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Original Article

Patients' experiences of transitioning between different renal replacement therapy modalities: A qualitative study

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Abstract

Background: Different kidney replacement therapy modalities are available to manage end-stage kidney disease, such as home-based dialysis, in-center hemodialysis, and kidney transplantation. Although transitioning between modalities is common, data on how patients experience these transitions are scarce. This study explores patients' perspectives of transitioning from a home-based to an in-center modality.

Methods: Patients transitioning from peritoneal dialysis to in-center hemodialysis were purposively selected. Semi-structured interviews were performed, digitally recorded, and transcribed verbatim. Data analysis, consistent with Charmaz' constructivist approach of grounded theory was performed.

Results: Fifteen patients (10 males; mean age 62 years) participated. The conditions of the transitioning process impacted the participants' experiences, resulting in divergent experiences and associated emotions. Some participants experienced a loss of control due to the therapy-related changes. Some felt tied down and having lost independence, whereas others stated they regained control as they felt relieved from responsibility. This paradox of control was related to the patient having or not having (1) experienced a fit of hemodialysis with their personal lifestyle, (2) a frame of reference, (3) higher care requirements, (4) insight into the underlying reasons for transitioning, and (5) trust in the healthcare providers.

Conclusions: Care teams need to offer opportunities to elicit patients' knowledge and fears, dispel myths, forge connections with other patients, and visit the dialysis unit before transition to alleviate anxiety. Interventions that facilitate a sense of control should be grounded in the meaning that the disorder has for the person and how it impacts their sense of self.

Keywords

Decision-making, dialysis, experiences, home-based therapy, in-center modality, patient, process

Introduction

The evolution of kidney function of patients diagnosed with chronic kidney disease (CKD) is often unpredictable and may deteriorate progressively to end-stage kidney disease (ESKD). Different treatment regimens are available for patients with ESKD, with the most distinct groups being home-based dialysis therapies (either hemodialysis (HD) or peritoneal dialysis (PD)), in-center HD, kidney transplantation, and conservative care. The clinical needs of these patients are mostly best served by sequential use of different modalities. The clinical journey of patients with ESKD is often not limited to a single modality due to changing medical conditions, occurrence of complications, changes in patient choice and preference, and/or changes in availability of treatment.²

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Changes between kidney replacement therapy (KRT) modalities should be seen as transitional processes.³ These are ongoing processes characterized by change for an individual during which a new situation or circumstance is incorporated into their lives.^{4,5} In the current literature, numerous studies have investigated the experience of individuals with starting of dialysis, or of the HD procedure itself, but few of these studies seek to understand the actual experience of switching between KRT modalities, and only limited knowledge is available regarding this topic. Nurses and other healthcare providers (HCPs) need to understand the lived experiences of patients transitioning KRT modalities to properly respond to the experienced physical, psychological, emotional, and spiritual changes. Developing an understanding of transitions and the psychological processes involved in adapting to them is essential to addressing the unique needs of this vulnerable population. Therefore, the purpose of this study was to explore the transition experience and perceptions of aspects related to the transitioning process, and what these mean to patients. We focused on the transition between PD, the most frequently used home-based therapy, and in-center HD.

Methods

Study design

This study was designed as an explanatory qualitative study with an inductive approach including interviews. Qualitative research can provide data about patients' values, beliefs, motivations, and priorities for the purpose of explaining social and experiential phenomena. The 32-item Consolidated Criteria for Reporting Qualitative Studies (COREQ) was used as a guiding tool to verify whether all necessary and valuable information was included in the article. 9

Setting and sampling

In order to gain rich information from a range of perspectives, patients transitioning from self-managed home-based therapy (PD) to healthcare worker managed (in-center HD) treatments were recruited purposively between June 2017 and February 2019 in five hospitals in Flanders, Belgium. Hospitals included two university-based tertiary care centers, two non-university based regional hospitals, and one smaller satellite unit, representing the variety of possible units for the dialysis population in Flanders. Inclusion criteria were (1) currently receiving maintenance in-center HD after a period of home-based dialysis (PD), (2) being able to speak and understand Dutch, (3) age >18 years, and (4) capacity to consent. Participants were purposively selected to ensure diversity in demographics and potential patient experience, gender, age, and dialysis vintage. Recruitment was conducted in conjunction with analysis and continued until interviews did not yield new insights

Table 1. Exemplary questions of the interview guide.

- Please tell me, what is it like to face the transition from PD to HD?
- Please, tell me more about your experience.
- How are you doing since you made the transition?
- Can you describe in your own words why you had to make the transition to in-center hemodialysis?
- What was the transition like for you? How did you experience this change? Which feelings were emerging?
- How do you look back on the past period since the idea of transitioning was introduced?
- Which aspects made it difficult to cope with the transition?
 Which aspects made it easier to cope with the transition?
- What's changed since the transition? What stayed the same?
- Do you see the transition as something successful or unsuccessful?
- How does a good day look like?
- How do you see your future? What are you worried about?
- How do you cope when feeling overwhelmed by your situation?
- How did you experience the contact with the healthcare providers?

(saturation). Patients were approached by a trusted HCP. Only when permission was given, contact information was passed on to the researcher (EH). Interviews were either conducted at the patient's home or in the hospital, as preferred by the patient.

Data collection

Data were collected through one-time semi-structured interviews with open-ended questions, conducted by a female researcher (EH). The opening questions were "Please tell me, what is it like to face the transition from PD to HD." and "Please tell me more about your experience." The interviewer adopted a conversational and emphatic approach. Interviews in the beginning of the study were more open than the later ones as important concepts emerged from the earlier analyses. 10 In addition, a set of probing questions was used in order to clarify the participants' responses throughout the interviews. Probing questions were used to discover deeper detail, meaning, and reasons underlying participants' statements, different for each interview. 11 All interviews were audio recorded and lasted between 30 min and 115 min. The interviewer had no previous relationship with the participants. The interviewer (EH), a renal nurse and researcher, was trained and coached by two experienced qualitative researchers (LVH and SV). The interviews began with exploratory questions about the person's illness trajectory and how patients learned about and initiated in-center HD. Subsequently, engagement in decision-making and prior knowledge about dialysis were explored. The interview guide (Table 1) was refined progressively throughout analysis. Field notes were taken during and shortly after the interview.

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Data analysis

Analysis was based on the principles of Charmaz' constructivist grounded theory approach. 12 This method enables the exploration of conceptual categories and underlying mechanisms at play. First, interviews were read entirely to obtain an overall picture of the interview. Subsequently, each interview was coded by LVH and EH. An entirely inductive approach to coding was employed without any predetermined coding scheme. Coding discrepancies were reconciled through discussion between the two main coders (LVH and EH) and within the research team. By comparing interviews and coded fragments, concepts were developed that guided the next wave of data collection. Finally, the emerging concepts, categories, and relationships between categories were clarified by carrying out new interviews and reanalyzing previous interviews. The interpretative process of analysis was underpinned by reflexivity, ensuring openness to the meaning of the data and a general tenet to question, criticize, and explicate understandings of the data. 13 Data analysis was supported by the software program NVivo10 (QSR International).

Rigor and trustworthiness

Several strategies were used to ensure trustworthiness of our results. ¹⁴ Each interview was audiotaped, transcribed verbatim, and verified for transcription accuracy by the researcher. The validity of data collection was enhanced by peer review of the interview style. To enhance the validity of the interpretations, multidisciplinary researcher triangulation was used in all phases of the study. All authors regularly discussed the emerging categories and their personal reactions to the material.

Results

A purposive sample of 15 end-stage renal disease patients was attained. The participants ranged in age from 27 years to 84 years. Prior to transition, patients were treated with PD with a mean treatment time of 15.6 months (range 3–48 months). The main factors contributing to the decision to switch dialysis treatment were recurrent peritonitis or other peritoneum-related complications, catheter dysfunction, and deteriorating health. Participants were interviewed within 7 months after transitioning to HD. Sociodemographic characteristics of the study sample can be found in Table 2.

Subsequently, we set out the key categories emerging from the stories of the patients. Although each category is discussed separately and in a linear fashion, they are interwoven in multiple and complex ways (Figure 1). Therefore, it is important to keep in mind the interconnected nature of our findings. Exemplar quotes (Q) are presented in Table 3.

Table 2. Sociodemographic and treatment-related characteristics of participants (n = 15).

Sociodemographic characteristics		
Gender, n		
Male	10	
Female	5	
Age (years), n		
<30	2	
30–40	1	
40–50	1	
50–60	2	
60–70	4	
>70	5	
Mean; range	62; 27–84	
Marital status, n		
Married or living together	12	
Widowed	2	
Single	1	
Professional status, n		
Employed	1	
Unemployed	4	
Retired	10	
Treatment-related characteristics		
Time since transition (months), <i>n</i>		
<2	3	
2–3	7	
3–4	2	
4–5	1	
5–6	1	
6–7	1	

Accepting dependence on dialysis as a lifeline

Most patients did not recognize the transition to in-center HD as a true decision. This was due to their perception that dialysis was needed to prevent imminent death or that the transition was not their decision (Q1). Many described an acute need for a transition that was rooted in fear and anxiety (Q2). The potential for transplantation gave some participants hope of an escape from dialysis. These participants saw HD as a temporary solution pending their transplant. Participants approached this by seeing the time on HD as a limited part of their life that would end by receiving a new kidney.

Changes and loss of control on different domains

The process of adjustment calls for participants to change their personal expectations. Once on in-center HD, patients faced new unexpected adjustments and challenges that extended far beyond their thrice-weekly dialysis sessions. Participants described losing time not only to have actual dialysis treatment but also by traveling, waiting, and recovering from their treatment. Participants acknowledged that changes had occurred to their lives and that future effects also may occur. However, there were differences in the way they adapted, carried on, and made the most of their

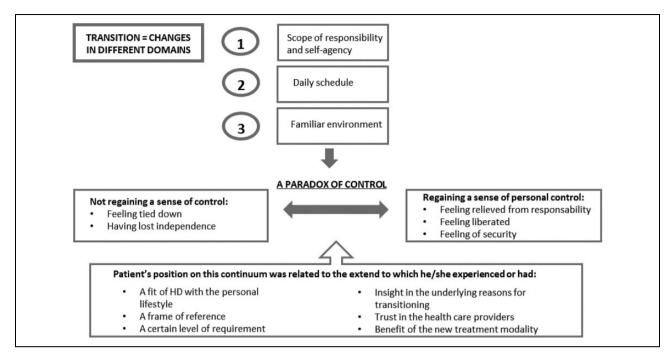


Figure 1. Visualization of the complex relationship between the different categories.

experiences (coping). The transition to in-center HD involved changes and a certain degree of loss of control in different domains. First, they experienced a substantially more restricted scope of responsibility and amount of selfagency (Q3). Second, the initiation of in-center HD meant a change in their daily schedule (Q4). Lastly, they attested to a change in familiar environment. Participants felt abandoned when transitioning to HD as they lost contact with their trusted nephrologist. They often felt a lack of personal connection with the dialysis team, particularly the nephrologist. Furthermore, the need to come to the hospital required them to oscillate emotionally between the renal world (e.g. being on dialysis) and home (e.g. days without dialysis) (Q5).

A paradox of control

We noticed differences between participants in the understanding of the changes in their responsibility, self-agency, daily schedule, and familiar environment. This feeling of no longer being in control, therefore, was not consistently accompanied by a feeling of being overwhelmed or limited in independence. It became clear that not every participant experienced the abovementioned changes as limiting or as a loss of control or possibilities. It therefore did not give rise to a feeling of being limited for every patient, and instead, even provided some of them with inner security and a foothold. These participants regained personal control as they felt relieved from responsibility for treatment (Q–Q8).

Others felt tied down and had lost independence when transitioning to in-center HD (Q9–10). These differences can be assigned to different elements and underlying

processes. Whether participants experienced this paradox of control was related to whether the patient (1) experienced a fit of in-center HD with their personal lifestyle, (2) had a previous frame of reference, (3) experienced a change in health state, (4) had a certain level of care requirement, and (5) had insight into the underlying reasons for transitioning. These elements formed the undercurrent of this paradox of control. These elements and processes are discussed in more detail below.

- 1. Experienced fit with their lifestyle: Participants exhibited great variety in their ease of ability to fit the new treatment schedule into their pattern of regular activities, interests, and daily lifestyle (Q11–12). This related to the patients' perceptions of the intrusiveness of the new treatment modality (Q13).
- Frame of reference: Some participants attested to having certain ideas and previous experiences with dialysis (e.g. a frame of reference). Often, in-center HD was considered as ominous and something that would impinge on their lives in the near future. This frame of reference underpinned their perceptions of the transition to in-center dialysis (Q14–15).
- 3. Experienced change in health state, functional status, and condition: The interviews highlighted differences in the extents to which participants experienced a certain benefit of the new treatment modality. Some experienced significant improvement in their overall health after the transition (Q16), whereas others remained in a relatively severe dysfunctional state or felt worse off (Q17).

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 Table 3. Illustrative quotes from participants.

QI	Accepting dependence Dialysis as a lifeline	"The PD treatment was not working anymore. I was poisoning myself. My legs were swollen, I felt very uncomfortable. I lost my appetite, I vomited. I really wasn't fine. Then the doctor decided that I had to change therapy, hemodialysis. It wasn't my choice." (IV 13, male,
Q2	Accepting dependence Fear and anxiety	52 years) "I really hicked up against it. I was very scared and emotional (). During the predialysis consultations, it was made very clear that PD was the best option for my health and that hemodialysis would have a negative impact on my heart function. Once a while you hear that hemodialysis takes years of your life. I don't want that, I don't want that for my son." (IV 15, female, 30 years)
Q3	Changes and loss of control Responsibility and self-agency	"Laying down for 4 hours, it's a disaster. It's so frustrating. With PD I never had any problem. I could do it all by myself. I did it at home, I could prepare everything in advance. I went upstairs and I connected myself to the machine. My life was very different in comparison with the life I am living now." (IV 18, female, 55 years)
Q4	Changes and loss of control Daily schedule	"I feel strongly restricted. It is Monday, Wednesday, Friday or Tuesday, Thursday, Saturday. You need to abide. You do not really have a choice. With PD it is more flexible, that's a great advantage. With HD you need to come to the hospital trice a week. So I only have the opportunity to meet with friends on Tuesday, Thursday and in the weekends, but not on the remaining days." (IV 7, male, 66 years)
Q5	Changes and loss of control Familiar environment	"When you start PD, they help you to get to know this machine inside out. You can adjust the machine at home. You can work with it. Moreover, you're always cared for by the same nurses and doctors. So you can built a confidential relationship. And that is not possible when treated with in-center hemodialysis. You see a dozen or more different nurses at your bedside and every time a different doctor." (IV 9, male, 73 years)
Q6	Regaining control	"It's perfect. It's much better than PD. I only have to come to hospital three times a week. I don't have to work (PD) every day anymore." (IV 14, male, 82 years)
Q7	Regaining control	"In the hospital, you are always under supervision. There is always someone who keeps an eye on you. There is always a nurse who takes your blood pressure every half an hour. Previously I felt save, but now I know how it works in the hospital." (IV 6, female, 68 years)
Q8	Regaining control	When doing PD, you are always on your own. Yes you can always call; but with infections and so on my partner worried about that. () And now it's not amusing to lay still for 4 h, but I feel better. They also respond adequately on everything." (IV 15, female, 30 years)
Q9	Not regaining control	"I think this is not living. I think I am not living right now. () It consumes my life. I cannot enjoyI cannot let it go. That's my life now. I live from dialysis to dialysis. In fact, it is surviving. I cannot get rid of it () I can do little about it, I am powerless. It happens to me. () PD I could handle. I could tailor it to my own preferences." (IV 18, female, 55 years)
Q10	Not regaining control	"You are no longer in control. You are no longer the master of your own life. You have to live on the rhythm of that machine. Even more than with PD. () I just let my mind go blank. I'm shutting out everything because you can't do what you want to do. That frustrates me a lot. I feel oppressed and so vulnerable." (IV 13, male, 52 years)
QII	Experienced fit with their lifestyle	
Q12	Experienced fit with their lifestyle	"With peritoneal dialysis, I was on my own 7 out of 7. That was quite a burden for me. PD is the best of the two, but I have more social contact with in-hospital hemodialysis. You chat with the nurses and other patients. You can watch television, read something, we get something to eat or to drink. In the end, for me the social aspect outweighed the rest because I'm recently bewidowed." (IV 7, male, 66 years)
QI3	Experienced fit with their lifestyle	"You must live to the rhythm of the machine. () you can't do what you want anymore. I feel that way since I'm on hemodialysis. PD wasn't an obstacle. But yes, my life is not like it was used to be." (IV 6, female, 68 years)
QI4	Frame of reference	"I knew what it meant. I experienced it with my father. My father was on hemodialysis. I've seen him deteriorate and eventually die." (IV 13, male, 52 years)
Q15	Frame of reference	"3 years ago, I was on hemodialysis for a period of 9 weeks when they had to replace my PD catheter. I couldn't cope with it, it was very difficult." (IV13, male, 52 years)
Q16	Experienced benefit in health state and condition	"If I am honest, I feel much better. You are much more vital. With PD you are walking with 2 L of water in your belly. You look like a pregnant lady." (IV 7, male, 66 years)
Q17		"I'm exhausted after a HD session. I cannot do anything. Yes I have more freedom, but I am too tired to do anything. I am so weak." (IV 5, male, 69 years)

Table 3. (continued)

O18 Certain level of dependency "It's a different life when you have to go to hospital. The dialysis starts at 7 a.m. and they pick on others me up at 6 a.m. They pick me up first because I live far away. At 6:15 a.m. I am in the waiting room staring at the wall. And in the afternoon I have to wait more than 30 min. That doesn't happen when you're dialyzing at home! I'm now always waiting for others to come or to do something." (IV 6, female, 68 years) Q19 Insight into underlying reasons "I said: look, today I decide not to do this PD stuff anymore. I don't want to know anything for transitioning about that anymore. This misery. Not sleeping at night, all these alarms. I have reached the limit. That is why I understood the doctor's suggestion to start HD." (IV 14, male, 82 years) Q20 Insight into underlying reasons "Yes I endure the dialysis. It's in my best interest. I try to deal with it in a way that it is for transitioning acceptable for me. This attitude makes my life less complicated. Don't understand me wrong, I still yearn for PD but the nephrologist has convinced me of the need for HD and I went along." (IV II, male, 74 years)

- 4. Certain level of dependency on others: This refers to the meaning patients gave to being cared for, and dependent on HCPs due to in-center dialysis. For some patients, being cared for was to be overwhelmingly vulnerable, or being treated like an object, making them feel forgotten about and embarrassed, all of which may have led to a feeling of insufficiency. In contrast to other patients, the increased professional attention was described as support and having a lifeline or a safety-net (O18).
- 5. Insight into underlying reasons for transitioning: Participants who described less-engaged decision-making during the transitioning process faced challenges reconciling their values with HD and felt that their preferences had been overlooked. Patients were distressed by unexpected outcomes not discussed during decision-making. Successes were found when patients expressed pride and confidence in decisions and understood the necessity for changing KRT modality. Those who felt prepared for HD approached dialysis with more confidence (Q19–20).

Discussion

While there is a vast body of research on dialysis outcomes, 15-19 our findings are novel in their focus on the transitioning experience when changing KRT modality. To our knowledge, this is the first study to use a truly inductive method to understand the process of transitioning between the different KRT modalities. In this qualitative study of ESKD patients, most patients who transitioned from PD to in-center HD felt they accepted in-center dialysis mainly because it was required for their survival, whereas most had unaddressed concerns about the impact on quality of life and domains of personal control.

Besides experiencing this new burden, prior research has demonstrated important differences in terms of emotional distress and quality of life across KRTs.²⁰ In addition to demands directly related to their illness and treatment, patients with ESKD are required to adjust to the psychosocial impacts of the disease, including changes in body image, social relationships, and employment.²¹

Our analysis further indicates the importance of exploring the patient's frame of reference and understanding of the reasons for transitioning. Different studies underpin that these illness representations predict a range of outcomes in patients undergoing dialysis. ^{22,23}

Our findings suggest that the preparation and initiation of dialysis therapy is emotionally fraught. A recent systematic review determined that while quality of life and survival considerations were important to patients, clinicians tended to focus mostly on biomedical factors and the desire to prolong life. ²⁴ This suggests that HCPs need to offer real opportunities to elicit what patients know about dialysis prior to initiation, a chance to explore their fears, dispel myths and forge connections with other patients, as well as visit the dialysis unit before starting treatment in order to alleviate anxiety.

The losses expressed by our participants signal a need for psychological support to facilitate coping during the transition phase of dialysis. Previous research suggests tailored psychosocial follow-up, such as cognitive behavioral therapy significantly improves depression, quality of life, and treatment adherence in patients with ESKD. ^{25–27} Maybe similar interventions (e.g. peer support groups) could empower patients in negotiating the physical and emotional impact of the transition. Furthermore, these interventions could support patients in managing anxieties and self-esteem issues. However, this requires proactively gaining insight into the patient's frame of reference and meanings of transitioning KRT modalities.

Our study underpins the need for HCPs to better plan and manage modality transitions through regular discussions with the patient and their caregivers. These discussions should not solely focus on optimizing patient survival but also on the associated patient experience and personal definition of how an optimal transition would look like. The decision to start in-center dialysis should incorporate shared decision-making (SDM), promoting patient autonomy, and helping patients make informed treatment decisions aligned with their preferences and values.²⁸

Choice is seen as central if patients are to take part in SDM and if doctors are to offer a patient-centered approach. Similarly, the absence of choice undermines

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self-efficacy and behavioral control. Without choice, a person is deemed powerless and unempowered. In contrast, the results from this study suggest that the relationship between choice and control may not be so straightforward. Interventions that facilitate a sense of control need to be grounded in exploring the meaning that the disorder has for the person and how it impacts on their sense of self. When HCPs do not take into consideration patients' knowledge or values, a diminished participation in care and relationally induced non-adherence can occur. Future treatment modalities should be discussed against an assessment of patient and caregiver capacity as well as their material, social, and cognitive resources. 29,30 Our study suggests that HCPs should gain insight into the meaning and importance of personal control for ESKD patients. Implementing a care plan in which sufficient time is provided for conversation with the patient seems essential to meet these recommendations.

Our study showed that patients often use different parameters to judge the success of their transition. During patient consultations, the main goal should be to strive for attunement and mutual understanding by means of taking into account that everyone's perspective may be different. This allows HCPs to develop shared frames of reference with ESKD patients.³¹ Our study emphasizes the importance of going beyond what seems apparent and obvious in a situation. Multidisciplinary services and integrated healthcare are recommended as new healthcare models during preparation for in-center HD, with specific strategies to detect patients' concerns and fears of initiating HD therapy.³²

The findings of this study must be considered in the light of some limitations. First, it should be noticed that our findings mainly pertain to white, Dutch-speaking, articulate, self-reflective patients. Second, participants were identified from five renal units in Belgium, such that the transferability beyond these sites is uncertain. Nonetheless, similarities in categories found in other studies and the representative nature of the units to the Flemish dialysis population suggest that our findings may resonate in other settings.

We identified important areas for future study. Further studies to determine how patients' psychosocial challenges and problems in life areas other than health can be sufficiently integrated into nephrology care are warranted; a deeper understanding of how ESKD patients may determine their locus of control may also be informative. Future studies should prospectively evaluate the dialysis decision-making process of individuals with ESKD. Future studies should explore ways to promote value clarification and to respect patient preferences regarding personal control. 33,34

Authors' note

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Author contributions

The authors confirm that the manuscript has been read and approved by all the named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. The order of authors listed in the manuscript has been approved by all the authors. EH, SD, GC, DJ, WVB, and LVH conceived and designed the study; EH, KF, and WVB were involved in patient recruitment; EH helped in data collection; EH, SV, WVB, and LVH performed data analysis; EH, WVB, and LVH drafted the manuscript; EH, SV, SD, GC, KF, DJ, WVB, and LVH helped in critical revision for important intellectual content; EH, SV, SD, GC, KF, DJ, WVB, and LVH were involved in final approval of the version to be published; EH, SV, SD, GC, KF, DJ, WVB, and LVH checked the agreement to be accountable for all aspects of the work.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: DJ has received consultancy fees, research grants, speaker's honoraria, and travel sponsorships from Baxter Healthcare and Fresenius Medical Care, as well as consultancy fees from Astra Zeneca and travel sponsorships from Amgen. He is also supported by an Australian National Health and Medical Research Council Practitioner Fellowship (1117534). The remaining authors declare no conflicts of interest related to the topics reported and discussed in this paper.

Ethical approval

The study protocol was approved by the Ethics Committee of the Ghent University Hospital (B670201732237).

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Informed consent to participate

All participants were given written and verbal information about the study and gave informed consent to participate. All data were anonymized.

Informed consent to publish

All identifying information has been deleted from quotes. Our paper does not contain information or image(s) pertaining to an individual patient that could render that patient identifiable to any reader when the article is published.

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