Involving patients as equal partners in choosing between treatment options is particularly important when there is considerable uncertainty about how the options could affect their survival and quality of life.

Such is often the case in treating older patients, who tend to be more frail and have more comorbid health problems than the highly selective group of patients on whom the treatment options will have been trialled. Yet it is precisely in this older patient population that efforts to move towards a more shared approach to decision making are having least impact.

Siri Rostoft, a specialist in geriatric medicine at Oslo University Hospital, recognises the irony in the situation. “Both doctors and patients still believe that the doctor will tell you what to do. Especially for older generations, the idea that patient preferences are integrated when making decisions about treatment is not adopted yet,” she says, and yet, “Because older patients are often excluded from clinical trials, we don’t really know what’s best for them.”

Last October, Rostoft was among a panel of speakers at a webinar that focused exclusively on how to ensure that older patients are enabled to play a full role in reaching decisions about their treatment options. The event was organised by the Anticancer Fund together with the International Society of Geriatric Oncology (SIOG).

Nicolò Matteo Luca Battisti, a Consultant Medical Oncologist at the Royal Marsden Hospital in London, and SIOG President, set the scene, with this summary of the challenges:

“How do we approach shared decision making in the context of a higher burden of comorbidities, competing risks or mortality? How can we navigate to share decisions with a patient that has advanced cognitive impairment? How do we deal with the concerns, preferences and assumptions of their caregivers?”

Step 1: Get onboard!

Rostoft has become a familiar figure at cancer conferences, where she has helped countless oncologists to do better for their older patients by avoid assumptions about their level of fitness, their priorities, and their circumstances. Yet, speaking to *Cancerworld*, she admits that, despite having worked in geriatric medicine for a long time, it was only “an embarrassingly few years ago” that she began to pay attention to involving her patients more in discussions about their own treatment and care. “I realised what a great help it is for me as a clinician to discuss decisions with patients,” she said.

Rostoft believes the first step towards promoting a more shared approach to decision making is to raise awareness about how it can improve the quality of care, and also to clear up some widespread misconceptions. Some oncologists are opposed to shared decision making because they feel it puts their expertise as specialists into question, she says. “Of course, the doctor is the specialist in the disease, treatments, side effects, and outcomes – while the patient is the expert on himself or herself, their life and their context, which is very different from patient to patient.”

Equal but dependent – overcoming the power dynamic

Accepting that the patient’s expertise is of equal value to the doctor’s when it comes to choosing the right treatment option is essential for truly shared decision making. But as Edgard Eeckman, founder of Dutch advocacy organisation Patient Empowerment, and a fellow panellist, pointed out, conducting conversations where equal weight is given to the contributions from patient and doctor can be difficult because of unhelpful power dynamics at play – particularly where older patients are concerned.

Patients facing a life-threatening diagnosis are in a position of dependence, said Eeckman. “The patient becomes dependent on the doctor and the resources the doctor possesses, such as knowledge, expertise, time and trust. If the resources are valuable and rare, the dependency increases.” While trust brings a sense of comfort, he adds, it also reinforces that sense of dependence. “You don’t want to harm that trustful relationship. The doctor has a power: it is not classic power related to coercion, but an implicit dependency power.”

This has implications for the feasibility of an equal sharing in decision making, said Eeckman. He quoted from a patient who had asked: “Why should we accept in sickness what we’d never dream of accepting in health?” “That patient is right,” he said. “Why do we accept it? Because people are dependent when they become sick.”

> Doctors need to recognise this unhelpful power dynamic and make an effort to give their patients a sense of empowerment

His point was not that shared decision making is not possible between doctor and patient, but that doctors need to recognise this power dynamic and make an effort to give them a sense of empowerment. The Patient Empowerment organisation offers healthcare organisations and healthcare professionals advice and coaching on strategies to achieve this. “Patient empowerment is about strengthening the feeling of autonomy and control,” he said, “By communication, you can give the patient the feeling of control.”

The Anticancer Fund itself, which started off as primarily a patient-driven research organisation, is now also heavily focused on empowering patients to play an informed role in decisions relating to their own treatment and care. The organisation now offers a personalised information service, My Cancer Navigator, that cancer patients can use to get answers to specific questions they have regarding treatment options. The answers are evidence-based and tailored to the patient’s own clinical situation, and can help them play a more confident and informed role in discussions with their oncologist (see panel below).

What if patients can’t or don’t want to engage?

One aspect of shared decision making and prioritisation is to know how much information the patient would actually like to receive. While some patients are deeply involved and want to know all the statistics, other patients are not ready to hear or do not want to receive such detailed information, says Rostoft. “This concept, called ‘control preference’, ranges on a scale from wanting the doctor to make all the decisions to wanting to know everything and discussing options with family members.” While a patient’s decision to not be involved should be respected, the doctor’s decision making should still be led by the patient’s stated goals and priorities, she stressed. “You can still ask the patient: What do you like to do in life? You can ask patients about themselves, without bringing in a lot of information about diagnosis.”

In some instances, says Rostoft, “a patient may refuse to accept or not be aware of how serious a diagnosis is, and say ‘I want to live for 20 more years’, even though it is not likely at all.” In the face of such unrealistic expectations, having a meaningful discussion about the pros and cons of alternative treatment options can be difficult, as the patient “just wants to live for 20 more years”.

When patients have this mindset, Rostoft's approach is to try to do repeat consultations, to give time for the patient to adjust to their new reality. She's well aware, however, that time is a limited commodity for most doctors and health systems.

> One practical tool that can help guide patients towards prioritisation is the use of 'scenarios'

One practical tool she mentioned that can help guide patients towards prioritisation is the use of 'scenarios'. When discussing a certain treatment option, a 'worst case scenario' and a 'best case scenario' are both described. "That's something people can understand – because we don't know exactly what's going to be the outcome. So worst case, you have surgery, you get a complication and you have to move to a nursing home. Or best case, you have surgery, everything goes well, and you go home. So the patient sees the limits of what can be achieved and what can happen in the worst case."

Adjusting the discussion where cognition is impaired

Issues with dementia and cognitive impairment can also impact heavily on the ability of patients to play a shared role in decisions regarding their treatment. Studies show that about a quarter of people aged 80 to 84 have mild cognitive impairment, a pre-dementia state, while the prevalence of dementia rises to nearly 40% in people over the age of 90.

A patient is generally seen as having the capacity to make decisions if they can understand the information, assess how that information applies to their own situation, reason logically, and both make and communicate their choice.

> "Even if you have cognitive impairment or mild dementia, you can say something about what matters to you"

Even when decision-making capacity is limited, that may not prevent patients from sharing important information about their wishes and priorities, says Rostoft. "Even if you have cognitive impairment or mild dementia, you can say something about what matters to you. Then we as doctors have to extrapolate. Having to adjust the discussion to the cognitive level of the patient can be demanding, but it is necessary." As she points out, many patients have been sick before and have thought about these issues, "so at least give them a chance to participate."

Advanced care planning, especially in early stages of cognitive impairment, can be important for continuing to follow patients' priorities, she adds, but she cautions that priorities and preferences may shift as patients enter a new stage of disease or impairment. It therefore becomes necessary to continuously re-assess the new situations and to plan in advance the decision-making process and the role of caregivers.

The (complicated) role of families

Family members can facilitate shared decision making by engaging patients in discussions, and helping them to ask the right questions. They can also be a valuable resource doctors can use to help build up a picture of the patient's priorities and realities. But doctors need to be sensitive to potential differences in perceptions and interests between the patient and members of their family, Rostoft stressed.

"In some cases, there are conflicting wishes – it is hard for people to accept that their mother or father is dying," she notes. "Sometimes the caregivers advocate for very heavy treatment for the patient, and you feel that the patient doesn't get a word in." In these instances, you need to try to work out who it is who wants the intensive treatment, "Is it the patient or the family? Maybe, the patient feels they just want to keep quality of life, keep function, and you have to respect that. So you have to be aware that you treat the patient because the patient wants that, and not because the caregivers push for it."

Such conflicts can lead to difficult conversations for everyone involved. In these situations, it is very helpful if you have done thorough geriatric assessment up-front – which should be standard practice – and are then able to refer to its findings. "If I have done a geriatric assessment, the argument is not just: 'Oh, she is 80 and frail,' but I can make arguments based on nutritional status, recent falls, and so on, and provide perspective." The conversation then goes more along the lines of, "Based on my experience, patients with these factors usually have more side effects, so maybe the treatment does more harm than good." This is a concept that people usually understand, she says. "Families shouldn't feel – and it shouldn't be the case – that the patient is undertreated because of age. If you do a thorough job, for the sake of the patient, that helps."

> "If I have done a geriatric assessment, I can make arguments based on nutritional status, recent falls, and so on"

In some situations, where Rostoft senses a conflict or discrepancies, she seeks to speak with the patient alone. "If they trust you, they know you want to do the best for the patient. Trust is essential for shared decision making. And a thorough assessment, with time spent with the patient, builds this trust. It's obviously the responsibility of healthcare professionals to create this trust."

As a general rule, she says, when formulating a care plan together, it is important to bear in mind that the outcomes that matter to older patients are often different to the priorities of younger patients. Questions around how various treatment options could impact on the patient's function, for instance – their independence or ability to keep doing things they enjoy – may be more important than time to progression or the chance of a living a few extra months… But then again, it may not.

The key thing, Rostoft stresses, is to avoid making any assumptions at all; always ask, and listen to the answers. "Very often, patients will want to keep their independence and ability to live on their own. But I've had consultations in which I told patients a likely scenario would be that they will have to move to a nursing home – and the patients were delighted, saying 'But that's what I want! I've wanted to move to a nursing home for so long, and always got refused, finally I can be accepted.' So never presume you know which outcome matters to your patient."