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End of life of patients treated with haemodialysis as narrated by their close relatives

AUTHOR DETAILS

Lena Axelsson RN, PhD , Sophiahemmet University, Stockholm, Sweden and Division of nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Contact: Sophiahemmet University
Box 5605
114 86 Stockholm
Sweden
Tel: +46 70 848 93 08
+46 08 406 29 12

lena.axelsson@shh.se

Birgitta Klang RNT, Associate professor, Division of nursing, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden

Carina Lundh Hagelin RN, PhD, Sophiahemmet University, Stockholm, Sweden and Department of Learning, Informatics, Management and Ethics, Medical Management Center, Karolinska Institutet, and Stockholms Sjukhem Foundation, Stockholm, Sweden

Stefan H. Jacobson MD, PhD, Professor, Division of Nephrology, Department of Clinical Sciences, Karolinska Institutet, Danderyd University Hospital, Stockholm, Sweden.

Sissel Andreassen Gleissman RN, PhD, Sophiahemmet University, Stockholm, Sweden and Department of Clinical Sciences, Karolinska Institutet, Danderyd University Hospital, Stockholm, Sweden

ABSTRACT

Aim The study aimed to describe end of life for patients treated with maintenance haemodialysis as narrated by their close relatives.

Introduction. Many patients undergoing haemodialysis are older, have several co-morbidities and underestimated symptoms and are in their last year of life. To improve care we need to know more about their end of life situation.

Design. Qualitative and descriptive.

Methods. Qualitative retrospective interviews were conducted with 14 close relatives of deceased haemodialysis patients (3-13 months after death). Data was analysed using qualitative content analysis. The study is ethically approved.

Findings. In the last months a gradual deterioration in health with acute episodes necessitating hospital admissions was described. This involved diminishing living space and expressions of dejection, but also of joy. Three patterns emerged in the last weeks: uncertain anticipation of death as life fades away; awaiting death after haemodialysis withdrawal; sudden but not unexpected death following intensive care. Findings show complexities of decisions on haemodialysis withdrawal.

Conclusions. Different end-of -life patterns all involved increasingly complex care needs and existential issues. Findings show a need for earlier care planning. The identification of organizational factors to facilitate continuity and whole person care to meet these patients' specific care needs with their complex symptom burdens and co-morbidities is needed. Findings indicate the need for integration of a palliative care approach in the treatment of patients in haemodialysis care.

Keywords. end of life, end stage renal disease, haemodialysis, hemodialysis, qualitative content analysis, qualitative interviews, retrospective interviews

INTRODUCTION

Persons undergoing maintenance haemodialysis are older and tend to have several co-morbidities (1, 2). Annual mortality rates for patients on haemodialysis are about 20% (1) to 28% (3), which indicates that many are in their last year of life. The World Health Organisation (WHO) emphasizes palliative care (4) for patients with life-threatening illness. Still, little is known about the experiences and perspectives of patients on haemodialysis at the end of life and their close relatives.

BACKGROUND

Patients undergoing maintenance haemodialysis suffer from many symptoms due to uraemia and their dialysis treatment (5-7). Co-morbidities such as diabetes, cardiac disease, cerebrovascular disease, and peripheral vascular disease add to the complexity and burden of their symptoms (8-10). Their symptom burden has been described as similar to that of patients with cancer (5, 6, 11) but is however found to be underestimated and undertreated (12-14). Co-morbidities also add to decreased life expectancy and high mortality rates, with cardiovascular disease as the main cause of death for haemodialysis patients (1). Dialysis withdrawal precedes about 16% (1, 15) to 19% (2) of deaths. The average time of survival after dialysis withdrawal is eight days (16, 17).

Glaser and Strauss earlier described the importance of understanding the prognosis and trajectories of the end of life in order to identify care needs (18). Later, different trajectories of death were described: sudden death with little warning; terminal illness with rapid decline; organ failure with episodes of acute deterioration, followed by improvement, but with a downward tendency; and for the very old and persons with dementia, a gradual decline and frailty (19, 20). For persons with end stage renal disease (ESRD) it is difficult to predict a general pattern of death trajectories as co-morbidities, and thus reasons for physical decline and death, vary. Hence the importance of identifying the individual trajectory in patients with ESRD has been acknowledged (21, 22). Treatment with haemodialysis adds to the complexity of the trajectory towards death, which may also involve haemodialysis withdrawal. A study of the meanings of being severely ill living with haemodialysis showed patients suffering in physical, psychosocial, emotional and existential dimensions as they hover between living in the present and worrying about the future (23). The presence of death is multifaceted and

significant (24). To identify ways to improve care for patients with progressive decline in haemodialysis care we need to know more about their end of life. It may be difficult to gain experiences of dying from these severely ill and frail patients, but their close relatives' perspectives may increase our understanding of life until death of patients in haemodialysis care and provide important insights into their care needs. Therefore, the aim of the study was to describe end of life for patients treated with maintenance haemodialysis as narrated by their close relatives.

METHOD

Design

The study has a qualitative descriptive design with an inductive approach.

Participants and setting

Participants were recruited through three dialysis clinics in an urban area of Sweden, two in university hospitals and one a dialysis satellite. Inclusion criteria were being a close relative listed in the medical record of a deceased haemodialysis patient who had been assessed as severely ill and whose death was therefore not surprising. Eligible participants had also to be able to speak Swedish.

Besides ESRD, the deceased patients had had a multiplicity of co-morbidities, such as cardiac disease, previous stroke, peripheral vascular disease, diabetes and cancer, and most had had several. Patients had not been listed for kidney transplantation. Age at death ranged from 71 to 87 years (mean = 80). They had been treated with haemodialysis between a few weeks and 12 years. Close relatives corresponding to inclusion criteria were identified in the medical record by a dialysis nurse, with the permission of the head of the department. Identified close relatives were sent an information letter regarding the study. The first author telephoned a few days later offering further information and invited participation. Six people declined to participate because of either emotional stress or an undisclosed reason. Fourteen close relatives; ten spouses (one husband), two daughters, one son, and one sister agreed to participate. Their ages ranged from 48 to 86 years.

Data collection

Qualitative interviews (25) were conducted from December 2011 to March 2012 (except one) to research retrospectively end of life experiences cf.(26, 27) . This was 3–13 months after the death of the patient. According to the participants' wishes, five interviews took place in participant's home and nine at the participant's or interviewer's workplace, all in a private room. Participants were encouraged to speak freely during the interviews, which began with the open-ended question, "Please tell me about xx's end of life." Open and clarifying questions were asked to help participants relate different dimensions of end of life. The audio-taped interviews (23 hours) were transcribed verbatim.

Data analysis

A qualitative content analysis as described by Graneheim and Lundman (28) was performed. A decision to focus mainly on manifest content, rather than latent content, was taken as the content area was a dying person's end of life narrated from the perspective of someone else. Initially, to grasp the overall content, the interview texts were read several times. Then "meaning units" were identified (i.e. sentences or paragraphs that corresponded to the study-aim), condensed, and coded. Coded units were read, compared concerning similarities and differences and thereafter combined. Thereafter the coded units were abstracted into subcategories and categories which during analysis also were sorted, as narrated, in a pattern of end-of-life paths over time. The analysis moved back and forth between the different steps of analysis. Two authors read all interviews and four authors discussed the findings until consensus was reached.

Ethical considerations

The interviewer strived to be considerate and attentive as interviews could be stressful for participants. It is, however, known, that after death interviews may be a positive experience (29-31). All participants received information including our wish to use quotations, before giving their written consent to participation. The study was approved by the Regional Ethical Review Board, Stockholm, Sweden, Dnr 2009/407-31 and 2011/1189-32.

FINDINGS

Findings are presented as five categories and seven sub-categories (see Figure 1) in end-of-life paths as narrated by close relatives, and categories are illustrated in the text with quotations.

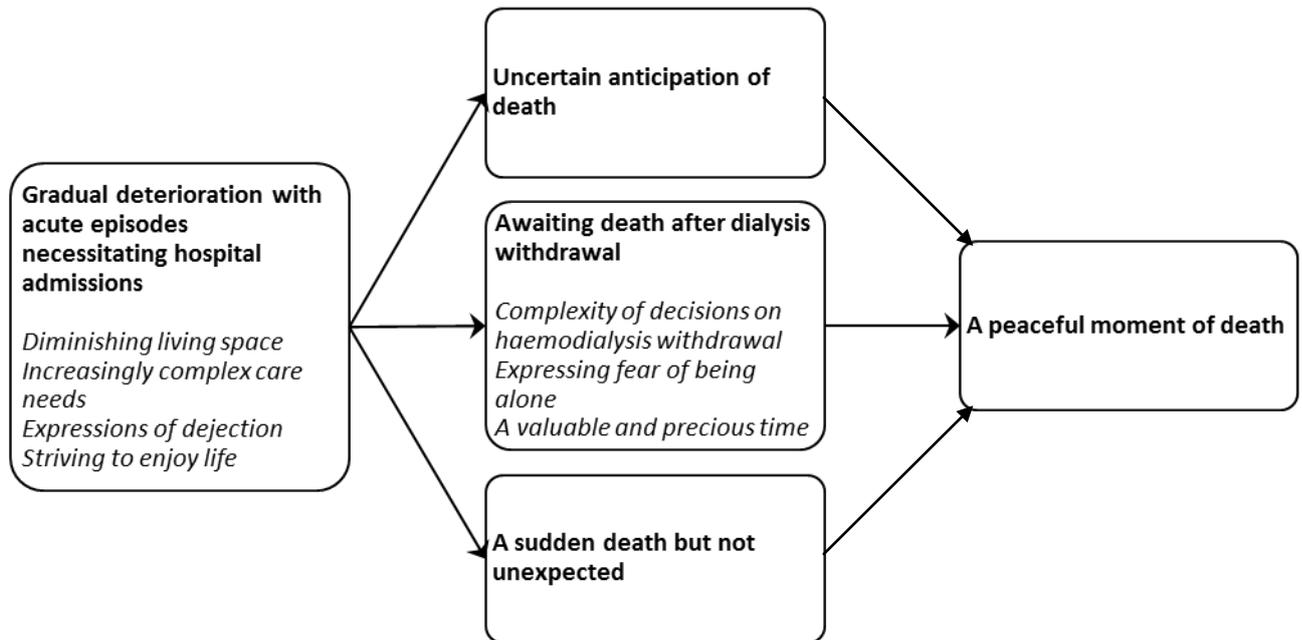


Figure 1. A gradual deterioration passed in the last weeks into three different end-of-life paths, which all were described to end in a peaceful moment of death. Sub-categories are in italics.

Gradual deterioration with acute episodes necessitating hospital admissions

Diminishing living space

Patients' living space diminished during their last months as their bodies deteriorated and their dependence on others increased. Declining health prevented patients to do what used to be of vital importance to them and their social world shrank. Co-morbidities together with haemodialysis treatment brought increasing illness. One spouse said, "There was like one

more problem: 'Isn't what I have already enough?' ... Yeah, imagine, one thing after the other, all the time ..." Dialysis treatments were also described as more difficult to tolerate: "I saw him all finished, coming home tired and worse and worse each time."

Patients had various co-morbidities, and thus various symptoms, fatigue and pain being the most recurrent. Itching and pain caused the most suffering, and were not always well managed.

With consequences of illness and changes of the body, patient's self-image was also threatened and this as well caused worries concerning after death. A son quoted his mother who worried about her appearance and said "Remember not to remember me like this."

Increasingly complex care needs

As their health deteriorated, patients' medical and nursing care needs increased. Participants described the difficulties of managing several co-morbidities and several different medical specialists and caregivers, which also caused uncertainty about who was responsible. With further deterioration and weakness, it became a problem when the ill person was sent to the general practitioner and care centre for issues other than dialysis.

They said they should only deal with dialyses. These other matters should her general practitioner attend to, many matters, but my mother didn't have the strength to go on these days when she was at home (free from dialysis), she just slept all day.

A lack of continuity and coordination of whole person care came forth as in their last months, some patients went back and forth constantly between the emergency ward, home, hospital, nursing home and dialysis clinics. At times they avoided and delayed going to the emergency ward, deciding instead to wait for their next dialysis treatment and deal with the problem then. During this period most patients were hospitalized at least some of the time for various reasons, and eventually it was their last admission and the very end of life. Their complex and exposed situation came forth also as participants described how upsetting a change in dialysis clinics was at a time when they were already more vulnerable.

Four months before death most patients lived at home with the help of their families or home help service. Still, in the end, only one patient died at home in spite of that institutional care was often described as unthinkable.

Expressions of dejection

With deterioration and recurrent problems and complications, patients expressed distress and dejection and feelings of having come to the end of their lives. Some reflected on haemodialysis withdrawal, though they did not further discuss it: “ ‘But you can’t do that,’ I said, ‘we have to go on living for some more time.’ // Yeah, but I could also see his point all too well.”

Participants felt that although life was a burden for the patients, patients then did not really wish it to end and could still find reasons to live longer. One participant told how the question of dialysis withdrawal was greeted with sorrow by her mother: ‘ Now they (dialysis-personnel) think I’ve been there for too long, now they don’t want me there anymore. Now they want me to’ ... “Yes, she knew of course, that it would mean death.”

However, some patients never spoke of dialysis withdrawal with their family.

Striving to enjoy life

The relatives also described how the ill person also found joy in life, and seized moments of well-being. One participant told that her husband struggled with long journeys to the dialysis treatments in order to spend his last summer at the country house, until a day when he had to give in and be hospitalized. “So he fought on // so he pressed his body a 110%, he fought to the last.” One son reflected that good care meant that “the person gets a chance to live and exist and not just be a patient.”

A gradual deterioration with acute episodes passed in the last weeks into a pattern of three different end-of-life paths presented as three categories: uncertain anticipation of death; awaiting death after haemodialysis withdrawal; sudden but not unexpected death (Figure 1).

Uncertain anticipation of death

For some, the last weeks were a gradual physical decline into an uncertain anticipation of death. Life gradually faded away as the weakened body demanded increasing care. One patient had long declared his wish to stay at home, but spent his last 10 days hospitalized. His wife told: “Every day when I visited him, he always said, ‘Take me home, away from here.’ But I told him, ‘You are in no shape to leave,’ but he said, ‘please take me home anyway.’”

She now thought that they could have managed the situation at home with more support.

Some participants had discussed practical issues like the funeral with the patient, but not death itself, although patients had expressed that they thought they were dying:

It was a couple of days before ... “I won’t live much longer,” he said ... “Oh yes,” I said, don’t talk like that,” “No, I don’t think so”, he said, otherwise we didn’t talk. I think he had a feeling, though.

Haemodialysis treatment was skipped for some patients in their final days, which increased the family’s understanding of the seriousness of the situation. One woman said, however, that her husband absolutely wanted to go the dialysis clinic on his final day of life. She interpreted this as his wish to say goodbye, as he had told the personnel that this was probably his last treatment. Back at the nursing home he died quietly.

Awaiting death after dialysis withdrawal

Complexity of decisions on haemodialysis withdrawal

Deterioration and treatment complications lead to questions of the meaning of haemodialysis treatment, and for some this resulted in the decision of dialysis withdrawal. This was mostly

reported as an independent decision by the patient, but prompted by a question from a physician:

Then a doctor asked her if she thought there was any meaning in living longer ... (weeping) ... They asked her if she wanted... and she replied, "I shall think about it." They talked to me as well, and I said no, I can't decide this, she will have to. // But later that same day, maybe four hours later she said, "No, I have no more strength. Let it be over."

Complexities of communication came forth. Some participants felt pressured by lack of time for reflection when the physician talked of the option of withdrawal, which some experienced as an ultimatum. A daughter was asked by the physician to talk to her mother about dialysis withdrawal and report a decision within the same evening. She described how she strived to put the alternatives, which she thought implied an ultimatum, forward with respect to her mother's autonomy.

Then we (two daughters) said that, you, you really don't have to go to the dialysis any more, you can end it if you want. But you have to decide this, Mother. Then ... she didn't answer but after a while I said, if you want to continue dialysis you will be transferred to the university hospital and you will not come back here. And then she looks at us, for a really long time and says, "Then I want to stay here" ... and then I let that sink in for a while and then after a while I said, but Mom, you realise that you then quit the dialysis ... and you realise that means that you will not have that many days left, and then I cried of course, and then she said, "It will be fine this way." And then I told my sister, now we stay for a while, to see if there is a reaction in an hour or two. But ... we sat on either side of her holding her hands as she fell into a calm sleep and when she woke up she said, "It will be fine this way."

At that time the daughter thought it was wrong to demand her to ask her mother about dialysis withdrawal, but a while later, she meant that she, who truly knew her mother, was the right person.

The decision on withdrawal was also described as a way for the patient to regain self-determination after a period of suffering from uncertainty and a deteriorating body. With

increasing illness close relatives experienced patients' change of attitude towards withdrawal and death, also in spite of earlier expressions of fear of death. The magnitude of suffering became apparent as participants could understand the change of attitudes and consequent decisions because of their suffering exemplified by pain and fatigue. Patient situations of haemodialysis initiation and withdrawal of treatment within a few weeks were also described. It came forth that patients, who have expected to begin haemodialysis for years, may not question dialysis initiation in spite of severe comorbidities. However, one wife described that as sessions were painful, and when the patient after initiation realized that dialysis would not really prolong his life because of his cancer, he decided to cease dialysis.

Patients who decided to cease dialysis treatment did not then ask for their relatives' opinion. However, the decision on withdrawal was sometimes, when the patient was considered too ill to take part, taken in a dialogue between the physician and the family. One daughter described how her mother, who had dementia, was told about the decision by the physician:

"You know how hard this dialysis is for you and how troubled you are by it, so now, now you don't need to" ... and Mom smiled, she was very polite towards the doctor, she belonged to that generation ... she then came across as very lucid and the doctor said, "You will not receive any more dialysis," as if it was a relief, "They will not mess with you anymore. Now you don't have to ... You are off it." ... Her eyes widened ... "I shall not" ... it was horrible.

Some days later the mother spoke of herself as dying.

Expressing fear of being alone

While awaiting death some patients expressed fear of being alone. In the words of one wife:

He called me after I had gone to bed and said, "I want you to come and sleep next to me here and onwards because I don't want to lie here alone, sad and scared." // You see, he knew himself that he was dying.

She had delayed staying in the hospital because she thought he would live longer and also because she did not want to be in the way of the personnel, which she later regretted.

Participants described nearness as important for the patients' well-being, and their own, when approaching the end.

A valuable and precious time

After dialysis withdrawal, the number of days between the last dialysis-session and death varied between 4 and 21 days. Some patients declined rapidly; others lived much longer than predicted.

The experiences awaiting death varied. Some described these days as valuable to the patient. Some had enjoyed friends visiting during the last week. One participant felt that planning the funeral was an opportunity to share the situation. Another described the last weeks as a valuable and dignified time together for the family "in the middle of the weirdness of a hospital" sharing memories, laughing, and crying. Their mother thus regained her identity: "Her illness then became a side issue. She then became that spirited young mom. // She became mom again."

Participants tended to think that the patients avoided talking of death either because it was too painful, or because they did not want to burden their relative. Some however had acknowledged nearness of death. Most patients had discussed their wishes for after death much earlier. Some participants thought this was easier to talk about when death was not so close; others said such plans had been brought up on being diagnosed with another life-threatening condition.

Some reported that after haemodialysis withdrawal, food and drink were also withdrawn, even though the patient still expressed hunger and thirst, which led them to question the nursing care.

Some patients in their last days were also described as suffering and wishing for life to end.

"Can't you scratch me?" he said, "Scratch, scratch, and scratch" again on the back and everywhere. He told me the last days, "I don't want to, I want it to end soon,"

A sudden death but not unexpected

For other patients, death was preceded by treatment in the intensive care unit. Their deaths were sudden, but they had expressed feeling death approaching. One participant thought her husband suffered by intensive care during his last week. She experienced it as a good period, appreciated the health care professionals' compassion, but later thought that were it not for dialysis, he should have been at home for his final days.

The possible need for professional support during communication with an ill family member in difficult circumstances was expressed. One wife told how she asked for the physician's support when she thought she should have an open communication with her husband about his and her perspective on the decision on no resuscitation.

I told the doctor, you must come with me, so I talked to my husband and said I know what you have said and I want you to know what we feel ... (weeping) and then he was so relieved.

Thus the woman and her husband came to shared understanding of goals of care at end of life.

A peaceful moment of death

Although different and individual, all end-of-life paths were described as ending in a peaceful moment of death and most patients died with family members present. One patient died of cardiac arrest during dialysis. However, death was perceived by the relatives as peaceful as it had been decided before not to resuscitate. During their last few days some patients remained awake and talked to family but most patients were described as falling asleep more and more. "Then we could see the fading away ... he passed away very still and peaceful. He didn't look tormented."

Seeing the family member dead was a significant moment that participants described as important to make beautiful and dignified, around the dead family member. Some had not seen a dead person before, and described feelings of uncertainty. "I didn't want to go in, at first, but the nurse said 'I'll come with you.' // and you know, somehow a certain calmness sets in, since then a chapter is finished."

Discussion

Through this study we have been able to describe the end of life of older patients treated with haemodialysis and thus to identify ways to improve nursing care for patients approaching end of life. Findings show that patients' gradual deterioration, complicated by co-morbidities and increasing acute episodes (marked by complex symptoms and existential issues) towards the end, may follow three main paths in the last weeks, when some face the boundary situation of deciding whether to withdraw from haemodialysis and when death becomes a certainty. However, regardless of the path, close relatives described that patients knew they were approaching death; they wanted to be at home or near their family, and they strived to maintain their identity or self-determination. Findings also show complexities/challenges of interaction and communication on death and decisions on haemodialysis withdrawal.

Participants described how increasing symptoms and suffering decreased patients' living space. This agrees with our earlier findings (23), of patients' experiences of being subordinate to their deteriorating bodies and feeling that their lives have been taken over by fatigue and other symptoms. The complexity of their symptoms also came forth in the present study and means their symptoms may be underestimated, causing more suffering and anguish. This coincides also with findings that symptoms are undertreated in renal care (12-14). Pain has been found to be a consideration in patients' decisions on haemodialysis withdrawal (32). In the present study participants described that the suffering of symptoms increased their understanding of the patient's decision to withdraw from dialysis. This illuminates the severity and meanings of their symptom burden and findings show a need for systematic overall assessment of symptoms and focus on symptom relief, which is also in focus in palliative care approach (4).

Participants described increased complex care needs together with complexity of co-morbidities and called for coordination of care, as patients did not have the strength to visit several different care providers. Some patients went back and forth constantly between different care facilities. Frequent acute episodes with increased hospitalization the last months were also described which coincide with Wong *et al.* (33), who reported on treatment intensity at end of life in older haemodialysis patients. They found that 76% of patients were hospitalized and 49% were admitted to intensive care unit during their last month. According to participants in the present study patients wished to stay at home, but in the end only one

died at home. Findings also suggest the impact of the routine of dialysis as it may not be questioned by the family although a patient is considered to be at end-of-life and the goal of care is redirected. Taken together these findings may indicate a lack of care-planning and form a challenge to co-ordinate and identify whole person and end-of-life care of these patients.

In addition, participants described that their ill family member in their suffering also strived to maintain self-determination and strived to enjoy life. This agrees with findings (23) of patients in haemodialysis care approaching the end of life who expressed living with suffering and well-being simultaneously and who were hoping for opportunities to enjoy life.

Findings illuminate complexities of communication and decisions on haemodialysis withdrawal. Participants in the present study described that although patients expressed dejection and some mentioned haemodialysis withdrawal, they then interpreted these expressions to mean life was heavy, rather than an actual wish to cease haemodialysis. This corresponds with our earlier findings (24) of severely ill persons' reflections on withdrawal as a hypothetical option, rather than a real alternative for them. However, patients' hypothetical criteria and attitudes towards withdrawal of dialysis were found to change, to both a more negative and a more positive approach, over time with deterioration (24). A change of attitude is also suggested in the present study, as some relatives were surprised when the patients later did decide to withdraw from haemodialysis, also in spite of earlier fear of death. It is important that nurses in dialysis and nephrology care are aware of the possibility of changes of attitude and develop communication skills on existential issues. A challenge in communication was also highlighted by the finding that when dialysis personnel bring up the question of withdrawal the patient may interpret this as questioning the worth of their life. This points to the challenge of communicating that life is allowed to end, and dialysis may be withdrawn, without lessening the patients' feeling of meaning and worth. This is important as feelings of worth are significant to the alleviation of suffering when nearing death (34). Present findings reveal further complexities in communication of decisions about withdrawal. Withdrawal was reported as an independent decision by the patient, but most often initiated by a question from the physician who thus faced them with a decision to make. Russ *et al.* (35) found that older patients in dialysis did not want to talk about withdrawal or they decided to decide later. However, this may also be related to hesitation about asking the facts of haemodialysis withdrawal because of their fear of being misunderstood as wishing to cease dialysis (24). In the present study some close relatives felt, that the question of withdrawal was an ultimatum and pressured to decide without enough time for reflection. This adds to

challenges of communication and timing. The complexities of the ethical dilemmas with questions of dialysis withdrawal (36) have also been found to cause conflicts for physicians working in haemodialysis care. Feelings of their authority over the patient also caused uncertainty about raising life and death questions. Grönlund *et al.* (36) concluded that enhanced communication between different professions could help to manage some of these issues.

Participants told that patients did not ask for their families' opinions when they made the decision to withdraw from dialysis. This may mean patients thought it was their decision to make, they felt ready to take it themselves, and they had made up their minds. It may also express patients' wish not to burden their families with existential issues (24). Ashby *et al.* (37) also found that the decision to withdraw from dialysis was not discussed with family until the patient was certain. Reasons to withdraw from dialysis are poor quality of life, pain, suffering and a desire not to be a burden (37), as supported by present findings. The decision was also understood by participants as a way for the ill person to regain control and self-determination. This highlights these patients' exposed situations.

Although participants described that patients wished to be close to their family at end of life only one died at home. Findings suggest that this may partly be due to their uncertainty about prognosis and death, what is to be expected at the end of life and of care possibilities. The difficulty of knowing when the process of dying begins in chronic disease may be a barrier to communication. However, present findings of narratives show a gradual deterioration with acute episodes and increasing hospital admissions towards end of life, which signals time to invite the patient and family to talk about the situation and their thoughts for the future. Due to the usually long time of maintenance haemodialysis treatment nurses in haemodialysis care have the opportunity to create a supportive relationship of safety and trust. This is in line with the nurse-patient relationship and interaction described by Travelbee (38) as the essence of nursing and that involvement and communication are key tools to helpful nursing actions. The theory supports the importance of active listening to human life experiences, also as existential encounters (38). Thus, nurses in haemodialysis care may facilitate the dialogue, the planning of end-of-life care, and follow up through the end-of-life period. This is of importance also to their close relatives when they are facing moral dilemmas and growing demands with the deterioration of their family member (39). Findings also show that patients may need closure after their long relationships with the /nurses/health care professionals in the haemodialysis unit. Thus closure or maintaining contact should be considered when a patient ends treatment in a dialysis unit at the end of life, whatever reason.

Patients express worries about their future and end of life (23, 24, 40) but experience that renal care professionals seldom talk to them about these matters (24, 40, 41). It has, however, been found that discussions of the prognosis and the end of life may enhance patients' hope, because more knowledge and earlier information helps them to plan for their future (42). Although death was anticipated in the present study with close relatives describing that patients expressed that they were dying, death was usually not talked of openly unless a decision was taken to withdraw dialysis.

Findings show that awaiting death with certainty, after dialysis withdrawal, may be a valuable time, but participants also described patients' fear of death and being alone. At the same time close relatives described their need for support of how to deal with the situation and their lack of preparedness about the uncertainty of length of survival after dialysis withdrawal. Findings also show that some close relatives experienced that withdrawal of haemodialysis also implied withdrawal of nursing care of basic needs as hunger and thirst i.e. lack of end-of-life care.

The present findings of complex care needs, together with the patients' struggle to increase their moments of well-being, and their wish to die close to family/at home, point to a need for planning and coordination of whole person care, supporting self-determination towards end of life. Findings also show a need to facilitate patients' and close relatives' negotiation of the health care system in their specific situations. Altogether, findings indicate that adopting the palliative care approach (4) in the haemodialysis unit with its focus on relief of symptoms, team work, communication and relation along with support to next of kin may support nurses and other health care professionals to improve end-of-life care for patients on haemodialysis and facilitate dying as they wish. A randomized controlled trial of early integrated palliative care in oncology care found that patients reported a higher quality of life, fewer emergency department visits and fewer hospitalizations (43). This points to a dignified end-of-life. However, access to specialized palliative care has been related to diagnosis of cancer and few patients treated with haemodialysis die with access to palliative care (44).

Conclusion

As narrated by close relatives end of life of older patients with co-morbidities in haemodialysis care may follow three main paths, all marked by complex (undertreated) symptoms and existential issues. Close relatives described patients' struggle for well-being;

for self-determination and their wish to be close to their family at end of life. Findings also show vulnerability in relation to living with maintenance treatment elucidated by changes of attitudes and the complex communication on haemodialysis withdrawal. The complexity, and sometimes lack of acknowledgement of their care needs, suggests the need for coordination of whole person care, also between different care facilities.

Nurses in haemodialysis settings need to invite and support patients and their close relatives to talk about their life situation with the illness and their thoughts for the future, thus giving them the opportunity to plan and prepare for a good life towards the end with or without haemodialysis.

Earlier care planning, followed by on-going communication, along with the identification of organizational factors with negotiation of health care systems to facilitate continuity and whole person care, will help to meet the specific care needs of these patients. Findings suggest a need to integrate palliative care philosophy in the haemodialysis unit and co-operation between haemodialysis and palliative care teams to support these patients as they strive for well-being towards the end of life.

Methodological considerations

Retrospective interviews may be a weakness of this study, as memories may be reconstructions, but in end-of-life research the method is recognized (27). Another limitation to consider is that data concerning the patient are from somebody else's perspective and interpretation, although a close relative. However, participants had rich narratives to tell and their experiences seemed well remembered. The interviewer strived to be compliant and considerate to encourage narratives at ease and narratives yielded rich data. Thus 14 interviews were considered satisfactory to describe end of life. Most participants were women and spouses. This should be reflected on concerning transferability. Yet this also reflects reality as ESRD is more common among men. The authors' different pre-understandings of the phenomenon under study contributed to critical reflections and analysis which strengthens its trustworthiness (28).

Author contributions

Study design: LA, BK, CLH, SHJ, SAG; data collection: LA; data analysis: LA, BK, CLH, SAG; manuscript preparation: LA, BK, CLH, SHJ, SAG

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