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Factors influencing family involvement in treatment decision-making for older patients with cancer: A scoping review

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ABSTRACT

Many older patients with cancer depend on their family members for care and support and involve their family members in treatment decision-making in different stages of the cancer trajectory. Although family involvement is advocated in person-centered care, little is known about family involvement in decision-making specifically for older patients, and evidence-based strategies are scarce. The aim of this scoping review is to provide deeper understanding of factors influencing family involvement in treatment decision-making for older patients with cancer. Four databases were searched for quantitative-, qualitative- and mixed-method empirical studies describing factors influencing family involvement in treatment decision-making for older patients with cancer: PubMed, EMBASE, CINAHL and PsycINFO. Three independent researchers reviewed the papers for eligibility and quality and contributed to the data extraction and analysis. Twenty-seven papers were included, sixteen quantitative studies, nine qualitative studies and two mixed-method studies. Five categories of factors influencing family involvement emerged: 1) patient characteristics, 2) family member characteristics, 3) family system characteristics, 4) physician's role and 5) cultural influences. These factors affect the level of family control in decision-making, treatment choice, decision agreement, and levels of stress and coping strategies of patients and family members. This review reveals a complex interplay of factors influencing family involvement in treatment decision-making for older patients with cancer that is rooted in characteristics of the family system. The findings underscore the need for development and implementation of evidence-based strategies for family involvement in treatment decision-making as part of patient-centered care for older patients with cancer.

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1. Introduction

As cancer occurs more commonly in older adults, the aging population in many countries is expected to lead to a marked increase in the number of older patients with cancer. The 2020 estimates of the European Commission revealed that 62% of new cancer diagnoses will occur in people over 65 years old [1]. Diagnosis and treatment of cancer in older patients are often complicated by factors such as comorbidities, cognitive impairment and frailty, among others [2]. Treatment decision-making, therefore, is not purely clinical in nature but also includes the patient's preferences and social situation. Along with the growing focus on patient-centered oncology, physicians need to engage patients and their families in treatment decision-making [3]. In recent decades, family members have become increasingly recognized as important

partners in the care of cancer patients. In general, partnering with patients and families in healthcare, inviting them to participate in decision-making, and identifying patient-directed goals contribute to a more patient-centered approach to healthcare [4,5]. As patients become older and their health deteriorates, they depend even more on family members and family members' involvement in decision-making increases. Most patients and family members appreciate family involvement in decision-making, and several studies have indicated that this involvement is associated with greater satisfaction with care, better understanding of cancer-related information, higher treatment adherence and better physical and mental health [6,7]. In this manuscript the term family is used for close relatives such as spouses, children and those who the patient refers to as family [7]. Family involvement in treatment decision making encompasses participation in a wide range of processes and activities related to providing logistical, informational and emotional support [8].

Although the literature describes a myriad of positive effects associated with family involvement in treatment decision-making, it remains

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challenging for physicians to involve family members in a process of shared decision-making. The lack of evidence-based family-centered strategies hinders implementation of partnering with patients and family members in clinical practice [4]. For the development of family-centered strategies, research into deeper concepts such as factors influencing family involvement in treatment decision-making is needed [3,8]. Research concerning shared decision-making shows limited attention to the engagement of families, the relationships between patients and family members and the impact these relationships have on the decision-making process [8–10]. Therefore, the objective of this scoping review is to provide a broad overview of factors that influence family involvement in treatment decision-making, specifically targeted at older patients with cancer in order to inform clinical practice and future research.

2. Methods

A scoping review was conducted because an initial search in the PubMed database revealed that the nature of the studies, as well as their methodological approaches widely differed. In order to provide a broad overview of influencing factors on family involvement, information was collected from both quantitative as well as qualitative studies. The scoping review is performed and reported in accordance with the Joanna Briggs Institute's (JBI) methodology for scoping reviews and the PRISMA-Scr guidelines for scoping reviews [11–13].

2.1. Search Strategy

The literature search aimed to identify quantitative-, qualitative- and mixed-method studies that investigate factors influencing family involvement in treatment decisions for older patients with cancer from the perspective of the patient, the family members and/or the healthcare professionals. A comprehensive literature search was conducted from October 2019 to December 2019, based on the PRISMA-Scr guidelines [13]. The following databases were searched: PubMed, EMBASE, CINAHL and PsycINFO. The search was limited to the English language. Eligible studies were identified using a broad range of key search terms and MeSH topics around the concepts of “decision-making,” “cancer,” “elderly” and “family members.” The search string for PubMed is included as an example in Appendix 1. In addition, reference lists from the eligible articles and previous reviews on the role of family members in shared decision-making were examined to identify other eligible articles.

2.2. Study Selection

After duplicates were removed, the search results were screened using the tool Rayyan to identify articles that might be eligible and need full text reading [14]. Studies eligible for inclusion met the following criteria: 1) included a patient population with a mean age of 60 years and older, 2) focused on cancer treatment decisions and 3) included factors influencing family involvement in treatment decision-making. For the assessment of the level of evidence of the included studies, we used the Oxford Levels of Evidence 2011, which distinguish five levels [15]. Single case studies and studies that did not contain original research, such as systematic reviews and expert opinions, were excluded. Rigour was addressed by two reviewers (BD, ML) independently screening the first 300 articles on title and abstract and to ensure same understanding about the inclusion criteria. One reviewer (BD) screened the rest of the articles on title and abstract and selected articles for full text reading. Two reviewers (BD, ML) independently screened and reviewed the full text of articles as needed to determine eligibility. In case of disagreement, the articles were discussed with a third reviewer (WP) and only included if the researchers reached agreement. To assess the quality of the selected studies, we used JBI Critical Appraisal Checklists fitting the different quantitative and qualitative study designs [16] and the Mixed Method Appraisal Tool (MMAT) for the mixed method studies [17]. Two reviewers (BD, ML) scored the

quality of the included studies independently. No studies were excluded based on the quality assessment.

2.3. Data Extraction and Analysis

An overview of the study characteristics of the included articles was created by one author (BD). The level of evidence was decided by agreement of three authors (BD, ML and WP). One author (BD) analyzed all included articles to identify factors influencing family involvement in treatment decision-making and listed these factors in tabular form. A narrative synthesis approach was used to describe the findings of the different studies [12]. All authors were involved in discussions regarding the synthesis of the data and grouping the factors into five main categories. Subsequently, summarizing the results within the framework of the five main categories was performed by one author (BD).

3. Results

After removal of duplicates, 1857 studies were identified from the four database searches. No additional articles were found from screening reference lists. After screening titles and abstracts for eligibility, 205 articles were selected for full text reading. After full text assessment, 27 articles were eligible for inclusion (Fig. 1).

3.1. Quality Assessment

The overall quality of the included studies was good. No studies were excluded based on the quality assessment. Thirteen quantitative studies fulfilled all criteria on the JBI Critical Appraisal Checklist for Cross sectional studies [6,18–29]. In three studies there was a lack of clarity regarding the use of confounding factors [30–32]. Five qualitative studies were of good quality, scoring 10 out of 10 on the JBI Critical Appraisal Checklist for Qualitative Research [33–37]. In three qualitative studies information about ethics or the influence of the researcher on the study was missing or unclear [38–40]. The quality of the two mixed method was good, based on the MMAT assessment criteria [41,42].

3.2. Characteristics of the Included Studies

The study characteristics of the 27 articles are summarized in Appendix 2. In total, sixteen of the 27 studies were conducted in the USA or Canada [6,18–21,23,24,26,27,36–42], seven in European countries [28,31–35,43] and four in Asian countries [22,25,29,30]. Family involvement in decision-making was investigated from the perspective of the patient [6,19,20,28,29,31,34,35,39], the family member [21–23,26,32,40,43] or both [24,25,27,37–39,42]. Only one study investigated the professional perspective on family involvement in decision-making [33] and one assessed family participation in decision-making from the perspective of the full triad, including the patient, family member and professional [41]. In addition, two studies conducted an analysis of patient records to investigate family involvement in decision-making [18,30]. Of the 27 selected studies, twelve focused on one specific type of cancer, with seven focusing on prostate cancer [18,19,26,27,32,36,38], two on breast cancer [34,39], two on lung cancer [24,28] and one on brain metastases [37]. The other studies included multiple types of cancer or did not specify the cancer type. The current review includes studies of family involvement with patients in different stages of cancer, varying from newly diagnosed cancer patients [19,38] to patients with advanced cancer, or even undergoing palliative and end of life care [21,22,28,33,43]. Eight studies investigated family involvement in treatment decisions for specific treatments such as chemotherapy, surgery and radiotherapy [6,18,25,27,32,35,37,39].

Nine of the sixteen quantitative studies assessed factors influencing family involvement related to the decisional control [6,19,20,23,25,28–31], referring to the preferred or perceived degree of control on decisions about medical treatment [44]. Two quantitative studies

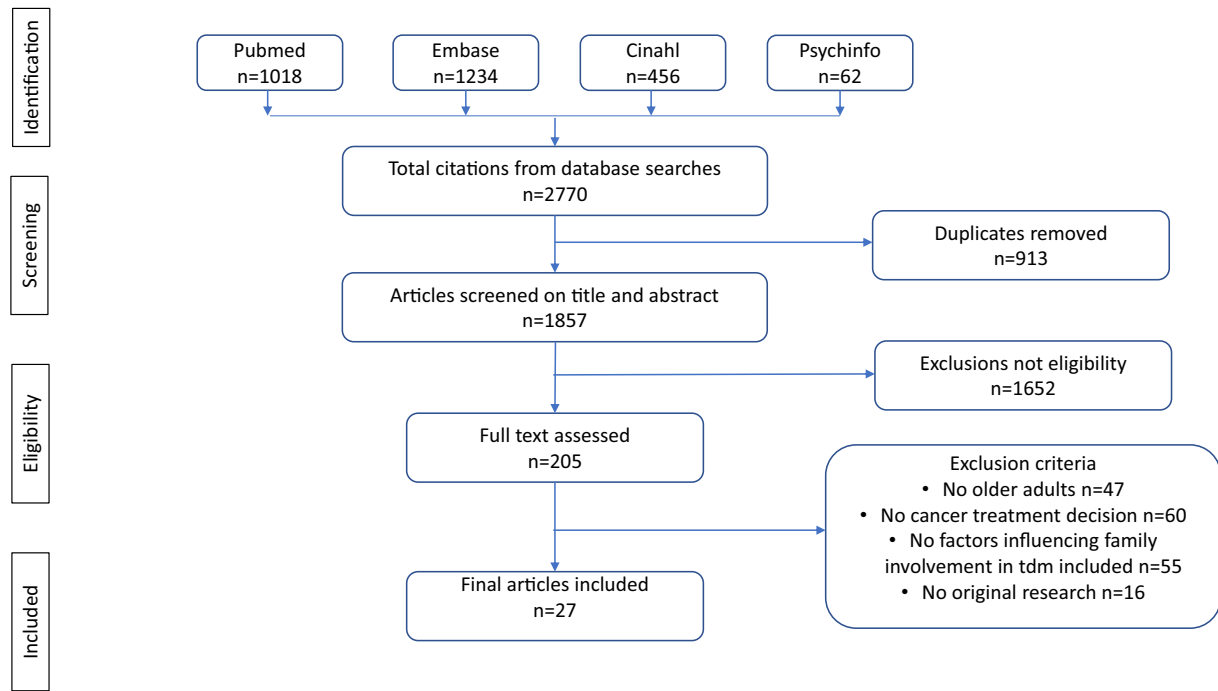


Fig. 1. The PRISMA flow diagram illustrating the systematic search process.

investigated the effect of family involvement on treatment choice [18,32]. Other studies assessed factors influencing family involvement related to patients' and family members' experiences about the treatment decision process. This includes decisional agreement between patient and family members [24,26], family conflict arising from decisional conflict [22,27] and patients' coping strategies to deal with the cancer [21]. All sixteen quantitative studies used descriptive statistics and secondary regression analysis methods to identify factors influencing family involvement. The nine qualitative and two mixed-method studies focused on deeper understanding of family involvement in the decision process, including the experiences of the participants and the different roles family members play in this process. These studies used thematic analysis approaches to identify factors that influence family involvement in care and treatment decisions in different phases of the cancer trajectory.

3.3. Factors Influencing Family Involvement in the Decision Process

An overview of factors influencing family involvement extracted from the included studies is summarized in Table 1. This revealed five

categories which were used to guide organization of the review findings (Fig. 2). These are 1) patient characteristics, 2) family member characteristics, 3) family system characteristics, 4) physician's role and 5) cultural influences.

3.4. Patient Characteristics

Several studies indicate that family involvement in the decision-making process is related to patient characteristics such as socio-demographic status, health status, cognitive abilities and psychological characteristics.

3.4.1. Socio-Demographic Status

Age, gender, marital status, educational level and income seem to influence the level of family influence and control in decision-making. Patients who prefer shared decision-making with family members or even prefer family-controlled decision-making tend to be older and/or female [6,28,30]. Patients with a partner prefer to share treatment decisions more often than patients without partners [6,20,28,38], although

Table 1

Overview of factors influencing family involvement in treatment decision-making related to decisional control, treatment choice and experiences decisional process.

Categories of factors	Factors	Family involvement & decisional control	Family involvement & treatment choice	Family involvement & experiences decisional process
1. Patients characteristics	• socio demographic status	(6,20,25,28-30,38)	-	(21,24)
	• health status	(6,28-30,40)	-	(31)
	• cognitive abilities	(25,28,33,40)	-	-
	• psychological characteristics	(6,19,20,28,31,34,43)	-	(24,27)
2. Family member characteristics	• caregiver role	(23,40)	-	(26,37,43)
	• relationship	(29,41)	-	(24)
	• socio demographic status	(23)	(32)	(26)
	• psychological characteristics	-	(33)	(21,24,27)
3. Family system characteristics	• communication patterns	(38)	-	(19,22-24,27,41)
	• support	(6,34,35,40)	(18,34,35,39,41)	-
	• reciprocal interdependence	(26,34,36,40)	(33,35,37,41)	-
	• family conflict	-	-	(22,27,31)
4. Physicians role	• actively involve family members	(33,38)	-	-
	• support family members	-	-	(33,42)
5. Culture	• individual vs family oriented	(6,30)	-	-

Factors influencing family involvement in treatment decision-making older cancer patients

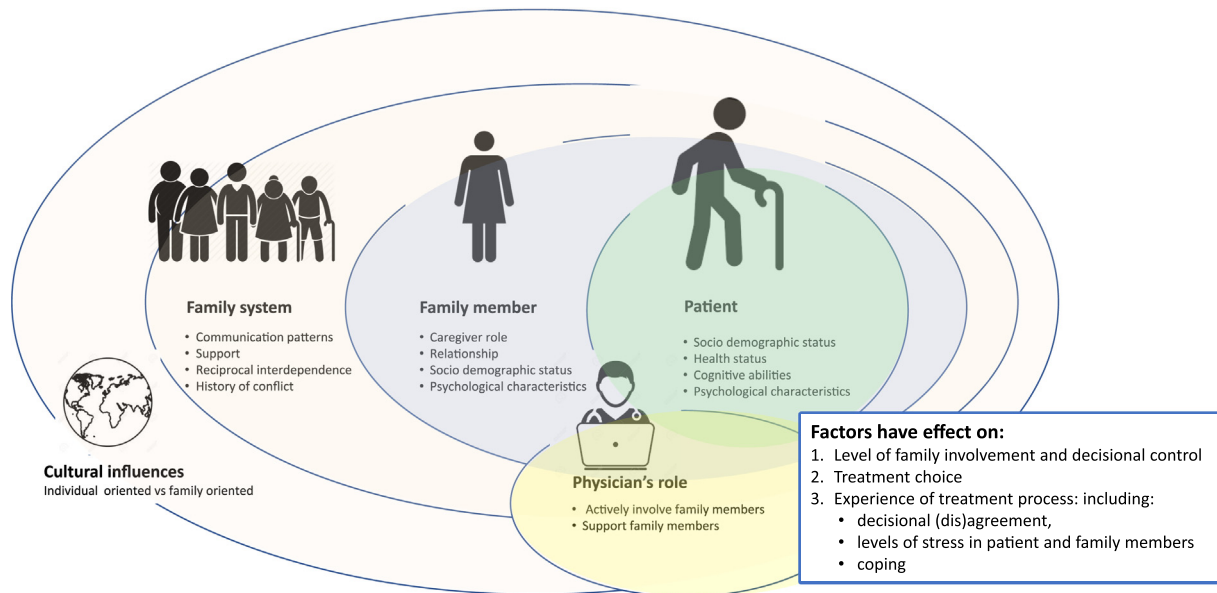


Fig. 2. Factors influencing family involvement in treatment decision-making of older patients with cancer.

some men with prostate cancer choose their treatment without much spousal consideration [38]. A more advanced educational level and higher income are associated with less family-controlled decision-making and with more patient dominance [6,25,29]. Family members of older patients tend to be more satisfied with and have a higher level of caregiver decision-making confidence than family members of younger patients [21,24].

3.4.2. Health Status

Patients in advanced stages of cancer, with more comorbidities, lower levels of functioning, more pain or declining decision-making competence prefer and experience more family control in decision-making [6,28]. Two Asian studies mention that in an advanced stage the patient may be excluded from the decision-making process completely [29,30]. Meeker has described how the family member's role in decision-making changes over three phases as cancer proceeds: 1) monitoring the patient's needs and assisting the patient, 2) buffering and trying to lessen some of the demands on the patient and 3) taking over decision-making as surrogates [40]. Severely ill patients and their family members might disagree more often about treatment goals as the disease duration extends [31].

3.4.3. Cognitive Abilities

Patients and family caregivers prefer greater family dominance in treatment decision-making as the level of cognitive impairment increases [25,28]. As long as patients are able to communicate, most families do not want to take over decision-making [33,40].

3.4.4. Psychological Characteristics

Patients with healthy emotional functioning prefer family involvement or family-controlled decision-making instead of physician-controlled decision-making [28,43]. These patients might see family as a resource to help cope with cancer and treatment options and preference identification [19,34]. Depressed patients and patients with high levels of fatalism are more likely to share healthcare decisions with others and are more likely to report family-controlled decisions [6,20]. Depressed feelings are also associated with negative perceptions of

the decision process and higher levels of perceived family disagreement [24,27]. Patients in denial of their situation involve family members in decision-making less often than patients with an appropriate perception of their situation [31,43].

3.5. Family Member Characteristics

Family member characteristics that were found to influence family involvement in decision-making are the family caregiver role, the relationship with the patient, and socio-demographic and psychological characteristics.

3.5.1. Caregiver Role

Spouses and children who spent more time per week as a caregiver reported greater involvement in treatment decision-making [23,40]. Family caregivers seem to be more satisfied with their role in decision-making when communication with the patient is good and when they are actively involved in conversations with the physician [26,37,43].

3.5.2. Relationship

Several studies describe differences between the way partners and adult children are involved in treatment decision-making for older patients with cancer. Older patients with cancer appear to have a higher level of decisional agreement and experience less conflict with their partners than with their adult children [24,29,41].

3.5.3. Sociodemographic Status

Female family members with lower income tend to have higher levels of involvement in treatment decision-making [23]. Older and retired partners of prostate cancer patients show a preference for radiotherapy rather than surgery [32]. Partners who are not working tend to be more satisfied with the treatment choice [26].

3.5.3.1. Psychological Characteristics

Family members with depressive feelings more often perceive family disagreement and negative feelings about the decision process [24,27]. Family caregivers who do not accept the patient's situation and use avoidant coping strategies tend to experience lower caregiving

decision-making confidence and have a stronger preference for life-prolonging treatment [21,33].

3.6. Family System Characteristics

Characteristics of the family system influence how family members of older patients are involved in the treatment decision process. These include family communication patterns, level of support, history of family conflicts and reciprocal interdependence between the patients and their family members.

3.6.1. Communication Patterns

Studies about the role of the partner of the older cancer patient have concluded that the way the partner is involved in treatment decision-making reflects the couple's communication style [36,38]. When a patient spends more time discussing treatment options with family, it helps the patient to cope with the cancer diagnosis and facilitates cognitive processing, which may improve the patient's level of stress over time [19]. Feelings of not being listened to are determinants for negative perceptions of the decision process [24]. Communication constraints among family members can cause conflict [22]. For both patients and family caregivers, higher depression scores are associated with perceived family disagreement, fewer family members being informed about treatment and care decisions, and sometimes even with exclusion of family members from decision-making [27]. Patients and family members might need help to improve their communication, particular around goals of treatment [23,41].

3.6.2. Support

Patients experiencing higher levels of social support are more likely to involve family members in decision-making [6]. Patients with weak family support have more confidence in the medical staff [35]. Some patients cannot rely on family support or want to avoid burdening family, and this can also influence their treatment decision [18,34,39–41].

3.6.3. Reciprocal Interdependence

The way family members are involved in decision-making often is congruent with the preferences of the patient [26,36]. Some patients don't want to burden their family members and sometimes family members want to protect the patient [34,40]. Although family members tend to respect the patient's decision, some studies have shown that family members influence the type of treatment chosen. Family members often prefer a treatment with the highest chance of prolonging life [18,35,39]. Some older patients may choose a certain therapy because they see their family as a reason to live or because their family persuades them [33,35,37,39,41].

3.6.4. History of Family Conflict

Decisional disagreement and family conflict occur more often in families with a history of conflict and when family members assert control [22]. Disagreement occurs more often in cases of depression and when relatives do not support patient's wishes [27,31]. Absent family members renewing contact with the patient might reduce family conflict [22].

3.7. Physician's Role

Family involvement increases when physicians actively involve family members in the decision process and encourage patients to discuss treatment options with their partner or other family members. This seems to positively influence the experience patients and their family members have with the decision process [38,42]. One study emphasized the importance of supporting family members in their changing role as decision-makers with and for older patients with cancer toward the end of life [33].

3.8. Cultural Influences

The level of family involvement in treatment decision-making for older patients with cancer depends on whether a society is more family-oriented or more individual-oriented. In collective cultures, severe illness is seen as a family matter, and family members may even decide not to disclose the diagnosis or treatment to the patient. Within a single country, cultural differences in family involvement in decision-making are found between different ethnic minorities, between native-speaking and non-native-speaking patients, and between urban and rural areas [6,30].

4. Discussion

The aim of this scoping review is to offer deeper understanding of factors influencing family involvement in the treatment decision-making of older patients with cancer. Although a number of previous reviews have investigated family involvement in medical consultations and decision-making [8,9], to our knowledge this is the first review focusing on factors that influence family involvement specifically in the care of older patients with cancer. It includes older patients with different types of cancer, in different stages and facing different types of treatment decisions. The factors identified are visualized in a model (Fig. 2) representing patient characteristics, family member characteristics, family system characteristics, cultural influences and physicians' roles. Previous conducted studies targeting different patient groups have also found evidence that factors related to the patient, the family and the physician influence family involvement in decision-making, and some have added related factors, relational characteristics and decisional characteristics to this context [8–10,45–47].

Evidence about the interaction between factors and their impact on patient outcomes and quality of healthcare is scarce [7,45]. The five categories we have established, reveal the impact on the level of family involvement and decisional control, treatment choice, and experiences of the treatment process.

The categories patient-related factors and cultural factors seem to highly influence the level of family involvement and decisional control preferences. In general, when patients become older and their health status worsens, patients and families prefer higher levels of family control in decision-making. Whether patient autonomy is highly valued in treatment decision-making depends on cultural aspects as well. Problems might arise when members in the triad of patient, family and physician have different opinions about the preferred level of family involvement in decision-making. Results show that patient and family member psychological characteristics and characteristics in the family system are the most important factors that affect family influence on treatment choices. This can lead to challenging situations for physicians, such as cases in which patients choose a treatment because their family persuades them to do so. Psychological characteristics of the patient and the family member, such as depression and communication styles, seem to influence whether family involvement is experienced as positive and supportive and can affect coping styles of the patient and family members. To provide patient- and family-centered care for older patients with cancer, one must identify these kinds of risks early in the cancer trajectory so that family members can be helpful partners in care, during treatment decision-making and in the period afterwards. The treatment decision process should therefore consider relational autonomy, focusing not only on the individual perspectives of patients, families, physicians and other members of the healthcare team, but also on perspectives that emerge from the interactions among them [48].

Family involvement in treatment decision-making is shaped by cultural factors as well. A limitation of our study is that only English studies were included. As a result, it is likely that non-English speaking populations are not fully represented in the literature overview. Due to the fact that the included studies varied in objectives, type of respondents, type of cancer, type of treatment decisions and research methodology, only

qualitative analysis was applicable and the level of evidence supporting the factors and their impact is not very high. It is recommended that more quantitative research be initiated to provide evidence for the complex interplay of factors influencing family involvement in treatment decision-making. Most research has focused on the involvement of only one family member in treatment decisions, and few studies have addressed differences between partners and adult children. The use of a family systems approach in research is recommended as it provides deeper understanding of family relations, involvement in treatment decision-making and the impact on the patient and family members [45]. Further research is needed to develop evidence-based strategies to improve family involvement in treatment decision-making in clinical practice.

4.1. Implications for Clinical Practice

The findings of this review support the need for implementing family-centered strategies in clinical practice that acknowledge the interdependence between patients and family members. Recommended family-centered strategies include assessing family functioning, family unity and history of family conflict [22,33]; asking patients how they prefer their family members to be involved in treatment decision-making and communicating with the patient and family members regularly, as this might change over time [6,24,28,30,31]; encouraging patients to discuss treatment options with their family members [19,38,42,43]; involving family members in treatment decision-making early on [26,32]; providing support when the patient and family members experience barriers in their communication about treatment decisions [6,22,23,31,35,41,43]; and preparing family members and patients for their changing roles in decision-making toward the end of life [21,23,40]. There is also a need to develop tools and decision support interventions that facilitate the involvement of both patients and family members in decision-making [21,23,25,31,33,34,37,39,40].

More research is needed, as lack of evidence may contribute to unwillingness by organizations and health professionals to adopt these family-centered strategies [4]. For successful implementation of these strategies in the care of older patients with cancer, it is important to recognize that family involvement in treatment decision-making is part of a wider patient- and family-centered approach to healthcare in which patients and their families are seen as partners in care. It requires an organizational culture in which physicians embrace the basic principles of patient- and family-centered care [49,50]. Barriers that can hinder implementation include lack of time and lack of financial and administrative support for activities that promote patient and family engagement [49]. Furthermore, training is needed for physicians and other healthcare professionals about how to effectively partner with patients and families and how to use family-centered strategies in treatment decision-making in clinical practice [4,49–51].

4.2. In Conclusion

This review reveals a complex interplay of factors influencing family involvement in the treatment decision-making process for older patients with cancer and shows that family involvement in decision-making is rooted in the family system. When physicians take these factors into account, they can influence family involvement in treatment decisions, which seems to have a positive effect on patients and their family members. The findings underscore the need for implementing evidence-based strategies for family involvement in treatment decision-making as part of patient-centered care for older patients with cancer.

Declaration of Competing Interest

The authors declare to have no conflicts of interest.

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Author contributions

Dijkman: Conceptualization, methodology, data collection, data analysis and writing original draft. **Luttik and Paans:** Conceptualization, methodology, data analysis and reviewing original draft. **Van der Wal-Huisman:** Conceptualization, methodology, reviewing original draft. **Van Leeuwen:** Supervision, responsible for overall content.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jgo.2021.11.003>.

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