

Individualised decision-making

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In their article, Berkhout-Byrne et al. report that the majority of older patients do not regret their decision to start dialysis. That being said, 7.4% of patients, however, did regret their choice. Especially the patients who felt they had not made the decision themselves, but had followed the advice of their nephrologist, showed remorse. Berkhout-Byrne concludes that it is of importance that decision-making is attuned to values and preferences of individual patients.¹

I can think of no argument to contradict this statement. In an ideal world, the patient and the physician decide what to do in a joint operation. The professional provides the technical knowhow and explains the different options, and allows the patient to decide which road to take. By making the decision, the patient must consider his own preferences. Shared decision-making, instead of the professional telling the patient what to do.

However, taking into account the patient's values and preferences raises a number of questions.

Looking at the role of physicians: are we able to inform our patients about the technical aspects of an intervention in such a way that the patient fully understands, but while informing the patient, keep our own opinion out of it? In hindsight, regret can be felt about a certain decision. But nobody can tell what would have happened had that individual decided not to start with this specific treatment. It could be argued that perhaps other regrets would have emerged, with the inevitable physical symptoms that would have occurred in end-stage renal disease.

Secondly, how can one determine the values and preferences of each individual patient? Olthuis et al. wrote that the understanding of a patient's past, his lived experiences, will help in determining what is important to this specific patient. This could contribute to making medical decisions in a manner that is suitable for that unique patient.² This method of exploring lived experiences is not in our standard of care, particularly not in the outpatient clinic of a hospital. Should it be made a routine part of any workup for invasive treatments or procedures? If I look at my own patients, there are a number of patients with whom I have talked about their past life and wishes for the future. As a result, I have an insight of how this individual patient wants to shape his life for the future, how for example he would prefer to

die. Knowing the background of a patient, having shared their previous experiences in a hospital or nursing home and being made privy of their beliefs about life and death enables me to understand their point of view. When a new disease appears, and treatment decisions must be made, I do inform them about all the technically possible treatment options. But, at the same time, I bear in mind their wishes. For instance, if I know a patient has had horrific experiences in the hospital and has declared a firm wish to renounce any surgical procedure, I will accept her refusal of surgery for colon carcinoma without feeling the need to convince her to reconsider. This is what she wants, as I have known for the last years. There is no need for me to try and persuade her to go against her own well-made decision.

Another interesting question is: where should the dialogue around values and preferences be initiated? In the hospital, with the nephrologist? Is the topic of said conversation directed only at the dialysis? And, for instance, will a cardiologist do exactly the same, only to change the topic of conversation to, for example, a TAVI procedure? Or should we strive towards a dialogue regarding preferences and wishes concerning treatment decisions in its broadest sense, without addressing a specific treatment or intervention? This conversation should, in my opinion, be started before a life-threatening illness arises because, as an Dutch saying goes: 'fear is a bad advisor'. Perhaps the office of the general practitioner is a far more suitable environment to explore the wishes of an individual patient.

Even when the values and preferences of a patient are investigated and recorded, it is very likely that beliefs and convictions will vary with the progression of life and illness. The topic of wishes concerning treatments and/or interventions should be revisited regularly, especially when changes in general health are apparent.

REFERENCES

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