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## REVIEW

# Shared decision-making with older adults with cancer: Adaptation of a model through literature review and expert opinion

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## Abstract

**Objective:** To provide a literature overview of characteristics of Shared Decision Making (SDM) with specific importance to the older adult population with cancer and to tailor an existing model of SDM in patients with cancer to the needs of older adults.

**Methods:** A systematic search of several databases was conducted. Eligible studies described factors influencing SDM concerning cancer treatment with adults aged 65 years or above, with any type of cancer. We included qualitative or mixed-methods studies. Themes were identified and discussed in an expert panel, including a patient-representative, until consensus was reached on an adjusted model.

**Results:** Overall 29 studies were included and nine themes were identified from the literature. The themes related to the importance of goal setting, need for tailored information provision, the role of significant others, uncertainty of evidence, the importance of time during and outside of consultations, the possible ill-informed preconceptions that health care professionals (HCPs) might have about older adults and the specific competencies they need to engage in the SDM process with older adults. No new themes emerged from discussion with expert panel. This study presents a visual model of SDM with older patients with cancer based on the identified themes.

**Conclusions:** Our model shows key elements that are specific to SDM with older adults. Further research needs to focus on how to educate HCPs on the competencies needed to engage in SDM with older patients, and how to implement the model into everyday practice.

## KEYWORDS

cancer, decision making, frail elderly, multimorbidity, oncology, qualitative research, shared decision making, systematic review

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## 1 | BACKGROUND

Cancer treatments are becoming more effective and numerous.<sup>1,2</sup> Simultaneous to the increase in the number of options, the amount of preference-sensitive decisions have risen.<sup>3-5</sup> When multiple medically appropriate options exist, patient values are key, alongside scientific evidence and clinical expertise. The progression of age and multimorbidity amongst patients with cancer are contributing to the rise of preference-sensitive decisions. Risks of serious adverse events may outweigh chances of being cured, halting, or slowing down disease progression.<sup>6</sup> Lack of evidence, due to the underrepresentation of older patients in clinical trials, leads to uncertainty of treatment outcomes.<sup>7,8</sup> In addition, outcomes specifically important to older adults, such as maintaining functional and cognitive capacities, are not usually assessed in trials.<sup>8,9</sup>

Shared decision-making (SDM) has been widely recognized as the preferred model to make preference-sensitive decisions.<sup>10,11</sup> SDM supports patients in considering all available options, to achieve informed preferences.<sup>12</sup> Various models of SDM have been introduced that often share components, but lack uniformity.<sup>13</sup> Recently, a comprehensive model of SDM in patients with cancer was developed based on literature and interviews with patients, health care professionals (HCPs) and SDM researchers.<sup>14</sup> Considering that 58% of patients newly diagnosed with cancer in 2035 are expected to be 65 years or older,<sup>15</sup> and older patients present unique challenges such as a higher prevalence of multiple long-term conditions (MLTC), including cognitive impairment,<sup>16</sup> and uncertainty of evidence,<sup>7,8</sup> it is important to assess the model's applicability to older adults.

Specific models for SDM with patients with MLTC<sup>17,18</sup> and for SDM with frail older patients<sup>19</sup> have been developed. Both models put patients' goals and values at the heart of SDM. The model of SDM with frail older patients emphasizes the importance to assess decision-making capacity and to actively involve next-of-kin. These context-specific models underscore the potential value of tailoring the SDM process to specific patient groups.

This study aims to (1) provide an overview of characteristics of SDM reported to be of specific importance to older adults with cancer, based on a systematic literature review and (2) tailor the existing model of SDM in patients with cancer to the needs of older adults, informed by the literature and expert opinion.

## 2 | METHODS

### 2.1 | Search strategy

A systematic search in databases (Pubmed, PsycINFO (Ovid), Embase) was conducted on 22-11-2019 and updated on 08-02-2022. The search, developed with a medical librarian, used terms from existing models and SDM studies. The search was created for Pubmed using Mesh- and associated terms, and translated to other databases. The search was restricted to articles in English/Dutch, and cited references in eligible studies were reviewed. The search was

limited to publications  $\geq$  year 2000, because the concept of SDM first appeared in medical research literature in 1997<sup>20</sup> and gained momentum over the course of the 2000s.<sup>21</sup> For the detailed search strategy, see Supporting Information S1: file 1.

### 2.2 | Eligibility criteria

Eligible studies explored factors in SDM concerning cancer treatment with older adults, encompassing completed, ongoing, or planned treatments. We included qualitative and mixed-methods studies, or reviews of such studies. Eligible studies included patients aged  $\geq 65$  years, or reported a mean or median  $\geq 65$  years, with any type of cancer, or HCPs who care for older adults with cancer. Excluded studies focused on screening or prevention, lacked full-text access, or had poor methodological quality. Two researchers (FvS & EG) assessed the methodological quality using the Criteria for Appraisal of Qualitative Research as recommended by Cochrane Netherlands,<sup>22</sup> and the Mixed Methods Appraisal Tool.<sup>23</sup>

### 2.3 | Selection process

Two researchers (FvS & lvs) screened titles/abstracts and 59 full-texts of the publications retrieved in the original search for eligibility. Disagreements, often concerning whether the full-text addressed SDM or a related concept, were resolved through discussion with a third researcher (FvdB).

For the update, title/abstract screening was performed using ASReview, an Artificial Intelligence (AI) tool that increases efficiency while minimizing errors.<sup>24</sup> The included studies from the first search were used to prime the tool. To train the tool, the calibration set (random 1% of total sample) was independently screened by two researchers (EG & FvS). Disagreements were discussed and resolved. Next, ASReview organized the remaining records by relevance. One reviewer (EG) screened titles/abstracts until our data-driven stop-strategy was met: 30 consecutive irrelevant records. The remaining records were excluded. A random sample (1% of total set) from the excluded records were checked by one researcher (EG) to verify no relevant records had been missed. One researcher (EG) screened full-texts; any doubts were resolved through discussion amongst three researchers (EG, FvS and FvdB).

### 2.4 | Data extraction

One researcher (EG) performed data extraction, including: study design, target population, number of participants, patient characteristics (e.g. age, sex, comorbidities, functional status), and qualitative data on factors that influenced (shared) decision-making. Concerning the qualitative data, we extracted second-order constructs (i.e., authors' interpretations and conclusions) as well as first-order constructs (i.e., participants' quotes) that supported these.<sup>25</sup>

## 2.5 | Data analysis

Two coders with experience in oncogeriatric care and SDM research (EG & FvS) inductively coded HCPs-reported elements that play a role in SDM with older patients and patient-reported elements that play a role in SDM. These were categorized into overarching themes and sub-themes. Discussion followed with two researchers with extensive experience in SDM research (AP & FvdB) to reach consensus. Based on the themes, the existing SDM model developed by Bomhof-Roordink et al. (Supporting Information S1: file 2)<sup>14</sup> was adapted (EG).

The adapted model was reviewed during a consensus panel discussion amongst eight experts in the field of SDM: two oncogeriatric care medical specialists, a geriatric care resident, a geriatric and palliative care nurse practitioner, a primary care professor, a nursing home physician, a medical decision-making associate professor, and a patient representative. Most experts (5/7) were also researchers in the field of SDM. After a discussion of the identified themes and the applied adaptations to the model, two questions were asked: (1) do you recognize this model as an accurate representation of SDM with older adults with cancer? (2) are any elements of SDM with older adults with cancer missing from this model?

## 3 | RESULTS

The original search identified 12,544 unique records, of which 12,485 records were excluded based on title/abstract screening, and 52 records after full-text screening and quality assessment. Seven articles

were included. The second search identified 4,753 unique records, of which 4,671 were excluded based on title/abstract screening and 63 records after full-text screening and quality assessment. Nineteen articles were included. Reference checking identified another three articles. Overall, 29 articles were included in the analysis, describing 29 unique studies. Four studies were excluded because of poor methodological quality (Figure 1).

Supporting Information S1: file 2 provides an overview of the included studies. Half of the studies focused on breast (10/29)<sup>26-35</sup> or prostate (5/29)<sup>36-40</sup> cancer. Three studies focused on any type of cancer and comorbid dementia (3/29).<sup>41-43</sup> Eight studies included both patients and HCPs,<sup>26,35,41-46</sup> one study included HCPs only,<sup>40</sup> 16 studies focused on patients<sup>27-34,36-39,47-50</sup> and four focused on patients and their caregivers.<sup>51-54</sup> Information available on patient characteristics can be found in the supplements as well.

## 3.1 | Thematic analysis of the literature

Nine themes and 20 subthemes emerged from the data, categorized by patient-related factors, HCP-related factors and overarching factors that influence decision making (Table 1).

### 3.1.1 | Patient-related factors that influence decision making

**Theme 1** *Older patients report a wide variety of preferences, priorities and lifegoals*

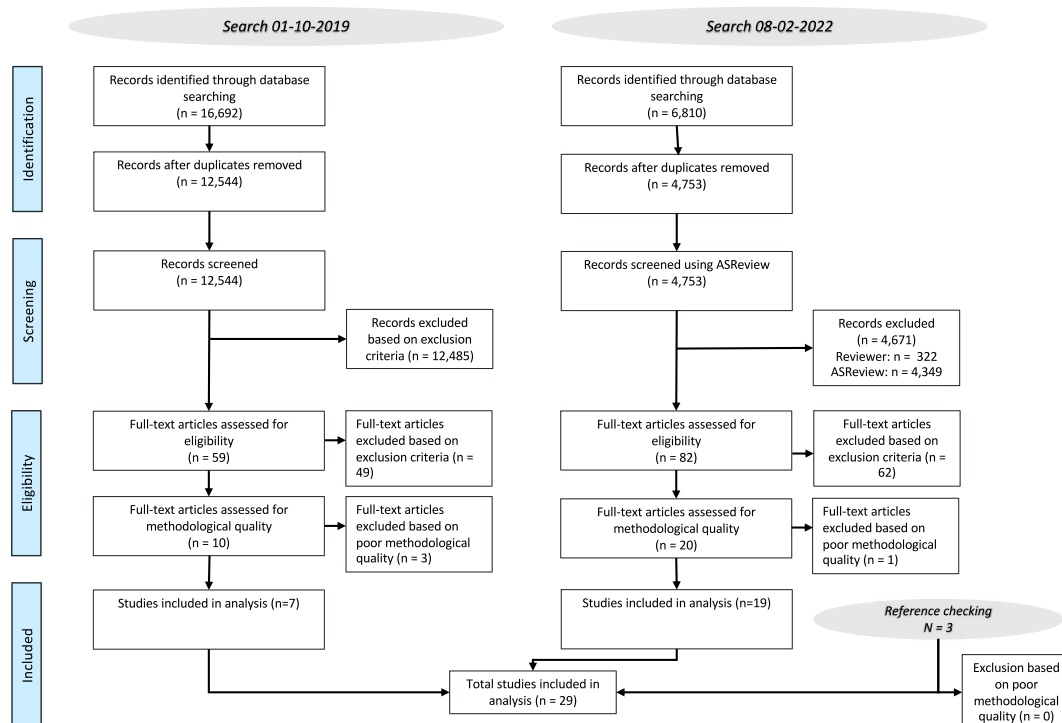


FIGURE 1 PRISMA flowchart of the screening process.

TABLE 1 Identified themes and subthemes concerning factors influencing decision making with older patients with cancer.

Themes	Subthemes	Sources
Patient-related factors that influence decision making		
1. Older patients report a wide variety of preferences, priorities and lifegoals	<ul style="list-style-type: none"> <li>i. It is necessary to discuss expectations and life goals with older patients</li> <li>ii. Older patients are aware of their comorbidities and life expectancy and this influences their treatment preferences</li> </ul>	27–29, 31–38, 40, 45, 49–51, 53, 54
2. Older patients' prior life experiences influence their ideas concerning cancer diagnosis and therapy		27–29, 31–36, 40
3. Significant others play an important role in decision-making with older patients	<ul style="list-style-type: none"> <li>i. Older patients and their significant others may make decisions as a unit</li> <li>ii. Presence of significant others in the consultation room may hinder older patients to express themselves freely</li> <li>iii. Older patients' fear of becoming dependent on others may influence their treatment preference</li> <li>iv. Significant others of older patients may speak for them or take over decision-making</li> </ul>	27, 29, 31, 32, 34, 35, 37, 38, 40, 42–45, 47–49, 52, 53, 55
HCP-related factors that influence decision making		
4. HCPs need to provide information in ways older patients' can access and process it	<ul style="list-style-type: none"> <li>i. Older patients prefer in-person information</li> <li>ii. HCPs should consider cognitive abilities of older patients' when providing information</li> <li>iii. Significant others can help older patients in processing and retaining information</li> </ul>	34, 42, 44, 50
5. HCPs need to provide information about treatment options tailored to the older patients' individual situation	<ul style="list-style-type: none"> <li>i. Older patients require information about what treatment options, including palliative care, mean for their daily life</li> <li>ii. Older patients may experience information that does not pertain to their situation as overwhelming</li> <li>iii. HCPs should provide information on how treatment options affect significant others and caregivers</li> </ul>	27, 28, 30, 34, 43–45, 53–55
6. HCPs may have preconceptions about older patients that are ill-informed	<ul style="list-style-type: none"> <li>i. HCPs may have preconceptions about older patients' preferences which influence the treatment options offered</li> <li>ii. HCPs may believe that older patients prefer to know less and do not want to participate in decision-making</li> <li>iii. Older patients may be afraid that treatment is denied based on age alone</li> </ul>	27, 28, 36, 39, 44, 46, 51
7. SDM with older patients with cancer requires HCPs to have specific, additional knowledge	<ul style="list-style-type: none"> <li>i. HCPs need to approach older patients holistically, in order to assess decision making capacity, appropriateness of treatment options and risk of complications</li> <li>ii. Some HCPs express a need to optimize their skills to differentiate between frail and non-frail patients, while others do not</li> <li>iii. HCPs need to coordinate care with other HCPs involved</li> </ul>	27, 34, 41–46, 51
8. Evidence on the impact of age, frailty and comorbidities on tolerance for standard cancer treatment is uncertain		33
Overarching factors that influence decision making		
9. Time during and outside of consultation(s) is essential to SDM with older patients	<ul style="list-style-type: none"> <li>i. Geriatric assessment of older patients takes additional time, which is not always available</li> <li>ii. Dividing the consultation in two allows patients time to process information and consult others</li> </ul>	27, 34, 36, 42, 44, 45

Abbreviations: HCP, health care professional; SDM, shared decision-making.

- i. It is necessary to discuss expectations and life goals with older patients

Reported preferences, priorities and goals varied widely amongst older patients. Some prioritized quality of life and wished to minimize side-effects and time spent in the hospital:

*Patient: "I want the quality of my life to be more fun, I want to go swimming and golfing (...) I don't want to sit with a needle in my arm, being sick and having chemotherapy."*

(32)

Others prioritized quantity of life and were willing to endure side-effects:

*Patient: "I chose to have chemotherapy. I have three grandchildren, I want to see them grow up. (...) Honey, I love life, and so I lose my hair, I got my beautician already working on wigs."*

(32)

HCPs recognized the importance of this discussion:

*HCP: "We need to look at the goals and expectations of the life that still needs to be lived, and the wishes of the person living it."*

(44)

- ii. Older patients are aware of their comorbidities and life expectancy and this influences their treatment preferences

Patients expressed an awareness of having a limited amount of years left to live due to age and comorbidities, irrespective of their newly-diagnosed cancer, and thus described an understanding of competing mortality:

*Patient: "They did suggest when I had cancer that I have radiation and chemotherapy but I refused (...) because I was 80 years old and I figured that if it was going to come back in five years I would be dead anyway. How long can you live?"*

(28)

### Theme 2 Older patients' prior life experiences influence their ideas concerning cancer diagnosis and therapy

Older patients expressed that their own previous experiences, as well as experiences of family members and friends, influenced their ideas concerning cancer diagnosis and therapy:

*Patient: "My mother-in-law had it, and I went through it with her. So I know a little bit about it and she had*

*such a horrible bad reaction to the radiation that I kind of decided unless it's really just mandated, I'm skipping that."*

(34)

### Theme 3 Significant others play an important role in decision-making with older patients

- i. Older patients and their significant others may make decisions as a unit

Often, older patients made healthcare decisions through a shared perspective and consensus with their significant other, frequently their partner:

*Significant other: "We sat down at home and thought about what we'd find to be the best. (...) Each of us was able to say clearly: what do I want, what (burden) am I willing to carry as a wife?"*

(51)

Carrying family responsibilities oneself, especially a caregiver role, can influence treatment choice as well. Practical considerations, such as recovery time, then became pertinent:

*Patient: "I chose lumpectomy and radiation because my husband's in bad health, so I didn't want to be down for a longer period of time."*

(34)

- ii. Presence of significant others in the consultation room may hinder older patients to express themselves freely

Older patients sometimes found the presence of significant others in the consultation room restrictive. Divergent information needs, such as prognosis inquiries, arose. In other cases, patients hesitated to inquire about opting out of treatment:

*Patient: "I didn't want to ask in front of my daughter, what happens if I don't have chemo?"*

(30)

- iii. Older patients' fear of becoming dependent on others may influence their treatment preference

Patients who were not used to being dependent on others, sometimes made treatment decisions that were influenced by a fear of becoming a burden:

Patient: "When I have to become dependent on somebody else, it's not a good thing. I wanted to maintain my independence, and the people who did look after me, I wanted to make their looking after me as easy as possible."

(34)

- iv. Significant others of older patients may speak for them or take over decision-making

HCPs expressed difficulty in communicating with patients with dementia, because significant others had a tendency to speak for them:

HCP: "I did try to actually talk to the patient (with dementia) and look at her and the husband would answer."

(43)

Sometimes, significant others made decisions for the patient because they deemed their involvement vital for adequate treatment:

Significant other: "the question was, the woman is over 90, what is one to do? I tried to pave the way. Sensible diagnostics, sensible decision."

(51)

### 3.1.2 | HCP-related factors that influence decision-making

**Theme 4 :** HCPs need to provide information in ways older patients' can access and process it

- i. Older patients prefer in-person information

Older patients expressed a clear preference for in-person information from HCPs. If given information through other media such as books or videos, this was perceived as excessive and disregarded:

Patient: "They dumped a lot of information on me. (..) The doctor gave me a videotape with a book for me to look at. I took it home and came across it the other day. I didn't watch it."

(33)

- ii. HCPs should consider cognitive abilities of older patients' when providing information

Older patients conveyed difficulty processing and retaining information. HCPs were uncertain about effective communication with older adults, but often continued to communicate in their usual manner, hoping it sufficed:

HCP: "Because he looked reliable for his age, I explained the disease as I usually do for younger patients. But I'm not sure it worked."

(49)

Patients with dementia and their significant others expressed a need for verbal and written information to be adjusted:

Patient: "They had given us these leaflets; they had to be read to me because I just can't do it."

(43)

Some HCPs recognized this and spoke more slowly for older patients with cognitive impairment.

- iii. Significant others can help older patients in processing and retaining information

Older patient often relied on significant others in the room for asking important questions, and for processing and retaining information:

Patient: "She (spouse) brought up good points and good questions. It would have been so much harder for me if I didn't have that additional help from her."

(52)

**Theme 5 :** HCPs need to provide information about treatment options tailored to the older patients' individual situation

- i. Older patients require information about what treatment options, including palliative care, mean for their daily life

Older patients needed information to be tailored to their situation, and to include practicalities and logistics such as how often it is necessary to travel to the hospital for a certain treatment. However, information they received was often limited to the medical domain:

Patient: "They explained the mechanics [of a colostomy bag] and everything very clearly, but not the consequences. How will it affect your daily life?"

(44)

This also applied to palliative care:

Significant other: "they didn't really go through what we need to know now (after making the decision not to have cancer treatment).. I don't really know what's happening, which isn't a great position to be in."

(43)



- ii. Older patients may experience information that does not pertain to their situation as overwhelming

Information that did not apply directly to the older patient in question, was experienced as burdensome:

*Patient: "I'm usually very curious about everything, but not this time. I didn't want to know anything except what applied to my case."*

(33)

- iii. HCPs should provide information on how treatment options affect significant others and caregivers

Patients expressed that cancer treatment had a tremendous effect on their significant others, as they often became reliant on them:

*Patient: "I took the bus 33 times for my, you know, radiation. He (husband) rode with me every day.. Oh yeah, he takes me everywhere."*

(28)

HCPs were aware of the impact on caregivers, especially for patients with dementia. While keeping the patients' best interest at heart, HCPs also weighed caregiver burden:

*HCP: "We have to do the best for the patient (with dementia) because ultimately it's the patient we're treating, but we've still got to be mindful that things fit for the carer."*

(43)

**Theme 6** HCPs may have preconceptions about older patients that are ill-informed

- i. HCPs may have preconceptions about older patients' preferences which influence the treatment options offered

Some HCPs expressed the belief that all older patients value quality of life more than longevity. Other HCPs were convinced that cosmesis and sexuality were unimportant to older women:

*HCP: "They don't care if their breasts don't match so well."*

(26)

These ideas influenced the treatment options offered to the patient, such as discussing lower-intensity treatment options only, or not discussing breast-conserving surgery.

- ii. HCPs may believe that older patients prefer to know less and do not want to participate in decision-making

Some HCPs expressed preconceived ideas that older patients want little to no information about their illness and

treatment options, do not wish to play an active role in decision-making, and prefer to defer the decision to a relative or doctor:

*HCP: "They're of that era you just do what the doctor says and don't necessarily challenge it as much."*

(26)

This belief may limit the HCPs' attempts to involve the patient in decision-making.

- iii. Older patients may be afraid that treatment is denied based on age alone

Some patients expressed concern that care was rationed based on age alone:

*Patient: "I don't know how he came to that treatment decision. Whether there's an age cut-off where they decide not to operate, because apparently the most successful method is an operation to have it taken away."*

(38)

**Theme 7** : SDM with older patients with cancer requires HCPs to have specific, additional knowledge

- i. HCPs need to approach older patients holistically, in order to assess decision making capacity, appropriateness of treatment options and the risk of complications

HCPs, patients and significant others all conveyed the importance of an holistic approach to older patients. The treating physician should consider factors such as decision-making capacity, frailty, comorbidities, living situation, social support system, and cognitive and functional abilities:

*Significant other: "The important thing is to look not only at the illness, but also at the patient as a whole - how are they doing, are they alone, (...) what kind of shape are they in, what is their nutritional status, (...) do they have any social contacts or people who can look after them?"*

(44)

HCPs also expressed that a consideration of these factors directly influenced how they treat patients because of the increased risk of complications:

*HCP: "I start changing my surgical approach more in women in their 80s or if women have a lot of comorbidities and they're in their 70s."*

(26)



- ii. Some HCPs express a need to optimize their skills to differentiate between frail and non-frail patients, while others do not

Differentiating between frail and non-frail patients was deemed important, due to the increased risk of adverse outcomes in frail patients. However, distinguishing between the two groups was found difficult by some HCPs and they need more guidance and skills to do this adequately:

*HCP: "A kind of funnel, or a sieve to put people into categories like, with this person things will probably be fine, no problem, no need to think any more about it. (...). Or this one should maybe visit the geriatrician."*

(44)

Other HCPs believed that identifying frail patients was easy:

*HCP: "Good surgeons are good at selecting.. Part of it, I think is innate."*

(40)

- iii. HCPs need to coordinate care with other HCPs involved

For older patients with MLTC, HCPs, patients and significant others conveyed the importance of aligning cancer treatment with the other conditions. This entailed evaluating treatment interactions and preventing clashes of care pathways through communication with other HCPs. HCPs expressed that limited knowledge of comorbid conditions diminished their ability to take them into consideration.

Significant others indicated that due to the amount of different HCPs involved, coordinating and navigating care was difficult:

*Significant other: "I found it quite difficult, (...) because a lot of the care is sectioned off. For example, the district nurses don't do incontinence. And the carers at first wouldn't do colostomy bags."*

(41)

**Theme 8** Evidence on the impact of age, frailty and comorbidities on tolerance for standard cancer treatment is uncertain

Patients expressed awareness that older patients and patients with MLTC are underrepresented in clinical trials, meaning that the data on (side) effects are limited:

*Patient: "There's very little research that's been done on older people. It's a real curiosity to me why."*

(32)

### 3.1.3 | Overarching factors that influence decision making

**Theme 9** Time during and outside of consultation(s) is essential to SDM with older patients

- i. Geriatric assessment of older patients with cancer takes additional time, which is not always available

Despite finding it important that a holistic assessment that covers all geriatric domains takes place, HCPs expressed that due to time constraints, this was unachievable:

*HCP: "It is, unfortunately, unrealistic that the physician in a busy clinic is going to do all that stuff and take care of the cancer, and take care of all the other stuff."*

(26)

HCPs would prefer to take additional time for consultations or treatments, especially for patients with cognitive impairment or dementia:

*HCP: "It would be nice if the system would say, actually, Jane's got dementia, she needs a two hour, an hour slot, and if we had the capacity to do that."*

(41)

- ii. Dividing the consultation in two allows patients time to process information and consult others

Patients found unhurried dialog and ample consultation time pivotal to adequate decision-making. HCPs recognized that additional time was necessary for older patients to properly process information and to consult others. Ideally, the consultation is divided into two sessions:

*HCP: "That's why it's better to not make such a decision in only one session with this older patient. Rather give it some time and say, 'Alright, we'll get back to this next week, think about it [...], take your time and you'll come to a well-considered decision.'"*

(44)

## 3.2 | Expert panel discussion

Based on the nine overarching themes, the original model by Bomhof-Roordink et al. (Supporting Information S1: file 2)<sup>14</sup> was adjusted to accommodate SDM with older patients with cancer. The preliminary figure based on the themes was reviewed during the expert panel discussion. The panel emphasized the importance of

discussing life and treatment goals, and taking the individual context of the patient into consideration. No new themes emerged from the discussion. Consensus was reached on the adjusted model, see Figure 2.

### 3.3 | An adjusted model for SDM with older patients with cancer

The adapted model builds upon the process portrayed in the original model, based on the themes and subthemes we identified. In contrast to the original model, the significant other is portrayed in the outer ring, indicating their active role in decision-making (theme 3) and retaining information (theme 4iii). This emphasizes their importance as active partners in SDM consultations.

During consultations, in addition to expressing the importance of the patient's opinion, HCPs determine decision-making capacity (subtheme 7i) and the role of the significant other (theme 3). The newly added second step is to learn about the patient, specifically their preferences and goals (theme 1) and prior life experiences (theme 2). Third, the HCP provides information. The adjusted model addresses three requirements: information is provided in ways older patients can process and retain it (theme 4); information is tailored to the patient's situation (theme 5) and informed by a geriatric assessment (subtheme 7i); and the HCP communicates the uncertainty of evidence (theme 8). Then, the HCP supports the patient to connect treatment options to priorities and goals (theme 1), and asks about preferences concerning treatment. Lastly, the HCP provides a recommendation that is in line with the patient's priorities and goals. The patients' actions become more elaborate due to engagement

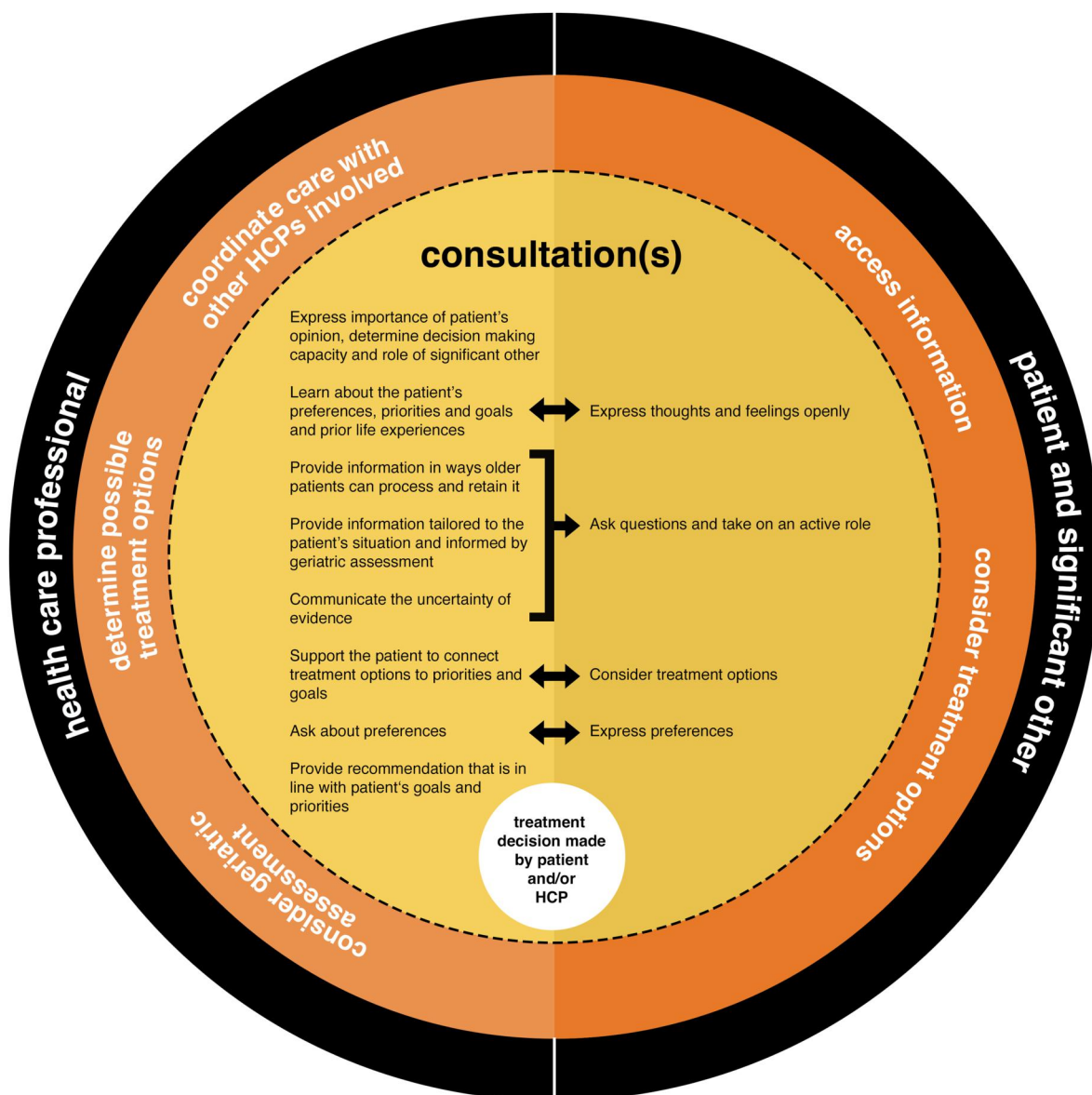


FIGURE 2 Model of Shared Decision-Making (SDM) in oncology with older patients with cancer, depicting health care professionals and patient behaviors as they unfold over time, during as well as outside consultations. HCP, health care professional.

with HCPs' additional steps. The adjusted model emphasizes active patient involvement to ensure they receive tailored information that they understand well.

Outside consultations, the patients' actions are twofold: consider treatment options and access information. For the HCP, two additional actions are necessary, next to determining appropriate treatment options: coordinate care with other HCPs involved (subtheme 7iii) and perform or refer for a geriatric assessment if necessary (subtheme 7i).

## 4 | DISCUSSION

This review identifies nine themes that are important to SDM with older patients with cancer. We incorporated the identified themes into an existing model of SDM with patients with cancer, thus developing a comprehensive model of (1) elements relevant throughout adult age ranges and (2) elements of specific importance to older adults.

The first notable adjustment is the identification of the key participants in the SDM process. The original model describes the HCP and patient as key participants; our new model includes the significant other as an integral actor. Our analysis shows that significant others play a role in the decision-making process in a multifaceted way. This is supported by the literature: older patients are more likely to be dependent on others for information processing, in part due to normal aging of the brain, leading to more difficulties in processing factual and statistical information.<sup>55</sup> They are also more likely to be functionally dependent (e.g. reliant on others for transportation, medication management) on others or become so due to illness or treatment.<sup>56</sup>

Other key modifications are to, first, establish the older patients' individual priorities and goals, and second, to provide information that is directly relevant to that. Next, the expressed priorities and goals should be revisited when considering the different options, to align the treatment decision accordingly. Highlighting the importance of goal setting early on is in line with the SDM models for frail older patients and for patients with MLTC.<sup>17–19</sup> By putting the patient's preferences, priorities and goals at the heart of the consultation, our model follows the principles of patient-centered care.<sup>57</sup> Delivering patient-centered care is especially recommended for older adults, because they are more likely to have complex care needs.<sup>58</sup>

Another important addition is to assess decision-making capacity, catering to older adults with cognitive impairment or dementia. The SDM model for frail older patients also includes this.<sup>19</sup> To secure this step, HCPs could screen for cognitive impairment and refer for further assessment if needed. Another adjustment, unique to our model, relating to cognitive functioning of older adults, is to provide information in ways older patients can process and retain it. Older patients have more difficulties with deliberative information processing, tend to look up information less often and take longer to process it.<sup>55</sup> It is therefore important to adjust the manner in which

information is provided, for example, by speaking more slowly, addressing one idea at a time, and writing down takeaway points.<sup>59</sup>

Another adjustment is to communicate the uncertainty of evidence. Data on risks and benefits for older patients are often limited, especially if patients are frail or have MLTC.<sup>58,60</sup> Shedding a light on this is essential to reaching an informed decision. A major challenge is how to convey evidence uncertainty in ways that patients understand it, without affecting them negatively.<sup>61</sup> Communicating uncertainty can decrease patients' decision satisfaction<sup>62</sup> or increase satisfaction when combined with other methods such as providing more information and partnership building.<sup>63</sup> The authors of the SDM model with frail older patients<sup>19</sup> also highlighted that evidence uncertainty complicates discussing treatment options, but did not incorporate this into their model. Recommendations on how to convey uncertainty orally during medical encounters are available, yet more research on the effect is necessary.<sup>64</sup>

Outside of the consultation room, our model highlights two HCP steps that are specific to older adults and unique to our model. First, considering the need for a geriatric assessment. This is in line with recommendations in international guidelines,<sup>65–67</sup> which states that a frailty assessment is necessary to reach patient-tailored decisions. HCPs can seek multidisciplinary collaboration with geriatricians to perform a geriatric assessment, and integrate the findings into treatment recommendations. Secondly, coordinating care with other HCPs involved. Our analysis shows that cancer treatment decisions must be integrated into existing care plans through interdisciplinary communication, rather than being made in isolation. This approach aligns with the principles of patient-centered care.<sup>57</sup>

Three themes emerged that have implications for the implementation of SDM with older patients. First, the possible presence of ill-informed, preconceived ideas of HCPs about older patients. Second, the potential lack of specific knowledge that HCPs require to engage in SDM with older patients with cancer. These themes have important implications for education and training needs. Third, the importance of time. The SDM process as visualized is conditional upon time, both during and outside consultations. However, time is the most common barrier to SDM, as reported by both patients and clinicians.<sup>68</sup>

This review has several strengths. To our knowledge, this is the first systematic review of qualitative studies that assesses factors that are important to SDM with older adults with cancer from both the HCP and patient perspective. Considering the demographics of patients with cancer, this is highly relevant for everyday practice.

Moreover, our expert panel consisted of a patient representative, and professionals from different backgrounds: medical specialists in onco-geriatric care, a nursing home physician, a primary care physician, SDM researchers and communication experts. Their review of our model ensures dependability of our findings.<sup>69</sup>

In addition, cancer can be considered exemplary for a potentially life-threatening disease for which, especially in older populations, medical uncertainty prevails, and therefore our findings are also highly relevant to other fields.<sup>14</sup> The adaptations of the model are

also likely to be applicable to particular groups of patients aged <65, as chronological age often does not correspond with biological age. Also, younger patients may face similar challenges, such as cognitive impairment and multimorbidity. However, it remains an empirical question whether additional themes may be relevant to other patient groups. At the same time, it is not the goal to develop different models for different subpopulations and illnesses, but rather to explore how the existing model of SDM can be improved to be inclusive to a wide range of patient subgroups. Ultimately, these insights can contribute to the development of an inclusive, comprehensive model of SDM.

#### 4.1 | Study limitations

A possible limitation of this review is the use of an AI tool for title/abstract screening. This tool has proven its value in numerous studies.<sup>24</sup> We were able to use the included articles from the first search as a robust training set. The random set (1%) of excluded studies that was screened manually, did not include any relevant papers. The recurring themes across included studies make it unlikely that missing a relevant paper would significantly impact our conclusions.

Furthermore, most studies (17/29) did not provide patient characteristics concerning frailty, comorbidities, cognitive- or physical functioning, meaning that it is possible that the included patients are generally fit. However, the other 12 studies included patients across the fit-frail spectrum. Further, half of the included studies focused on breast or prostate cancer. We expect the effects of the underrepresentation in both situations to be limited because of the qualitative nature of our review and the equal importance of the themes identified.

Lastly, studies provided very little information on socio-economic backgrounds of the participants. Studies were predominantly (20/29) set in the United States of America and United Kingdom, and participants were predominantly white. Cultural nuances related to the SDM process might exist, which are not captured in our model. It is unknown if the included studies recruited participants from diverse educational backgrounds and professions.

## 5 | CONCLUSIONS

SDM requires a patient-centered approach, where learning about preferences, priorities and goals is at the heart of decision-making. This holds true for older patients with cancer, who represent a challenging group: the disease is life-threatening, there may be multiple management strategies to choose from, evidence on treatment effects is typically limited, comorbidity is often-times present and renders the alignment of care plans complex, and significant others are even more important in determining best options and providing care than with younger adults.

## 5.1 | Clinical implications

The adjusted model for SDM with older patients with cancer may support older patients and HCPs to make care decisions about cancer in effective ways, and may potentially be applied in case of other illnesses. The adjusted model depicts the complexities of this process: SDM with older patients is embedded in a larger care context where geriatric assessment and interprofessional collaboration may need to play a part. Further research needs to focus on how to effectively educate HCPs on the competencies needed to engage in SDM with older patients, such as how to adequately support goal setting and elicit preferences. Developing interventions aimed at training and supporting HCPs, and educating and empowering patients, is expected to facilitate effective SDM in everyday practice.

### AUTHOR CONTRIBUTIONS

Concept and design of the study: Emma A. Gans, Arwen H. Pieterse, Feikje van Stiphout, Frederiek van den Bos. Data collection: Emma A. Gans, Feikje van Stiphout, Irma J. van Steenberg, Frederiek van den Bos. Data analysis and interpretation: Emma A. Gans, Feikje van Stiphout, Arwen H. Pieterse, Frederiek van den Bos, Johanneke E.A. Portielje, Maartje S. Klapwijk. Writing manuscript: Emma A. Gans, Arwen H. Pieterse, Frederiek van den Bos. Critical revision of findings: Janke F. de Groot, Barbara C. van Munster. Critical review final manuscript and approval: Emma A. Gans, Arwen H. Pieterse, Maartje S. Klapwijk, Feikje van Stiphout, Irma J. van Steenberg, Johanneke E.A. Portielje, Janke F. de Groot, Barbara C. van Munster, Frederiek van den Bos.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

### ETHICS STATEMENT

This systematic review does not fall under the Medical Research Involving Human Subjects Act (WMO) and no official ethical approval is required.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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