.096	.225	-.281	.186	.291	-.140	-.050	-.009	.155	.440*	-.128	.137	.262	-.232	-

* $p < .05$; ** $p < .01$

Efficacy of the psychological consultation.

No significant differences were found in the level of adherence to treatments due to the psychological intervention. Regarding patients, the experimental group showed a significant higher score in physical health at the follow up ($t_{(31)} = -3.03$, $p < .01$) and empathy toward physicians ($t_{(28)} = -2.33$, $p < .05$). Although no statistically significant data emerged, a slight trend of improvement in the experimental group can be inferred for dyadic communication, depression, mental health, SDM, and satisfaction with decisions. The caregivers did not show any difference based on the intervention.

3.3.3. Discussion

Understanding psychological reactions and treatment decisions following a cancer diagnosis, and the interdependence between patient and caregiver along cancer trajectory, has always been an important issue in the context of SDM (Gorini & Pravettoni, 2011b; Howell et al., 2021). Our contribution provided evidence of how patients and caregivers react to BC diagnosis and after the starting of treatments, along with their involvement in SDM, their alignment toward the decisions and their reactions. As summarized in the introductory chapter of this dissertation, cancer can be considered a family disease, impacting both patients and caregivers (Chen et al., 2021; Kayser et al., 2007; Minuchin, 2018; Ștefănuț et al., 2023). Members of the dyad also influenced each other during the course of the illness, sometimes enacting what has been called dyadic coping (Dorros et al., 2010; Ferraris et al., 2022; Kelley et al., 2019; Segrin et al., 2020; Ștefănuț et al., 2023). Finally, patients and caregivers were involved in the SDM, even if in different way as reported in our previous systematic review and in the pilot study (Cincidda et al., 2023; Laidsaar-Powell et al., 2017)

Our sample was composed predominantly by middle-aged adults, married and well-educated. Only one patient was under 35 years old. Indeed, three quarters of BC cases occurred in individuals aged over 50 years, with an incidence of less than 5% in people aged up to 35 years (Dafni et al., 2019). Moreover, over half of the sample was from southern Italy. This figure might seem at odds with data found by the Ministry of Health that cancer incidence was declining in southern Italy compared to the north Italy (www.salute.gov.it). There was still a large gap between the North and the South Italy in terms of quality of medical care, leading people from the South to choose the North as a place to get treatment (Betti et al., 2023).

Regarding the patients and caregivers involvement in the DM, what emerged from our follow-up assessment was that the majority of the patients enacted the type of involvement in the DM they said they would prefer at baseline, in contrast to caregivers who just under half enacted involvement in line with their expressed preference. Specifically, patients preferred and actually shared their decision with caregivers, either sharing the responsibility or considering only caregivers' opinion. In contrast, caregivers preferred to have an active role in the DM, albeit considering patients' preferences/opinions, but ultimately let the patient decide or share the choice with them. These results were in line with our previous systematic review (Cincidda et al., 2023). Another important result was that the same percentage of dyads who, at baseline, agreed on the

preferred involvement in SDM (most of them preferred to share the responsibility of the decisions), continued to agree about medical treatment over time (e.g., surgery or neoadjuvant chemotherapy). Specifically, most dyads shared the responsibility of the decision, or the patient decided after having consulted the caregiver, as they preferred at the baseline. However, this percentage was not so high: only half of the dyads agreed on how they would be involved, or they were actually involved. This might be explained by probable communication problems: assuming they shared the same with about involvement, dyads did not mutually communicate about that. A confirmation came also from the pilot study on prostate cancer patients, which highlighted that few dyads agreed in sharing the DM responsibility. Finally, it was important to note that the majority of patients, regardless of the involvement that both they and the caregivers implemented, perceived the caregiver's involvement in SDM as helpful for communication, DM, and psychological support. Only a couple reported that the caregiver's involvement was detrimental for psychological support. These results supported the idea that the patient and caregivers can be seen as an autonomous DM unit, lending credence to the theories of relational autonomy previously stated in the introduction (Gómez-Vírseda et al., 2019, 2020; Ștefănuț et al., 2023). However, dyads reported experiencing an open and flowing exchange of ideas between them and more than half of the dyad agreed on their communication style, both at the baseline and at the follow up. A better communication style was related to an improved social support and empathy toward physicians along with less depression over time in the patients' sample (except for the empathy that is significant only at the baseline). This result suggested that patients in our sample talked openly to the caregivers, communicating their needs, and feeling supported. Taken together these results might seem conflicting; indeed, the fact that dyads openly communicated to each other their needs and fears did not mean that they also discussed what role they should/would play in the DM. It might also seem that DM involvement was something taken for granted, something did not need to be discussed. However, our data suggested the importance of helping dyads expressing their desired level of involvement in DM so as to improve cancer care pathway and prevent possible frictions.

If initially, after diagnosis at baseline, patients had higher psychological distress than caregivers, as for our previous pilot study, however, following treatment initiation, there was no more difference between dyad members in terms of psychological distress, thus caregivers reported higher psychological distress than the baseline. The psychological distress experienced at the baseline may predict the distress levels at the follow up for the dyads. A good overall mental health demonstrated to be protective for anxiety levels both at the baseline and follow up. Finally, it is important to emphasize that our results supported the theory of interdependence, showing that at follow-up there was a mutual influence on depression levels between dyad members (Ferraris et al., 2022; Segrin et al., 2020; Ștefănuț et al., 2023).

Concerning changes over time, our data showed that the effect of time after the treatment reduced the QoL in both patients and caregivers. Specifically, after the BC diagnosis, patients showed a worst mental health than the caregivers, while caregiver reported a better physical health than patients at the follow up. This confirms what already reported in literature, that treatments for BC have an impact on patient's physical health (Grusdat et al., 2022). Indeed, most of the patients underwent surgery (e.g., mastectomy or quadrantectomy) and the rest underwent neoadjuvant chemotherapy (Grusdat et al., 2022), and we were aware that surgery

compromise physical status and body image. As per the mental health, a good QoL at the baseline predicts a good QoL at the follow up.

The perceived social support reported by the patients mutually influence the one of the caregivers over time. Our data show that patients and caregivers perceived enhanced social support when they had good dyadic communication, mental health, or DM involvement, or less anxiety.

Dyads reported empathy and involvement in the DM with physicians at the two time points. This might mean that health professionals have taken charge of the patient and caregiver, providing the appropriate information in a clear manner. They made the dyads feel comfortable, inspiring confidence in them. However, caregivers reported overall lower level of involvement in the DM than the patients. This could happen since the patient remained the real focus for the physicians. Moreover, patients reported lower level of involvement at the follow up compared to the baseline, and this may be in line with the fact that tend to delegate the caregiver in managing the relationship with care and doctors over time. Few caregivers implement the real involvement they would have preferred at baseline. One possible explanation could be that caregivers are driven by wish to help patients and feel increasingly involved in the care process to the point of assuming a symbiotic position with the patient's condition. One confirmation from our results was that the more physician showed empathy to patients, the more the patients felt to be involved in DM. Patients who felt understood and welcomed in their entirety tend to trust physicians more and cooperate with them in treatment choices (Gorini & Pravettoni, 2011a; Laidsaar-Powell et al., 2017; Lamore et al., 2017). Finally, there was an interdependence between the involvement in DM and the empathy toward physicians among patients and caregivers' dyads. Patients are most satisfied with the decision made when they found the information received useful, communication with physicians clear, and perceived good support.

Finally, our sample reported a high satisfaction with decisions, especially who reported a high empathy toward physicians. Our sample of patients reported high adherence to treatment. In particular, they had a higher perception of cancer susceptibility and severity than the reference sample. However, it appeared that worse physical health is associated with higher adherence. This indicated to us that patients who had large effects on their health trusted the treatments and followed them to find improvement. Finally, better dyadic communication reduced beliefs about disease severity.

In conclusion, although our sample was divided into experimental and control, data on the effectiveness of the encounter with the psychologist emerged concerning, enhanced physical health and empathetic relation with physicians. A one-hour meeting could not be effective on adherence to cancer treatment, but this result gives us evidence about the usefulness of psychological support in oncology to improve the triadic relationship.

Notwithstanding, it is necessary to mention some of the limitations linked to this study. The relatively small sample size and the non-homogeneity of the sample may limit the generalization of results. Likewise, the lack of a sample representation for each dyad type makes it difficult to understand whether the results obtained may depend on specific relationship factors or not. Another limitation of this research is the lack of a good number of participants at the follow up. Questionnaires to assess psychological variables were self-

report and this may lead potential bias. Moreover, we didn't collect information about the quality of the relationship, and this may have impact on the results.

3.3.4. Conclusion

In conclusion, our results supported the idea of cancer as a family/unit disease and the interdependence between patients and caregiver in different psychological variables (Coyne et al., 2020; Ferraris et al., 2022; Kong & Guan, 2019; Ștefănuț et al., 2023; Trevino et al., 2019). Our result was in line with the conceptual framework proposed by Laidsaar-Powell and colleagues (2017), according to which caregivers are involved in various ways in the DM process, transforming the classic patient-physician interaction into a triadic relationship (patient, caregiver, and physician) (Laidsaar-Powell et al., 2017; LeBlanc et al., 2018; Mitnick et al., 2010; Renzi et al., 2016; Tulskey et al., 2022), and to the new theoretical framework of the relational autonomy (Gómez-Vírseda et al., 2019, 2020). These findings are important in that they make us reflect on the little agreement there is between patient and caregiver, which may turn into an unspoken that in the long run can lead to conflict and consequently worsen the care process and psychological distress. Starting from these results, it could be useful to develop a specific intervention protocol to promote a functional caregivers' involvement in cancer care pathway, improve patient's wellbeing, the interaction with physicians and the patient's compliance with the cancer treatment.

3.4. Study 4: Preliminary results of a qualitative assessment of diagnosis experience of Breast Cancer Patients and their Caregivers

3.4.1. Material and methods

This is a secondary analysis, in which researchers analyzed the qualitative data originally provided by participants in the experimental group of the previous longitudinal study. The Institutional Review Board (IRB) of the European Institute of Oncology approved the original trial, and all individuals enrolled in the study provided written documentation of consent to participate in research.

Specifically, 23 dyads were interviewed after 2 weeks from the enrollment for the clinical trial. Inclusion criteria for patients and caregivers as the one reported in the previous study.

Interviews and Study Procedure

As described in the previous study, after obtaining their informed consent and completing the first survey, a psychologist called the participants to schedule the meeting. An online or face to face meeting were conducted by the PhD candidate, a psychologist specialized in clinical and health psychology.

Face to face meeting were undertaken at the European Institute of Oncology for dyads living near the Institute, instead for those who lived far from the hospital, the psychologist conducted online meetings. In this case, the psychologist was always inside the Institute, while the dyads at their home. The meeting with the psychologist lasted 60 minutes. They were audio-recorded and subsequently transcribed verbatim. The meetings were conducted as a semi-structured interview. The interview guide was built by the PhD candidate along with her supervisor and co-supervisor, two highly specialized psychologists and psychotherapists. A pilot test was done with 3 dyads (excluded from this study). As no problem or difficulty was observed, no change was made in the interview schedule.

The analysis was conducted on the first part of the interview. This part was dedicated to the narrative expression of the experience of the diagnosis, the dyad's preferences regarding mutual involvement in the DM process, mutual emotions/fears, and needs, as well as the clarity of the information received by the medical team (see Table 19). In the second part of the intervention, the psychologist, after assessing the need for psychological support, provided personalized input and feedback on the themes that emerged during the first part of the intervention to foster the relationship between patient and caregiver.

Table 19. The interview schedule

The interview schedule
• How did you experience the cancer diagnosis? ◦ <i>Deepen the practical and emotional aspects and the exchanges between the dyads regarding the diagnosis (Who told who?).</i> • How have you experienced caregiver involvement in the care pathway?

- *For patients: elaborate on how the involvement happened and what psychological impact it had on them.*
- *For caregivers: elaborate on the degree of agreement on their involvement and what psychological impact it had on them.*
- How were the medical examinations and information received?
 - *Deepen the empathy of physicians and how they relate to caregivers and the quality of information received.*
- Which difficulties did and do you face?
 - *Deepen the needs and concerns they have experienced or think they may experience in the coming months.*

Statistical Analysis

Thematic analysis was used to analyze the transcribed data, which were entered into NVivo 12 of QSRInternational (Braun & Clarke, 2006; Creswell & Creswell, 2017). First, audio-recordings of dyads interviews were reviewed for accuracy and subsequently transcribed by the coders. Codes were generated by the researcher during the transcription process, which resulted in the generation of themes based on the research questions. The initial themes were reviewed by two experts in qualitative research and clinical practice (co-supervisor and internal advisor) and revised accordingly, resulting in concise themes reflecting the lived experiences of patients and caregivers. These themes were guided by the research questions and emerged from the thematic analysis. Thematic analysis is compatible with phenomenology, as both focus on providing meaning to people's subjective experiences (Guest et al., 2012).

3.4.2. Results

There were 23 eligible dyads who participated in this study. Their demographic characteristics are illustrated in Table 20.

Table 20. Descriptive statistics for the dyads' demographic variables

Variable	Patient (N = 23)	Caregiver (N = 23)
Age (M ± SD, range)	51.48 ± 8.22 31-63	48.87 ± 10.30 30-63
Gender		
Male	0%	82.6%
Female	100%	17.4%
Educational level		
Primary/middle school	8.7%	4.3%
High school	47.8%	56.5%
Bachelor/Master's degree	39.1%	34.8%
Post PhD	%	4.3%

Employment		
Blue-collar	4.3%	13%
White-collar	65.2%	87%
Unemployed	21.7%	0%
Retired	8.7%	0%
Origin		
North of Italy	39.1%	43.4%
Center of Italy	8.7%	8.6%
South of Italy	52.2%	52%
Relationship		
Parent/child	13%	13%
Sibling	8.7%	8.7%
Spouse/Partner	78.2%	78.2%
Treatment		
Surgery	100%	
Radiotherapy	30.43%	
Chemotherapy	21.74%	
Hormone Therapy	65.22%	

The thematic analysis of the patients' and caregivers' responses resulted in four themes which revolved around shock, being as a unit, trust, and fear, as seen in Figure 8. These themes are described in greater detail in the following sections.

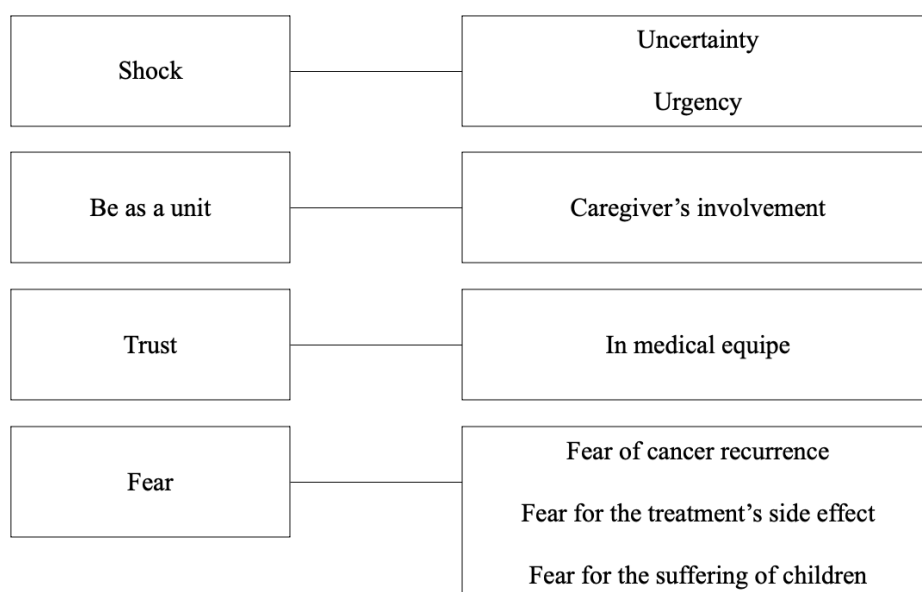


Figure 6. Summary table of themes generated from dyadic interviews.

Theme 1: Shock

This theme explores how dyads described and experienced the BC diagnosis. There was a sense of uncertainty and urgency as a central threat. Most patients report that the diagnosis was a shock, a trauma for them. "I didn't expect it, I still don't believe it, it's like it's about others" are some of the main sentences reported by the patients regarding cancer diagnosis. Following the diagnosis, patients felt lost, panicked,

surrounded by uncertainty and insecurity. The women saw themselves as overwhelmed, but also doing their best to navigate some tough decisions. Similarly, caregivers report experiencing the diagnosis as a shocking, unexpected event. Caregivers saw the patients as strong, able to handle the impact of cancer, sometimes much more than they did. Some caregivers did not expect this strength and courage in the patients and were pleasantly impressed. However, they remembered that patients have cancer and that they would make themselves available to patients for any needs.

Most dyads to cope with the anxiety and uncertainty they experienced sought information on the Internet, asked advice from those who had been through it before. What drove the dyads to seek information was the need for concreteness. Following the visit with the oncologist in which the course of treatment was outlined, the dyads felt reassured. Having a set path helped them in some way to manage the emotional component. However, there remained that feeling of urgency to start treatments (*I want to speed up the process*). Some patients report that "*the sooner you start, the sooner you finish*", although they recognize this feeling as a paradox. Patients reported that they would do whatever had to be done to get rid of the cancer. In fact, most of them see the initiation of treatment as the first concrete step in dealing with cancer.

This result highlighted that, even though cancer may only directly affect one person, it may impact both patients and caregivers and it can be understood as a family disease.

Theme 2: We are we in this together, is it so?

During the course of treatment, patients wanted to have caregivers by their side, to share with them the information they received and the decisions to be made. In addition, most patients would have liked to have had the caregiver next to them when they received the diagnosis so that they could allow themselves to let go of their emotions and not feel that they had to take in all the information on their own and then have to report it to the caregiver. Some patients received confirmation of the diagnosis via email by reading it together with the caregiver, in which case, although they felt a unity and able to share the emotional reaction, they felt full of uncertainty and confusion about what to do. The dyads composed of mother and children show how the patients (mothers in this case) wanted to share the journey with their children, to make them participants, albeit making the decisions themselves.

Similarly, caregivers wanted to be by the patients' side, ready to support them in the decisions and the journey ahead. This shows how the dyads wanted to receive and digest information together. A dyad reported that "*we're in this boat and we need to get through this thing together*". Although the dyads wanted to go through this journey together, not all patients perceived caregiver support as effective. In particular, one patient reported that her caregiver was not an emotional support for her at all because of character differences.

Theme 3: trust in healthcare professional

All dyads reported that they felt welcomed by all professionals in the hospital. During their visits, the information they received was clear and precise enough to leave no doubt. Only a few dyads reported feeling judged by the oncologist as unable to handle a cancer diagnosis. Almost all of the dyads were not faced with a

decision, as there was only one direction to go because of the tumor characteristics. In any case, all dyads trusted the doctors and what was proposed to them.

Themes 4: Our fears

When asked what the patients' and caregivers' current fears were, we received different answers. Most patients reported that they were afraid of the adverse effects of treatments, such as chemotherapy or radiotherapy. In fact, due to chemotherapy patients could lose their hair and undergo body changes. These alterations made it difficult for patients to continue living their lives, being ashamed of their appearance. Other patients, on the other hand, feared that they would not be able to do normal daily chores, such as cooking, shopping, and driving. These worries especially affected patients with minor children, and they felt guilty about not being able to take care of their children for a while. Other patients, on the other hand, feared the surgery and were uncomfortable with the idea of breast reconstruction, experiencing it as something foreign, outside of them.

Another fear that emerged was the fear of cancer recurrence. Many patients were focused on the possibility of having a recurrence. Some of them emphasized the fact that once you have cancer, it stays inside you, like a time bomb, ready to explode again.

In contrast, the caregivers did not report these fears, feeling more positive than the patients. Some of them really did not want to think about the possibility of the return of cancer or the possibility of death. Moreover, caregivers did not perceive the possible adverse effects of treatments as negatively, finding different solutions to them. Caregivers were worried about their ability to support the patients along the cancer journey and about their capacity to take care of the entire family system.

However, dyads with minor children were concerned about how they could communicate the diagnosis to their children, if they had not yet done so, or how best to manage post-surgery and post-treatment. Parents did not want to hurt or worry their children too much.

3.4.3. Discussion

The purpose of this semi-structured interview was to investigate how the dyads experienced the moment of BC diagnosis, mutual involvement in the treatment pathway, trust in doctors and their fears. The analysis has provided an insight into the process for the dyad, as they walk together the care path. The most striking aspect is that although the dyads wanted to walk the path of care together as a unit, their fears were completely different.

As reported in literature, both patients and caregivers perceived the diagnosis as an unexpected and shocking event that brought with it a variety of emotions, such as anxiety, fear, guilt, and anger (Di Giuseppe et al., 2018; Petrocchi et al., 2022). The need for information on what to do leads dyads to search for information on the Internet or to ask those who have been there before, risking receiving untrue information. In fact, the experience of illness is very subjective and differs from patient to patient. In addition, as technologies advance, therapeutic treatments may also have changed. This fact, however, leads us to recognize

the importance of providing a diagnosis in person, along with all the information she needs. Dyads not only need to know the type of tumor they have, the severity, etc., but also need to know what steps they need to go through, what visits to book, who to refer to in case of need. It is crucial not to leave dyads alone with many doubts in their minds.

Both patients and caregivers preferred to be together during the visit, and this finding may lead us to support the idea that the gold standard in medical decisions is the SDM among patients, physicians, and, caregivers (Charles et al., 1999; Chichua et al., 2022; Elliott & Olver, 2008; Gómez-Vírseda et al., 2020; Kashaf & McGill, 2015; Levine & Zuckerman, 2000; Maes-Carballo et al., 2021; Osamor & Grady, 2018; Politi et al., 2012; Pravettoni et al., 2016; Sahlberg-Blom et al., 2000; Steffensen et al., 2018; Ullrich et al., 2020). However, it is very subjective how patients want to make decisions, in fact it emerges that although they want caregivers by their side, some of them prefer to make their own decisions and then share them with caregivers. This finding seen from a relational perspective, however, supports the importance of SDM and relational autonomy (Gómez-Vírseda et al., 2019, 2020). Indeed, patients are placed in a relational context and although not directly affected by it (Blackler, 2016; Chan, 2004; Ikonomidis & Singer, 1999; Mackenzie & Rogers, 2013; Wardrope, 2014; F. Wilson et al., 2014).

Finally, the most interesting result concerns the fears expressed by the dyads. Patients who are those who experience cancer on their own skin have fears that are focused on cancer. For example, the fear of adverse effects on the body has also been extensively studied in the literature (Sebri et al., 2021; Ștefănuț et al., 2023). Physical changes can also go to affect caregivers when dyads are composed of couples, going to impact the sphere of intimacy and sexuality. In addition, physical changes impact patients' personal image, which also spills over into their social self-image. The FCR seems to be an irrational to experience when patients receive a cancer diagnosis, however, most of them experienced this fear due to past experience of others (Cincidda, Pizzoli, et al., 2022). Whereas caregivers were less focus on cancer and more focus on their ability to support patients and take care of the entire family. Indeed, caregivers assisted patients with daily living activities, sometimes modifying their lifestyle by restricting their leisure activities (Johnson & Ross, 2023; Karimi Moghaddam et al., 2023; Rohith & Patel, 2022). All these issues may enhance the level of psychological distress in caregivers along the cancer journey. However, this result is in contrast with literature (Martinez et al., 2020).

Form these interviews we had the sensation that patients and caregivers reported to be always align with the decisions to make, hiding the real situation. This sensation was confirmed looking at the results from the quantitative study.

3.4.4. Conclusion

In conclusion, taking together all the results from the three studies, we can affirm that cancer is a family disease impacting both on patients and caregivers (Minuchin, 2018; Petrocchi et al., 2022; Ștefănuț et al., 2023). However, not always patients and caregivers had a mutually psychological influence. It is important to underlying that there was an interdependence among patient and caregiver involvement in SDM. This

means that when patients felt themselves involved by the physicians in the SDM, at the same time even caregiver felt the same.

The main finding of our studies was the low level of agreement between patients and caregivers in their involvement in the DM, that is in contrast with what they assumed during the semi-structured interview. This led us to assess the importance of a specific psychological intervention for dyads in order to let the dyad able to express their need, preferences, and fear.

4. Moral conflicts among patients-caregivers' dyads in oncological care pathway.

The last two studies involved in the present thesis focused on the bioethical aspects related to the caregivers' involvement in the oncological care path. Firstly, a systematic review exploring the nature of conflicts within dyads from an ethical standpoint (Cincidda et al., under review) was conducted. Then, a case study was presented with the aim to explore and assess the concept of moral conflict, investigating it in a qualitative manner, at the beginning of the cancer trajectory.

4.1. Study 5: A systematic review of the moral conflicts emerging along the cancer care.

During the cancer treatment trajectory, patients may be asked to take several decisions, concerning from the hospital at which to be treated, the daily management of cancer treatments' effect, to the order not-to-resuscitate (DNR) (R. Laidsaar-Powell et al., 2017; Renzi et al., 2016). From a (bio)ethical standpoint, individuals have the right to act in accordance with a principle of autonomy, which entitles them to decide by themselves and exercise self-determination regarding their own health (Gómez-Vírseda et al., 2020). However, as we demonstrate in this PhD dissertation, cancer patients are almost always in a network of interpersonal relationships that can influence their decisions; such network may impact their autonomy, if interpreted in its traditional, non-relational, meaning (Gómez-Vírseda et al., 2020; Levine & Zuckerman, 2000; Osamor & Grady, 2018; Sahlberg-Blom et al., 2000; Ullrich et al., 2020). Moreover, quite often patients intentionally involve caregivers in the DM process; by doing this, caregivers themselves may feel entitled to influence patients' decisions; they also inevitably bring a series of emotional reactions, interpersonal dynamics, and expectations (Blackler, 2016; Cincidda et al., 2023; Hobbs et al., 2015; Laryionava et al., 2021; Meeker & Jezewski, 2005; Reiter-Theil, 2003; Schäfer et al., 2006; Ullrich et al., 2020). Such considerations suggest that the best practice in medical DM cannot rest in one single actor – either the patient or the caregiver – taking the decision. Accordingly, the gold standard in medical decisions has become the SDM among patient, physicians and in some cases caregivers (Charles et al., 1999; Chichua et al., 2022; Kashaf & McGill, 2015; Maes-Carballo et al., 2021; Politi et al., 2012; Steffensen et al., 2018), which, from an ethical standpoint, seems to incorporate an interpretation of autonomy as a relational principle, namely “relational autonomy” (Baumann, 2008; Cranley et al., 2020; Gómez-Vírseda et al., 2020; Grignoli et al., 2018; Lolich & Lynch, 2017; Mackenzie & Stoljar, 2000; F. Wilson et al., 2014).

However, social relations in the context of cancer and its treatment trajectory have proven not only supportive, but also conflictual and stressful (Hansen & Tjørnhøj-Thomsen, 2020). In other words, the presence of the caregiver may be both a facilitator and a barrier to the DM process (Blackler, 2016; Cincidda et al., 2023; Cincidda, Oliveri, et al., 2022). In particular, it has been shown that agreement among patients and their caregivers on the decisions to be made may reduce patient's “decision regret” and improve adherence to care process (Calderon et al., 2019; Cincidda et al., 2023; A. Wilson et al., 2017). Conversely, disagreement among the two appears to have a negative impact on the patient, affecting the understanding of medical information, compliance with therapies and, consequently, the patient's quality of life, including his/her relationship with the

caregiver (Benson et al., 2019; François et al., 2017; Hamano et al., 2018; Hopeck & Harrison, 2017; Shin et al., 2016). In some specific contexts, these decisions may appear ever more complex because of the implications these may have for the patients involved. For instance, in the context of palliative and end-of-life care, patients (and/or their caregiver) may have to choose over life-prolonging treatment, the “do not to resuscitate” (DNR) option, palliative sedation, medically assisted nutrition and hydration. In addition to deciding on these important aspects of the treatment pathway, there are also a range of more practical and organizational choices to be made: on the preferred place of death, burial indications, funeral arrangements, etc. Such decisions may generate additional stress and conflicts and can be experienced as stressful and burdensome not only by patients, but also by caregivers (Ullrich et al., 2020).

Conflictual DM processes can arise when the (competent) patient and the caregiver are not aligned on the decision to be made, but even when the caregiver disagrees with the decision taken by an incompetent patient at the time when he/she was competent. However, conflicts within a family may be somehow considered as a natural phenomenon that not necessarily ends up in a disruptive event. On the contrary, if generator of mutual dialogue and perceived as solvable, family conflict may also turn into something positive (Benson et al., 2019; Laryionava et al., 2018).

The aim of this systematic review is to investigate decisional conflicts arising in cancer patients’ care process, originating from caregiver’s involvement, as well their outcomes on the dyadic relationship and the care process. Although there may be several perspectives through which this phenomenon may be analyzed, such conflict will be here explored through the lens of (bio)ethical scrutiny, namely as an ethical concept.

Although several studies explore this phenomenon from a psychological perspective (i.e., psychological conflicts occurring in the patient-caregiver relationships) (Higginson et al., 2015; Nissen et al., 2016; Rajanala et al., 2020; Taurisano et al., 2022), to the best of our knowledge no systematic collection of “moral conflicts” (i.e., conflicts pertaining to ethically related issues) occurring among patients and their caregivers in cancer care path is available in current bioethics literature. Filling this scholarly gap appears of utmost importance not only to shed some light on a still underexplored research perspective, but also to have a comprehensive view of the cancer patient care process, including the fundamental component of the relationship with caregivers. Therefore, better clarifying the origin, nature, impact, and potential solutions to moral conflicts occurring among the patients-caregivers’ dyads appear, to us, as a further step towards the improvement of the cancer patient condition.

4.1.1. Material and methods

To have a comprehensive overview of potential moral conflicts originating from caregiver’s involvement during the oncological care process, we conducted a systematic review of bioethics literature, broadly considered, thus including also applied philosophy and medical anthropology literature.

The review process consisted of the following steps: first, we identified our research questions; second, we defined thematic groups; third, based on the thematic groups, we developed research strings to be

inserted in databases which were then queried; then, results were all screened according to the process described in the PRISMA guidelines¹ (Liberati et al., 2009a). The whole process is described in detail below.

Research questions

This systematic review aims to provide an answer to the following groups of research questions:

- Are there some moral conflicts, i.e., conflicts related to ethically related issues, occurring among patients and their caregivers within in cancer care path? If yes, what is the origin and nature of these moral conflicts?
- What are the triggers of (or factors leading to) moral conflicts occurring in oncological care process? What is the impact of moral conflicts for patients and caregivers?
- What are the solutions proposed by the literature to moral conflicts occurring in oncological care process?

Search strategy

The afore research questions were then drawn out in four groups of concepts to systematize our literature research (Table 21).

Table 21. Group of organizing concepts and associated database search terms.

Group 1: Caregiver	Group 2: Involvement	Group 3: Cancer	Group 4: Ethics
Caregiver - Caregivers Attendant Parent - Parents Relative - Relatives Partner Spouse Significant others Caretaker Companion	Involvement Relationship Agreement Disagreement Engagement Support Participation	Cancer Cancer patient Cancer treatment Cancer path Cancer trajectory Oncology Oncological patient Oncological treatment Oncological path Palliative care End of life Decision-making	Ethics Bioethics Medical anthropology Ethical issue Ethical challenge Bioethical issue Bioethical challenge Moral dilemma

The purpose of Group 1 was to gather scientific papers focusing on the concept of caregiving and/or akin concepts, e.g., caregiver, spouse, parent. The purpose of Group 2 was to collect scientific papers focusing on the concept of involvement and/or akin concepts, e.g., relationship, and the concept of conflict and/or akin concepts, e.g., disagreement. The purpose of Group 3 was to select a specific population of investigation, i.e., cancer patients. The purpose of Group 4 was to define the disciplinary domains where to find

¹ A PRISMA guidelines statement specifically designed for ethics literature was recently published (PRISMA-Ethics – Reporting Guideline for Systematic Reviews on Ethics Literature: development, explanations and examples Kahrass et al. 2021). However, since the search for this systematic review was done prior to the publication of this article, we followed Liberati et al. 2009.

conceptualizations of the terms belonging to Group 2. As mentioned in the Introduction, the concept of conflict may be analyzed from different perspectives: clinical, psychological, bioethical, philosophical, anthropological, etc. We narrowed to publications exploring this issue from a (bio)ethical perspective, broadly considered, thus also including applied philosophy and medical anthropology. Some publications raised considerations at the crossroads of applied ethics and clinical psychology. In case of a thematic overlap between these two disciplinary domains, publications were eventually included, to be sure to include contributions potentially relevant from a bioethical perspective.

Each group concept was expressed in specific database search terms in a suitable format for the different database queries (Table 22). Research strings were developed by the PhD candidate in consultation with the internal advisor.

Table 22. Search strings.

Database	Date	Group 1: Family		Group 2: Involvement		Group 3: Cancer		Group 4: Ethics	Results
PubMed	10 March 2021	((((((((((((caregivers[MeSH Terms]) OR (spouses[MeSH Terms])) OR (parents[MeSH Terms])) OR (companion[MeSH Terms])) OR (caregiver[Title/Abstract])) OR (caregivers[Title/Abstract])) OR (attendant[Title/Abstract])) OR (spouse[Title/Abstract])) OR (parents[Title/Abstract])) OR (parent[Title/Abstract])) OR (relatives[Title/Abstract])) OR (partner[Title/Abstract])) OR (significant others[Title/Abstract])) OR (companion[Title/Abstract])) OR (caretaker[Title/Abstract]))	A N D	((((((((((((consensus[MeSH Terms]) OR (family conflicts[MeSH Terms])) OR (social support[MeSH Terms])) OR (involvement[Title/Abstract])) OR (relationship[Title/Abstract])) OR (engagement[Title/Abstract])) OR (agreement[Title/Abstract])) OR (consensus[Title/Abstract])) OR (disagreement[Title/Abstract])) OR (family conflicts[Title/Abstract])) OR (support[Title/Abstract])) OR (social support[Title/Abstract])) OR (participation[Title/Abstract]))	A N D	((((((((((((((((neoplasm[MeSH Terms]) OR (palliative care[MeSH Terms])) OR (terminal care[MeSH Terms])) OR (decision making[MeSH Terms])) OR (decision making, shared[MeSH Terms])) OR (cancer[Title/Abstract])) OR (neoplasm[Title/Abstract])) OR (cancer patient[Title/Abstract])) OR (cancer treatment[Title/Abstract])) OR (cancer path[Title/Abstract])) OR (cancer trajectory[Title/Abstract])) OR (oncology[Title/Abstract])) OR (oncological path[Title/Abstract])) OR (oncological treatment[Title/Abstract])) OR (oncological patient[Title/Abstract])) OR (palliative care[Title/Abstract])) OR (end of life[Title/Abstract])) OR (terminal care[Title/Abstract])) OR (decision making[Title/Abstract])) OR (shared decision making[Title/Abstract]))	A N D	(((((((ethics[MeSH Terms]) OR (bioethics[MeSH Terms])) OR (anthropology, medical[MeSH Terms])) OR (ethics[Title/Abstract])) OR (bioethics[Title/Abstract])) OR (anthropology, medical[Title/Abstract])) OR (ethical challenge*[Title/Abstract])) OR (bioethical challenge*[Title/Abstract]))	n = 1494
Web of Science	10 March 2021	TS=(caregiver* OR spouse* OR parents OR companion OR attendant OR relatives OR partner OR significant others OR caretaker)	A N D	TS=(consensus OR family conflicts OR social support OR involvement OR relationship OR engagement OR agreement OR disagreement OR support OR participation)	A N D	TS=(neoplasm OR palliative care OR terminal care OR decision making OR shared decision making OR cancer OR cancer patient OR cancer treatment OR cancer path OR cancer trajectory OR oncology OR oncological path OR oncological treatment OR oncological patient OR end of life)	A N D	TS=(ethics OR bioethics OR medical anthropology OR ethical challenge* OR bioethical challenge*)	n = 1697

PsycINFO	10 March 2021	(caregivers or spouses or parents or companion).mh. or caregivers.ti. or caregivers.ab. or attendant.ti. or attendant.ab. or spouse.ti. or spouse.ab. or parents.ti. or parents.ab. or relatives.ti. or relatives.ab. or partner.ti. or partner.ab. or significant others.ti. or significant others.ab. or companion.ti. or companion.ab. or caretaker.ti. or caretaker.ab.	A N D (consensus or family conflicts or social support).mh. or involvement.ab. or involvement.ti. or relationship.ab. or relationship.ti. or engagement.ab. or engagement.ti. or agreement.ab. or agreement.ti. or consensus.ab. or consensus.ti. or disagreement.ab. or disagreement.ti. or family conflicts.ab. or family conflicts.ti. or support.ab. or support.ti. or social support.ab. or social support.ti. or participation.ab. or participation.ti.	A N D (neoplasm or palliative care or terminal care or decision making or shared decision making).mh. or cancer.ab. or cancer.ti. or neoplasm.ab. or neoplasm.ti. or cancer patient.ab. or cancer patient.ti. or cancer treatment.ab. or cancer treatment.ti. or cancer path.ab. or cancer path.ti. or cancer trajectory.ab. or cancer trajectory.ti. or oncology.ab. or oncology.ti. or oncological path.ab. or oncological path.ti. or oncological treatment.ab. or oncological treatment.ti. or oncological patient.ti. or oncological patient.ab. or palliative care.ti. or palliative care.ab. or end of life.ti. or end of life.ab. or terminal care.ti. or terminal care.ab. or decision making.ti. or decision making.ab. or shared decision making.ti. or shared decision making.ab.	A N D (ethics or bioethics or medical anthropology).mh. or ethics.ti. or ethics.ab. or bioethics.ti. or bioethics.ab. or medical anthropology.ti. or medical anthropology.ab. or ethical challenge*.ti. or ethical challenge*.ab. or bioethical challenge*.ti. or bioethical challenge*.ab.	n = 154
Philosopher's Index	10 March 2021	noft(caregiver*) OR noft(spouse*) OR noft(parents) OR noft(companion) OR noft(attendant) OR noft(relatives) OR noft(partner) OR noft(significant others) OR noft(caretaker)	A N D noft(consensus) OR noft(family conflict) OR noft(social support) OR noft(involvement) OR noft(relationship) OR noft(engagement) OR noft(agreement) OR noft(disagreement) OR noft(support) OR noft(participation)	A N D noft(neoplasm) OR noft(palliative care) OR noft(terminal care) OR noft(decision making) OR noft(shared decision making) OR noft(cancer) OR noft(cancer patient) OR noft(cancer treatment) OR noft(cancer path) OR noft(cancer trajectory) OR noft(oncology) OR noft(oncological path) OR noft(oncological treatment) OR noft(oncological patient) OR noft(end of life)	A N D noft(ethics) OR noft(bioethics) OR noft(medical anthropology) OR noft(ethical challenge*) OR noft(bioethical challenge*)	n = 220
Cinahl	10 March 2021	(MH caregivers or MH spouses or MH parents or MH companion or TI caregiver or	(MH consensus or MH family conflicts or MH social support or TI involvement or	(MH neoplasm or MH palliative care or MH terminal care or MH decision making or MH shared	(MH ethics or MH bioethics or MH medical anthropology or TI ethics or AB ethics or TI bioethics	n = 370

		AB caregiver or TI caregivers or AB caregivers or TI attendant or AB attendant or TI spouse or AB spouse or TI parents or AB parents or TI parent or AB parent or TI relatives or AB relatives or TI partner or AB partner or TI significant others or AB significant others or TI companion or AB companion or TI caretaker or AB caretaker)	A N D	AB involvement or TI relationship or AB relationship or TI engagement or AB engagement or TI agreement or AB agreement or TI consensus or AB consensus or TI disagreement or AB disagreement or TI family conflicts or AB family conflicts or TI support or AB support or TI social support or AB social support or TI participation or AB participation)	A N D	decision making or TI cancer or AB cancer or TI neoplasm or AB neoplasm or TI cancer patient or AB cancer patient or TI cancer treatment or AB cancer treatment or TI cancer path or AB cancer path or TI cancer trajectory or AB cancer trajectory or TI oncology or AB oncology or TI oncological path or AB oncological path or TI oncological treatment or AB oncological treatment or TI oncological patient or AB oncological patient or TI palliative care or AB palliative care or TI end of life or AB end of life or TI terminal care or AB terminal care or TI decision making or AB decision making or TI shared decision making or AB shared decision making)	A N D	or AB bioethics or TI medical anthropology or AB medical anthropology or TI ethical challenge* or AB ethical challenge* or TI bioethical challenge* or AB bioethical challenge*)	
TOTAL									3935

Five major databases were queried: PubMed, Web of Science, PsycINFO, Philosopher's Index, Cinahl. These databases cover the fields of ethics, bioethics, philosophy, and medical anthropology.

Research was conducted on the 10th of March 2021, using only the language filter restriction: only paper available in English. Table 2 shows not only the terms used to make the search, but also the number of results returned using the search terms.

Using EndNote (version X9, Clarivate Analytics, Philadelphia, PA, USA) reference library, resulting citations of the identified papers were merged, and duplicates (N=866) were manually deleted by the PhD candidate. Then, titles, abstracts, and full texts of identified papers were screened according to the inclusion and exclusion criteria (see the section Inclusion and Exclusion criteria below). Abstract screening (N=580) was performed independently by the PhD candidate and the internal advisor to verify the consistency of our criteria and to ensure scientific and methodological rigorousness of the abstract selection. In 91.53% of the abstracts (N=540 out of 580), authors agreed to include them for the next step. The remaining abstracts (8.47%, corresponding to 40 articles) were subjected to discussion until an agreement was reached. Then, the PhD candidate and the internal advisor screened the full text of the remaining records (N=60) independently. A total of 17 articles were included in the review process. In case of unavailable papers, authors contacted the first and/or corresponding author to request a PDF copy of it. Snowball technique and citation tracking were also used to identify potentially additional relevant publications: six additional articles that met the inclusion criteria were retrieved through reference manual searching and included.

Finally, a total of 21 studies were included in the review. The search process was conducted according to the statement and flowchart of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Liberati et al., 2009a) (Fig. 9). The final list of included publications is reported in Table 23.

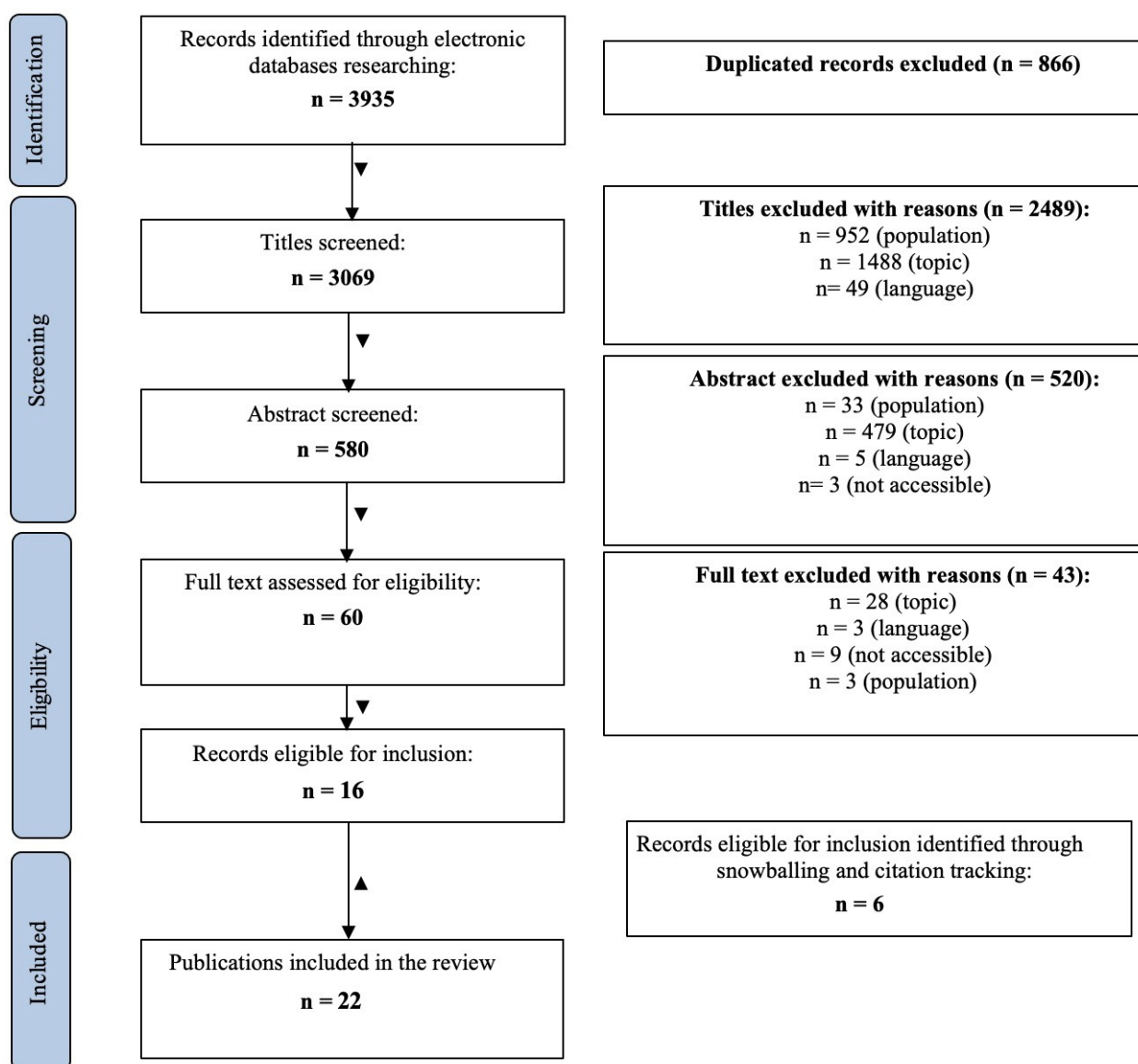


Figure 7. PRISMA flowchart.

Table 23. Final list of included publications.

Nº	Author	First author's publication country	Publication Year	First author's background
1	Benson, J. J.,	USA	2019	Family gerontology
2	Blackler, L.	USA	2016	Bioethics
3	Elliott, J.,	Australia	2008	Social Scientist
4	Hansen, H. P.	Denmark	2020	Anthropology
5	Hauke, D.	Germany	2011	Internal medicine
6	Kagawa-Singer, M.	USA	2003	Nursing and anthropology
7	Korfage, I. J.	UK/Netherland	2013	Economy and epidemiology
8	Laryionava, K.	Germany	2021	Oncology
9	Laryionava, K.	Germany	2018	Oncology
10	Levine, C.	USA	1999	Psychology
11	Levine, C.	USA	2000	Psychology
12	Mazer, B. L.	USA	2014	Anatomic and clinical pathology
13	Osamor, P. E.	USA	2018	Medical sociology

14	Sahlberg-Blom, E.	Sweden	2000	Nursing
15	Ullrich, A.	Germany	2020	Medical Psychology
16	François, K.	Australia	2017	Life Science and Public Health
17	Hamano, J.	Japan	2018	Internal medicine
18	Kramer, B.J.	USA	2009	Qualitative Social Research
19	Kramer, B.J.	USA	2013	Qualitative Social Research
20	Hopeck, P.	USA	2017	Communication
21	Boelk, A.Z	USA	2012	Sociology and social work
22	Vivian, R.	UK	2006	Nursing

Inclusion criteria

Only the candidate publications that met all the inclusion criteria and had no exclusionary ones were included in our systematic review. Publications were included based on the following conditions: (a) they address the concept of conflict resulting from caregiver's involvement in cancer patient's care process as specific topic; (b) they include only actually legally-competent patients (i.e., patients considered as capable of DM capacity), or patients who had expressed their own perspective when still competent; (c) the conflict was analyzed and discussed from a bioethical perspective, broadly considered (see above); (d) research articles were published in English.

Exclusion criteria

The following publications were excluded from the review: (a) studies addressing the caregiver's involvement in the oncological care path of the competent patient, but which do not present conflict as specific topic of investigation; (b) studies focusing on the concept of conflict generated by caregiver's involvement, but not specific to the oncological context; (c) studies focusing on the concept of conflict generated by caregiver's involvement in the oncological context, but where conflict originates from previously stated decisions taken by currently incompetent patients; (d) studies focusing on the concept of conflict generated by caregiver's involvement in the oncological context, occurring among competent patients and their caregivers, but where conflict is not analyzed also as an ethical concept (e.g., as purely psychological phenomenon); (e) contributions not published in English, (f) editorials, books, conference proceeding, and book chapters.

Data extraction and synthesis

Data analysis and synthesis were conducted according to the five preparatory steps of the coding process detailed in the "Qualitative Analysis Guide of Leuven" (QUAGOL) (Dierckx de Casterlé et al., 2021). Initially, the first author (CC) read and reread all the included articles, underlining the relevant parts for the purpose of the review. Subsequently, the same author summarized narratively these parts and created a conceptual scheme for each publication (an example of the conceptual scheme is available in Appendix 1). Then, the first (CC) and the co-first author (VS) examined each conceptual scheme to assess the accuracy of them in relation to publications included, and in case of doubt, they discussed the content of the conceptual schemes until they agreed on their adequacy. Finally, conceptual schemes were analyzed in relation to our research questions. This led to a comprehensive scheme that integrated the most relevant ethical issues

emerging from caregiver's involvement during the oncological care process of competent patients (e.g., types of ethical conflicts, nature of these conflicts, etc.). This scheme was controlled against previous QUAGOL steps to ensure its adequacy. Finally, we synthesized a description of the results.

4.1.2. Results

General description of included publications

Twenty-two publications met our inclusion criteria and were therefore included in our systematic review. A detailed description of the general characteristics of the included publications is reported in Table 24.

Table 24. Description of characteristics of included publications

Analyzed features (Number of Publication) / Paper N as listed in Table 3
<i>Type of research</i> Theoretical: 2, 11, 13, 22 Qualitative: 1, 3, 4, 7, 8, 9, 10, 12, 14, 15, 16, 19, 20, 21 Quantitative: 5, 17 Mixed methods: 6, 19
<i>Participants enrolled.</i> Patients: 2, 3, 4, 5, 6, 7, 12, 14, 22 Caregivers: 1, 3, 5, 12, 15, 16, 17, 21, 22 Healthcare professional: 7, 8, 9, 10, 12, 16, 19, 20, 21, 22
<i>First author's publication country</i> Americas: 1, 2, 6, 11, 12, 13, 14, 19, 20, 21, 22 Europe: 4, 5, 7, 8, 9, 10, 15, 16, 17 Australia: 3 Asia: 18
<i>Years of publication</i> 2021-2016: 1, 2, 4, 7, 9, 10, 14, 16, 17, 18, 21, 2015-2011: 5, 8, 13, 20, 22 2010-2006: 3, 19 2005-2001: 6 Before 2001: 11, 12, 15

Because of the very specific focus of the topic investigated, we included publications covering a theoretical, qualitative, and quantitative literature giving different ethical perspectives regarding a conflictual involvement of caregivers during the oncological care path of competent patients. Of the twenty-two articles included in the review, fourteen made a qualitative evaluation of the concepts through interviews (1, 3, 4, 7, 8,

9, 10, 12, 14, 15, 16, 18, 20, 21), four articles describe theoretical models for family conflict management (2, 11, 13, 22), two of which made a qualitative evaluation through a case report (2, 22). The remaining papers used mixed methods (6, 19) and only two were quantitative studies (5, 17).

Most of the publications were published between 2016 and 2021 (1, 2, 4, 8, 9, 13, 15, 16, 17, 20), the others covered a period up to 1999. Studies were from the Americas, Europe, Australia, and Asia; that is, the first author and/or corresponding author was from one of these continents. However, most of the papers came from studies conducted in the Americas (N = 11) and in Europe (N = 9).

The enrolled participants are healthcare professionals in five studies (8, 9, 10, 19, 20), caregivers (e.g., family members) in three studies (1, 15, 17), patients in four studies (2, 4, 6, 14). In the remaining six studies, participants were composed of both patients and caregivers (3, 5), or patients and healthcare professionals (7) or patients, caregivers, and healthcare professionals (12, 22). Only in three studies, patients were not included as participants (16, 21). No sample was present in the three theoretical studies (11, 13, 18).

Our analysis and synthesis supported a fourfold structure of the included publications (Table 25). This structure can be conceived of as sections. The first section provides an overview of who the caregivers are in our selected publications, thus better clarifying the concept of “dyads” and how dyads are usually composed. Then, we outline the different theoretical conceptualizations of the broadly defined concept of “moral conflict”. In this second section, for each conceptualization, the conflict is analyzed mostly considering the perspective of the two members of the dyad, patients, and caregivers. In case where patient-caregiver conflict was referred to as originating from (or strictly related to) physician’s involvement, we also analyzed the triadic relationship among the patient, his/her caregiver, and the caring physician (mostly the oncologist). The third section presents the factors associated to conflicts occurring among patients and caregivers. The fourth section deals with the strategies proposed by the literature that could be used to address such conflicts.

Table 25. Global scheme emerging from analysis of the 22 included publications*

Main results	Included articles
1. Caregivers identity	
Relatives	1, 5, 8, 14, 15, 16, 18
Children	1
Spouse/partners	1, 2, 4, 6, 13, 15
Family members	2, 3, 7, 9, 10, 11, 17, 18, 20, 21, 22
Friends	15
2. Type of conflict	
Conflict between values	1, 5, 7, 8, 9, 10, 16, 18, 19, 20, 21
Conflict between interests	1, 2, 5, 8, 9, 10, 11, 12, 14
Conflict related to decisional responsibilities	1, 2, 3, 5, 9, 13, 14, 15, 17, 22
Relational conflicts	4, 6
3. Factors related to conflict	
Caregiver's stressors	1, 2, 8, 9, 11, 15
Familial context	9, 11, 17, 18, 19, 21
Disease duration and/or severity	5, 10, 21
4. Conflict management	
Formal support provider (e.g., psycho-oncologist, clinical ethics consultant/clinical ethics support services)	1, 2, 7, 9, 11, 16,
Co-determination	13, 14
Psychological techniques (e.g., assertive communication, emotional self-care, refocusing, reconciling, referring, reflecting, reframing)	1, 20

* A single article can be represented more than once

“Caregivers”: who are they and what follows from their involvement.

The presence of at least one caregiver during the cancer patient's care path, from the diagnosis to the end of life, emerges in half of the articles identified in this review (1, 2, 4, 5, 6, 7, 8, 12, 14, 15, 17).

Throughout the care process, the oncological patient and her caregiver are so strictly connected that they may be viewed as a unit in a relationship or as a dyad (11).

In the included articles caregivers are relatives (1, 5, 8, 14, 15, 16, 18), partners/spouses (1, 2, 4, 6, 13, 15), children of the patients (1), friends (15), and others family members who provide unpaid care and assistance in daily living activities of patients (2, 3, 7, 9, 10, 11, 17, 18, 20, 21, 22).

Caregiver's involvement in medical DM process is considered important by oncologists and nurses (17). Indeed, family members appear to play a supportive and accompanying role that may facilitate the understanding and management of information related to treatment decisions (8, 9). However, caregivers may also feel some psychological and psychosocial stressors that affect their coping strategies, mood, and DM abilities (1, 2, 11, 18).

Although in some articles patients actively involve their caregivers (1, 2, 4, 5, 10, 11, 18, 21, 22), this is not always the case (9). This may generate episodes of conflicts or tensions among them (1, 2, 4, 5, 10, 11, 18, 21, 22). The nature of these conflicts, their origins, and implications on the care process will be explained in detail below.

"Conflicts" among patients and caregivers in the care process: labels, meanings, and object under discussion

In the included articles, what we referred to as "conflict" is labelled differently and presents different connotations, sometimes overlapping. We identified four types of moral conflicts, which we will refer herein to as "conflict between values" or "ethical disagreement" (1, 5, 7, 8, 9, 10, 16, 18, 19, 20, 21), "conflict between interests" (1, 2, 5, 8, 9, 10, 11, 12), "conflict related to decisional responsibilities and autonomous DM" (1, 2, 3, 5, 9, 13, 14, 15, 17, 22), and "relational conflicts related to existential and/or ontological differences" (4, 6). In order to provide a better conceptualization of our results, we will present these types of conflicts one after the other.

However, in the included publications, these are sometimes presented as overlapping, sometimes defined as occurring at the same time.

Conflict between values

In some articles, the term conflict has been interpreted as conflict between values (1, 5, 7, 8, 10, 16, 18, 19, 20, 21). It refers to the disagreement between the patient and his/her caregiver on the decision to be taken, that originates from the different values and/or preferences endorsed by the members of the dyad, practically operationalized in the decisional options (1, 5, 7, 8, 10, 18, 19, 20, 21). In other words, in some cases the conflict between patient and caregiver arises because the two would opt in favor of highly different (decisional) options, on the basis of value-based reasons (i.e., different moral values underlying the different decisional options). This phenomenon has been extensively investigated in bioethics literature, under the label of "ethical disagreement". The conflict between values, in the oncological care path, may regard decisions concerning treatment goals, whether to opt in favor of formal caregiving or bring the patient into a hospice, discharge or leave the patient hospitalized, move the patient to formal care facilities, decide who should provide care, especially at the end of patient's life (1, 5, 7, 8, 10, 16, 18, 20, 21). These conflicts are framed by the parties as discussion, arguments, discord, or expressed dissent, and may emerge during consultations with clinicians (1, 7, 18). In this case, the conflict between values may become both an obstacle

to the patient's care path or provide useful information to the clinician who can intervene and manage the conflict (7, 8, 9).

Sometimes, conflict between values may also occur between the patient-caregiver dyad and the medical team (5, 10, 18). Examples of the latter regard the inadequacy of service resources, unprofessional behavior of the staff, lack of proper communication on advance care planning (16).

Conflict between interests

"Moral conflict" may arise when patients or caregivers ground their decisions in personal interests, creating what we refer to here as "conflict between interests" (1, 2, 5, 8, 9, 10, 11, 12, 14, 17, 22). In this case, conflict does not result from the opposition between genuinely endorsed moral perspectives, but rather from the clash of partisan interests, at least by one side of the dyad, more often caregivers. Sometimes caregivers consider their own and familial interest above that of the patient, because patient's best interest may be not always in line with the interests of other family members, thus creating a form of hidden conflict (1, 2, 9, 10, 11, 12, 17, 22). In other cases, faced with the idea of losing a beloved one, caregivers may cling to patients in advanced stages of their disease, desperately demanding that all steps be taken to prolong life regardless of the patient's wishes and real-life prospects (2, 8). Some caregivers were even found to act against patients' known or assumed wishes/preferences (5). This happened because of several reasons: caregivers felt the economic or care burden, they did not accept patients' critical situation, or simply because they were too intimately involved in relationship with the patient to find it inconceivable to let her go (1, 2, 9, 10). Although it does not appear appropriate to speak of conflict between values in these scenarios, the former is sometimes invoked to cover conflicts based on more strictly individualistic reasons.

Conflict related to decisional responsibilities and autonomous DM.

Some authors show that conflicts among patients and caregivers can be also related to decisional responsibilities. These may originate from the non-recognition of the other as entitled of (but not obliged to) autonomous DM, thus misinterpreting what it means respecting the other's decisional autonomy. Throughout the oncological care path, patients and caregivers are agents that may be asked to make medical decisions in autonomy. An autonomous individual is a person with the power to make her own decisions, speak or act without the interference from others (1, 2, 13, 14, 22). However, in daily oncological practice two problems may occur. On the one hand, it may happen that, albeit ideally fully entitled to take the decision, patients experience a compromise of their autonomy, because of caregivers' interferences (1, 2, 5). On the other hand, some patients may decide to give up their autonomous choices, completely relying on their caregivers. With respect to this second scenario, while in some cases caregivers willingly take on this role, in other circumstances caregivers may perceive such a decisional responsibility as a burden. This means that they feel obliged to exercise their autonomy in contexts where they feel they would not be necessarily required to do so (1, 3).

In our included publications, the concept of autonomy does not only emerge as a topic of overt conflict, but also as an underlying source and/or consequence of other conflicts (1). Most people make decisions influenced by a complex network of social relationships (13). This happens also to patients, even if throughout the care pathway they struggle to maintain their autonomy, or to recover it, if actually missing (1). This is experienced as a direct threat to the caregiver's autonomy, especially when the decision puts the patient at risk or increases caregiver's practical responsibilities, by delaying or prolonging their commitment (1). In other cases, conflicts over autonomy are about patients' reluctance to assume responsibility over their own care decisions (1, 3, 14). This may happen especially at the end of life when the medical decisions to be made may involve cardiopulmonary resuscitation (CPR) and consequently the order not-to-resuscitate (DNR) (3). This decision is experienced by patients and caregivers as a decision regarding patient's life and death. In making these decisions, patients and caregivers implicitly raise moral judgments about the value of the patient's life and her relationship with significant others. Insofar as decisions in this context may be perceived as deeply related to personal (moral) integrity², this can lead patients and caregivers experiencing frustration both during the DM process, and once the decision is made (3).

In some cases, patient's autonomy could be compromised if they are (unintentionally) exposed by their families to undue influence, coercion, manipulation, all resulting in pushing them taking medical decisions that are not in line with previously held values, beliefs, or perspectives (2, 9, 13). Family pressure or coercion occurs through verbal threats, harassment, reprimand, intimidation, or other manipulative tactics designed to force vulnerable patients to change established beliefs or preferences (2). This most often happens to patients with a history of inequality of power, changes in family roles and relationship status, and progressive illness (2, 9). When family members do not accept the patient's condition, they may ask for more aggressive treatments which may even go against the treatment goals advocated by the medical team (9). Patients with compromised autonomy due to caregiver coercion may eventually comply with caregiver decisions but only to avoid conflict or protect the family. This way, patients may experience moral distress (2, 9). Similarly, when caregivers violate what may be considered as values of "good" caregiving, patient autonomy and will, integrity and honesty, they experience moral suffering, namely, painful feelings of self-blame, insecurity, and personal disappointment or disappointment in others (15). Sometimes the patient's compromise of autonomy may be seen during the medical consultations. Indeed, sometimes caregivers speak or answer to the physician's questions as if the patient were not in the room or unable to speak for him/herself, making claims about the patient's views (12). Conflicts over autonomy also occurred among caregivers and the extended family. In this situation, primary caregivers felt themselves threatened and disheartened by the family in their role (1). During the patient's care pathway, the caregiver may experience the need to self-govern his/her personal life and to return to activities and relationships that they had suspended or neglected during caregiving. Even these cases may be interpreted as compromises of autonomy (1).

² Since no reference other than those of the publications included in the systematic review are usually included in the Results section, "personal integrity" is here interpreted in line with the definition proposed by Rendtorff 2002.

Relational conflicts related to existential and/or ontological differences.

In other cases, conflicts concern relational aspects, namely aspects genuinely related to (and originating from) the relationship between the members of the dyad. According to this account, conflicts may originate from the failure to recognize the individuality of the other, which may lead to a rupture in their social relationship (6). In this case, the other is not recognized as different from the subject, namely, as a separate entity (6). Not recognizing the other as a separate being, with her own feeling, experiences, and perspectives, has an impact on intersubjectivity (4). Some authors consider it also in contrast with the virtue of “compassion”, i.e., the ability to be aware of the emotions of others, to better understand how they feel and their desires and to harmony (4, 6). In other words, although cancer patients tend to appreciate caregivers’ support, it may occur that they do not feel understood or recognized in their own individuality (4). This issue is framed differently in different contributions. In some cases, caregivers are defined as unable to fully understand the needs and requirements of patients, because they have never had cancer, or because they are unable to meet patients’ needs without burdening patients (4). In other cases, male patients, frustrated by the loss of strength due to cancer, may come into more conflict with their wives (4, 6). Differences in expectations regarding the behavior of the other may generate some conflict within the dyads: the efforts of the caregivers are not always positively experienced by patients (4, 6).

Although some degree of conflict is generally present in social relationships, some authors believe that, at least in some cases, this may be so disruptive to impact on the structure the relationship itself, thus leading to specific disputes, challenges, breakups, and violence (4). The terms “friction” and “dissonance” are used in our selected papers precisely in relation to the kind of conflict that appear to destroy the social relationship (4).

However, not all relational conflicts are perceived negatively. Indeed, disagreement could be the symptom of a still existing relationship. When the dyad disagrees on the care treatment of patients, this shows that the dyadic relationship still exists, and that cancer may be addressed as a shared problem.

Triggers of and/or factors related to patients-caregivers’ dyads conflict.

Our included publications report that conflicts between patients and caregivers about care decisions may be exacerbated by several factors. On the one hand, during the oncological care process, caregivers may feel overwhelmed by the situation and can experience emotional and moral distress, burden, anxiety, and depression (1, 2, 8, 9). Moral distress consists of a painful feeling or psychological vulnerability caused by the inability to follow what is perceived/believed the right ethical course of actions, or to act according to one’s own values due to internal or external constraints (2, 15). In our publications, moral distress, and burden correlate with feelings of depression, helplessness, exhaustion, frustration, resentment, guilt, and self-accusation (1, 15). Such a burden may lead the caregiver to argue with his/her patient. Indeed, caregiver stressors – such as confusion, miscommunication, frustration, resentment, fear, and sadness – showed impacting on DM, in particular causing some conflicts within the family nucleus (1, 2, 8). In some cases, a feeling of resentment emerged in caregivers who perceived a reduction in their autonomy and a lack of

compassion and trust on the part of the patient or other family members (1). Indeed, the resentment experienced by caregivers was often also brought about by the involvement of a third party, such as a member of the extended family who did not support emotionally and practically the caregiver, for instance, allowing them no relief, denying them the possibility to share their feelings, or accepting sharing some of the caregiver's labor (1). Moreover, usually caregivers have their own private life outside the patient to take charge of, and sometimes, they have to act as a bridge with other family members; frustrations also originate in conditions where time for themselves was limited by the patient's care and needs, making it impossible for the caregivers to pursue their hobbies, interests or spend quality time with their own family (1, 11, 15). Feelings of frustrations are said as arising in particular in the context of difficult DM, or, differently, when there was a lack of DM options, i.e., when there was no further open therapeutic chance potentially offered to the patient (15). In this case, however, this cannot be configured specifically as moral conflict, but it was the result of the caregivers' frustration with an uncertain care process, or uncertain outcome, or lack of support. Caregivers affected by the aforementioned feelings (e.g., resentment, frustration, burden), may experience a great deal of "cognitive dissonance", that is, the state of discomfort felt when two or more modes of thought contradict each other (1). Indeed, caregivers may have contradictory feelings about the care they did (or did not) deliver, and about their attitudes toward their role, thus experiencing psychological distress (1). Caregivers may experience feelings of guilt and regret, struggling between their desire for more personal autonomy, and that of being more devoted caregivers (1). Frustration and guilt may also be experienced by patients, especially in context of end-life decisions (3).

Moreover, family context may be also an increasing factor for conflicts. Indeed, our publications showed that the younger age of the family, the assertiveness of family members in DM for patient care, and the limitations in communication between family members, are significantly associated with increased conflict (9, 11, 17, 18, 19). Moreover, historical relationship patterns, i.e., how families interacted before the onset of the disease, family structure, family socio-economic conditions, may influence how family members approach each other during the oncological care process, influencing the interactions between patients and caregivers (9, 11, 18, 21). Moreover, caregivers are surrounded by the so-called "extended family" and often they feel a lack of help/support, compassion, and trust from other family members, which increases the burden of caregivers and consequently creates a conflictual environment (1).

Finally, in one publication reporting results from a quantitative study, a statistically significant tendency was found between conflict and duration and/or severity of the disease: in presence of prolonged disease and/or diseases severity, conflicts appeared enhanced (5, 10, 21).

Conflict management's strategies

One of our research questions investigated whether current bioethics literature indicates potential strategies and/or solutions to address moral conflicts occurring among patients and caregivers in oncological care process. Publications included in our review provide some insights that may appear useful in this direction.

First, caregivers may manage the conflict by involving a formal support provider (i.e., a hospice staff member, a psycho-oncologist, even a clinical ethicist) both as a mediator to help caregivers communicating with the patient and the other members of the family, or to take on some of the caregiving responsibilities directly (1, 2, 7, 16, 20). To resolve conflicts, formal support providers can use some strategies, most of which belong originally to the psychological field. A first strategy indicated is “refocusing” both with the caregiver alone and with all family members; this consists in helping families to consider what would be the best actions for the patient, also remembering that is the patient who is entitled of the final decision. Refocusing allowed families to focus their attention on the patient, thus downsizing family wishes. Another strategy indicated is “reconciling”, namely, a formal support provider which may help caregivers and patients reconciling past grievances among family members and the patient. In this case, it is not necessary working together with the caregiver and the patient, but it may be sufficient to work with the dyadic members individually. The third most common strategy reported by formal support providers is “referring”, that is, rely on others who are part of their professional network (e.g., sending caregiver, patient or both to other professionals depending on their needs). The last two strategies identified in selected publications are “reframing”, namely a technique aimed to help family members to understand the patient’s medical condition by using simple words, and “reflecting”, that is consider the influence of their actions in helping caregivers and patients. By focusing on listening patients and caregivers, the formal support provider may be able to understand caregivers and patients’ need and adapt their responses to them. All these strategies are not self-excluding and therefore can be combined one with the other (20). In other cases, conflict was “resolved” once caregivers realized and accepted that some degrees of conflict were part of the oncological care path and of the relational differences set above. Therefore, the mere acceptance of the inevitability of some conflict was, in some cases, a driver for its resolution (1).

Other times, a solution to DM conflicts reported in the included publications was the active involvement of both members of the dyad, patients, and caregivers, resulting in a process defined “co-determination”. This strategy, mostly widespread across clinical ethicists, means that the patient actively takes part in the DM process, considering not only her own wishes and needs but also those of her caregiver; the resulting decision is actually shared between the two (13, 14).

Finally, some caregivers may cope with the conflictual environment showing high resilience during medical DM, using a direct and assertive communication, namely, affirming their needs and seeking formal support, emotional self-care through meditation, positive self-talk, cognitive restructuring, or engaging in positive internal dialogue (1). Thoughtful conversations among caregivers and patients about their different opinions and wishes allowed them to resolve the conflict, because caregivers and patients may become aware of each other’s’ views and, in some cases, agreed to disagree (2).

4.1.3. Discussion

The aim of this review was to provide a systematic collection of “moral conflicts”, i.e., conflicts concerning ethically related issues, occurring among patients and their caregivers in cancer care path, still absent in current literature. We analyzed relevant publications appeared from 1999 to 2021 in the bioethics literature, asking a three-fold question: (i) are there some moral conflicts occurring among patients and their caregivers in cancer care path? If yes, what is the origin and nature of these moral conflicts? (ii) What are the triggers of (and/or factors leading to) moral conflicts occurring in cancer care process? What is the impact of moral conflicts for patients and caregivers? (iii) What are the solutions proposed by the literature to moral conflicts occurring in cancer care process?

The main findings are discussed in depth in the following paragraphs, with the aim of gaining a better understanding of how to properly deal with caregiver’s involvement.

From our systematic review it emerges that patients are almost always accompanied by at least one caregiver along the oncological care path (Benson et al., 2019a; Blackler, 2016a; Hamano et al., 2018a; Hansen et al., 2020; Hauke et al., 2011; Kagawa-Singer et al., 2003a; Korfage et al., 2013a; Laryionava et al., 2021a; Mazer et al., 2014; Sahlberg-Blom et al., 2000a; Ullrich et al., 2020a), and this is in line with previous findings. If considered together with the interpretation of cancer as a family disease (Coyne et al., 2020; Hansen & Tjørnhøj-Thomsen, 2020; Minuchin, 2018), this leads to the consideration that a comprehensive approach to cancer treatment requires considering not only patients but also their caregivers, and, in particular, their relationship. In general, caregivers appear to help patients throughout the oncological care process; however, sometimes they also appear to interfere in the DM process, creating some issues for the patients themselves. Therefore, it appears of utmost importance understanding how to involve caregivers in the oncological care trajectory.

Regarding the first research question, our systematic review provides further evidence to the fact that cancer patients and their caregivers can experience episodes of conflicts or tensions about care decisions and treatment goals (Benson et al., 2019; Blackler, 2016; Boelk et al., 2012; Elliott et al., 2008; François et al., 2017; Hamano et al., 2018; Hansen et al., 2020; Hauke et al., 2011; Hopeck et al., 2017; Kagawa-Singer et al., 2003; Korfage et al., 2013; Kramer et al., 2010; Kramer et al., 2011; Laryionava et al., 2018, 2021; Levine, 1999; Levine et al., 2000; Mazer et al., 2014; Osamor et al., 2018; Sahlberg-Blom et al., 2000; Ullrich et al., 2020; Vivian, 2006). As extensively shown in the Result section, such conflict presents different meanings and connotations, sometimes overlapping. We distinguished four different types of conflict: “conflict between values”, “conflict between interests”, “conflict related to decisional responsibilities and autonomous DM”, and “relational conflicts related to existential and/or ontological differences”. In some case, conflict originates from a disagreement on the decision to be taken, that is, from the different values and/or preferences endorsed by the members of the dyad (Benson et al., 2019; Boelk & Kramer, 2012; Hauke et al., 2011; Korfage et al., 2013; Kramer et al., 2010; Kramer & Yonker, 2011; Laryionava et al., 2021; Levine, 1999). In other cases, conflict arises when the patient or the caregiver

ground her decisions in personal interests (Blackler, 2016; Laryionava et al., 2018; Levine, 1999; Levine & Zuckerman, 2000). Otherwise, conflicts may emerge due to the non-recognition of the other as entitled of (but not obliged to) autonomous DM and consequently to a compromise of their respective autonomy (Benson et al., 2019; Blackler, 2016; Laryionava et al., 2018; Osamor & Grady, 2018). Finally, conflict may originate from the failure to recognize the individuality of others which leads to a rupture in the social relationship (Hansen & Tjørnhøj-Thomsen, 2020; Kagawa-Singer & Wellisch, 2003).

The main finding in this respect is that conflict – at least in the oncological context – does not have only a clinical or psychological connotation, but it may also present an ethical connotation, deserving devoted consideration and analysis. Since in these cases conflict presents a multilayer dimension, the proper way to approach it is not from a single disciplinary perspective. Differently it requires the synergistic collaboration of different disciplines able to capture and analyze it from different angles, thus allowing a multidisciplinary approach to the problem. From a practical standpoint, these considerations corroborate the idea that the gold standard is establishing multidisciplinary teams composed, at least, by the devoted clinicians (e.g., the oncologist, the surgeon, the palliativist, the general practitioner, etc.), the psycho-oncologist, and the clinical ethicist. And, if in most cases the tendency nowadays is to approach complex oncological cases involving not only relevant clinicians but also the psycho-oncologist (Borras et al., 2014; Horlait et al., 2019; Licitra et al., 2016; Pillay et al., 2016; Taberna et al., 2020), clinical ethicists working shoulder to shoulder healthcare professionals are still (virtuous) exceptions. Regarding this issue, it may be here useful to recall that the so-called Clinical Ethics Support Services, in the form of single consultants working within multidisciplinary teams or Clinical Ethics Committees supporting, when necessary, healthcare professionals, are a rapidly growing reality, already implemented in several countries, especially the US, UK, France, and The Netherlands (Boniolo & Sanchini, 2016; Crico et al., 2021; Haltaufderheide et al., 2020; Horlait et al., 2019; Linkeviciute et al., 2016; Sanchini, 2015; Shuman et al., 2013). In line with current literature (Crico et al., 2022), our systematic review provides additional evidence on the importance to find strategies to further implement Clinical Ethics Support Services in those realities where they are still missing, particularly in the context of cancer care.

As to the second research question (factors related to conflict and impact of such conflict on patients and caregivers), from our analysis it emerges that conflict among patients and caregivers can be exacerbated by caregiver's distress or relational patterns (Benson et al., 2019; Blackler, 2016; Boelk & Kramer, 2012; Hamano et al., 2018; Kramer et al., 2010; Laryionava et al., 2018, 2021). Accordingly, it is important to explore caregivers' background (i.e., religion, culture, and ethnicity) and mood, since this information may help reducing conflict (Boelk & Kramer, 2012; François et al., 2017; Levine, 1999). Regardless of conflict's reasons, and with respect to its impact on the care process, our included articles show that conflict can both be an obstacle to the patient's care path and provide useful information, depending on how conflict is approached by the different parties (Korfage et al., 2013; Laryionava et al., 2018, 2021). In particular, as we saw, the conflict within the dyads is not always perceived negatively, since it is in any case the symptom of a still existing relationship. When the dyad disagrees on patient's care treatment, this shows that the dyadic

relationship still exists, and that cancer may be considered a shared problem, that has to be addressed together and as part of the relational process itself (Benson et al., 2019; Kagawa-Singer & Wellisch, 2003; Laryionava et al., 2018).

This finding, which leads us to the third research question, is in line with the idea that the gold standard in medical decisions is the SDM among patients, physicians, and, in some cases, caregivers (Charles et al., 1999; Chichua et al., 2022; Elliott & Olver, 2008; Gómez-Vírseda et al., 2020; Kashaf & McGill, 2015; Levine & Zuckerman, 2000; Maes-Carballo et al., 2021; Osamor & Grady, 2018; Politi et al., 2012; Pravettoni et al., 2016; Sahlberg-Blom et al., 2000; Steffensen et al., 2018; Ullrich et al., 2020). SDM is defined as the DM process which is purposed to arrive at a truly shared solution; in this case, it is the decision that both members of the dyad agree on or consent to. In the latter, although patients and caregivers may have very different opinions at the very beginning, after proper discussion, one of the members of the dyad may decide to embrace the idea of the other. Even in this case, the member who changes her mind and decides to embrace the other's viewpoint is not precluding herself the exercise of self-determination. In other words, SDM and autonomous DM should not necessarily be considered as mutually excluding approaches. The member of the dyad who decides to make this movement in the direction of the other is still exercising self-determination, in a more relational manner. The expression SDM points also to the fact that what is shared is not only the final decision, but also the decisional process, which takes the form of a dialogue between interlocutors. Interpreted through the lens of bioethics scrutiny, SDM is the dialogical approach which, theoretically, embeds a principle of "relational autonomy", and, from a practical standpoint, may end up resulting in a process of co-determination (Gómez-Vírseda et al., 2019, 2020). A relational understanding of autonomy focuses on the importance of the social reality around the individual in taking decisions. Accordingly, relational accounts of autonomy consider it as first of all a particularistic and contextual feature, conversely rejecting the idea that autonomy should be only a theoretical and a-contextual principle (Blackler, 2016; Chan, 2004; Ikonmidis & Singer, 1999; Mackenzie & Rogers, 2013; Wardrope, 2014; Wilson et al., 2014). In this context, relational autonomy possesses also additional traits, already pointed out by contemporary literature. Being interpreted in line with SDM, relational autonomy here means first of all promoting inclusiveness in the decisional process, therefore including the perspectives of patients and caregivers, and – if possible – also of caring physicians (Mackenzie & Stoljar, 2000; Weber et al., 2007; Westlund, 2009). Moreover, the idea reported above for which shared and autonomous DM are not mutually excluding approaches, is also in line with the interpretation of relational autonomy as a gradual principle, rather than an all-or-nothing concept (Kagawa-Singer & Blackhall, 2001; Rosenfeld et al., 2000; Tonelli & Misak, 2010; van Wijngaarden et al., 2016). This means considering autonomy as a dynamic gradual process, which may be expressed along a continuum and whose value and impact may vary depending on the specific context, decision, and care process (Dive & Newson, 2018; Kagawa-Singer & Blackhall, 2001; Levinson et al., 2005; Mackenzie & Stoljar, 2000; Pardon et al., 2011; Rosenfeld et al., 2000; Verkerk, 2001; Witkamp et al., 2016; Wright & Brajtman, 2011). Current bioethics literature also reports that the (perhaps) most important feature of relational autonomy is that, despite recognizing the importance of autonomy for

contemporary (bio)medicine, it interprets this feature only as one amongst other values, with which the former has to be balanced: in the oncological context, compassion (Dive & Newson, 2018; Weber et al., 2007), hope (Mackenzie, 2008), empathy (Fried et al., 2007; Kagawa-Singer & Blackhall, 2001; Tonelli & Misak, 2010; Weber et al., 2007) appear, in our view, of utmost importance. Finally, empirical studies have shown that the DM focused solely on individual exercise of autonomy is not even in line with patients' preferences and experiences, especially at the end of life (Laidsaar-Powell et al., 2016, 2017; Laryionava et al., 2018; Shin et al., 2013). Narrowing to the oncological field, it has been found that cancer patients prefer to share decisions with their physicians and/or caregivers, and, in some specific cases, even delegate them to decide (Sahlberg-Blom et al., 2000). Indeed, although some patients wish to have full control of the DM process, others prefer to defer DM to family members or, at least, considering their interests, trying to incorporate these interests in the final decision. While in the medical and psychological literature, this concept has been referred to as SDM, the same has appeared in the clinical ethics literature with the expressions of "joint DM" (Osamor & Grady, 2018) and/or "co-determination" (Greipp, 1996; Malmsten, 1999; Sahlberg-Blom et al., 2000). In these scenarios, patients actively participate in the DM process understanding their medical condition, discuss it with family members and doctors, listen to their opinions, beliefs, and perspectives, and ideally arrive at a joint decision. This does not necessarily mean that, after the dialogical process, decisional actors will surely agree on the content of the decision; it may also be those caregivers and/or healthcare professionals come to accept patient's will, considering the latter as the option in line with patient's best interest.

In conclusion, what discussed above seems to corroborate the idea that self-determination as a non-relational concept may appear as rather inadequate in the oncological field, where, differently, SDM and relational autonomy appear overriding. Indeed, from a diagnosis of cancer and its subsequent care process till the end-of-life, cancer has a very high impact both on the patient and her caregiver, and on the extended family more generally. As we tried to show, within the cancer care pathway, both the concept of moral conflict and the potential solutions to it, are deeply relational: the former, since it arises from the dyadic relationship between two actors, patients and caregivers, who experience such illness as affecting both parties; the latter, since solutions to conflicts require recovering a relational account of autonomy, where the patient is the final actor, but the caregiver turns out to be a major player in the cancer patient's care process, both directly and indirectly.

The present systematic review has some limitations. Of the 22 studies included in this review, 11 were conducted in America, 9 in Europe, 1 in Asia, and 1 in Oceania. Since most of the studies included in this review were conducted in America and Europe, the result may be limited in generalizability. Secondly, we considered only publications written in English. Finally, most of the included publication performed qualitative analysis.

4.1.4. Conclusion

The aim of this systematic review was to investigate the concept of moral conflict originating from caregiver's involvement along the oncological care process, which represents a still undertheorized issue in current bioethics debates. To gain a comprehensive overview of this topic, we probed the literature about the origin and nature of moral conflicts, factors leading to, impact of, and solutions to, moral conflicts occurring during the oncological care trajectory.

Our analysis resulted in a taxonomy composed of four types of moral conflicts, i.e., conflicts about ethically related issues, broadly conceived. Our analysis also showed that moral conflict may be further exacerbated by factors related to the caregiver's condition (e.g., psychological, and moral distress, demographic characteristics), the family context (e.g., relational pattern), but also the entity of the disease (i.e., duration and severity). Several strategies have been proposed in the literature to overcome moral conflicts, which span from psychological to ethical support services. Altogether, the evidence collected shows the importance of also considering the ethical dimension of the (oncological) care process, especially in its decisional component.

4.2. Study 6: Exploring moral conflicts among Breast Cancer Patient and her Caregiver.

Based on the results of the systematic literature review, we set out to explore the presence and nature of ethical disagreements within dyadic relationships in the context of cancer diagnosis and treatment. Differently from most of the bioethics literature which focuses on advanced cancer, i.e., when the patient is proxy to death, our study aims to investigate this phenomenon at the beginning of cancer trajectory, when potential moral conflicts may impact throughout the entire therapeutic process (Davies et al., 2015). A group of 20–25 dyads already enrolled for the main study will be invited to reply to in-depth qualitative face-to-face semi-structured interviews aimed at identifying and mapping possible DM conflicts of a moral nature, namely “moral conflict”, arising in the patient-caregiver relationship and potentially affecting the care process. After a very brief explanation of what an ethical issue is and to what extent it differentiates from, e.g., psychological issues, dyads will be asked whether they have already experienced some sort of moral conflict, to describe its nature, and to report whether and how this conflict impacted on their relationship, medical decisions, and adherence to cure. Furthermore, it will be investigated whether dyads would consider useful/beneficial to be offered for free a support service dedicated to the discussion and management of moral conflicts occurring within the patient-caregiver relationship and potentially affecting the oncological care process. We hypothesized that cancer patients-caregivers’ dyads would experience moral conflict even at the early stage of cancer trajectory. This information will further facilitate the development of effective and sustainable interventions to manage moral conflict in patients and caregivers’ dyads.

The present study is still in progress, however below we present a dyad that has already been interviewed, whose experience is of particular relevance.

4.2.1. Material and methods

Semi-structured interviews

An online meeting was conducted by the internal advisor, a bioethicist, and the PhD candidate, with a patient and caregiver dyad. The meeting lasted 90 minutes and was audio-recorded and subsequently transcribed verbatim. The interview guide was built by the PhD candidate along with her internal advisor, an Adjunct Professor of Clinical Ethics and ethical expert. A pilot test was done with lay people, survivors, and PhD students. As no problem or difficulty was observed, no change was made in the interview schedule. Table 26 showed the interview’s schedule.

Table 26. The interview schedule

The interview schedule
• A general introduction on the study. ◦ <i>Explanation of the reason why we explore the clinical ethics standpoint.</i> • Brief account of the care pathway and caregiver choice.

- *For patients: trace the main stages of the care pathway: diagnosis, DM choices, treatment options, treatments performed. Explain how the choice of caregiver came about.*
- Do you know what ethics is? Do you think there is an ethical/moral dimension to care and especially to your experience of care? Have you ever had conflicts/disagreements in the management of care/therapies/choices to be made?
 - *Ethics/bioethics literacy is investigated, and if necessary, it is explained what ethics is and its implication in clinical settings. Finally, we try to reason about possible disagreements/conflicts that the dyads may have experienced.*
 - *Examples of the conflicts that emerged from our literature review are provided to explore their presence.*
- What solutions, if any, have you used to address them? Would you have any additional implementation suggestions with respect to resolving/managing these conflicts?

Statistical analysis

Thematic analysis was used to analyze the transcribed data. First, audio-recording of dyad's interview was reviewed for accuracy and subsequently transcribed by the coders. Codes were generated by the researcher during the transcription process, which resulted in the generation of themes based on the research questions through a deductive process. These themes were guided by the research questions and emerged from the thematic analysis.

4.2.2. Case report

Socio-demographic, Medical and Psychological Characteristics

Gina (all names have been changed) was a 63-year-old woman, at the time of the diagnosis, retired, and lived with her husband and one of the two young adult children. She was menopausal, suffering from hormone responsive Stage II BC and had had breast-preserving surgery (supero-external quadrantectomy of the right breast with sentinel lymph node biopsy in the ipsilateral axillary), as well as radiation treatments, and the endocrine therapy. She underwent the Oncotype Dx test, which analyzes the molecular profile of the tumor to assess the actual usefulness of postoperative adjuvant chemotherapy in addition to hormone therapy, which found that chemotherapy was not necessary. She described being psychologically stressed by her cancer diagnosis and impending medical treatments, reporting feeling anxiety and a negative mood.

Gina discovered suspected cancer during a screening mammogram scheduled by the NHS. To ascertain the diagnosis Gina underwent ultrasound, needle aspiration, and MRI, which confirmed the presence of hormone-responsive breast cancer. The referring oncologist prospected Gina for the following

inter-therapy: quadrantectomy and ipsilateral axillary sentinel lymph node biopsy, radiation therapy, and hormone therapy. The option of postoperative adjuvant chemotherapy was evaluated after the outcome of the Oncotype Dx test. However, Gina was proposed to participate in a clinical trial. Specifically, a protocol of ablative breast lump radiotherapy with Cyberknife in a single session. In addition, Gina agreed to participate in our study, involving a caregiver. She decided to choose her daughter as her caregiver, even though they no longer live together, at her daughter's request.

Emy (all names have been changed) was a 30-year-old woman at the time of her mother's diagnosis, working as a nurse in a senior center, and living alone. She reported being psychologically stressed because of her job, which has since changed, and not because of her mother's diagnosis. Emy wanted to be her mother's caregiver and shared with her various decisions about the disease.

Qualitative Case Report

We present here the most relevant information in line with the previous systematic review and the purpose of the protocol (see Table 27).

Along the trajectory of cancer, Gina was faced with having to make decisions. First, deciding whether to participate in our project, then whether to participate in a clinical trial or continue with the standard treatment course, and finally, how to handle an example of medical malpractice. Gina and Emy were very curious to participate in this interview, stating that they did not have any kind of conflicts.

As for our study, which we will call a psychological study, Gina had to decide who to involve as a caregiver. Initially, she thought of a friend who had been very close to her at the time of her diagnosis (the friend's sister had gone through a similar experience the year before). Then she discussed the possibility to participate in that study with her daughter, who immediately asked to be her caregiver. Gina would not have wanted to choose her daughter because, despite personal concerns, as a mother she would have wanted to protect her daughter by not letting her enter so deeply into the path of the disease. In this decision, Gina set aside her own will to accommodate her daughter's wishes. From an ethical standpoint, this disagreement about who to involve as a caregiver may be an example of *conflict related to DM responsibilities*. This conflict, as extensively described in the previous systematic literature review, may arise from not recognizing the other's right (but not obligation) to make autonomous decisions, thus misunderstanding the meaning of respecting the other's DM autonomy. In this case, Emy, the daughter, influenced her mother's decision, almost imposing herself and not leaving her mother free to decide in line with her values, beliefs, or perspectives.

Gina's second decision concerned the diagnostic pathway and in a certain sense even the treatment one. Specifically, Gina's oncologist had proposed a treatment pathway involving surgery within 8 weeks, radiotherapy, and endocrine therapy (possibly chemotherapy), while radiology had proposed a clinical trial involving a single session of ablative radiotherapy on the breast lump with Cyberknife before surgery. Gina discussed with her daughter the pros and cons of both paths, discussed them with a trusted physician, and initially decided to participate in the clinical trial, as firm treatment dates were coming up. In the meantime,

Gina received the call for prehospitalization and this led her to change her mind. The change of decision was shared with the daughter. In this case, the conflict emerges not between Gina and her daughter, but between the dyad and the medical team because of the lack of adequate communication about advance care planning. Indeed, Gina reported that she was unable to make an informed decision because they had not provided her with the necessary information during the call she received. The only information she had been given was about the timing of the various treatments if she chose the clinical trial. Gina then based her decision on the urgency of starting the treatments, believing that the sooner you start the treatments, the sooner this whole ordeal ends. This referred to as *conflict between values or ethical disagreement*, that means disagree on the decision to be taken on the basis of value-based reasons (i.e., different moral values underlying the different decisional options). This choice, dictated by the urgency of starting treatment (the most important value for the dyad), led Gina and her daughter to experience moral and emotional distress and decision regret, due to a failure of physicians to take charge and explain the advantages and disadvantages of the two treatment options. Gina repeatedly questioned whether she had made the right choice, and this was amplified by a case of medical malpractice.

Finally, Gina was the victim of what we can call a case of medical malpractice. After the supero-external quadrantectomy, Gina waited for the result of the Oncotype Dx test, which was due within a few weeks. However, Gina received the result after 2 months, but only after sending numerous emails to the institute and contacting the surgeon who had operated on her. During these two months, Gina was very worried and anxious, she knew that if the result did not come in time, she would lose too much time for radiotherapy going to alter the results of the treatment. SO, Gina tried to express her emotions and fears to her daughter, to confront her about what she should do. Emy, caught up in her work problems/commitments, could not accommodate her mother's requests. In this case, in addition to seeing an example of malpractice, we can also see an example of the *conflict related to existential/ontological differences*. Specifically, the conflict originated from the failure to recognize the other's individuality, with feelings, experiences, and perspectives of their own. The daughter was unable to fully understand her mother's needs and requirements, being unable to meet them.

All these experiences led Gina to experience moral and emotional distress, to wonder if the choice not to participate in the clinical trial had been the right one. Gina then sought help from the psycho-oncology division and was taken in for a course of psychological support.

Table 27. Summary of principal results.

	Decisions	How to manage?	Conflict?
Psychological trial	Who to point out as caregiver? Daughter or friend?	Discussion with daughter Daughter demands to be her caregiver	Conflict related to decisional responsibilities (among patient and daughter)
Treatment trial	New clinical trial or classic procedure?	Discussion with the daughter of the pros and cons.	Conflict between values or ethical disagreements (Experience Moral/decisional regret)
Chemotherapy	Yes or no depending on Oncotype Dx test (Example of malpractice)	Discussion with oncologist and psychologist. Discussion with daughter on Gina's emotions	Relational conflict related to existential/ontological differences

4.2.3. Discussion

Based on this case study, it was illustrated how conflicts can emerge even in the early stages of illness. Although the presented dyad was not aware that they experienced conflicts, situations emerged during the interview where conflicts, although covered, were present. This case study is in line with our previous literature review, underlying that cancer patients and their caregivers can experience episodes of conflicts or tensions about care decisions and treatment goals (Benson et al., 2019a; Hamano et al., 2018a; Hansen et al., 2020; Laryionava et al., 2018a, 2021a; Osamor et al., 2018a; Ullrich et al., 2020a). This result suggested the importance of continuing to investigate the presence of conflicts in a larger sample to be able to bring out the importance of integrating patient care from an ethical perspective as well.

Through the qualitative case evaluation, it emerged that this dyad experienced three different type of conflict: *conflict between values or ethical disagreement*, *conflict related to DM responsibilities*, and *conflict related to existential/ontological differences*. Specifically, the first conflict originated from a lack of adequate communication about advance care planning between the dyad and the medical team (Korfage et al., 2013; Laryionava et al., 2018, 2021). After receiving a cancer diagnosis, patients and caregivers felt the urgency to start the treatment and perceived the surgery as the way to erase the cancer. This finding is in line with the one from the qualitative analysis presented before. The second conflict that emerged due to the non-

recognition of the other as entitled of autonomous DM, was a real covert conflict (Benson et al., 2019; Blackler, 2016; Laryionava et al., 2018; Osamor & Grady, 2018). In this case, the daughter unknowingly did not recognize her mother's freedom of choice, believing that the role of caregiver was hers. Finally, the last conflict originated from the failure to recognize the individuality of others which leads to a rupture in the social relationship (Hansen & Tjørnhøj-Thomsen, 2020; Kagawa-Singer & Wellisch, 2003). This means that the daughter, being unable to recognize her mother's need and accommodate it, created a rupture in her relationship with her mother, who, as a result, sought support elsewhere.

As reported in our previous systematic review, caregivers' background and relational patterns may exacerbated conflicts among the dyads (Benson et al., 2019; Blackler, 2016; Boelk & Kramer, 2012; Hamano et al., 2018; Kramer et al., 2010; Laryionava et al., 2018, 2021). Accordingly, Emy's work problems do not allow her to accommodate her mother's emotional needs and support her during a rather stressful time.

These findings suggest that conflict-at least in the oncology context-may have an ethical connotation, which deserves to be addressed by specialists in the field. As we reported in the previous systematic review, it could be useful to integrate even in Italy the so-called Clinical Ethics Support Services (Boniolo & Sanchini, 2016; Crico et al., 2021; Haltaufderheide et al., 2020; Horlait et al., 2019; Linkeviciute et al., 2016; Sanchini, 2015; Shuman et al., 2013). More broadly, these findings suggested the importance of multidisciplinary teams composed, at least, by the clinicians, the psycho-oncologist, and the clinical ethicist (Borras et al., 2014; Horlait et al., 2019; Licitra et al., 2016; Pillay et al., 2016; Taberna et al., 2020), in order to take care of the patient and the caregiver in a whole way.

Finally, this case study supported the idea that the gold standard in medical decisions is SDM among patients, physicians, and, in some cases, caregivers (Chichua et al., 2022; Gómez-Vírseda et al., 2020; Kashaf & McGill, 2015; Maes-Carballo et al., 2021; Osamor & Grady, 2018; Politi et al., 2012; Pravettoni et al., 2016; Steffensen et al., 2018; Ullrich et al., 2020). In fact, Gina discussed all the various decisions regarding the care pathway with her daughter, her caregiver, who attended the visits. As discussed in the introduction of this dissertation, SDM is the dialogical approach which, theoretically, embeds a principle of "relational autonomy", and, from a practical standpoint, may end up resulting in a process of co-determination (Gómez-Vírseda et al., 2019, 2020). Included patient and caregiver in the decisional process, may enhance the cancer care for all the members (Mackenzie & Stoljar, 2000; Weber et al., 2007; Westlund, 2009). In this case study, patient actively participated in the DM process understanding their medical condition, discuss it with her daughter (caregiver), listen to their opinions, beliefs, and perspectives, and arrived at a joint decision.

4.2.4. Conclusion

The aim of this case study was to show the presence of moral conflict during the first phase of cancer care, when patients had to decide about cancer treatment and the involvement of a caregiver.

Our analysis corroborated the idea that three of the four types of moral conflicts presented in the previous systematic review, emerged after a BC diagnosis. Altogether, the evidence collected shows the

importance of also considering the ethical dimension of the (oncological) care process, especially in its decisional component.

5. *General discussion of the empirical studies*

Cancer can be considered a family disease, having the same or similar impact both on the patient and the family members, in terms of psychological distress and changes in physical health, resulting in a decline in social functioning and reduction in QoL (Rolland, 2005; Kayser et al., 2007). Moreover, patients and their family members may have a reciprocal influence on their respective psychological well-being, and this means that both members of the cancer dyad are under cancer-related pressures (Rolland, 2005; Berg & Upchurch, 2007).

Following a cancer diagnosis, one or more family members are usually added to the role of caregiver (Petrocchi et al., 2022; Rohith & Patel, 2022). Patients have at least one caregiver by their side who provides practical, emotional, and psychosocial support, as well as helping patients in understanding cancer-related information and in treatment decision making (Karimi Moghaddam et al., 2023; Laryionava et al., 2021). However, caregivers' involvement in DM can vary on a spectrum from passive to dominant and the form/extent of involvement may be influenced by contextual factors (patient's age, gender, health status, cultural background, and relationship with the family caregiver) (Laidsaar-Powell et al., 2017). However, caregivers' involvement may be a potential resource and not only a potential source of tension along the cancer trajectory.

Based on the idea that caregivers are involved in the TDM and more in general in the care pathway, this research project is aimed at addressing the phenomenon of agreement and disagreement among patient and caregiver along the cancer care pathway, from the diagnosis onward, and their mutual influence on the psychological adjustment to breast and prostate cancer.

Regarding the involvement of dyads in DM, in the systematic review was found a similarity in the preferences of patients and caregivers with respect to their involvement in DM, preferring a collaborative or semi-active role of the patient. Pilot and longitudinal studies conducted on dyads with prostate and breast cancer confirmed that most dyads prefer a collaborative or semi-active patient role in DM, corroborating the findings of the systematic review. However, a medium to low degree of agreement on DM involvement preferences was found among the dyads, along with low consistency in implemented involvement. Indeed, in the sample facing with breast cancer, only patients implemented the preferred type of DM involvement. Qualitative analysis of the semi-structured interviews, however, showed that patients wanted to involve caregivers in the care process and DM, and at the same time, caregivers wanted to be involved along the cancer care process. These results suggested that patients and caregivers do not always state their preferences on how to be involved in the DM process, and this could lead to friction within the dyad, even if not explicit, and worsen the psychological well-being of both. Finally, the systematic review highlighted that caregivers' involvement in DM would appear to have a positive influence on patients' medical decisions, since it reduced patient's decision regret, but this data was not statistically significant. In the empirical studies no data was

found supporting this aspect, further studies are needed to explore the caregivers' involvement influences on patients outcome.

Regarding the experience of a cancer diagnosis, the results of the systematic review and the qualitative assessment of the semi-structured interview stated that dyads considered the diagnosis a true shock, a trauma, something unexpected, to live as a shared challenge with a sense of being together. Indeed, patients felt the dyads as a unit/team, feeling supported by caregivers in the DM. Moreover, patients wanted to have caregivers by their side, to share with them the information they received and the decisions to be made. Caregivers can help patients in understanding all the information and not to lose some of them. However, during the cancer trajectory, patients and caregivers could disagree about whom to tell about the cancer or about seeking a second opinion or because patients perceived the support provided by caregivers as inappropriate, causing tension or conflict.

Regarding the psychological response within dyads facing a prostate or breast cancer diagnosis, the majority exhibited a monitoring coping style, directing their attention towards, and amplifying threatening cues in response to the diagnosis. Following the diagnosis, patients generally experienced higher psychological distress than caregivers, particularly elevated levels of depression, although both groups reported an overall good quality of life (QoL). This finding suggests a more significant negative impact of the diagnosis on patients. However, after breast cancer treatment, including procedures such as surgery and neoadjuvant chemotherapy, patients and caregivers reported similar levels of psychological distress. These results indicate that cancer treatments may have had a greater impact on dyads than the initial diagnosis. Nonetheless, the systematic review noted an improvement in psychological distress over time. Furthermore, both patients and caregivers reported a high level of perceived social support, although one dyad mentioned not receiving support from the caregiver. Breast cancer patients were worried about adverse side effects from treatments, such as loss of hair, body changes, ability to perform normal daily activities, and about the possibility of a cancer recurrence. Some of them emphasized the fact that once you have cancer, it stays inside you, like a time bomb, ready to explode again. In contrast, the caregivers did not report these fears, feeling more positive than the patients, but were worried about their ability to support the patients along the cancer journey and about their capacity to take care of the entire family system. Moreover, dyads with young children were concerned about how they could communicate the diagnosis to their children, if they had not yet done so, or how best to manage post-surgery and post-treatment, thinking not to be able to take care of them as before.

Cancer patients and their caregivers can experience episodes of conflicts or disagreement along the care trajectory. In the systematic review was found episodes of disagreement about whom to tell about the cancer or about seeking a second opinion or because patients perceived the support provided by caregivers as inappropriate. From the empirical studies emerged a low agreement among the dyads regarding their involvement in DM. The concept of conflict can be explored by a bioethical perspective and four different types of conflict were found: conflict between values, moral conflict or conflict between interest, conflict related to decisional responsibilities and autonomous DM, relational conflicts related to existential and/or

ontological differences. Although dyads may experience episodes of conflict, some strategies can be used to manage them: assertive communication, dyads' involvement in the DM and a multidisciplinary team.

All these findings may lead us to support the idea to involve not only patients but also their caregivers in the DM and more in general in the cancer care process, as stated by the TRIO framework (Laidsaar-Powell et al., 2017). However, the caregivers' involvement in the cancer care processes the dyadic relationship between patients and caregivers should be assessed by a multidisciplinary perspective. The medial team should provide the right information to dyads and accompanied them in the cancer journey, the psycho-oncologist should help dyads in expressing their needs, fear, emotions, and their desired level of involvement in DM to improve cancer care pathway and the bioethicists should help dyads in managing possible conflict that may arise from the caregivers' involvement. Although our single psychological consultation did not show a statistically significant improvement in dyads' psychological well-being and treatment adherence, the positive trend found may suggest the importance of psychological support. We were aware that more meetings were needed to have a real impact on psychological variables and adherence, but the fact that most of the dyads who completed the trial belonged to the experimental group suggested that a psychological consultation can make dyads feel more taken care of and engaged in the cancer care pathway. Starting from these results, it could be useful to develop a specific intervention protocol to promote caregivers' involvement in cancer care pathway based on dyadic preferences and to improve dyad's wellbeing, and the patient's compliance with the cancer treatment.

6. *New directions and a study protocol*

The advancement of technology (e.g., eHealth and Virtual Reality) and the experience of the Covid-19 pandemic, has led to the increasing use of technological devices to address different stages of the care pathway, from diagnosis to choosing better treatments. Psychology has also aligned with this advancement by providing psychological support not only in-person but also remotely. This is in line with the promotion of personalized interventions in cancer patients (Gorini et al., 2018).

6.1. *Dyadic psychological intervention to promote agreement and a better adjustment to cancer care: a meta-analysis.*

In our dissertation we showed how a cancer diagnosis and its subsequent treatment affect both patients and caregivers. The negative psychological reactions experienced by patients and caregivers lasted over time, specifically from the diagnosis and the start of the treatments. Surprisingly, we found that not all the patients and caregivers dyads agreed on how they want to be involved in the DM. Although no differences were found between those who agreed and those who disagreed in terms of psychological distress, conflicts in dyads are present, as demonstrated by the bioethics literature review and case study. For those reasons, it would be interesting to assess the efficacy of the dyadic psychological intervention in promoting patients and caregivers' agreement and in reducing their psychological distress, that has been demonstrated to be interdependent. We started to conduct a systematic review and a meta-analysis aim to investigate the efficacy of dyadic psychological intervention for breast and prostate cancer patients and their caregivers in improving their agreement and in reducing the psychological distress over time. This systematic review and meta-analysis try to provide an answer to the following groups of research questions:

- Dyadic psychological intervention on breast and prostate cancer patient-caregiver dyads are effective in improving their agreement in DM and in reducing psychological distress?
- Does the psychological intervention have a positive or negative impact in breast and prostate cancer patient-caregiver dyads? Under what conditions is the psychological intervention effective? When is it delivered separately or together?
- Which are the better outcomes of the psychological intervention both on patients and caregivers? Does the psychological intervention facilitate the relationship between the cancer patient and his/her doctor, creating a triadic relationship?

Four major databases were queried: PubMed, Web of Science, PsycINFO, and Embase. Research was conducted on the 15th of May 2023, using only the language filter restriction: only paper available in English. The review process is still in progress, we hope to finish all the process until December.

Although several studies explore this phenomenon, to the best of our knowledge no systematic collection of dyadic psychological interventions for breast and prostate cancer patients and their caregivers in cancer care path is available in current literature. Filling this scholarly gap appears of utmost importance to have a comprehensive view of dyadic psychological interventions, which is the most effective, to provide to the oncological setting a support in helping patients and caregivers facing a cancer diagnosis. Analysis is still in process.

6.2. *A study protocol to manage the Fear of Cancer Recurrence: Change Of Recurrence*

Based on the results of the qualitative assessment in which emerged that one of the most important fears reported by patients was the fear of cancer recurrence (FCR) but not for the caregivers, I decided to better explore this topic and try to help dyads coping with that. Starting from scoping review in which emerged that FCR may also impact caregivers, and in general may negatively influence the cancer care process, I decided to draw up a dyadic intervention for the FCR. Although my PhD project was focused on the caregivers' involvement in the SDM and their alignment, I explored even the psychological impact of a cancer diagnosis and its subsequent treatment both on patients and caregivers. Discovering that the FCR was present from the early stage of cancer (soon after the diagnosis), I thought it could be helpful for dyads to receive a specific intervention for FCR to prevent possible negative impact.

Along the cancer trajectory patients might experience fear of cancer recurrence (FCR) and this may have an impact even on the caregivers (Smith et al., 2022). Low levels of FCR may promote and encourage the maintenance of medical follow-up, engagement in healthy lifestyle changes, and greater attention to signs of new or recurring cancer (Simonelli et., 2017). When FCR becomes distressing, patients can engage in negative health behaviors and experience higher psychological distress and poorer QoL (Chen, 2018; Simonelli et., 2017; Tauber et al., 2019). The need to identify effective evidence-based treatments to help people cope with FCR has increased in the past decade. Empirical data showed that psychological interventions for FCR are feasible, acceptable, and efficacious for managing FCR (Chen, 2018; Hall et al., 2018; Sharpe et al., 2017; Tauber et al., 2019). Systematic reviews on this topic reported mostly psychological interventions based on traditional cognitive behavioral therapies (CBTs) or contemporary CBTs (e.g., mindfulness and acceptance and commitment therapies [ACTs]). The traditional CBTs focused on the contents of thoughts and aimed to identify and modify people's negative thoughts or biases to reduce dysfunctional emotions and promote psychological adjustment, whereas the contemporary CBTs focused on mental processes and aimed to modify how people relate to their inner experiences (Chen, 2018; Hall et al., 2018; Sharpe et al., 2017; Simonelli et al., 2017; Tauber et al., 2019). Tauber and colleagues (2019) found that FCR symptoms were more responsive to contemporary CBTs (Hedge $g=0.42$) compared with traditional CBT (Hedge $g=0.24$) only after the intervention but did not persist over time (Tauber et al., 2019). Considering the existence of several declinations of CBT approaches, it is important to understand the interventions that are effective in decreasing FCR. Due to the progress in technology, blended (a mixed

method comprising both web-based and face-to-face therapy) and remote care for cancer patients has been increasingly applied (Islind et al., 2021). A recent scoping review critically revised and systematized the available evidence on the effectiveness of different modalities and approaches of CBT psychological interventions for FCR (Cincidda et al., 2022). This review showed that psychological intervention based on CBT is efficacious in managing FCR, especially at posttreatment. Specifically, traditional CBT reduced FCR at postintervention and follow-up regardless of whether it was delivered face to face, on the web, or blended. Moreover, there was a lack of data on the efficacy of 2 blended interventions based on traditional CBT. To date, no study has simultaneously compared the effectiveness of face-to-face, web-based, and blended interventions. Contemporary CBT delivered face-to-face or on the web reduced FCR at posttreatment. However, there was a lack of studies on blended interventions based on contemporary CBT. To date, it was difficult to decide which one to choose. If for interventions based on traditional CBT, there were more data, for the contemporary CBT, the information would still be limited.

Based on these premises and our clinical experience, patients and caregivers might benefit from blended interventions as they have the potential benefits of face-to-face and web-based approaches. In particular, through a blended intervention, dyads might maintain the therapeutic alliance with the therapist without the necessity of meeting them weekly because of, for example, a website in which they have to do some homework to practice the skills learned during the face-to-face session. We propose an integrative intervention based on both traditional CBT and contemporary CBT to cope with FCR, named Change Of Recurrence.

6.2.1. Material and methods

Participants

Participants will be volunteers, over 18 years of age who have previously completed some treatment for breast or prostate cancer. Exclusion criteria will be the development of metastasis elsewhere in the body. Caregivers will be volunteers, over 18 years of age, as well. There are no limits on the type of dyads to be enrolled. This study will be conducted at the European Institute of Oncology of Milan (Italy).

Study design

The dyads will be contacted by the clinical psychologist to schedule an appointment to explain the protocol. The consultation will be performed after the conclusion of the first treatment for cancer. The consultation will be carried out by a clinical psychologist with a master's degree in clinical psychology, a state certificate exam, and previous internship in psychological support intervention for cancer patients.

Based on the retrieved evidence, we propose an intervention based on a mix of the key elements that characterize the effective approaches retrieved in the aforementioned literature (CBT, ACT, and mindfulness), delivered through a combination of face-to-face and remote sessions and psychoeducational material.

The program would be structured by first conducting face-to-face sessions at the hospital where the patient is treated. This choice could help patients follow the therapy, especially if we insert the session on the same day that the patient goes to the hospital for other visits or checks. Indeed, dropout from psychological interventions is a relevant issue to be considered. In addition, we will create a web-based platform comprising 10 modules that can be accessed only when patients finish the previous one. The web-based platform will provide interactive sessions, psychoeducational exercises, and homework. The latter has the objective of trying to render patients as autonomous as possible by applying the techniques learned in the face-to-face sessions.

First Face-to-face Session

During the first face-to-face session, the therapist gets to know the patient and the caregiver, assessing the level of FCR both qualitatively and quantitatively, using the questionnaire Fear of Cancer Recurrence Inventory. In particular, the dyad provides details about themselves and has the opportunity to discuss diagnosis, treatment, recovery, and, in general, their experience. Moreover, this will be a psychoeducational session in which the therapist will explain the FCR model, identify the internal and external triggers that increase the FCR, and focus on the dyad's FCR experience, particularly on their maladaptive thoughts and coping strategies. At the end of the session, the therapist will give the dyad two different link to the web-based platform. Through the platform, participants will be asked to write their negative automatic thoughts using a typical 3-column grid, the so-called cognitive ABC.

First Web-Based Session

In the first web-based module, participant will find a summary of the key concepts addressed during the first face-to-face session and exercises to do, such as writing down the thoughts and actions that she performs and that increase the FCR.

Second Face-to-face Session

During the second face-to-face session, the therapist will discuss the dyad's homework to clarify the eventual unsolved aspects. In this way, the dyad will be encouraged to share their experience and start to work on it. Sharing the thoughts and actions that each member of the has performed during daily life allows the dyad to align and establish dyadic coping strategies. The therapist will then introduce the notion of cognitive restructuring, and through the Socratic questioning of cognitive therapy, attempt to challenge the negative automatic thoughts written by the dyad during homework. Finally, the therapist and the dyad will start to reframe negative thinking into alternative thoughts that are more based on reality to explain the homework that the dyad will have to do during the week.

Second Web-Based Session

In the second web-based module, the participant will find a summary of the key concepts addressed during the second face-to-face session. The assigned homework that the dyad will have to do is to write the negative automatic thoughts using a typical 5-column grid and reframe them into realistic thinking.

Third Web-Based Interactive Session

During the third web-based interactive session, the therapist will review the dyad's homework. Then, the therapist and the dyad will discuss thoughts and feelings related to cancer and the actions they will take to get rid of or escape those feelings and those that increase the FCR. In particular, the therapist will provide psychoeducational concepts about worry, explaining the importance of expressing fears. To do that, the dyad will have to describe their worst-fear scenario related to cancer, providing thoughts and behaviors that they will engage in. Then, the therapist will use metaphors such as the bus metaphor, in which the dyad will identify thoughts, feelings, and memories or images as passengers persistently challenging cancer. In this way, the dyad will learn to actively accept, defuse, and respond compassionately to passengers while not allowing them to dominate their lives. The presence of the caregiver can be supportive to the patient in this case. Through the exchange of emotions and thoughts, the dyad enters more into a relationship and structures a collaborative pathway. Finally, the therapist will introduce the concept of relaxation, in particular, body scan meditation.

Fourth Web-Based Session

Following the third module, the dyad will find a summary of the key concepts addressed during the third face-to-face session on his or her platform. The dyad will also be provided with other metaphors and experiential exercises (e.g., daily body scan meditation) aimed at improving the strategies built in the web-based interactive session with the therapist.

Fourth Face-to-face Session

During the fourth face-to-face session, the therapist will focus on adaptive coping strategies that enhance acceptance, cognitive defusion, awareness, and psychological flexibility in general. In this way, the dyad will begin to become aware and accept thoughts and emotions about cancer, eliminate rigid thoughts and beliefs about cancer, and define personal values and commit to pursuing meaningful activities in line with those values. Finally, the therapist will introduce the concept of mindfulness and its basic principles.

Fifth Web-Based Session

In this web-based module, the dyad will be provided with a summary of the key concepts addressed during the fourth face-to-face session, with particular attention to mindfulness. Specifically, the dyad will be presented with mindfulness and relaxation exercises through audio and videotape. The audio clips will contain fully automated exercises meant to bring awareness to breathing and bodily sensations. The video

clips will provide additional explanations on the techniques, along with some practical guidelines on how to practice during the daytime without clips.

Fifth Face-to-face Session

During the last face-to-face session, the therapist will evaluate the changes that occurred in the dyad's emotional and cognitive reactions, making a summary of the current situation and the changes that occurred. The therapist and the dyad will talk about the differences between how the dyad coped with FCR before the treatment and how they cope now. Moreover, the therapist and the dyad will draw up an action plan based on the dyad's values. Finally, the therapist will build, together with the dyad, an exercise schedule to maintain the improvements. The contents of the exercises (audio or video clips) will be available on patients' platforms and will be accessible for a year.

Follow-up Web-Based Interactive Session

A final web-based interactive session will be provided 1 month after the fifth face-to-face session to monitor the psychological state of the dyad, their alignment, and their reciprocal support. If effective, this program would lead to a time and cost-saving care pathway for treating FCR, putting together the benefits of real-time interaction with the clinical staff and the ease of having tailored clinical materials available daily to allow for a continuous improvement.

6.2.2. Expected results.

From the theoretical background, some expected results were presented. First, since an intervention is proposed that is based on both traditional and contemporary CBT, the dyads participating in it could find benefit both in the immediate and over time in reducing FCR. Second, being a dyad-based intervention, caregivers, who seem to experience less FCR than patients, may help patients manage FCR in their daily lives and feel more of a unit in fighting cancer and its effects. Finally, because it is a blended intervention, as many dyads as possible can participate, including those who do not reside near the hospital.

General conclusion

We have seen earlier from the introduction to this dissertation that breast and prostate cancer, from the diagnosis onward, can be considered a family disease, having an impact both on the patients and their caregivers. Consequently, caregivers' involvement in the SDM and along the cancer trajectory may help patients understand medical information, feel supported and experienced less decisional regret. Indeed, caregivers may provide emotional and practical support to patients, helping them to cope with cancer and treatments. Involving caregivers in the cancer journey and in the SDM may let the caregivers feel entitled to influence patients' decisions. For that reason, clinicians are moving toward a family-centered model of care, considering even caregivers along the care path. This new model of care supported the SDM and the relational autonomy. However, patients and caregiver may experience some conflict along the cancer trajectory, especially at the end of life, bringing with them a variety of negative psychological reaction. Understanding how dyad walk the path of cancer cares together and the nature of conflict that they may experience, may improve patient's wellbeing and satisfaction with care, and reduce caregiver's burden.

It is paramount to consider the relationship among breast and prostate cancer patients and their caregivers in order to explore how the dyad react and copes with cancer diagnosis, how they dyads would be involved in the cancer trajectory and SDM. Currently, there is a lack of knowledge about the agreement between patients and caregivers along the cancer trajectory. For that reason, the main thesis of the present dissertation is that patients and caregivers may agree on how they would be involved in the cancer trajectory and SDM.

The dissertation presented six experimental studies to deepen the relationship between breast and prostate cancer patients and their caregivers at the initial stage of the illness. Specifically, the first study evidenced that patients preferred to have an active or collaborative role in the DM, it means that they preferred to decide alone, after considering the caregivers' opinion or sharing with caregivers the responsibility of the decisions. Whereas caregivers proffered to have a collaborative or a passive role, sharing the responsibility of the decision with the patients or letting the patients decided alone after having been considered. Moreover, patients and caregivers experienced the cancer diagnosis as a shared shocking experience, with a sense of unity. Finally, cancer impact psychologically both patients and caregivers, although caregivers reported lower level of psychological distress than the patients. Findings of this study lead to better exploring the patients' and caregivers' involvement and their agreement in the SDM and the psychological impact of a cancer diagnosis. Coherently, we conducted three related studies to investigate more deeply the degree of agreement between patients and caregivers about their involvement in the care pathway and DM process and the psychological impact a diagnosis has on the patient-caregiver dyad. Findings showed that few dyads agreed on how they would be involved in the DM, although they reported verbally that the role of caregivers was to stay at the patients side, supporting her, and letting her decide or sharing with her the decision. Regarding the reciprocal influence among the dyads, we found contrasting results. However, both patients and caregivers experienced the same psychological reaction facing a cancer diagnosis. Finally, patients and caregivers had different fears depending on their role and personal

characteristics. Then, we explored another interesting construct (conflict, which takes place from disagreement between the dyad) from a bioethical perspective to build an even more comprehensive background on caregiver involvement in the care of cancer patients. Firstly, a systematic review of the literature revealed which moral conflicts may arise between patient and caregiver during the oncological care pathway. Finally, a qualitative study showed the relevance of addressing this issue in the early stages of the disease. Specifically, in this case study we highlight that even at the early stage of cancer care, dyads may experience different type of conflict, without being aware. These conflicts may have a bioethical connotation that need to be take into consideration.

Considering the results of the presented studies, five main conclusions can be drawn:

- Cancer can be considered a family disease, having an impact on both patients and caregivers.
- Caregivers' role is to support the patients along the cancer trajectory and to be involved in the SDM.
- Patients and caregivers are not always aligned in how to be involved and there is not always and interdependence between patients and caregivers psychological reaction.
- Patients and caregivers may experience a different kind of conflict along the cancer trajectory that can be assess through the lens of bioethics.
- Dyads are not aware of the conflict that they experience.

In the end, all results highlight the importance of considering the caregivers' involvement in the oncological care path of breast and prostate cancer patients. However, it is important to set a specific support intervention for dyads that may help dyad in express their need, preferences, and fears. Moreover, it is important to let dyads aware about the possible conflict that they may experience in order to help them to manage it. Future research could explore the agreement and conflict along a longer period, evaluating patients and caregivers separately and more than one time.

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