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Decisional needs in people with kidney failure, their relatives, and health professionals about end-of-life care options: a qualitative interview study.

Journal of Advanced Nursing. (accepted 17th December 2023)

Abstract

Aim: To investigate the decisional needs in Denmark of people with kidney failure, relatives, and health professionals when planning end-of-life care.

Design: A qualitative interview study.

Methods: Individual semi-structured interviews were carried out with people with kidney failure, relatives, and health professionals from November 2021 to June 2022. Malterud's systematic text condensation was used to analyse transcripts.

Results: A total of 13 patients, 10 relatives, and 12 health professionals were interviewed. Overall, four concepts were agreed on: 1) Talking about end of life is difficult, 2) Patients and relatives need more knowledge and information, 3) Health professionals need more tools and training, and 4) Experiencing busyness as a barrier to conversations about end of life.

Conclusion: People with kidney failure, relatives, and health professionals shared certain decisional needs while also having some different decisional needs about end of life care. To meet these various needs, end-of-life conversations should be systematic and organised according to the patients' needs and wishes.

Impact: Non-systematic end-of-life care decision-making processes limit patients' involvement. Patients and relatives need more knowledge about end-of-life care, and health professionals need more competences and time to discuss decisional needs. A shared decision making intervention for people with kidney failure when making end-of-life care decisions will be developed.

Reporting Method: This empirical qualitative research is reported according to the Consolidated Criteria for Reporting Qualitative Research checklist.

Patient or Public Contribution: Patients, relatives, and health professionals have been involved throughout the research process as part of the research team and advisory board. The patients are people with kidney failure and the relatives are relatives of a person with kidney failure. For this study, the advisory board has particularly contributed to the validation of the invitation letter for participation, the interview guides, and the preparation of the manuscript.

Keywords: Complex interventions, Decisional needs, End-of-life care, Involvement, Kidney care, Kidney disease, Shared decision making

What does this paper contribute to the wider global clinical community?

- Decisional needs regarding end-of-life care have not previously been investigated simultaneously within all the stakeholder groups of people with kidney failure, relatives of people with kidney failure, and health professionals in kidney services. Thus, the research contributes new knowledge by being the first to explore these groups together.
- Patients and relatives expressed the need for more knowledge and information. Health professionals in kidney services should support patients and relatives in obtaining more knowledge about the health trajectory of kidney failure.
- Lack of tools and training supporting health professionals to provide shared decision making conversations around end-of-life care to patients and relatives may leave the health professionals feeling inadequate in relation to their professional role. Health professionals should be provided with appropriate tools and training accordingly.

Introduction

Kidney failure (KF) is a life-threatening disease potentially causing many complications and a heavy burden from accompanying symptoms likely to emerge throughout the disease trajectory (1). An increasing number of frail elderly people with KF (PwKF) raises the need for improved care pathways towards end of life (EoL) (2). However, there is evidence that the palliative care needs of PwKF are not met as they progress towards EoL (3). Indeed, they may die without having shared their wishes about end-of-life care (EoLC) and advance care planning (ACP) with their relatives or health professionals (HPs) (4). Studies show a lack of communication between PwKF and HPs about EoLC (3, 5). It has been suggested that the reason for this is HPs thinking that patients do not want or need such information (6). Some relatives find it burdensome to not know what a patient's wishes are for their care and treatment when they are nearing EoL, especially if they are cognitively unable to express such wishes. Talking about EoL issues can be a barrier for families and the issue may therefore not be addressed in a timely fashion (7). However, a timely fashion refers to that talking about EoL could both be too early and too late. HPs might assist patients and relatives in addressing issues to support families in planning EoLC for patients. However, HPs may encounter difficulties in discussing these issues during consultations, perhaps because they do not want to upset or alarm patients and/or their relatives with such a hard topic (8).

Background

Planning EoLC in advance helps to ensure that patients and their relatives have had the opportunity to express their preferences about EoL as well as decreasing the burden on relatives when a patient is cognitively unable to take part in the decision-making process. Sudore et al. define ACP as a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care (9). In this study, the focus on ACP is in relation to KF and thereby the decisions needs to be made in a hospital setting. ACP is used in hospital settings and in several models of care for example in kidney supportive care clinics or in kidney palliative care clinics (10). However, our focus was not on developing or implementing a model of care but to develop an intervention, which can be used in different models of care. When having these discussions in an environment where patients and relatives can share their needs for EoLC and plan for the future, shared decision making (SDM) conversations can be beneficial. Discussing EoLC in advance with PwKF may improve SDM. A Cochrane review from 2018 defined SDM as an interpersonal, interdependent process in which HPs, patients, and their relatives relate to and influence each other, as they collaborate in making decisions about a patient's health (11). SDM consultations can create an environment for patients and relatives where the risks, and benefits, of different care and treatment options can be discussed with consideration for patients' preferences and values (11). In Denmark, SDM interventions are an integral part of care when choosing a treatment modality for patients with chronic kidney disease (12). When planning EoLC, however, we still need to know the decisional needs and experiences of involvement in the decision-making process of PwKF, their relatives, and HPs.

The study

Aim

To investigate the decisional needs in Denmark of PwKF, relatives, and HPs when planning EoLC. Findings will inform the development of a complex intervention for integration within kidney services to support SDM for EoLC.

Research question

What are the experiences of involvement in EoLC decision making among PwKF, their relatives, and HPs, and what decisional needs do they have?

Methods/Methodology

This study is a part of a PhD project to develop and test the feasibility of an intervention to support SDM between PwKF, relatives, and HPs when planning EoLC. To design the study process, we used the UK Medical Research Council (MRC) complex intervention development and evaluation research framework for interventions involving several components and impacting on different stakeholders (13), and the Making Informed Decisions Individually and Together (MIND-IT) (14) theoretical framework to support multiple decision-makers in healthcare making the same decision. Thus, the process included a scoping review of the literature, interviews, co-design of the intervention, and feasibility testing of the intervention.

A detailed description of the overall study design and methods has already been reported in a published *a priori* protocol paper (15).

Design

We conducted a qualitative study as recommended for complex interventions in the development phase (16) based on semi-structured interviews with PwKF, relatives of PwKF, and HPs in kidney services in Denmark.

The participants were selected consecutively for the interviews using purposeful sampling methods focusing on selecting participants consistent with the aim and purpose of the research and attaining variation within the target population. Female and male participants from different age groups were included. During the interview process, we evaluated whether there was sufficient participant variation.

Theoretical framework

The theoretical frameworks supporting the different parts of this interview research were based on an interaction between using a hermeneutic approach guided by Gadamer's philosophy (16) or a phenomenological approach guided by Malterud's systematic text condensation based on Amedeo Giorgi's psychological phenomenological analysis (17). Table 1 shows this interaction approach.

Table 1. The study's interaction between using either a hermeneutic or a phenomenological approach

	Aim	Interview guide	Interviews	Findings	Discussion	Recommendations for further Research
Hermeneutic approach	Investigate decisional needs	Focused on eliciting evidence about patients' and relatives' decisional needs	Active listening		MIND-IT	Identifying which components are needed to address the findings
Phenomeno-logical approach			Mirroring	Systematic text condensation		

The Ottawa Decision Support Framework (ODSF) (18), which provides an explanation of decisional needs, was used to focus the interview guide questions on exploring relevant EoLC decisional needs.

The theoretical framework MIND-IT by Bekker (14) guided the structuring of the exploration of the decisional needs of the multiple stakeholders included in the interview study.

Study setting

Two large university hospitals in Denmark and two regional hospitals with satellite haemodialysis units were the setting for the study.

Recruitment of patient-participants

People with KF on haemodialysis, peritoneal dialysis, or conservative kidney management were considered for participation. Patients were included using a clinical provider-initiated indicator, the surprise question (SQ): "Would you be surprised if this patient died in the next 12 months?" (19). The HPs answered the question on a 5-point Likert scale ("definitely not surprised", "not surprised", "neutral", "surprised", or "very surprised"). If the HPs answered either "definitely not surprised" or "not surprised", the patient was eligible for inclusion. Patient-participants in the interview research were recruited through the two large university hospitals and the two regional hospitals. A clinical staff member who knew the patients well was asked to approach them face-to-face, inform them about the project, and provide them with an invitation letter. All patient-participants were asked to give written consent prior to the interviews. All patients who were approached agreed to participate, none dropped out of the study.

Recruitment of relative-participants

Relatives of PwKF were considered for participation. We have chosen the term 'relatives' being well aware that this refers to people being connected by blood or marriage but we use the term in a broader scope so this also covers the terms 'next of kin' or 'informal caregiver'. The Danish Kidney Association recruited eligible relatives by contacting them, explaining the project, and sending them an invitation letter by email. If they consented to participate, they were contacted by the first author and asked where and when they were able to meet for the interview. All relative-participants were asked to give written consent prior to the interviews. Of the relatives asked, three declined to participate as the interview was too close to the recent death of their relative, and they were not ready to talk about EoLC. Relative-participants were individuals who were not related to the patient-participants in all but two cases.

Recruitment of health professional-participants

HP-participants were recruited via the lead staff in the participating nephrology units, who approached the HPs, explained the project to them, and provided them with an invitation letter asking them to participate. If they agreed to take part, the first author contacted them to ask where and when they would prefer the interview to take place. All HP-participants were asked to give written consent prior to the interviews. All the HPs who were asked to participate agreed to be interviewed. We have chosen only to recruit nephrologists and nurses because in the four settings they are the only HPs having these conversations with PwKF.

Inclusion and/or exclusion criteria

All patient-participants had to be diagnosed with KF, ≥18 years old, able to speak and read Danish, and at a point in their illness trajectory where EoLC might be considered. Patients were excluded if they were considered cognitively unable to participate in the interview. Relative-participants had to be ≥18 years old, able to speak and read Danish, and experienced in the role of being a relative during the patient's health consultations. Participating HPs had to be employees at one of the involved nephrology units and have a minimum of two years' experience within kidney services.

Data collection

The first author conducted individual semi-structured interviews between November 2021 and June 2022. The interview guides were prepared according to the guidance from Kvale and Brinkmann (20), and based on the Patient Experience of Shared Decision Making (SHARED) instrument (21), which measures patient-reported SDM. The frameworks for preparing the interview guides were the ODSF (18) and MIND-IT by Bekker (14). These frameworks helped identify the components and areas to investigate when making decisions about the methods and designing materials such as the interview guides. The interview guides are presented in the supporting information.

The interview guides were pilot tested as part of the interview process. The pilot interviews were included in the research as the interview questions were semi-structured and were refined throughout the piloting process. These interviews were included because they could be of just as much value to the research outcomes as the interviews conducted after the piloting process. The purpose of the questions in the interview guide was to get the patients and the relatives to talk about their decisional needs in EoLC planning and decision making when the patients' health deteriorates, and to get the HPs talking about their needs and experiences related to EoLC planning and the involvement of patients and relatives in the decision making process when the patients' health deteriorates.

The participants decided on their preferred setting for the interview and whether they wanted a relative present during the interview. Data were collected either in the participants' homes or at the hospital.

The communication skills of mirroring and active listening were used during interview sessions. Mirroring was used to bring the participants' decisional needs to the foreground. Active listening, with the interviewer retelling the participants' story, allowed the participants to adjust their story if needed. Before the end of each interview, the interviewer gave a summary of the participant's story to enable them to agree with or make corrections to the interviewer's perception of what had been said. Each interview was scheduled to take one hour. As data saturation is not a goal for Malterud (17), interviews were conducted only with the number of participants recommended by the theory of information power (22). The first author produced transcripts of the interviews.

Data analysis

We used systematic text condensation, as described by Malterud, for data analysis (17). The strategy is based on Amedeo Giorgi's psychological phenomenological analysis, which is also used in decision making. Data were coded and analysed according to the four stages of systematic text condensation using the software program NVivo (QSR International, United Kingdom): 1) Total impression – from chaos to themes, 2) Identifying and sorting meaning units – from themes to codes, 3) Condensation – from code to meaning, and 4) Synthesizing – from condensation to descriptions and concepts (17). Two of the authors (AK and JBK) conducted data analyses with supervision from the first, third, and last author.

Stage 1. From chaos to themes

Naïve reading of all transcribed interviews was carried out as a first stage of the analysis, looking for overall patterns. Transcripts for one study group at a time were read, and AK and JBK subsequently discussed which themes immediately stood out for the given participant group. Next, five preliminary themes were agreed on for each participant group. Both researchers read all 35 transcripts to appreciate both perspectives on the stories and to validate each other's understanding of the empirical data.

Stage 2. From themes to codes

Following the naïve reading, AK and JBK immersed themselves in each individual interview. In this second stage, the 35 interviews were distributed equally between them, so that they both analysed interviews from patients, relatives, and HPs. Because the available version of NVivo did not make it possible for AK and JBK to work on the same participant groups at the same time, stage two of the data analysis was carried out for all three participant groups in parallel. The individual interviews were read thoroughly sentence-by-sentence. Meaningful units were identified, marked, and organised into codes. AK and JBK started by coding three interviews. This process was repeated to ensure that neither too many nor too few pieces of text were coded. The individual codes were reassessed continually, e.g., when a new meaningful unit was encountered, which ensured a continuous overview of the many interviews. When new codes were added, already coded interviews were reviewed again to include any meaningful units for the new code in the analysis.

Stage 3. From code to meaning

In the third stage, AK and JBK were critical of the individual codes and their content, and codes with very few meaningful units were removed. Sub-codes for codes with many meaningful units were created. This was executed collaboratively. When the final codes were created and all meaningful units organised into the correct codes, one to two short sentences about the content of the piece of text were produced as a summary for each of the individual meaningful units, e.g., the phrase "I want to know how I'm going to die" was based on the quote:

"Anyone might likely want to know how it [death] would happen." (Patient 3)

Stage 4. From condensation to descriptions and concepts

In the fourth stage, a short overall description of the main points of the individual codes was created based on the short sentences from stage three, ensuring that all the informants' statements within the individual code were represented in this one common description. To obtain analytical agreement and to validate each other’s work, this process was carried out in collaboration. Finally, the codes were gathered into a number of categories and subcategories.

Ethical considerations

Before they gave their consent to participate, participants were provided with verbal and written information emphasising the voluntary nature of their participation, right to withdraw, intended use of quotations, and confidentiality. Interviews about sensitive areas such as EoL should be conducted with care. However, interviewees may also experience positive outputs from such conversations. To accommodate the distress the interviews might have evoked in the interviewees, the interviewer stayed and listened to each participant for as long as necessary and offered them the opportunity to telephone the interviewer later if needed. This project was conducted in accordance with the ethical principles for medical research involving human subjects (23) by obtaining verbal and written consent. According to Danish legislation, interview research is exempted from further ethical approval. The authors were granted approval for data management by the Danish Data Protection Agency (jr. 1-16-02-243-21).

Rigor and reflexivity

Thoroughness of data analysis was achieved by ensuring that the four stages of systematic text condensation were properly followed. Furthermore, the authors AK and JBK collaborated closely on analysing the data with supervision from the first, third, and last author. To maintain a reflexive stance, AK, JBK, the first, third, and last author met regularly throughout the data analysis phase to discuss findings and interpretations. Each analysis step was documented in NVivo to ensure the transparency and integrity of the research.

Findings

Characteristics of participants

Thirteen PwKF were interviewed (Table 2), more than half being women (n=8). Five were 80 years old or over, with only one being in the age group 60-69 years, and none below 50. Most PwKF were being treated with haemodialysis (n=9).

Ten relatives were interviewed. The majority were women (n=8). Most were between 60- and 69 years old (n=4). Six were relatives of PwKF who were still alive, and four were relatives of deceased PwKF.

Twelve HPs were interviewed, with most being women (n=10). There were nine nurses and three nephrology physicians with ages ranging from below 50 to 69 years. Nine were employed at the university hospitals and three in one of the two satellite units.

Table 2. Characteristics of interview participants

	Patients	Relatives	HPs
Gender			
Female	8	8	10
Male	5	2	2
Age (years)			
Below 50	0	0	4
50 - 59	3	2	4
60 - 69	1	4	4
70 - 79	4	3	0
Over 80	5	1	0
Treatment modality			
HD	9	N/A	N/A
PD	2	N/A	N/A
CKM	2	N/A	N/A
Profession			
Nurse	N/A	N/A	9
Nephrology consultant	N/A	N/A	3

HPs = Health professionals; HD = Haemodialysis; N/A = Not applicable; PD = Peritoneal dialysis; CKM = Conservative kidney management

Systematic text condensation analysis

The findings of the systematic text condensation analysis were formulated as four concepts: *Talking about end of life is difficult; Patients and relatives need more knowledge and information; Health professionals need more tools and training; Experiencing busyness as a barrier to conversations about end of life.* These concepts are illustrated in the text with representative quotations from the interviews.

Talking about end of life is difficult

Being reminded of death and dying can provoke thoughts about people's passing and an urge to focus on life rather than EoL. Patients had different experiences of discussing EoL issues and different wishes for thinking and talking about EoL. Ten patients had not thought about EoL and six did not want to talk about it. This was a conscious choice, either because they did not see it as relevant yet or because they generally focused more on the present. Five expressed that they were clear about their situation and wanted to talk about EoL with relatives or HPs. Four stated that they did not think about EoL, after which they described their thoughts about EoL:

"Well, I have not really thought about it, because I know very well that the last sell-by date is near. I have always said that if I have to spend the last years of my life on dialysis, I will quit because I am fine as it is now." (Patient 12)

Being a close relative of a person with a chronic disease such as KF means that you may be engaged in most of what evolves around managing the disease together with the person with KF. This does not necessarily mean that relatives feel involved in obtaining information about the disease from e.g. the HPs, and if they are, they may not always agree with the patient or the HPs about EoLC decisions. The narratives revealed that some relatives were ready to talk about EoLC planning earlier than the person with KF. The relatives also had different experiences of and wishes for talking about the patients' EoLC. Some related that either they or the patient did not want to talk or think about EoL. Others explained that they had had good conversations with either the patient or the HPs about EoLC. These conversations, however, were often very difficult to have, because death was experienced as a tangible and sensitive subject that not everyone felt comfortable to talk about. A wife described feeling thankful for having crossed the boundary of talking about EoLC with the patient and HPs:

"Yes, it was a relief, really a relief, and I became strong, you see. Are you crazy? I am so happy today that I accepted it, and, you see, it ended by us planning everything, right? (…) And it really was an enormous strength to be able to say it, because I dared to face it. I knew I could bear it; I knew I could follow him, which I would not have been able to on my own, because it terrified me when we started, right?" (Relative 1)

For some of the relatives, a contributing reason for not talking about EoL was that they themselves, the patient, or both, more or less consciously chose not to deal with death and the time leading up to it, instead focusing on living in the present. One expressed that the patient "lives here and now and no longer" and that it was difficult for her because, as a relative, she needed to know his wishes for EoLC. Otherwise, it would be her responsibility to decide what was going to happen. In contrast, five other relatives expressed that they did not want to deal with death themselves, either because they believed that they could not plan for the future anyway and would therefore rather take things as they came, or because they focused on the practical matters that could be handled here and now. One relative who did not want to think about EoL nevertheless faced up to it because the patient wished to do so. She said:

"But I also want to say, when it came down to it, he was more open than I was, but he was also the one who was ill. He realised very quickly that this, it had an end date, and he wanted us to talk about it, and I could not at first." (Relative 1)

Most HPs regarded supporting patients and relatives in EoLC conversations and decision making as part of their professional role. However, the HPs found that it was very difficult to talk about EoL with the patients. One HP reflected:

"Then of course you see there is this whole thing that talking about death is difficult. I do not always find it easy." (HP 4)

This was due to personal barriers, as well as the fear of scaring or upsetting patients and relatives, and experiences of patients and relatives not wanting to talk about EoL. Eight HPs stated that personal barriers were a contributory or direct reason for them not taking the initiative to talk with patients about EoL. They described having to address topics around EoL as "a hurdle" or "crossing a line". They pointed out that it could be stressful to know that you had to bring up the subject with a patient, and they had experiences where some colleagues definitely "feared" having to talk about EoL. One HP said:

"Sometimes I think that the barrier in fact has been a bit within myself perhaps sometimes, in relation to getting a handle on it." (HP 9)

They also expressed the views that the subject of EoL was culturally taboo, and that there was a need for a cultural change within nephrology, and among HPs in general, as well as among patients. Most of the HPs explained that there was a great focus on treatment and too little focus on quality of life both within their own standard practice and in their department. Some narratives pointed out that the focus was on "optimal treatment" or "effective dialysis", and the HPs stated that this was one of the things where most of their efforts were directed:

"It is very much about keeping our patients alive. We tend to forget that they should also live. So, it [healthcare] becomes very treatment oriented." (HP 1)

As well as HPs, patients, and relatives described EoL as a taboo and sensitive subject. Narratives from all three participant groups described finding it difficult to talk about. This was a barrier to carrying out EoLC conversations, thereby hindering patients' involvement in EoLC decision making. At the same time, the study showed that not all patients and relatives wanted to think or talk about EoL issues.

Patients and relatives need more knowledge and information

Patient interviewees expressed a need for patients to be informed and gain knowledge about their own possible disease trajectory, treatment, and future prospects as a person with KF whose health might deteriorate. Some would just need knowledge, while others, who had unrealistic expectations, would need further explanation and reasoning from the HPs. Nine patients expressed that they lacked knowledge about KF in general, about their own disease status, or about the future with KF. One described lacking knowledge about what KF is and "how bad it is". Another explained that they needed more knowledge about "what happens in my body". Six patients mentioned that they lacked knowledge or had received misleading information about what to expect from their treatment:

"I expected that when you then had dialysis, well then you were fit and ready for all the rest. I have realised that it is not like that, partly from stories, but I also feel myself that you are more and more affected." (Patient 4)

Three patients described experiences of a lack of connection between what the HPs said and what happened. One patient said:

"They [HPs] only tell you that all is fine; and then, the next day, you are admitted." (Patient 3)

Another described how HPs told him that his blood tests "were fine", but that he still did not experience "getting better", indicating both a need for more explanation and inconsistency between what was being said and what happened. At the same time, two of the patients stated that they felt that HPs withheld information and that they wished the HPs themselves would take more initiative in providing information. One patient felt that the HPs either withheld information or knew too little:

"I find that the HPs I ask about something know too little... Either they do not say anything, or they do not know anything." (Patient 3)

Relatives emphasised the importance of feeling heard and seen, being involved in the decision-making process, knowing the patient's wishes, and receiving adequate information from the HPs. In addition, it was important to them that the patient's wishes for EoLC were followed, and they felt a great responsibility in relation to ensuring this. Just over half of the relatives felt that their and the patient's wishes for EoLC were followed by the HPs. Various patient wishes were mentioned, such as treatment modality, opting out of resuscitation or amputation, stopping dialysis, and dying at home or in a hospice. Relatives placed particular emphasis on the importance of the HPs respecting the patient's wishes for EoLC and helping to fulfil them:

"At that time it had been decided that he should not have more treatment, I mean more dialysis and (…) and it just should be... He had decided that he wanted to die, and then the consultant said ‘Well, you can also, X [patient], [stop having more treatment], but it should take place properly.’” (Relative 6)

Some relatives had experienced speaking to HPs about EoLC on behalf of a patient, often on their own or the patient's initiative. They found it positive to have talked to the HPs about this and felt that it contributed to the patient's EoLC wishes being followed. One of the relatives described how a doctor had spoken to the patient about what had happened recently:

"Well, he [the doctor] sat down on the bed and talked to X [patient] almost like face-to-face and things like that, and he looks...’Do you understand this, X [patient]? And do you understand this, X [relative]?’ So he had time for that, didn’t he?” (Relative 8)

It meant a lot to the relatives that the HPs had spoken to them about what EoLC entailed in a way where the HP was at eye level and where the patient and the relative understood the information.

Patients, relatives, and HPs all confirmed that a lack of knowledge and skills limited patient involvement in EoLC decision making. They also mentioned that the patients in particular lacked knowledge about their own disease status, treatment options, and future prospects. Patients and relatives expressed a need for more information, and fear caused by insufficient knowledge.

Health professionals need more tools and training

HPs voiced the need for more tools and training to help them articulate the necessary information and involve patients and relatives in EoLC conversations and decision making. They felt that EoLC conversations made great demands on both their professional and personal skills, and that they needed more skills and practical tools to deal with any lack of knowledge or disagreement between patients and relatives.

Eight HPs described feeling poorly prepared for the task, and their education having failed to fully equip them for what was necessary:

"We simply need someone who can provide us with tools for this task. We need some education, some kind of training.” (HP 6)

Seven HPs specifically stated that they lacked practical tools in the form of a guide or questionnaire for use in EoLC conversations, and that it could be helpful if the patients were given a pamphlet or other informational material to prepare for such a conversation. Four others highlighted that they lacked "language for" this difficult conversation and that they needed some "phrases" or "questions" to support them in it:

"It can be nice to have such questions or phrases that you can use. You really think about how to put it and how to get the conversation started.” (HP 12)

Half of the HPs also felt that talking about EoL made great demands on their personal skills, energy, and courage. Many did not have the necessary energy:

"A certain amount of tiredness arises, I think, and during the years as a HP, you do not always have the energy to handle those things." (HP 3)

Several patients and relatives pointed out that the HPs’ skills were crucial when conducting EoLC conversations with the patients and their relatives. They described the importance of HPs being trained to talk about EoL if it did not come naturally to them, and they experienced it as problematic when HPs lacked the skills to talk to the patient about EoLC. One relative said:

"There were also different cultures in the kidney department, right? (….) and that perhaps was something that should be addressed within the group of HPs working in such a department. That we need to be able to talk with patients about death, we have to respect the individual patient's perspectives on death and EoL, and that, I think, was a problem.” (Relative 1)

In addition, half of the relatives mentioned the importance of the HPs being good at communicating in clear and succinct language for the patient and relatives to understand the information. One emphasised in particular the HPs being able to consider the patient’s and relatives’ culture and language during the conversation:

"I find it very, very important to realise that not always the same language is spoken, and it is awfully important to ensure a completely accurate communication, and that there, despite barriers of language and culture and what not, is a complete understanding.” (Relative 2)

Similarly, other relatives pointed out the importance of the HPs having the ability to "read the situation" by, for example, being able to interpret the EoLC needs of the patient and the relative and, at the same time, create a safe dialogue based on these needs.

HPs described EoL conversations as particularly difficult when the patient and relatives had unrealistic expectations for the future or when they disagreed about future treatment. The HPs expressed a need for more skills and helpful tools to articulate the subject and to deal with a lack of knowledge or disagreement between patients and relatives. In these situations, they could feel "squeezed" between two understandable but contrasting views:

"It is kind of difficult, because if they disagree a lot and are very far from each other, it really can become quite enervating sitting with them." (HP 12)

All participant groups shared the view that HPs needed more skills to conduct difficult conversations. Patients and relatives in particular highlighted the importance of HPs being able to communicate and pass on information in a clear and comprehensible way.

Experiencing busyness as a barrier to conversations about end of life

Patient-participants described a noticeable lack of time among HPs as a barrier to patients in terms of feeling comfortable initiate EoL conversations. They need more time for EoL conversations:

"They do not have time for that here, you see... It is in through the door and out again and they rush around due to lack of staff and there is no time for it, is there, when more and more patients are coming." (Patient 5)

"But there are many times as well when they [HPs] are stressed, and I am holding back my thoughts about something, where I do not get to express them [thoughts]. They [HPs] do not have time to listen, and then sometimes I become frustrated because I cannot get it off my chest [thoughts]." (Patient 6)

At the same time, just under half of the patients emphasised the importance of having good communication with HPs, and expressed a need for EoLC conversations to be conducted with HPs whom they knew and who had the skills to talk about EoL.

The structure of the EoLC conversation with the HPs was an important factor for the relatives. They particularly emphasised the importance of having time for the EoLC conversation, and that a lack of time and communication skills was a barrier to having conversations about wishes for EoLC and treatment. Thus, the relatives experienced the busyness of the HPs as a barrier to the conversation:

"Having time to ask and things like that, right, (…) but they must hurry on, you see. (...) It is all about the time, it is like sometimes you just feel: 'Well, yes, okay, that had to be over as quick as lightning', and then out the door again." (Relative 8)

Seven relatives had experienced HPs wanting EoLC conversations to be conducted rapidly, and a lack of time to ask important and sometimes difficult questions. This applied both to planned consultations with the HPs, where a fixed time frame could be frustrating for some relatives, and to spontaneous EoL conversations.

HPs pointed out that EoLC conversations require time and a private space, and that it could be difficult to find the extra time needed in a busy kidney department that is responsible for fulfilling various different healthcare functions:

“There must be time set aside for that. It is not just something I handle in five minutes, and it must be scheduled time.” (HP 11)

Some HPs indicated that they had previously avoided or forgotten to have conversations with patients about their wishes for EoLC due to busyness. It was often the case that neither the nephrology consultant, the nurse, nor the patient had time for this conversation:

"And for me, it is very much about lacking time and space. So, there are things [tasks] that we do neglect, because we do not have time.” (HP 1)

One participant also acknowledges that patients' opportunities to ask for or start EoLC conversations on their own initiative were limited by HPs' busyness and the fact that many consultations had a short time frame:

"Often, it turns out, you see, that they themselves are thinking a lot about it, and maybe have not dared to ask, or have not asked because time is running short when we see them [at the hospital]." (HP 9)

Another experience related to time, pointed out by several HPs, was that patients being treated with in-centre haemodialysis did not want to stay at the hospital for any longer than they already had to. Thus, the patients wished for the conversations to be held during dialysis treatment. According to the HPs, however, this would present several practical and organisational challenges, requiring the relevant HPs to have both time and an available room for the conversation during the patient's dialysis treatment. Six HPs had the specific perspective that EoLC conversations should be conducted in a private space, which required prior planning to ensure the patient would have a single-bed room on that day, as dialysis treatment often takes place on a multi-bed ward:

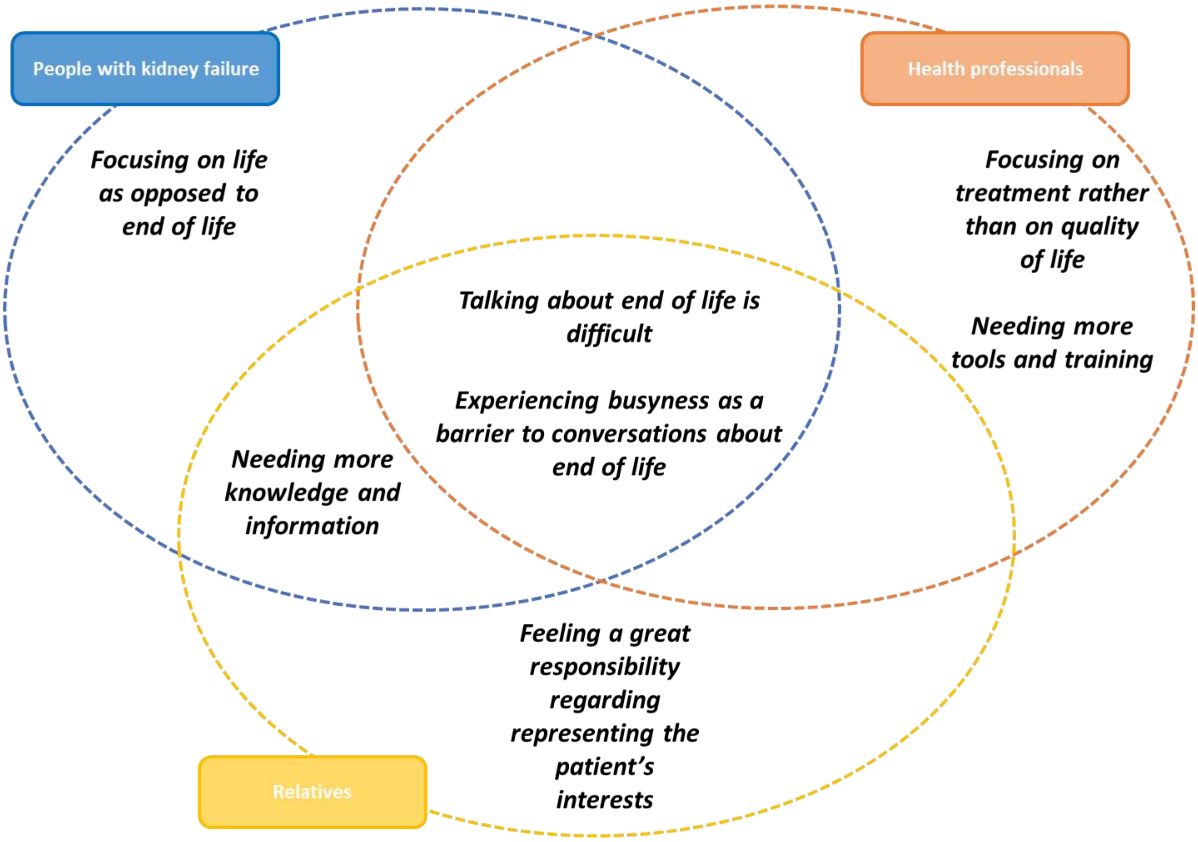
"You should plan for this patient to be in a side room, so they are there on their own, not having anyone by the side who can listen (…) And sometimes, the number of beds is simply challenging, and beds are simply occupied.” (HP 4)

Patients and relatives, as well as the HPs, agreed that busyness among HPs constituted a barrier to having EoLC conversations. Patients and relatives pointed out that the HPs were generally busy, that consultations often went very rapidly, and that they experienced a lack of time as a contributing factor to them not being able to talk about EoLC. The HPs described a similar picture and emphasised that they often prioritised other tasks over conversations about patients' wishes for EoLC.

Discussion

This qualitative study of 35 interviews with PwKF, relatives, and HPs is the first to our knowledge to investigate decisional needs about EoLC within all three stakeholder groups at the same time. These findings will inform the development of a complex intervention to support SDM between PwKF, their relatives, and HPs about EoLC in Danish kidney services. Adopting MIND-IT (14), a multiple decision-maker theoretical framework, as part of the complex intervention methodological process (13) helped identify similarities in needs across different stakeholder groups but also differences in the needs of different stakeholders (see Figure 1). Identifying PwKF's decisional needs about EoLC is key not only to being able to support them but also to meeting the different needs of the other stakeholders.

Figure 1. Findings derived from analyses of interviews categorised by stakeholder group



The findings align with previous qualitative study results on the experiences and needs of patients with either chronic kidney disease or KF, relatives, or HPs obtained by other researchers (2, 24-28).

Studies have shown that PwKF and their relatives perceive EoL as a taboo subject that is hard to talk about (2, 24). However, studies have also shown that it is important for PwKF to feel prepared and plan ahead in case of death (5). At the same time, a study that examined patients' and relatives' perspectives on ACP found that not everyone wants to talk about EoL (24). We found similar results in our study, with a particularly large number of patients confirming that they did not want to think or talk about EoL at all, and the topic being described as extremely hard to talk about. Similar results have been found in studies of HPs caring for and treating PwKF (25, 29-31), emphasising that HPs found EoLC conversations difficult because they were afraid of upsetting the patients (25, 30, 31) or making them feel that the HPs had given up on them (25, 30). Studies have also described HPs finding it difficult to let go if a patient did not want more treatment (29, 31). The same picture emerged in our study, as it showed that HPs experienced EoLC conversations as difficult because they were used to focusing on treatment rather than on quality of life, and because it could be difficult to accept that patients were opting out of treatment.

Our findings revealed that it is difficult for PwKF, relatives, and HPs to be open and talk about EoL. This finding can be explained by the MIND-IT framework (14) showing that the different stakeholders are influenced by their individual socio-cultural backgrounds and may need to exchange experiences in an SDM communication context to be able to make informed decisions together, based on reasoning about their own preferences. When making difficult EoLC decisions, people often rely on others' support (32), which underpins the importance of communication-skills training for HPs when developing a complex intervention to support SDM about EoLC.

Data also showed that patients and relatives need more knowledge and information on what may happen if the patient's health deteriorates, about the disease, treatment, and prognosis, and about what may be relevant to discuss regarding EoLC in terms of what options the patient has and the potential harms and benefits of each option. These findings are observed in other studies, which concluded that patients lack knowledge about their disease and prognosis (2, 25, 33) and are not always aware of how close they are to death (24). In addition, studies from Australia and the UK have shown that patients experienced HPs withholding information about the status of their disease, e.g. so as not to take hope away from them (24, 33), which supports the finding that patients lack knowledge. A similar picture emerged in our study, where patients and relatives as well as HPs felt that a lack of patient knowledge around the possible disease trajectory for a person with KF was a real problem, among other things because HPs in some cases deliberately avoided divulging all the information.

One of the elements of the MIND-IT framework on which individuals base their reasoning is knowledge. A Cochrane review from 2017 including 105 randomised controlled studies (34) assessed the effects of patient decision aids (PtDAs) on people making decisions in healthcare. It found that using PtDAs to support people in making healthcare decisions improved the participants’ knowledge. The findings of our study and the Cochrane review confirm the need to develop a PtDA for PwKF, relatives, and HPs to support EoLC decision making.

Our findings show that HPs need more tools and training to feel prepared for planning and making health care decisions together with patients and relatives. Several studies support this by highlighting the importance of HPs having the right skills to be able to communicate in clear and easily understandable language and give the right information to patients and relatives (2, 26, 30, 33). Similar experiences became evident in our study, where all stakeholder groups described HPs lacking the skills to be able to communicate about EoLC, and communication about EoLC between patients, relatives, and HPs often resulting in misconceptions. This finding emphasises that a training programme for HPs may be an important component of an EoLC SDM intervention to support HPs in feeling prepared to have EoLC decision-making conversations with PwKF and relatives.

The study also found that busyness was experienced as a barrier to EoL conversations. Patients and relatives expressed a need for time and an appropriate room to discuss and make decisions about EoLC. Selman et al. (33) showed that PwKF appreciate HPs having time to talk about EoL. At the same time, studies have shown that HPs do not always feel that they have time for these conversations (30, 31). The same picture emerged in our study, where all stakeholder groups expressed busyness among HPs as a barrier to EoL conversations. Busyness was a barrier to conversations being initiated, to patients and relatives being able to ask about the things they wanted to ask about, and to HPs having capacity to talk about difficult topics such as EoL. Knowledge in this field in a Danish context is very sparse, and no relevant Danish studies were identified in our literature search. Since then, however, a new Danish cross-sectional study has been published (35), which describes an investigation of HPs' knowledge and attitudes regarding the use of ACP in patients with chronic kidney disease. The study found that 66% of participating HPs lacked access to material on how ACP can be used, and that 46% conducted EoL conversations sporadically. The HPs also described lacking time, experience, and procedures, and confirmed that these deficiencies constituted barriers to the systematic use of ACP.

Strengths and Limitations

Prior to this study, we carried out a systematic literature search, and concluded that this area had not previously been investigated in a Danish context. A strength of this research is its contribution to new knowledge, emphasising the relevance of this subject. Furthermore, none of the studies included in the literature search examined all three stakeholder groups at the same time, so our study also contributed with a new aspect in an international context. A recent Danish study by Kurita et al. (36) looking at the impact of caring on caregivers of patients with life-threatening organ failure, including caregivers of PwKF, found that relatives of PwKF had the highest care burden compared to caregivers of patients with either cystic fibrosis or intestinal failure. Stress communication among PwKF and their caregivers was shown to be similar to patients with advanced cancer and their caregivers, and the study indicated that relatives of PwKF spend many hours every day caring for the person with KF (36). This may emphasise the importance of considering the experiences of the relatives of PwKF in EoLC decision making. Another strength of this research is that the results are contributing to the development of an SDM intervention for PwKF, their relatives, and HPs, aiming to support the different stakeholders in EoLC decision making. A few limitations must be acknowledged. First, the experiences reported by the participants in our study refer to a specific country and therefore the results may be transferable only to other countries with a similar population and healthcare system. Second, the patient- and HP-participants were all from two of the five Danish regions, and the relative-participants represented four of the five regions, leaving experiences in some Danish regions unrepresented. However, these regions were represented by the university hospitals covering a wide range of Danish PwKF and HPs in kidney services and therefore we believe this did not hamper the richness of the data. One limitation however, is that the HPs in this study only represent nephrologists and nurses.

Recommendations for Further Research

In order to ensure that all PwKF, their relatives, and HPs are involved in EoLC decision making, an intervention can be developed to assure that EoL conversations and decision-making processes are conducted systematically with the aim of meeting the needs of PwKF, relatives, and HPs in kidney services. The intervention can focus on meeting HPs' need for practical tools to articulate EoL, and patients' and relatives' need for more knowledge. At the same time, the intervention can focus on supporting patients' individual health competence to create greater equality in the outcomes of EoL conversations, thereby contributing to more equal opportunities for patient involvement. The intervention should clarify where, when, and how the dialogue is to be held. Ideally, it should include practical decision support tools and PtDAs and be based on existing ACP methods. The intervention can also be inspired by the way in which SDM is currently used for dialysis modality decision making in some Danish hospitals (12). This could contribute relevant tools that may be used to make decisions about, for example, EoLC. The implication of these research findings for the design of a complex intervention to support SDM for EoLC decision making in Danish kidney services is the need to include components such as a training programme for HPs and a PtDA (see Table 3).

Table 3. Findings of the interview research and components needed to address the findings

Findings	**How to address**
Focusing on life as opposed to end of life	SDM conversations including a PtDA focusing on important things in the patient's life and what affects them
Needing more knowledge and information	SDM conversations including a PtDA
Feeling a great responsibility regarding representing the patient's interests	SDM conversation
Focusing on treatment rather than on quality of life	A focus on quality of life in the PtDA
Needing more tools and training	PtDA as a tool for HPs in SDM conversations and a training programme for HPs
Talking about end of life is difficult	SDM conversations
Experiencing busyness as a barrier to conversations about end of life	Time and a room for SDM conversations

Implications for policy and practice

Our study supports existing knowledge in the area and contributes to an understanding that experiences and needs in connection with EoL coincide across different western countries. In Denmark, there are no guidelines in kidney services for when and how EoLC conversations may be conducted between PwKF, relatives, and HPs. The findings of this research may contribute information on this so that the responsibility for organising such conversations is not left to the patients and/or relatives themselves. The results of this study may inform clinical practices on how to support systematic conversations about EoLC for PwKF and other patient groups according to their needs. This could contribute to patients being more involved in EoLC decision making processes, and better fulfilment of their legal right to self-determination.

Conclusion

In conclusion, novel key findings from this study confirm that PwKF, relatives, and HPs experience EoLC decision making differently, and that there are different needs both within and between the three participant groups. Despite this, four findings in particular were common to all the stakeholder groups. First, all three groups confirmed that it was very difficult to talk about EoL. The topic was perceived as taboo and sensitive, which affected their desire and ability to talk about it. Second, there was a general feeling that the patients and relatives needed more knowledge about the disease and its course. Third, the HPs lacked the skills to supply this information, and tools to facilitate a dialogue about the patient's EoLC. Fourth, all three groups stated that they found busyness among HPs to be a barrier to EoLC conversations. To meet these various needs, EoLC conversations may benefit from being systematic and organised according to patients' needs and wishes, which may enable better patient involvement.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section at the end of this article.