

# Exploring family perspectives in geriatric oncology: a triadic approach to shared decision-making – a qualitative study

Received: 16 October 2024

Accepted: 4 November 2025

Published online: 21 November 2025

Cite this article as: Dijkman B.L., Luttik M.L., Paans W. *et al.* Exploring family perspectives in geriatric oncology: a triadic approach to shared decision-making – a qualitative study. *BMC Geriatr* (2025). <https://doi.org/10.1186/s12877-025-06744-5>

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**Title:****Exploring family perspectives in geriatric oncology: a triadic approach to shared decision-making - a qualitative study****Authors**

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**Abstract****Background**

In geriatric oncology, family members frequently accompany patients during medical consultations, providing emotional and practical support while participating in shared decision-making (SDM). Family involvement in SDM can facilitate the decision-making process but also pose challenges for healthcare professionals. Additionally, much of the SDM deliberation occurs outside the clinical setting, making it important to understand family dynamics to ensure treatment decisions align with the patient's values and preferences. Therefore this study aims to explore the experiences and perspectives of family members regarding their

involvement in decision-making processes for older patients with cancer, and the subsequent impact on roles and family dynamics.

## **Methods**

Qualitative open in-depth interviews were conducted with 16 family members of 11 patients with cancer of 70 years and older in the Netherlands. Qualitative data analysis was conducted using a thematic analysis approach.

## **Results**

Four interconnected themes emerged. The first theme, “Roles” revealed that family members often provide both practical and informational support, and sometimes act as advocates for the patient. The second theme, “Family Values and Beliefs,” highlighted a strong sense of unconditional and reciprocal support within families, emphasizing the core value of caring for one another. Third, “Family Dynamics,” encompasses: keeping everyone informed, dividing caregiver tasks, dealing with disappointment and sadness, managing different opinions, and coping with uncertainty. Finally, “Dilemma’s” describes: family members balancing their own opinions with the patient’s preferences, reconciling hope and fear, weighing trust in medical professionals against their own judgment, and balancing caregiving responsibilities with their personal lives. These dilemmas were shaped by roles the family members assumed, the underlying values and beliefs, and family dynamics.

## **Conclusion**

The findings of this interview study provide valuable insights into the complex roles that family members of older patients with cancer play in medical consultations and treatment decision-making and their dilemma's. These roles are deeply influenced by family values and dynamics, which can significantly shape decision-making processes and outcomes. Understanding these factors can help healthcare professionals as it highlights the evolving responsibilities of family caregivers and the importance of supporting them in navigating the intricacies of treatment decisions while maintaining respect for patient autonomy.

## **Keywords**

Triadic decision making, Geriatric oncology, Shared decision making, Family members, Family systems, Older patients with cancer, Treatment decision making

## **Background**

In geriatric oncology practice, patients are commonly accompanied by one or more family members during medical consultations, typically their partner and/or adult children, and occasionally by others (1,2). Most of these family members provide emotional and practical support to the patient, actively participate in conversations with physicians, and consequently are involved in shared decision-making processes regarding the patient's treatment and care (1). Shared decision making (SDM) in this context is defined as 'an approach where physicians and patients

share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences (3).

Physicians observe a wide range of behaviors from family members during medical consultations and decision-making processes, varying from passive observation to actively asking questions and expressing their opinions about the patient's condition and treatment options (4). Family involvement in SDM is considered important as it can enhance patient satisfaction with care, improve understanding of medical information, and lead to better health outcomes (1,5). However, behaviour of family members can also present significant challenges for physicians. These include navigating different opinions among family members, managing dominant family voices, and ensuring that the patient's autonomy is respected (6,7). Additionally, much of the deliberation that occurs at home between patients and their families is out of the physician's sight, making it difficult to fully understand the dynamics and influences that shape treatment decisions. Recognizing and addressing these challenges is crucial for optimizing patient-centered care and ensuring that treatment decisions align with the patient's values and preferences.

Family members' involvement in decision-making is closely tied to their caregiving role, with a primary caregiver often becoming the main coordinator and advocate for the patient's care and treatment options

(8). As patients age and experience declining health and increasing frailty, their reliance on family members for care and support increases, leading to greater involvement in decision-making processes (1).

Patient's growing needs for care and support place higher demands on family caregivers, which not only affects the caregivers themselves but also has an impact on the entire family system. The dynamics within the family can result in diverse caregiving experiences, impacting decision-making processes that can range from well-coordinated efforts to challenging decisions or even miscommunication and conflicts (9). The intricate values and dynamics of the family system, its subsystems, and the broader cultural context significantly influence this involvement. Emotional connectedness within the family, including the strength of bonds and the quality of relationships, plays a pivotal role in collaborative decision-making. Additionally, openness in information sharing among family members is vital, as transparent communication fosters more informed and cohesive decisions (10).

Given that much of the deliberation in SDM takes place at home, investigating the perspectives of family members is essential to gaining a comprehensive understanding of their motivations, concerns, and the support they provide to patients (11-13). This helps to understand how family dynamics shape treatment decisions and caregiving experiences and enables healthcare providers to develop more effective strategies to engage families in the decision-making process, ultimately improving the care and support provided to older cancer patients. Additionally,

recognizing the challenges family members encounter can lead to better support systems for family caregivers, enhancing their ability to contribute positively to the patient's care.

Despite growing recognition of shared decision-making (SDM) in cancer care, there is limited understanding of how family members experience and perceive their involvement in this process for older patients. Existing research largely centers on the patient-clinician interaction, overlooking both the broader family dynamics and the fact that aspects of the decision-making process, such as information seeking and reflection, often occur outside clinical consultations (14). While family involvement in decision-making has been studied in the context of dementia, these dynamics differ substantially due to cognitive decline and the more frequent shift toward surrogate decision-making (15,16). By contrast, less is known about how families contribute to SDM in older adults with cancer who retain decision-making capacity.

The objective of this study is to examine the experiences and perspectives of family members of older cancer patients regarding their involvement in medical visits and treatment decision-making, and how this involvement affects family roles and dynamics.

## **Methods**

This study utilized a qualitative descriptive design guided by the principles of thematic analysis. Open, face-to-face interviews were

conducted with family members of older patients with cancer to explore their experiences and perceptions regarding the decision-making processes. The findings are presented in accordance with the guidelines for reporting qualitative studies established by COREQ-32 (17).

## **Participants**

Patients and their family members were selected from oncology outpatient wards in three hospitals in the northern Netherlands, in close collaboration with physicians or nurses, during the period from January to June 2024. Inclusion criteria encompassed patients aged 70 years and above, who had been (re)diagnosed with cancer within the past 18 months. Exclusion criteria included patients with dementia, current hospitalization or recent post-surgery recovery. Eligible patients received written information about the study and were asked for their permission to contact family members. To ensure a comprehensive understanding of family dynamics and incorporate diverse viewpoints, one or two family members were recruited for each patient. Family members aged 18 years and older were eligible for inclusion. Exclusion criteria encompassed family members with cognitive decline. Participant recruitment continued until three researchers (BD, ML, WP) agreed that no new information was emerging and data saturation had been reached. Data saturation was assessed through an iterative process of data collection and analysis, with two weekly meetings held to review emerging themes and ensure rigour (18).

## **Ethical considerations**

The ethical committee of the University Medical Center Groningen (UMCG) approved the study protocol (research number UMCG 17633). All participants were fully informed about the study, and formal written informed consent was obtained from patients as well as the included family members. To ensure anonymity, all data that may plausibly identify any of the participants were eliminated from the transcripts. In line with general data protection regulations and data minimization guidelines, the audio recordings were deleted after transcription of the interviews (19).

## **Data Collection**

Open interviews were conducted separately with each family member to capture individual viewpoints accurately, with some conducted in the presence of the patient but without their involvement. To enhance participant comfort and minimize burden, interviews were conducted at participants' homes. Occasionally, when preferred by family members, interviews were conducted in a video call, or in the hospital. The interviews were conducted by one experienced researcher in social sciences (BD), trained in interview techniques.

After explaining the purpose of the study, the interviews uniformly began with the opening question: "Could you please provide an overview of the process that unfolded following the cancer diagnosis of your family member?" Additional probes and prompts were used to clarify information and encourage detailed accounts. An interview topic guide

was developed and employed to ensure coverage of relevant aspects, including interactions with the healthcare providers, the patient, other family members and the wider social network (Appendix 1). Special attention was paid to the family's involvement in the decision-making process, their experiences and perspectives on familial roles and dynamics, and any challenges encountered. The interviews, each lasting between 20 and 50 minutes, were all audio-recorded and transcribed verbatim.

## **Data Analysis**

Reflexive thematic analysis, as outlined by Braun and Clarke, was used to analyze the interview transcripts (20). This approach involved familiarization with the data, generating initial codes, searching for and reviewing themes, and defining and naming themes. The method relies on the active role of researchers in developing themes through an iterative process, enabling a nuanced understanding of family dynamics and decision-making. Themes were continuously refined during data collection and analysis, in line with recent recommendations emphasizing reflexivity and transparency in qualitative research (20). Atlas -ti (version 8.4.5) was used to facilitate the process of coding and analysing the data.

Three researchers (BD, ML,WP) familiarized themselves with the data, discussed initial coding, and identified meaningful overarching themes. They deliberated on different interpretations of the codes and themes until reaching a consensus on the final coding framework and theme

names. BD then coded all transcripts using this final framework. Reporting the themes involved synthesizing the underlying codes, resulting in a summary of the family members' perceptions and experiences, illustrated with quotes. Quotes use the annotation P\*F\*, where P\* refers to the patient and F\* denotes their family members. Rigour was ensured through discussions two weekly meetings attended by the three researchers (BD, ML, WP), which aimed to resolve differing interpretations of the data during the analysis process.

### **Rigour**

Rigour in this qualitative interview study was guided by the quality indicators for rigour (21) and the principles outlined by Long and Johnson (22), which emphasize addressing reliability and validity through strategies suitable for interpretive research. In this context, reliability refers to the consistency and transparency of the research process (22). Reliability was supported by maintaining a detailed record of the research process and through researcher triangulation: three researchers independently analysed the first five transcripts and later discussed their interpretations to reach consensus. Validity, understood here as the credibility and authenticity of the findings (22), was enhanced through several measures, including the use of verbatim participant quotes to ground findings in the data and researcher reflexivity through field notes. Additionally, validity was further supported through prolonged engagement with participants, which involved using open-ended, nonjudgmental questions, allowing sufficient

time for interviews, and offering participants the option to be interviewed in their preferred settings, such as at home.

## Results

### Participants

Sixteen family members participated in the study. To reach them, 33 patients were provided with study information, and 11 patients gave consent for their family members to be involved. Reasons for declining participation varied, including having too much going on in their lives at the moment, health issues of a family member, and the patient's desire not to burden their family members. The 16 participants included six partners, three sons, and seven daughters of the patients (Table 1). Average age of family members was 67 years (SD12.3).

<b>Patients</b>	<b>N=11</b>
Age	mean = 80 (SD 5.76)
Gender	6 male 5 female
Type of cancer	4 Gastrointestinal cancer 3 Breast cancer 4 Other
<b>Family members</b>	<b>N=16</b>
Type family members	6 partners (5 female, 1 male)

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	7 daughters
	3 sons
Age family members	mean = 67 (SD12.3)

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*Table 1: Patients' and family members' characteristics*

## **Themes**

Thematic analysis of family members' experiences and perspectives on their involvement in medical conversations and decision-making revealed four interconnected themes (see Figure 1). The first theme, "Roles," outlines the various ways in which family members assist the patient throughout these conversations and decision making processes. The second theme, "Family Values and Beliefs," is related to personal motivations that drive family members to take on supportive roles. The third theme, "Family Dynamics," shows that family involvement decision-making processes is also shaped by the relationships and interactions within the family. This theme includes stories about how the family system manages different caregiving roles, the flow of information, and the interactions among members. The fourth theme, "Dilemmas," explores the challenges that family members encounter during this process, often related to the roles they assume, the family values and beliefs they hold, and the dynamics within the family.

*Figure 1: Family member's perspectives on their involvement in medical conversations and SDM processes for an older patient with cancer.*

## **Theme 1: Roles**

When supporting a patient during medical visits and treatment decision-making processes, family members often take on various essential roles. The data revealed that all participants provided practical and informational support, while only a few took on the role of advocate for the patient.

### **Practical support**

Most participants mentioned practical support including driving the patient to the hospital, accompanying them to consultations and helping them with scheduling appointments. This practical support is often related to having a car, living in nearby and being able to combine this with personal and professional duties. One son referred to himself as the "process manager" for his father. He arranged all hospital appointments and drives his parents, as he is the only one among his siblings with a car (P4F2). Another participant shared that due to their parents' health issues, she and her brother take turns driving their mother to the hospital, a responsibility they wouldn't have assumed if their father was still able to drive (P10F1).

### **Informational support**

Family members provide informational support before, during, and after medical conversations with physicians and nurses. All family members emphasized the importance of having multiple people present during consultations to ensure a complete understanding of the situation. Some mentioned helping the patient prepare a list of questions before hospital visits and discussing the answers afterward to ensure clarity (P4F2, P9F1). When one of the children has a medical background, they often take on this role in various ways. For instance, one daughter, a professional nurse, remains silent during consultations to keep the doctor's focus on her mother. She then discusses the information with her mother and shares it with homecare nurses, ensuring accurate communication with everyone involved (P7F1). Some participants also mentioned that their role is to ask questions, as one partner explained: "I am the one who asks the questions because I want to fully understand the situation. This has always been my role in our relationship" (P11F1).

### **Advocate for the patient**

In their role as advocates for the patient, family members are proactively involved in ensuring that hospital processes run smoothly, that different doctors and wards communicate effectively, and that every decision made is in the best interest of the patient. This role is mentioned only a few times, often caused by previous experiences with the patient or with another close family member, as illustrated by the following quotes: "You have to do a lot of phone calls because different wards don't communicate well and information about the patient sometimes get lost

(P2F1)"; And "We are very alert because of earlier experiences with my father. My mother is getting forgetful, so we make sure everything is going alright in contact with the doctors and home care nurses (P7F2)".

## **Theme 2: Family values & beliefs**

### **Care for each other**

The core family value of "care for each other" is reflected in the shared stories, illustrated by statements as, "We support each other through laughter and tears" (P9F1) and "You don't leave her alone" (P7F2). The narratives expressing this value revealed two key beliefs: that family acts as a unit of unconditional support during illness, and that there is a reciprocal care between parents and children.

#### ***Unit of unconditional support***

Family members believe that the family functions as a unit of unconditional support, with members emphasizing the importance of close relatives accompanying patients to hospital visits and participating in decision-making, rather than involving friends or neighbors. Some partners expressed this by saying "we are in this together" (P1F1, P3F1, P11F1). When a patient's partner passes away or faces health issues, adult children step in to provide support. "...of course she prefers supported by us because that feels familiar." (P7F2). "Only when me or my brother cannot support her, we look for other options" (P10F1).

#### ***Reciprocal care***

Some adult children emphasized the reciprocal nature of care between parents and their children throughout life. This sentiment was reflected in statements such as, "They always took care of me, so I want to take care of him, especially after my mother/father passed away" (P7F2, P8F1). These reflections highlight how the care and support they received from their parents serve as a powerful motivation to provide similar care in return, including accompanying and supporting the patient during critical medical appointments.

### **Theme 3: Family dynamics**

The narratives revealed that family dynamics play a vital role in navigating the complexities of supporting the patient during medical conversations and decision-making processes. Family members noted that this responsibility is just one of many caregiving tasks that emerge as older patients with cancer become more frail and the illness progresses. This theme "Family dynamics" encompasses several subthemes: keeping everyone informed, dividing caregiver tasks, dealing with disappointment and sadness, managing different opinions, and coping with uncertainty.

#### **Keeping everyone informed**

The participants stressed the importance of keeping their families informed about the patient's health conditions, primarily through text messages and phone calls. The frequency of these updates varies depending on the closeness of family relationships. Several participants

mentioned providing updates to their children or siblings after every hospital visit. To ensure everyone is on the same page, one son explained, "I send the report I wrote to the app shared with my brother and sister. They can use this to inform their children as well, helping us avoid misunderstandings" (P4F2). One partner, with looser family bonds, mentioned informing her sons by email and occasionally calling one of them (P6F1). Many also have a wider network of friends and neighbors who need to be kept updated on the patient's situation.

#### **Dividing caregiver tasks**

The narratives showed that family members view involvement in medical conversations and treatment decisions as a crucial caregiving responsibility, alongside other tasks. Many families divide these responsibilities based on practical considerations, such as proximity or medical knowledge, which usually fosters harmony but occasionally leads to unspoken irritation. For example, two participants with medical backgrounds attend appointments, while another sibling manages financial matters and gardening tasks, illustrating a collaborative approach (P2F1, P7F1). Another participant described how she accompanies their mother to hospital visits, while a sister living abroad steps in during critical periods like surgery, demonstrating a balanced contribution (P9F1). However, tensions can arise when siblings hold different opinions. For instance, in one case, a daughter withdrew from caregiving after facing criticism from their mother, leaving another

daughter to shoulder all responsibilities—a situation they find excessive but choose not to discuss openly (P5F1&F2).

### **Dealing with disappointment and sadness**

Two partners expressed feelings of disappointment and sadness due to their children's lack of connection and availability for support, each for different reasons. One participant shared, "My daughter lives a few hours away and has health issues herself, which is why she can't visit us. It's really sad we cannot see each other" (P4F1). Another said, "One of my sons lives abroad. We videocall regularly, and I would love to see him, but that is impossible. Sadly, my other son is no help—we keep him informed, but he is so brief in his responses" (P6F1). These experiences highlight the emotional challenges and disappointment that can arise in maintaining family connections under difficult circumstances, whether due to physical distance or strained relationships.

### **Managing different opinions**

Most families did not report differing opinions between family members, although a few did. One daughter expressed difficulty due to family dynamics: "My sister and I are very different and have varying opinions on what is best for our mother. I have medical experience, but my sister tells me to stay quiet during doctor visits, insisting that we follow the doctor's advice rather than my own (P5F2)". Another participant mentioned encountering different opinions but also finding consensus. "My sister and I had a difference of opinion about whether my mother

should investigate the chemotherapy option. My sister said not to ask her because she wouldn't want to do it. We talked about it and I insisted on it. My mother agreed to investigate but chose not to go for it. In the end we resolved it easily." (P9F1).

### **Coping with uncertainty**

Several participants expressed uncertainty about their supportive roles. For instance, one partner, uncertain about her role as an advocate for the patient, explained, "Sometimes I am not sure if I am doing the right thing, and since I can't talk with my husband about this, I call my daughter" (P2F1). Many participants also mentioned uncertainties arising from the impact of the cancer process on the patient and the potential consequences for the near future. Some spouses were able to discuss these uncertainties with the patient. For example, one spouse described how she was preparing for an uncertain future by taking on tasks her husband used to handle, like financial management (P1F1). However, others felt unable to share their fears and doubts with the patient. One partner mentioned that her spouse did not want to talk about the illness, leaving her to cope with these feelings alone or by reaching out to a friend (P6F1). Overall, talking to the patient, other family members, or friends seemed crucial for coping with these feelings of uncertainty.

### **Theme 4: Dilemma's**

Family members expressed four different dilemmas' related to their involvement in medical conversations and treatment decision processes. Three of these dilemmas focus on striving for the best outcome for the patient while respecting their autonomy, while the fourth concerns the balance between being a supportive family member and managing one's own life.

### **Own opinion versus patient's choice**

Some family members expressed their struggles in balancing their own viewpoints with respecting the patient's autonomy. As one participant articulated, "I want her to fully understand chemotherapy as an option before she decides. However, I was careful not to pressure her too much because the decision ultimately has to be hers" (P9F1), illustrating the tension between providing information and supporting independent decision-making. Other participants mentioned similar sentiments, explaining, "We can suggest things, but ultimately it's his decision, so I don't want to intervene too much (P8F1)," and " My mother has strong opinions about what kind of treatment she doesn't want anymore. If my brother and I suggest, 'Why don't you do it this way?' we can still discuss it with her, and she will consider it. However, when she is firm about it and says 'Why I have to go through this all?' we also think, Yes, fine. It's your life. You are indeed 82." (P10F1).

### **Trust in professionals versus own opinion**

Several participants expressed a dilemma regarding the balance between trusting healthcare professionals and their own personal opinions. One participant mentioned her concerns, stating “I had my doubts about whether the doctor’s recommendation for major surgery was in my husband's best interest, but I didn't want to question it at the time” (P1F1). Another one said: “I feel you have to be cautious about whether it is truly in the patient's best interest because sometimes it seems like the doctor is just offering another surgery or experimental study, even when the patient does not want to pursue this and it is not in their best interest” (P2F2).

#### **Realistic scenario versus hope and fear**

Balancing realistic scenarios with the interplay of feelings of fear and hope was mentioned several times as a challenge. One participant reflected, “That the surgeon was offering this surgery gave him hope so he directly said yes to this. I had my doubts but he was not ready to discuss this. I did not want to take away his hope. (P1F1).” This highlights the tension between supporting the patient's hopeful outlook and the need to consider realistic medical outcomes. Fear also led to miscommunication, as one respondent noted, “He was so scared for further treatment, that he told the doctor that he was doing well, but he was not. (P2F1)”. “When my parents start to doubt and worry, I help them to stay realistic and go back to what was actually said by the doctor” (P4F2). A different perspective was shared by a son who said: “It is good that the doctor presented a realistic scenario but please make

sure you don't take away hope" (P3F2). Another participant recalled the doctor's reassurance about a specific type of cancer: "The doctor said that with this special type of cancer, it will be alright. The trajectory might be difficult, but you will get better. That helps and that is what my wife and I focus on all the time. (P11F1)"

### **Caregiver role and personal situation**

A significant theme emerged around the challenge of balancing caregiving responsibilities, such as accompanying the patient to hospital visits, with personal and professional obligations. Several participants emphasized the importance of spousal support in caregiving. One participant shared, "Sometimes it's a lot, but my husband supports me when I need to be with my parents. Then he takes care of the children." (P2F2). Another participant noted, "Luckily, my wife gets along very well with my mother, and she encourages me to take care of her, but sometimes I think that my mother should take some more responsibility herself " (P7F2). That caregiving can be overwhelming was expressed by several participants as well. "All though it sometimes is a lot, but I think she is still here, so I do that for her." (P5F1) and "Supporting her became too much for me because my energy level is not good due to my own history of breast cancer. Now, I only accompany her and my sister to hospital visits when further treatment is discussed" (P5F2). Several participants shared the advantage of having workplace flexibility as illustrated by this quote, "Fortunately, I can arrange it with my job when my mother/father needs to go to the hospital. My colleagues know

my situation, and I can manage my agenda (P4F2, P7F1, P9F1).” Other participants noted the challenges of not always being available for example by stating: “I am a teacher, so I cannot join her all the time; that is difficult (P10F1).”

## **Discussion**

This study examined the experiences and perspectives of family members of older cancer patients regarding their involvement in medical visits and treatment decision-making, as well as the impact of this involvement on family roles and dynamics. The findings showed that such involvement is not a single, isolated event but rather part of a continuous process closely linked to other caregiving tasks and shaped by family values and family dynamics. Family members take on various roles in supporting their older relatives with cancer, driven by family values and beliefs that emphasize mutual care and responsibility. How they assume these roles and the dilemma’s the is influenced by family dynamics, including factors such as the division of caregiving tasks and the management of differing opinions among family members. These values and dynamics can either facilitate or complicate family member’s supportive roles. Personal dilemmas often arise as family members try to balance their desire to act in the patient’s best interest with the challenges of managing their own lives.

Family members in this study frequently highlighted their role in providing practical and informational support. Although previous research also emphasizes the importance of emotional support (1,23), this aspect was not explicitly mentioned by participants in our study. Instead, participants expressed beliefs such as “you don’t leave him alone” and “we are in this together”, indirectly reflecting their commitment to providing emotional support when needed. By offering informational support before, during, and after medical visits - such as helping patients prepare questions and understand medical information - family members can enhance patient autonomy (24). This type of support is helpful for effective communication between patients and healthcare professionals and aligns with previous research indicating that family members who encourage patient participation significantly improve decision-making (25). The advocacy role, however, was mentioned only occasionally and typically arose when trust in professionals had diminished due to previous experiences, often resulting from miscommunication between different healthcare professionals or a failure to align care and treatment with the patient's preferences. In their advocacy role, family members often face a dilemma between their personal opinions and their trust in healthcare professionals. This highlights the need for effective coordination among different healthcare professionals involved in treatment decisions for older patients with cancer (13).

The results indicate that patient and partner prefer to attend hospital visits together if possible. This aligns with family systems theory, describing families as a unit including relational subsystems such as the spousal subsystem (10). The patient-partner duo is being described as a vital subsystem dedicated to mutual support and joint decision-making, including for treatment choices. This helps them to maintain autonomy and manage decisions independently (10), and reduce the burden on their children and other close ones (26). However, when this spousal subsystem faces increased frailty or the death of one member, the subsystem's capacity to fulfil this role diminishes (10). Consequently, the involvement of other family members, particularly children, becomes more pronounced (27). This transition highlights the fluidity and adaptive nature of family dynamics in response to changing health conditions and caregiving needs (28). Adult children often take on caregiving and decision-making responsibilities out of love and a sense of duty. However, this role can result in dilemmas, such as balancing their own lives with caregiving demands and managing tensions with less-involved siblings. These challenges are further compounded by the risk of caregiver burden, a common issue highlighted in research on caregiving for aging parents. (29). Additionally, balancing caregiving duties with personal life obligations emerged as a significant challenge for many, with some participants highlighting the risk of caregiver burden.

Family dynamics impact the division of caregiver tasks among siblings, which in our study is largely based on practical factors such as

availability, proximity, and medical background. In most families, this division of caregiver tasks is agreed upon, sometimes implicitly, without being explicitly discussed. Complex challenges arise when family members hold different opinions on the patient's best interests or when certain siblings are unable or unwilling to participate in caregiving responsibilities. The manner in which these challenges are addressed is closely tied to the family's values, communication patterns, and relationship dynamics (10,30). In this study, family members reported encountering specific difficulties, particularly when the patient expressed unrealistic hopes or fears regarding treatment, or was resistant to discussing future care needs. These issues can be further exacerbated when family members feel they cannot openly communicate with the patient, leading to heightened emotional stress and ethical dilemmas. Poor communication and conflicting values further exacerbate moral distress and emotional burden on family members (31).

Research showed that nurse-led family conversations can positively impact family functioning in the care of older patients, facilitate decision-making processes, and help prevent caregiver burden (32,33). This type of family conversations aim to foster open communication, align differing perspectives, and distribute caregiving tasks more effectively.

This study offers a valuable new perspective through the rich narratives shared by family members—including both partners and adult children—about their experiences and perceptions of involvement in decision-making. A key strength is the depth of these insights, supported by data

saturation, which enhances the credibility of the findings and their contribution to understanding family dynamics and dilemma's in this context. However, due to the small number of participants, the findings should be treated cautiously and are not necessarily transferable to other settings.

Most participants mentioned their down-to-earth and realistic view of the situation and noted that they do not often discuss emotions. This could be due to selection bias, as we did not reach out to families in the midst of a hectic emotional process, and participants may have declined to participate if they felt too emotional or were experiencing family problems. Consequently, the study may not fully capture the challenges faced by families navigating difficult situations related to supporting an older patient with cancer during medical conversations and treatment decision-making processes, which limits the richness of the findings.

This research aligns with the holistic approach to personalized care in geriatric oncology and reflects the societal trend emphasizing the increasing role of family in supporting older patients at home. Our findings about the interplay between family values, dynamics, family member's roles, and caregivers' dilemmas underscore the importance of these factors in triadic decision making processes. Understanding how these elements influence the medical conversations and decision-making process can enhance healthcare professionals' ability to engage families effectively, ultimately leading to improved person centered care in geriatric oncology.

A comprehensive family assessment helps to gain insight into family values and dynamics that might influence decision making processes and outcomes. Health care professionals need strong triadic communication skills, which are needed for facilitating medical conversations that include patients' and family members' perspectives. In addition, managing challenging interactions is crucial, particularly when important treatment decisions are involved (7,34). Family conversations can help in improving decision-making by aligning differing perspectives (32). Additionally, recognizing the personal dilemmas faced by family members - such as balancing their own opinions with trust in medical professionals - enables healthcare providers to engage more effectively with families. Offering support to family members, particularly in understanding their role, navigating complex decisions, and preventing caregiver burden, is highly recommended.

Further research is recommended to explore the specific strategies and interventions that can effectively support families in their caregiving roles, particularly in the context of treatment decision-making for older cancer patients. Additionally, it is recommended to investigate the impact of cultural differences on family dynamics and caregiving practices to develop tailored approaches that respect diverse family structures and values.

## **Conclusions**

The findings of this interview study offer valuable insights into the

complex roles of family members of older cancer patients in medical consultations and treatment decisions. These roles are shaped by family values and dynamics and often involve dilemmas, such as supporting patient autonomy while offering guidance, or balancing caregiving duties with personal responsibilities. These factors can strongly influence decision-making processes and patient outcomes. Understanding these factors is helpful for healthcare professionals as it highlights the evolving responsibilities of family caregivers and the importance of supporting them in navigating the intricacies of treatment decisions while maintaining respect for patient autonomy.

#### **Authors' contributions:**

Study concept and design: BD, ML, WP, BL, HW. Acquisition of data: BD. Analysis and interpretation of data: BD, ML, WP. Preparation of the manuscript: BD. Critical revision of the manuscript: ML, WP, BL, HW. All authors have read and approved the manuscript.

#### **Abbreviations**

SDM: shared decision making

**Acknowledgements** Not applicable.

**Funding** None

#### **Ethics approval and consent to participate:**

The ethical committee of the University Medical Center Groningen (UMCG) approved the study protocol (research number UMCG 17633).

Written informed consent was obtained from all patients and family members.

**Clinical trial number:** not applicable.

**Consent for publication** Not applicable.

### **Availability of data and materials**

The code structure is available from the corresponding author on reasonable request.

**Competing interests** The authors declare that they have no competing interests.

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