

## EDITORIAL COMMENT

# Involving patients in treatment decisions, disease management and research for end-stage kidney disease

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## INTRODUCTION

Over recent decades, people have argued for replacing paternalistic methods of managing long-term conditions with models that consider patients to be equal partners in treatment decision-making, disease management, and health service design and research [1–3]. We see this reflected, for example, by an increasing call for adequately informing people with kidney disease about their treatment options and actively involving them in treatment decisions [4]. Ultimately, the aim is to offer services and facilitate shared treatment decisions that better align with patients' experiences, preferences, circumstances and needs.

Without intending to provide an exhaustive overview, we will introduce several topics in this editorial related to involving people with end-stage kidney disease (ESKD) in the decision-making for and management of their condition. Each topic is linked to an article in this supplement, and is illustrated by quotes from translated interviews with seven people with ESKD from The Netherlands; three of these interviews were published on [Nierwizjer.nl](https://www.nierwizjer.nl), a website developed by the Dutch Kidney Patient Association.

## HEALTH LITERACY AND PATIENT INVOLVEMENT

It is essential that people have an adequate level of health literacy, i.e. sufficient knowledge, skills and confidence, before they can play an active role in making decisions about and managing their health and treatment. The article by Toapanta *et al.* [5] discusses this central role of health literacy in shared decision-making for ESKD. They present how poor health literacy is associated with less efficient use of health services, decreased adherence to treatment, poorer health-related quality of life and increased mortality. In addition, they suggest ways of improving health literacy levels for people with ESKD, and highlight that differences in patients' information needs and preferences require consideration when designing patient education and training. For example, Peter was in his twenties when he needed to choose a kidney replacement therapy (KRT) modality, and felt confident using the internet to enhance his knowledge.

*At first, I received large amounts of information from the nephrologist and the nurse, as well as an information pack. And then I went online myself to find lots more information on the*

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website of the patient association and the national kidney foundation. I prefer to explore options myself and what things I need to prepare for. So, when they mentioned a preference for transplantation or maybe dialysis, I find it all out myself, so that I know early on what I might want. That information was all very clear.

In contrast, Edward felt less confident in going online when he was in his seventies and needed to make his treatment choice.

*All that business with those computers, it is going over my head a little. I prefer a phone call. There are many other older folks who don't know their way with that stuff. Computers are a barrier. Rather speak to people than using the internet.*

In terms of skills, modalities that require patients to be willing and able to independently take responsibility for elements of their treatment may not be suitable for everyone. Sonja, a middle-aged woman on nocturnal home haemodialysis at home, said:

*What attracted me to this treatment was regaining my freedom; there would be no need of being surrounded by white coats anymore and I would be completely in charge myself. But I'm very aware that I belong to the limited group of patients who is able to perform this level of self-management – you need to be very alert and make decisions quickly by yourself. I am sure that this treatment is not suitable for everyone.*

Similar considerations around independence and freedom may lead to different treatment choices, as illustrated by this quote from Gertruce, who opted for conservative treatment:

*When I heard I had to go onto dialysis, I hardly needed time to think. This was not what I wanted. I am alone and was adamant that I didn't want to become dependent on other people. I do not want dialysis. I don't want my condition to take over my life. Sometimes things are bad and sometimes they are better. I'm not hiding it. Death is part of life. I want to stay in control of my own life till the end.*

## PATIENT INVOLVEMENT IN DECISION-MAKING

Two papers in the supplement talk in more detail about shared decision-making between patients and healthcare professionals. The first one, by Hole et al. [6], provides a personal view on the shared decision-making process from the perspective of a patient and two clinicians. They describe how a shared decision combines the clinician's expertise on disease management with the patient's expertise on their lived experience and what matters to them. This quote from Marian, a woman in her early sixties, confirms the importance of understanding what matters to patients in order to meaningfully involving them in decision-making and helping them to come to terms with their situation:

*The whole process caused a lot of stress, so I went looking for a psychologist on my own initiative... The information on treatment is mostly technical, while I also needed psychological support.*

Foreseeing many barriers for adopting shared decision making in routine kidney care, the authors argue that support from nephrologists is crucial: only if they are willing to abandon traditional paternalistic models of care, can care be recentred around patients' values and preferences. This viewpoint is supported by Sonja, who suggested that the kidney team should help patients

with gaining an understanding of the different modalities before deciding if and how that would fit into their daily lives.

*I would like to suggest to nurses and doctors to ask themselves who they have in front of them, and to try and imagine what it's like to be that patient. They need to help the patient by suggesting possible questions, as often the patient himself has no idea what information to ask for.*

Cor, an older patient, explains how he chose conservative care once he had the information he needed about different treatment options:

*For me, it doesn't have to be over. Nobody wants to step out just like that. It is never enough but life ends. And if the prospects with or without dialysis are the same, then it's clear, right?*

In the second paper on shared decision-making, Bekker et al. [7] highlight the role of theory- and evidence-informed decision aids to improve both individual and shared decision-making processes for kidney professionals and people with ESKD. In contrast to leaflets, decision aids enable people to compare and trade-off treatment options with uncertain outcomes, and offer support for deciding which option aligns best with their needs. This often includes prompts for patients to help them ask the right questions, which would have been helpful for Edward:

*You don't know what to ask. If I had the knowledge I have now, I might have asked completely different things.*

Decision aids can also support patients and health professionals to come to a shared understanding about clinically versus personally relevant outcomes. As an example, Marian said she was unprepared for the emotional impact of starting KRT, and felt this information would have been useful when she opted for dialysis:

*The information [about treatments] I received was clear enough, but in hindsight I missed information about the enormous emotional impact starting dialysis has on you.*

Lastly, Bekker and colleagues describe how decision aids can help focus on the information needed for developing care plans for ESKD. This would include conservative management and end-of-life options, such as in the case of Tilly, an older patient who opted for conservative care:

*I thought about the pros and cons for a year. And then I asked my GP: what if I decide not to go on dialysis? My children support me, my husband found it harder. But even if they don't support me, it's my choice. At some point, you run out of resilience, and I've run out.*

## PATIENT INVOLVEMENT IN DISEASE MANAGEMENT

After making a shared treatment decision, patients are encouraged to continue playing an active role in managing their kidney disease, especially if they opted for home dialysis. Although home therapies treatments may put a substantial burden on patients and their caregivers [8], Lambie and Davies [9] describe in their paper that absolute contraindications for these are rare. However, kidney centres may apply relative (contra)indications reflecting local capacity, capabilities and preferences. The authors acknowledge that these are relevant to consider, but also argue that relative contraindications should not outweigh

or reduce room for addressing patients' preferences. Related to this, Sonja said:

*I very much appreciate that nephrologists have expressed their sympathy that along my patient journey my [treatment] options had been so limited. People talk about shared decision making but in my case there was very little to choose from.*

In addition, the authors give examples of how contraindications are sometimes based on unsupported assumptions about modalities, for example, that home therapies may be less suitable for older people. This quote from Edward (in his seventies) illustrates, however, that older people are willing to give home dialysis a try if offered by the kidney team:

*I appreciated the nurse recommending nocturnal peritoneal dialysis and I am glad that I tried it. I had to transfer to continuous ambulatory peritoneal dialysis already after one week, but if I had to do again, I would do exactly the same.*

People who opt for in-centre modalities can also be actively involved in their treatment through shared haemodialysis care, as described in the article by Barnes and Wilkie [10]. They report on a virtual training program that was developed to provide health-care professionals with the confidence and skills to engage, involve, support and train patients in their care. As a result, patients will learn about and participate in simple and more complex tasks relating to their own treatment, ranging from weight and blood pressure measurement to machine preparation or vascular access care.

## PATIENT INVOLVEMENT IN RESEARCH

The third type of patient involvement covered in this supplement concerns involvement in research, from prioritizing research questions to disseminating and implementing findings. Living with ESKD is an unsettling experience with often far-reaching consequences, as illustrated by this quote from Sonja:

*One should not underestimate the traumatic impact of a serious health problem on someone's life... I would like to ask for more attention for the impact on a patient's mind and body, for example on their sex life. Personally, I would have appreciated a support program, just like the one offered to patients with breast cancer.*

Ensuring that such experiences and support needs inform the design and implementation of studies and interventions is crucial for research to be relevant for and have impact on kidney care and outcomes. In their paper, Cazzolli et al. [11] give an overview of values and strategies to guide meaningful and effective involvement of people with kidney disease and their caregivers in research. It also helpfully suggests approaches to incorporating a variety of, sometimes conflicting, viewpoints.

In contrast to in the past, in many countries nowadays patients are considered equal partners in treatment decision-making, disease management, and health service design and research. This supplement of *Clinical Kidney Journal* includes six

papers providing examples of how this increased involvement may take shape and makes suggestions on how this involvement process may be expedited.

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## CONFLICT OF INTEREST STATEMENT

None declared.

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