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## Shared decision-making in older patients with cancer - What does the patient want?

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### ABSTRACT

Shared decision-making in cancer care, where we move away from the paternalistic “the doctor knows best” attitude to involving the patient in decisions regarding her or his health, is now universally accepted in western societies. However, in many situations this is easier said than done. For instance, if the interaction with the patient is not performed in a skillful manner, shared decision-making can make the patient feel unsafe – shouldn't the specialist know how to treat a serious disease such as cancer? Why would the doctor ask the patient about this? In other cases, what the patient wants in unrealistic, for example a severely frail patient aged 85 years with more than one life-limiting comorbidity who is diagnosed with an advanced cancer and has a goal of living to be at least 100 years. And what does a patient with advanced dementia want in the context of a cancer disease? In this perspectives piece, we will describe different scenarios that may arise within geriatric oncology and shared decision-making, make recommendations about how to handle such situations, and provide some food for thought.

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### 1. Introduction

Shared decision-making (SDM) in cancer care, where we move away from the paternalistic “the doctor knows best” attitude to involving the patient in decisions regarding her or his health, is now universally accepted in western societies. However, in many situations this is easier said than done. For instance, if the interaction with the patient is not performed in a skillful manner, SDM can make the patient feel unsafe – shouldn't the specialist know how to treat a serious disease such as cancer? Why would the doctor ask the patient about this? In other cases, what the patient wants in unrealistic, for example a severely frail patient aged 85 years with more than one life-limiting comorbidity who is diagnosed with an advanced cancer and has a goal of living to be at least 100 years. And what does a patient with advanced dementia want in the context of a cancer disease? In this perspectives piece, we will describe different scenarios that may arise within geriatric oncology and SDM, make recommendations about how to handle such situations, and provide some food for thought. There are many relevant questions and ethical dilemmas when older patients get cancer – for example who

should decide what represents sufficient quality of life, how to prioritize scarce resources and avoid ageism, how to deal with disagreement with relatives, and the possible use of coercion when this seems in the best interest of a patient who does not have decision-making capacity. However, our main focus is on how to adequately assess the patient prognosis and integrate this with an equally thoroughly assessment of the individual patient's perspective.

### 2. Cancer Stage and Expected Outcome - Prognosis

When patients have cancer, there is often a question of prognosis. An aggressive, rapidly progressive form of cancer that may lead to death in a few months calls for an entirely different approach to treatment and care than a potentially curable or slowly progressive disease. On the other hand, a fit patient with a potentially curable disease may have a good prognosis, but this will change significantly if they are frail and suffer from multiple comorbidities and functional impairment. Then, the risk of death due to treatment may be much higher than the likelihood of cure and the likelihood of death from other causes increases. The prognosis thus depends on the cancer, the treatment possibilities, and the patient's general health status, and decision-making may need to involve a discussion of treatment possibilities and prognosis between the cancer specialist and a geriatrician.

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According to Paladino and colleagues, prognosis should be understood beyond survival statistics [1], encompassing instead “the anticipated course of living with an illness”. In this context, discussing prognosis is essential to make sure patients have the opportunity to set and reach goals that align with their priorities. Survival and complication risks with treatment are two aspects of prognosis, but we also need to address the patient's quality of life, functional status, and cognitive function before and after treatment, as well as the possibility of unpredictable events. There are structured ways to approach communication about prognosis, but a review found that a lack of knowledge and skills, difficulties in prognostication, insecurity about timing, and poor coordination and documentation of care may impede this type of communication [2].

Prognosis is very much about medical knowledge and judgment, broadly understood. However, SDM also requires integration of the patient's individual interests, preferences, hopes, worries, and expectations about the future [1]. One recommended method is to use a language that pairs our hopes and worries for the patients in “I” statements, as described by Lakin and colleagues [3]. For example: “I am hoping that you have a long time to live and I am also worried that the time may be short, as short as a few years.” Lakin et al. explain that when a patient asks about prognosis, they don't expect that the clinician will actually “know”, but they do want and need to hear the clinician's opinion [3]. By combining hopes and worries, the discussion of prognosis becomes softened, without denying reality.

### 3. Geriatric Assessment and Patient Frailty

In geriatric oncology, personalized cancer treatment means treatment that is adapted to the individual patient's general health status. Since heterogeneity increases with increasing age, we need additional measures than age and performance status when considering treatment options in older adults with cancer. A geriatric assessment evaluates the individual patient's general health status through assessing the patient's functional status, mobility, comorbidities, polypharmacy, cognition, nutritional status, emotional status and social network in a structured way, and serves many purposes [4]. Based on a geriatric assessment we can evaluate the degree of frailty in an individual patient. Frailty is an age-related medical syndrome, and it is triggered by multiple causes and contributors, among them sarcopenia, functional and cognitive disability, and comorbidities. With increasing frailty, the risk of mortality and negative side effects of cancer treatment increases.

Prior studies have shown that performing a geriatric assessment has significant impact on oncologic and non-oncologic treatment decisions in older cancer patients [5,6]. Some components of frailty may be reversible, for example by improving nutritional status and optimizing polypharmacy, improving the prognosis. An assessment of frailty may also provide important information for individual goal setting and tailoring of treatment in the context of cancer care.

### 4. Assessing Patient Goals and Preferences

The work of SDM requires specific skills from the clinician. The patient's own situation, values and preferences are at the center, and we have to ask: Does the decision about treatment make intellectual, practical and emotional sense for the patient [7]? In order to successfully perform SDM there is a need to develop a shared understanding by using time, skills, and specific tools. Guidelines about treatment are generic and may be of limited value because they are based on studies in younger and more healthy individuals. However, the patient will usually be able to tell you what matters most in his or her life. This is likely to be much more informative than simply asking the patient if they do or do not want a specific treatment option.

Adequately assessing a patient's goals requires finding out what they understand about the choices they need to make and which personal priorities and motivation are driving their choices. For instance, a

patient may be worried that their partner or children would feel rejected if they do not do everything possible, no matter how burdensome, to stay with their family for as long as possible. Exploring below the surface of a patient's wishes will often help uncover underlying concerns, fears or assumptions. These need to be addressed before a patient is able to make a decision that provides the highest likelihood of achieving what the patient wants within the spectrum of what is possible in their situation. For example, if a very fit 80-year-old women with no prior medical history chooses not to undergo surgery for early stage breast cancer, further questioning can reveal a whole range of underlying thought processes. Her choice could be based on having experienced a close friend go through cancer treatment, or motivated by an overwhelming fear of not waking up after anesthesia, or the idea that given her age, she may only have one or two more years to live anyway. Simply accepting this patient's choice of no surgery at face value would be a missed opportunity.

In other cases, the patient has goals that are not aligned with the expected medical realities. The patient may say that he or she wants to live to be 100 years, even in the context of severe frailty combined with an advanced cancer diagnosis. In such cases, it may be necessary to spend some time with the patient and caregivers to balance reality with acknowledgement of hope in a sensible way. Hopes may be unrealistic, but it is problematic if we give information that set too high expectations for the patient and family about the advantages of treatment. If we ask the wrong question – “do you want to undergo aggressive treatment for this cancer although it is very risky?” – and the patient answers “yes, I will do anything”, we run into a problem in cases where the treatment is considered too risky compared to the potential benefits, and thus something that should not be done or prioritized. Thus, we need to think through such conversations in advance.

### 5. Cognitive Impairment and Decision-Making Capacity

These conversations are usually even more complex in cases where the patient has cognitive impairment. Studies show that the prevalence of mild cognitive impairment (a pre-dementia state) in people aged 80–84 years is about 25% [8], while the prevalence of dementia in people over the age of 85 years is an additional 20%, rising to nearly 40% over the age of 90 [9]. Interestingly, cognitive impairment can easily be overlooked by health care providers. This is particularly true when a family member takes the lead in the consultation, sometimes prompted by the patient through the ‘head-turning sign’. This is the term used to describe a patient who automatically defers to a caregiver when asked a direct question. When observing these kinds of interactions between patients and their caregivers, being alert to the possibility of cognitive impairment is especially relevant.

Impaired cognition will make it more difficult and sometimes impossible for a patient to weigh various treatment options against their own priorities. Assessing decision-making capacity (DMC) is a necessary step in SDM for older patients with cancer. In short, a patient has DMC if they can understand the provided information, assess this in light of their own situation, reason logically, and make and communicate a treatment choice [10]. A person who knows the patient well, and whom the patient trusts, may assist patients, e.g. a formal and/or informal caregiver. This may contribute to increase the patient's DMC through *supported* decision-making. Thus, asking a patient with mild cognitive impairments to bring along a caregiver and adapting the information and questions to the patient can be quite helpful. However, if a patient does not have DMC, *substituted* decision-making becomes necessary. In such cases, it is important to assess the status of the family member(s) or caregiver(s) and involve them in accordance with the national legislation [11] [12].

Another way to safeguard the patient's wishes is to offer advance care planning whilst the patient retains DMC. Advance care planning may result in a so-called advance directive specifying the patient's future wishes. However, advance directives are not legally binding in

all countries, and it may also be challenging to know whether it applies to the current situation [11]. Thus, the key ingredients of the advanced care planning are often to elicit what is important for the patient to live a good life, more general preferences for health care, and for decision-making processes and the role of caregivers, such as choice of a surrogate decision-maker, in case the patient's DMC is lacking later on.

Knowledge of the patient's individual history, preferences, values and relations, in the past and present, is key to increasing the patient's DMC as much as possible, to adapt the information and SDM-process to the patient, and to reduce the need for substituted decision-making. Using supported decision-making as much as possible, to reduce the need for substituted decision-making, is important to comply with both the ideals of SDM and recent human rights developments ([www.un.org](http://www.un.org)).

## 6. The Role of Caregivers

In general, when the patient lacks DMC, the next-of-kin has the right to receive information, to be able to provide information about the patient's preferences, and often to decide on behalf of the patient in accordance with what is known about the patient's interests and presumed wishes. However, there are legal complexities that may vary from country to country, and doctors need to know the local legislation. For example, the next-of-kin may not have the right to decide on behalf of the patient. Furthermore, the definition of next-of-kin and how to settle who is the next-of-kin may vary. Irrespective of cognitive status, caregivers often support patients in their decision-making. They can facilitate this process by being a sparring partner to the patient and helping to verbalize which questions are relevant to them and what information is needed to be able to reach a decision [13]. Having an extra person in the consultation provides more opportunity for information to be recollected once the patient goes home to consider and discuss the treatment options (two people will generally remember more than one). However, caregivers can also play roles that reduce the opportunity for SDM, for example in reducing patient autonomy by controlling the patient or the consultation [13]. Family preferences and family burden are often relevant factors that patients take into consideration when weighing treatment options [14]. It is important to remember that family members and caregivers also have their own fears, desires and assumptions – both regarding treatment as well as their loved one – that will influence the decision-making process and may need to be addressed before a definitive decision can be made.

## 7. Emotional Responses and Depression

An essential aspect of communication about serious illness and treatment options is responding to emotion. A diagnosis of advanced disease is often a trigger of emotion for patients as they could be facing their own approaching death. Their state of mind may fluctuate between hopelessness and more optimistic thinking. Suggested strategies that clinicians can utilize to improve coping are emphasizing control of physical symptoms, providing emotional support, identifying realistic goals, and balancing prognostic information with giving hope [15]. If clinicians are not able to deal with patient and personal emotions when caring for individuals with a poor prognosis, the consequence may be increased anxiety and a distanced relationship, and SDM becomes impossible.

Depression in older with patients with cancer is a specific challenge, especially if the cancer is potentially curable, but the patient refuses to undergo treatment. They could argue that he or she is “too old and will die soon anyway” or may not believe their symptoms can be alleviated, which could change how they feel about their situation. The geriatric assessment includes a screening for depression, and if the screening is positive, follow-up is required. This should be done in collaboration with either the primary care physician, the geriatrician, or the old age psychiatrist, depending on the setting. Depression is often

a treatable condition that – if unnoticed – may influence the patient's wishes (“it would be best if I died”), cognitive capacity, and DMC.

## 8. Outcomes that Matter to Older Patients

When forming a care plan for older patients with cancer, factors other than evidence from research come into play. In cancer research, disease-specific outcome measures such as cancer-specific survival and time to progression have traditionally been favored. Outcomes that matter to older patients may be functional status, independence, the ability to perform a specific activity or symptom control [16,17].

When forming a care plan, the starting point is the patient's own life, values and priorities. However, these are not set in stone but may change over time, making it important to reevaluate periodically. A patient may feel that having once said yes to a treatment option, they have no right to say no at a later point in the treatment trajectory. On the other hand, people have a remarkable capacity of adapting to their circumstances: while a patient may have stated that a specific situation – for example, becoming care-dependent or bed-ridden – would be unacceptable to them, they may feel quite different once this situation actually arises, being able to experience sufficient quality of life despite their circumstances (the response-shift phenomenon) [18]. This highlights the relevance of keeping an ongoing dialogue with the patient about what is important to them and what they want now and for their future.

Burden of care is a specific aspect to address. A patient with mobility limitations and reluctance to become a burden for family members, where the specific cancer treatment calls for extensive outpatient controls, blood work-up, multiple x-rays and CT scans – may decide to forego treatment. It is valuable to address these concerns and weigh them into the treatment decisions. In some cases, concerns may be solved by help of a social worker, while in other cases the patient may prioritize less extensive treatment because the burden of care does not make sense to them. Again, the geriatric assessment has already addressed mobility and social network and is a valuable starting point for such discussions.

## 9. Shared-Decision Making and Multidisciplinary Teams

Multidisciplinary team (MDT) meetings are essential in the choice of a therapeutic strategy in patients with cancer. These days, an MDT meeting is mostly a technical discussion, in which – on the basis of the cancer characteristics, imaging, and guidelines – a decision is made. Patient's wishes and preferences remain largely out of consideration in MDTs [19,20]. A study from the Netherlands found that in patients aged over 70 years, patient-centered information such as (age-related) patient characteristics and preferences were rarely discussed at MDT meetings. Furthermore, a geriatric perspective or geriatric input was largely missing in these teams [21]. As a result, the complexity of decision-making for older patients with cancer, especially frail ones, is not adequately addressed in the current MDT structure. Tailoring of treatment decisions to the patient's situation – for example, determining if a patient has sufficient reserves for a specific treatment, or if perhaps a less aggressive treatment alternative is more suitable given the patient's health status or wishes – generally takes place outside the multidisciplinary process, and without a multidisciplinary perspective. Instead, these discussions are limited to a specific cancer specialist and the patient, often taking place after the MDT has already made its technical recommendation.

For improving the quality of cancer care for older patients in day-to-day practice, the patient characteristics, such as the degree of vulnerability and resilience, and the preferences of the patient should be given equal importance to cancer characteristics in the agenda at MDT meetings. This approach requires collecting patient assessments, including a geriatric evaluation, patient goals and input from various physicians involved in a patient's care prior to the MDT meeting, so that all

relevant information is available to the MDT. This is much more likely to yield treatment recommendations that align with the patient's health status and preferences. After the MDT meeting, the cancer specialist will still need to discuss and weigh benefits and risks with the patient, but this time with relevant multidisciplinary input and tailored treatment options.

## 10. Conclusion

SDM – involving patient in the decision-making process regarding treatment – requires not only asking the patient what they want, but also taking time to understand what underlying priorities, fears and hopes motivate their choices and integrating this with a thorough assessment of the patient's health status, reserves and prognosis. Particularly in older and frail patients, these aspects should be given equal importance to disease characteristics during the decision-making process, including MDT meetings.

## Author Contribution

SR, FvdB, RP, and MEH have no conflicts of interest to declare. SR, FvdB, and MEH contributed to study concepts. SR, FvdB, RP, and MEH contributed to manuscript preparation, manuscript editing, and manuscript review.

## Declaration of Competing Interest

None.

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