

When kidney transplantation is not an option: Haemodialysis patients' and partners' experiences—A qualitative study

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Abstract

Aim: To investigate the experiences and perspectives of everyday life among patients on lifelong haemodialysis and their partners.

Design: A qualitative exploratory study with a phenomenological–hermeneutic approach.

Method: Data were collected through individual interviews. In total, five patients in haemodialysis and their partners were included in the study. Data were analysed with inspiration from Ricoeur's theory around narratives and interpretation on three levels: naïve reading, structural analysis and critical interpretation and discussion. Data was collected between February 2018–June 2019.

Results: Limitations caused by the disease and time-consuming treatment influenced daily life. In particular, the partners needed to have time on their own. Knowledge about the disease and participation in treatment were significant to both patients and partners. There were considerations about illness progression. Relationships to their social networks and healthcare professionals were a significant and important part of daily life for both parties.

KEYWORDS

caregivers, chronic kidney disease, dialysis, everyday life, experience, family, haemodialysis, interviews, patients, relatives

1 | INTRODUCTION

This paper deals with how patients receiving haemodialysis (HD) and their partners experience everyday life, when kidney transplantation is not an option. This is an important area in nursing practice, because it raises important issues around caregiving and support for the whole family.

The number of people with end-stage kidney disease (ESKD) receiving HD has increased during the recent years, with an estimated 2 million plus people receiving HD globally in 2010 (Liyanage et al., 2015). This number is expected to have doubled by 2030 (Liyanage

et al., 2015). In 2016, 5,363 people received uraemic treatment in Denmark. Out of those, 2,797 individuals were kidney transplanted and 2,566 individuals received HD or peritoneal dialysis (Danish Nephrology Society, 2017).

End-stage kidney disease can cause a physiological and emotional impact on well-being and everyday life and includes fear of disease progression and risk of treatment complications. People with a chronic disease employ a range of internal resources to maintain a meaningful role in their life, where coping with fear, anger, frustration and increased mortality risk have to be managed (Clarkson & Robinson, 2010). When an individual has a disease, it is not only the individual who is affected. There are also many impacts on the

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person's family. Close relatives can be exposed to stress and caregiver burden as a result of the daily care interventions or challenges that a serious illness can imply (Kang, Li, & Nolan, 2011; Northouse, Katapodi, Song, Zhang, & Mood, 2010).

2 | BACKGROUND

End-stage kidney disease is one of the most frequent long-term illnesses and involves a significantly increased risk of morbidity and mortality. Statistics shows that people with chronic kidney disease have a low overall survival in comparison with the general population (Tamura et al., 2016). Kidney transplantation is the preferred choice of treatment; however, due to the importance of several physical conditions such as cardiovascular conditions, malignancy and age, this is not an option to all patients (Terasaki, Cecka, Gjertson, & Takemoto, 1995; Wolfe et al., 1999). Qualitative studies show that patients receiving HD and peritoneal dialysis experience several changes in life and that they are constantly faced with thoughts and concerns about the past, the present and the future related to the disease and everyday life. Furthermore, they have ambivalent feelings towards dependency, restrictions, loneliness, notable changes to their social lives and how to manage everyday life (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001; Hagren, Pettersen, Severinsson, Lützn, & Clyne, 2005; White & Grenyer, 1999).

The person's family, however, is also affected by the disease in several ways and family members usually constitute a significant part of a shared life with the patient. Close relatives, such as spouses or partners, are often the most important support for the patients. Relatives are often expected to be involved as caregivers during periods of disease progression (Kang et al., 2011). However, studies show that the relatives feel a commitment to their sick loved ones and they experience it as tough and tiring to be an informal caregiver (Kang et al., 2011; White & Grenyer, 1999). Relatives feel an emotional pressure and powerlessness in relation to the ill person and the issues such as lifestyle changes and changes to family situation and social relations caused by the illness have an impacted on them (White & Grenyer, 1999). Moreover, they may experience scant support from healthcare professionals (HCPs) and have the feeling that they need to fight to be involved in the caregiving process (Aasen, Kvangarsnes, Wold, & Heggen, 2012; Mashayekhi, Pilevarzadeh, & Rafati, 2015; Ziegert, Fridlund, & Lidell, 2007).

Despite an increasing focus in recent years on involvement of both patients and relatives in healthcare services and despite knowledge about how relatives are exposed to caregiver burden, the experiences of relatives to patients with ESKD have been scarcely illuminated (Agnholt, Kritiansen, & Pedersen, 2017; Pelletier-Hibbert & Sohi, 2001; White & Grenyer, 1999). Furthermore, the specific situation about everyday life experiences and perspectives when receiving HD and not having kidney transplantation as an option has, to the best of our knowledge, so far not been addressed.

2.1 | Aim

To investigate the experiences and perspectives of everyday life among patients on lifelong haemodialysis and their partners.

3 | METHODS

3.1 | Design

Because the focus of the study was to explore patients' and partners' experiences of and perspectives on everyday life with lifelong HD, an explorative approach with a qualitative design was chosen for the study (Green & Thorogood, 2014). The study was conducted by taking a phenomenological-hermeneutic approach, based on Ricoeur's theory of narrative and interpretation (Ricoeur, 1976). The Criteria for Reporting Qualitative Research (COREQ) was used during the study (Tong, Sainsbury, & Craig, 2007). See File S1.

3.2 | Participants and setting

The participants were recruited from a Danish university hospital. All patients from the haemodialysis unit were screened, based on the following inclusion criteria: Danish-speaking patients who received HD and who were not accepted for kidney transplantation and their Danish-speaking spouses or co-habiting partners. The exclusion criteria were as follows: patients and spouses or partners who had other life-threatening diseases or amnesia.

The inclusion was done consecutively and patients and partners who fulfilled the criteria were invited to participate orally and in writing by a clinical nurse specialist known to the patients. The patients were invited at first, and if they showed interest, their partners were invited too. In total, eight couples were invited. Five couples agreed to participate and signed informed consent forms. Reasons for refusal were lack of time and/or energy by both patients and partners.

The participants' genders were distributed between four male and one female patient and one male and four female partners. The participants represented an age range from 57–70 years. Years on HD were between 2–13 years. One of the 10 participants was at the working market. Time spend in the dialysis unit by the patients was 4 hr three times a week to receive life-sustaining HD to remove waste substance and fluid from the blood. Normally the partners did not follow with the patients to dialysis. This represents the general picture in the Danish dialysis units. Data were collected between February 2018–June 2019.

3.3 | Data collection

Data were collected through individual, open, in-depth interviews (Kvale & Brinkmann, 2014). To facilitate the interviews, an interview

guide with open-ended questions was used for both patients and partners. The guide consisted of topics and was based on previous research in the field. The interview guide was used to lead the participants into narrating about their experiences of and perspectives on their everyday lives. Questions asked were "Please, tell me how you experience everyday life with chronic kidney disease?". A narrative approach allowed the participants to express the experiences that were important to them. However, the interviewer made an effort to cover topics such as intrapersonal issues, intra-familial issues and issues about everyday life with ESKD. The interviews were performed individually to give the participants space to talk about things that they might not address if their partner were present. The interviewer—who is the first author—was a nurse with a Master in health science and had skills in conducting interviews. She had several years of experience in nephrology and HD; however, she was not a member of the clinical team caring for the patients. The participants did not know the interviewer prior to the interviews. Seven interviews took place in the participants' homes and three interviews were held at the hospital in a quiet room. The interviews were audio-recorded and transcribed verbatim by first author. The interviews lasted between 30–60 min. Based on Ricoeur, narration allows for a process of reflection in the narrator which provides new perspectives into human lives and makes validation among the participants inappropriate (Ricoeur, 1976).

3.4 | Data analysis

Data analysis was conducted by a recognized method inspired by Paul Ricoeur's theory of narrative and interpretation (Pedersen, 1999/2005; Ricoeur, 1976). The data were analysed on three levels: naïve reading, structural analysis and critical interpretation and discussion (Pedersen, 1999/2005; Ricoeur, 1976). During the analysis, the transcriptions of individual interviews were considered as one coherent text. During the naïve reading, the text was read several times with an open-minded approach to get an initial impression and an overall understanding of what the text was about. According to Ricoeur, this initial level implies an understanding by looking and listening to how the text affects you (Pedersen, 1999/2005; Ricoeur, 1976).

In the structural analysis, the text was re-read to reach a deeper understanding of patients' and partners' experiences and perspectives of living an everyday life with ESKD and lifelong HD across the data material. This was done by identifying quotations in the text material "what is said" that illuminated the meaning. It was in this part of the analysis that the explanatory element emerged. By questioning the units of meaning ("what the text speaks about"), a further interpretation was made, which led to the emergence of themes, subthemes and patterns. At this level, the text was viewed as objectively as possible and the intention was to objectify the units of meaning from the text as a whole (Pedersen, 1999/2005; Ricoeur, 1976). Table 1 illustrates an example of the structural analysis as a dialectical movement between the parts and the whole of the text (Pedersen, 1999/2005).

TABLE 1 Example of structural analysis

Units of meaning "What is said"	Units of significance "What the text speaks about"	Themes
"I do everything. I clean the house, I do the laundry, I make dinner, I wash the car. We do not live in a house but in an apartment. A house would have been too much in this situation. I could not have done a garden too!" (R)	Much to do for the relatives. Not space to more daily tasks. A sense of exhaustion. Responsibility for most of the daily tasks at home	Changes in everyday life

In the critical interpretation and discussion, the themes were interpreted and discussed in relation to theory and other research results. This was a dialectical movement between explanation and understanding, which moved the findings from an individual to a universal level. At this final level, the findings were incorporated into possible appropriate interpretations and included a discussion of the study's implication for practice and its relation to national and international research (Pedersen, 1999/2005; Ricoeur, 1976). In this part of the analysis, new knowledge and understanding about how patients with ESKD and their partners experienced everyday life were formed. The study results were discussed in the research team.

3.5 | Ethical considerations

Participants were informed about the purpose of the study, that their participation was voluntary and that they could withdraw from the study at any time without any adverse consequences. Furthermore, they were informed that interview recordings and the transcribed material would be processed and stored confidentially and anonymously. The study was approved by the Danish Data Protection Agency (19/7219).

4 | RESULTS

The naïve reading revealed that illness and treatment were present and seemed to have impact on and lead to limitations in, the participants' everyday lives. Knowledge about the illness and participation in treatment and care activities seemed to be of importance in daily life. Furthermore, there could be considerations about the future that included a sense of uncertainty. Moreover, relationships with others in everyday life seemed to be of significance.

Through the structural analysis, four themes emerged:

- Changes in everyday life.
- The importance of knowledge about and participation in illness and treatment.

- Thoughts about the future.
- The importance of relationships.

In the following, spouses and partners will be termed partners. Quotations marked (Pt) refer to a patient and those marked (P) refer to a partner.

4.1 | Changes in everyday life

Since the start of HD, everyday life had changed. Reduced energy levels affected everyday life: "I can clearly feel that I don't have much energy. That's certain. I can do a little and then I have to rest" (Pt3). Because of fatigue, it was not possible to do things, such as daily tasks or hobbies. Nor was it possible to take part in social events, compared with before the start of HD. To both patients and partners, it was therefore important to take into consideration what was necessary and what was planned. However, even minor exertion was followed by feelings of being emotional and physically limited.

The changes in everyday life meant a new distribution of daily tasks at home: "I do everything. I clean the house, I do the laundry, I make dinner, I wash the car. We don't live in a house but in an apartment. A house would have been too much in this situation. I could not have done a garden too!" (P1). To make everyday life work, a greater level of responsibility and higher workload were taken on by the partners. It was of huge importance to be aware to strike a balance between doing the daily tasks and protecting their personal resources.

Therefore, partners needed some periods of time to themselves to create a distance to everyday life at home, where illness and treatment overshadowed their preferences and personal needs: "I would like to have a couple of evenings weekly to myself ... It means that your thoughts are on other things and you get to talk to others about things ... It's also a way of working on something" (P1).

Going out and taking care of their own interests was a way to restore and be part of significant relationships with others. It created a needed distance to an everyday life with challenges and worries related to the sick partner. However, it also involved a sense of ambivalence around leaving the sick relative at home and focusing instead on their own interests and needs.

The HD and the time spent in the haemodialysis unit were experienced as a change to and restriction to everyday life for both patients and partners: "Everything has to be organized. You can't just say - right, we're doing this tomorrow. No, we just don't!" (Pt1). The treatment meant that there were boundaries around what was possible and spontaneity in everyday life had disappeared. Planning was no longer up to them but was controlled by the scheduled HD. Planning became a central part of everyday life; however, it was accompanied by unpredictability related to the disease and the treatment. This led to uncertainty about how it would be possible to participate in social and cultural events and take vacations.

Despite the limitations, the participants had mental strategies to cope with the disease and treatment in daily life: "We have become

accustomed to that [going to HD treatment]. That's just the way it is, so it just works as best it can. We get ourselves organized and fortunately we can!" (P2). Both patients and partners accepted how everyday life turned out, even though it had changed into something different from what they had expected. They coped with the circumstances by way of keeping a positive mind.

4.2 | The importance of knowledge and participation in illness and treatment

To both patients and partners, knowledge of and participation in illness and treatment was important: "On the one hand you were unsure and on the other hand you thought 'now I know everything'. Now I know the machines and can control the whole thing [the HD treatment] and that gives a great sense of security" (Pt3). Knowledge about how to perform HD and collaboration with HCPs about, for example, fluid removal provided certainty and predictability about how symptoms and treatment should be managed. This gave both parties sufficient mental resources and a sense of control to handle situations related to the disease and treatment. On the other hand, a lack of knowledge and involvement caused distress and were followed by feelings of uncertainty, irritation and frustration.

Supporting each other in situations related to illness and treatment gave a common starting point in everyday life: "Well, I think it [being together in it] is an advantage. So, it's not just me who has to keep track of everything [the treatment] ... It makes it a bit easier that she [his partner] always knows what's going on as well" (Pt1). When the partners were involved in illness and treatment, both parties experienced that they were managing illness and treatment as a team. Furthermore, for the patient, it was a great support not to be left with feelings of being alone in it. Everyday life with illness and treatment was less onerous when their partners were involved.

4.3 | Thoughts about the future

Patients and partners were aware, to some extent, that the illness would progress over time: "I see that he is obviously getting worse. At one point or another it weakens him physically, that he is on dialysis" (P3). The illness became visible, because of physically reduced functioning and both parties were aware that the future had to be met with a realization of gradually deteriorating health for the person with ESKD. Consciousness about how the illness would progress was experienced with a lack of certainty and security, which involved feelings of vulnerability and perspectives on an uncertain future.

How patients and partners coped with and reflected on uncertainty about the future was expressed in different ways. One patient said:

I've been thinking about going for dialysis three times [a week]. So, I have to go along with what's happening. So, I have to live with that for the rest of my life, as long as it

lasts ... we don't know how long it will last ... of course we don't know when our Lord will call us.

(Pt1)

One partner said:

But, there is also a life after all this, you know? And as I say: I also have to learn to manage by myself for the day when I stand alone. I do that. We know, of course, that his illness won't be forever.

(P4)

The patients expressed an uncertainty about how life would turn out, with the disease and lifelong HD. However, they were determined to take one step at a time and not be concerned about what could happen in the future, before it became necessary. The partners expressed concerns about the future and made preparations for a new situation, such as planning a new and suitable place to live. There were thoughts about losing the sick partner and a realization that, in the future, they would continue to have a life after their sick partner had passed away.

4.4 | The importance of relationships

Relationships with family and friends were a significant part of everyday life: "It's good to get out and see other people besides my wife and my daughter and the grandchildren ... So, it's nice to have a little chat" (Pt2). Family and friends represented important relationships and were a support in everyday life and this involved feelings of being heard and recognized as a human. It was significant that family and friends paid attention to the vulnerable and stressful situations that could crop up in daily life with disease and treatment. It was important to know that they could rely on family and friends during challenging periods, such as illness progression and hospitalization.

Meeting fellow patients also played a significant role for both patients and partners:

So we also talk a little in the room [dialysis room], how it goes and how you feel. It's nice that there is someone who is concerned about one and I'm also concerned about the others, if they get bad or are hospitalized ... We are in the same boat, after all and therefore know what each other goes through to a great extent.

(Pt5)

Personal feelings about well-being and issues around illness and treatment were shared with interest. There were mutual concern and understanding between the patients and partners in the dialysis unit, which was experienced as supportive and helpful in everyday life.

Furthermore, it was important for both parties to have a positive approach to HCPs. One patient said: "The long-term relationship

with the staff means a lot. That they know you. It means that you feel secure in the situation" (Pt4). One partner said: "They [HCPs] go into the computer and look and show me tables and schedules [for treatment]. And if they can't answer something, then they find out. So, it's lovely. It gives you a sense of calm" (P4). The long-term relationships with the HCPs were important. To the patients, it provided a sense of certainty in knowing that the HCPs had extensive knowledge about them and their history and situation. It was important that the HCPs saw them as individual and unique persons and took their needs and preferences into consideration. For the partners, it was important that the HCPs met them and their needs by taking some time to talk to them and answer their questions.

5 | DISCUSSION

The study showed how everyday life had changed, from before the progression of the disease and start of HD. Because of patients' fatigue, there were limitations in everyday life for both patients and their partners. A greater responsibility and workload were placed on the partners to make everyday life work. Time spent on HD resulted in limitations in what was possible and spontaneity in everyday life disappeared. Both parties had mental strategies to cope with the disease and treatment in daily life. Having knowledge about HD and close collaboration with HCPs provided a sense of certainty and predictability. It was significant that family, friends and fellow patients paid attention to the vulnerable and stressful situation.

The findings of this study will be discussed in relation to research results and family nursing theory, as described by Wright and Leahey (2013). According to family nursing theory, in this study patients and partners can be regarded as one system, which is seen in reference to the world outside, which includes family, friends, the healthcare system and the society in general. All systems should be regarded as open systems, based on movement and reciprocity. In discussing the findings of this study in terms of family nursing theory, it becomes evident that there is scope to develop specialized knowledge and understanding of how patients and their partners experience everyday life with ESKD and lifelong HD.

The study showed that everyday life had changed for both patients and partners when ESKD progressed and lifelong HD was initiated. Because of patients' fatigue and reduced energy level, it was no longer possible to do certain tasks, hobbies, social and cultural events in the same way as before the disease. Hagren et al. (2005) found that illness and treatment had an impact on the patients' opportunity to live their life to the full and that illness and treatment meant that there were limitations in taking care of daily tasks and taking part in a social life. Similar, White and Grenyer (1999) found that relatives experienced the same changes and limitations. In our study, most participants were retired and only one partner was on the working market. We found that the changes in everyday life related to the illness and treatment resulted in a new distribution of daily tasks between the patients and partners—with the partners

taking over in most situations. These changes in the management of daily tasks were also found by White and Grenyer (1999). In their study, a big part of everyday life problems and decisions were dealt with by the relatives. In our study, the partners needed to go out and take care of their own interests as a way of recovering from doing tasks and taking responsibility at home. Other studies showed how the relatives found it hard, tiring and stressful to be an informal caregiver around the clock (Agnholt et al., 2017; White & Grenyer, 1999). The sick relative's fatigue and reduced energy levels could be mentally demanding and could cause a desire to scold their relative or to ask them to pull themselves together, even though they were aware of fatigue and reduced energy levels (Agnholt et al., 2017; White & Grenyer, 1999). In our study, we found that, although partners had ambivalent feelings about going out alone, it created a distance from their everyday life, which involved challenges and worries related to the sick partner.

Time spent on HD treatment meant that there were limitations for both patients and partners. The possibility of doing things spontaneously disappeared and the planning of daily life had to work around the scheduled HD treatment. How the treatment represented a limitation in everyday life was also shown by Hagren et al. (2001). They found that the frequency and duration of the treatment had a disruptive influence on marital, family and social life (Hagren et al., 2001). We found in our current study that, despite the changes and limitations in everyday life, there were also mental strategies which enabled participants to cope. Both patients and partners accepted how everyday life had turned out and coped with the circumstances by remaining positive. Studies have shown that patients and relatives are determined to handle everyday life under the given circumstances and focus on the positive elements in life (Agnholt et al., 2017; Hagren et al., 2001). However, Hagren et al. (2005) found that it could be hard for the patients to accept life with chronic kidney disease, involving thoughts of looking back on life before the disease progression and start of HD. White and Grenyer (1999) found that patients and relatives used denial as a way of coping with illness and treatment. If this finding is viewed in relation to our current study, it could offer an explanation for the expressed acceptance and optimism that we found in both patients and partners. From the perspective of family nursing theory, patients and partners constitute one open social system, which seeks to modify itself in relation to the changes to which it is exposed, with the intention of maintain the existence of the family on both a relational, emotional and practical level. One family member is a subsystem within a larger family system and this family system is a subsystem of an even greater system—such as a social network or society as a whole (Wright & Leahey, 2013). The study showed how the impact of the disease in daily life not only influenced the person with ESKD, but also their partner on physical, mental and social levels. Such findings are also seen in studies of being a relative to patients with other chronic diseases (Cruz, Marques, & Figueiredo, 2017; Dalteg, Benzein, Fridlund, & Malm, 2011). In our study, the partners felt the need to leave home and take a break in caregiving and benefitted from meeting and receiving support from significant others. Thus, in their everyday lives,

the partners needed their social networks and they had an impact on them.

In our findings, knowledge and skills about how to perform HD treatment and collaboration with HCPs were important to both patients and partners and provided certainty and predictability in everyday life. Hagren et al. (2005) found that patients felt a sense of vulnerability and concern in being dependent on the HCPs' knowledge and skills. In contrast, Agnholt et al. (2017) found that the relatives wished to be involved in illness and treatment process, as a significant part of the life of the sick relative. Furthermore, both studies found that long-term relationships with the HCPs provided certainty in everyday life and that it was of importance that they saw patients and relatives as individuals with unique needs and that they took their time in answering their questions (Agnholt et al., 2017; Hagren et al., 2005). These findings support the results of the current study. We found that, for both parties, knowledge and participation provided certainty and a feeling of being together as a team in illness and treatment. Furthermore, we found that the long-term relationship with the HCPs provided certainty in everyday life.

Both patients and partners were aware that illness would progress over time, which brought up feelings of uncertainty and insecurity about the future. Similarly, other studies found that patients and relatives experienced uncertainty about the future and that the uncertainty was associated with the deteriorating health of the patient (Pelletier-Hibbert & Sohi, 2001; White & Grenyer, 1999). How the patients and partners coped with and reflected on the future were expressed differently among the participants in our study. The patients were uncertain about how long they could live with ESKD and continue HD treatment. However, they were determined to take one day at a time. Nevertheless, partners were concerned about the future and made preparations for how to live alone after their partner had passed away. Patients' fear of death and worries about how HD treatment would turn out over time was also found by Hagren et al. (2001). In contrast, another study found that living with ESKD and being dependent on HD influenced their sense of hope for the future in relation to what was possible to do and dream about (Lindsay, MacGregor, & Fry, 2014). The partners' thoughts in our study about the future and their preparations for losing their sick partner are supported by Pelletier-Hibbert and Sohi (2001). They found that unpredictability about the future was stressful for relatives. They also found that thoughts about losing their sick relative caused both fear of being left alone and relief, including thoughts of a future opportunity to have a new beginning in life (Pelletier-Hibbert & Sohi, 2001). This finding supports the result of our current study about how the partners imagined a life after the disease.

Relationships with family, friends and fellow patients were a significant part of everyday life, for both patients and partners. Studies have shown that the interaction with people in their surroundings outside the home was meaningful and social networks and activities were appreciated (Agnholt et al., 2017; Hagren et al., 2001). Furthermore, it has been shown that it is important that

the social network is supportive and acknowledges the life-changing circumstances related to disease and treatment (Agnholt et al., 2017; Hagren et al., 2001, 2005). In our study, the feeling of being heard and recognized by others as a human being was important and therefore family and friends constituted an important relationship for both patients and their partners.

5.1 | Strengths and limitations

The main strength of this study is the narrative, open, in-depth individual interviews that produced rich data in relation to the perspectives of both patients and their partners in their considerations of everyday life with ESKD and lifelong HD. In total, five patients and five partners participated in the study. A sample size of 10 participants could be viewed as a limited group. However, in qualitative research, the focus is on the content of the participants' expression, rather than the number of the participants included (Kvale & Brinkmann, 2014) and in this study individual interviews of 10 participants provided a rich and nuanced data material. The results were discussed in relation to family nursing theory where attention to and involvement of the partner/spouse as a close family member explained the results. We chose to include patients living with a partner and the study showed that the relationships seemed to be supportive. A limitation is that patients living in bad relationships with unsupportive partners may simply have rejected participation. In this study, reasons for refusal were lack of time and/or energy by both patients and partners; however, there could be other reasons not expressed. Furthermore, many HD patients live alone which brings up issues not addressed in this study.

Demographic changes in the Western world will thus result in an increasing group of patients not living with a partner. Perspectives from other close family members or relatives might therefore also be relevant. It might be a limitation that only ethnic Danes participated. Perspectives from other ethnicities might have enriched the data material and provided results in a more nuanced way.

6 | CONCLUSION

The study clearly identifies that ESKD and HD treatment influence everyday life for both patients and their partners in several ways—with an impact on physical, psychological and social levels. Changes and limitations caused by the disease and time-consuming HD treatment influence daily life; however, both parties adapt themselves to the circumstances. Knowledge of and participation in disease and treatment process are important and provide a sense of certainty. Thoughts about illness progression in the future bring about feelings of being insecure and vulnerable; however, coping strategies are developed. Relationships with people in their social networks and HCPs are a significant and important part of daily life for both patients and partners and it is important to be met with understanding and support.

The results of this study indicate that, in clinical practice, it is essential that HCPs give attention to both patients' and their partners' needs. This could be achieved by initiating a family-centred care approach, where dialogue is initiated to address individual and shared needs. A family-centred care approach might furthermore include perspectives of understanding and recognizing how health-related problem in a family member with ESKD has impact on the entire family unit. Therefore, it is of great importance that the focus in clinical practice is on both the patient and their relatives, so that the entire family is supported in their everyday life with ESKD and lifelong HD.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest with respect to the research, authorship and/or publication of this article.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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