

BMJ Open 'You see the empty bed which means it's either a transplant or a death': a qualitative study exploring the impact of death in the haemodialysis community

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ABSTRACT

Objective To explore the impact of the death of a patient in the haemodialysis unit on fellow patients.

Methods We interviewed patients on dialysis in a tertiary dialysis centre using semistructured interviews. We purposively sampled patients who had experienced the death of a fellow patient. After interviews were transcribed, they were thematically analysed by independent members of the research team using inductive analysis. Input from the team during analysis ensured the rigour and quality of the findings.

Results 10 participants completed the interviews (6 females and 4 males with an age range of 42–88 years). The four core themes that emerged from the interviews included: (1) patients' relationship to haemodialysis, (2) how patients define the haemodialysis community, (3) patients' views on death and bereavement and (4) patients' expectations around death in the dialysis community. Patients noticed avoidance behaviour by staff in relation to discussing death in the unit and would prefer a culture of open acknowledgement.

Conclusion Staff acknowledgement of death is of central importance to patients on haemodialysis who feel that the staff are part of their community. This should guide the development of appropriate bereavement support services and a framework that promotes the provision of guidance for staff and patients in this unique clinical setting. However, the authors acknowledge the homogenous sample recruited in a single setting may limit the transferability of the study. Further work is needed to understand diverse patient and nurse experiences and perceptions when sharing the knowledge of a patient's death and how they react to loss.

INTRODUCTION

Patients on long-term haemodialysis attend life-sustaining treatment in a hospital setting. Patients forge special relationships with each other and with nursing staff while attending hospital dialysis treatment three times a week for 4 hours at a time.¹ Many of the patients discuss their treatments with each other and share transport to and from haemodialysis. The overall mortality rate among patients

Strengths and limitations of this study

- Semistructured interviews provided a flexible method of data collection to explore emotional and sensitive issues, allowing those interviewed to raise issues of significance to them.
- The broad research team reviewed findings to ensure their rigour and quality.
- The results are valuable as an initial exploration of a topic that has not been previously addressed in the literature.
- A purposive sampling technique obtained rich data, however, the sample size possibly limited our results.
- This study is limited to one region in the UK with a particular demographic, therefore care must be taken not to extrapolate the results to the whole haemodialysis population.

on dialysis is high. Sudden cardiac death is the single most common cause of death among these patients, causing about 22% of all deaths, secondary to cardiac disease or arrhythmia.² Overall there is a high risk of the dialysis community experiencing both expected and unexpected bereavement. Patients often infer the death of a fellow patient when they attend for dialysis and notice the absence of the other patient, which leaves an 'empty chair'.³

Most of the published literature to date has examined bereavement and loss from the nursing staff or family/carer perspective rather than from the patient perspective.¹ While the literature looks at issues of 'loss' in haemodialysis, it has predominantly focused on loss of self-identity, time and social contacts⁴ rather than loss of a patient from a community formed by attendance for haemodialysis.

The importance of appropriate interventions to support patients in the haemodialysis

cohort has been identified,⁵ yet the impact of bereavement and possible presence of survivor guilt within this community has been minimally researched. Bereavement is when someone loses a loved one to death whereas grief is the emotional and behavioural response to death or loss.⁶ Survivor guilt is a sense of wrongdoing as a consequence of surviving a traumatic event such as severe hardship or death when others did not.^{7,8} 'Bereavement' and 'survivor guilt' have been documented in other patient groups such as those with cancer⁹ and Huntington's disease.¹⁰

This qualitative study aims to explore the experience of death among patients on dialysis and to understand whether this changes patients' understanding of their own mortality.

METHODS

We undertook a qualitative study using semistructured interviews. We performed a literature search and several key areas of interest emerged. These were combined with clinical experience to create a topic guide (online supplemental file 1). Due to the sensitivity of the subject, it was important that the topic guide was flexible so that the questions we asked could be individualised to capture patients' experiences, feelings and views¹¹ on bereavement and survivor guilt. When participants raised issues of interest and importance to them these were followed up with open-ended questions, enabling these areas to be explored in detail.¹²

Members of the team (KG and SS) who conducted the interviews and analysed the data undertook a Qualitative Interview and Analysis course at University of Oxford Department of Continuing Education prior to the study. At the time the study was conducted, SS was a dialysis nurse and was aware of potential participants who may have experienced death of a fellow patient.

Setting

We conducted all interviews at the outpatient dialysis unit of a tertiary dialysis centre in Southern England between 31 January and 28 September 2017. The unit oversees the treatment of over 150 patients, with approximately 1:2 female to male ratio who attend dialysis three times a week for 4 hours. The patients are drawn from a fairly affluent area with a predominantly Caucasian population.

Study participants

Patients who were over 18 years old and receiving regular haemodialysis for longer than 90 days at the unit were eligible for the study. We excluded patients who were admitted to hospital or lacking the capacity to consent and used purposive sampling in order to interview patients who had experienced a death of a fellow patient. Of the prevalent dialysis population at the time of the study, 78 patients had a dialysis vintage of longer than 3 months. Of these 78 patients, the authors knew that 12 had experienced the death of a fellow patient. These 12 patients

were approached on one of their haemodialysis sessions by a research nurse. All participants were provided with a study information leaflet. The study was discussed in detail and written informed consent obtained on a subsequent session.

Data collection

We conducted all but one of the semistructured interviews in the haemodialysis unit. One patient opted to be interviewed in their own home. The interviews took place at an agreed time that was acceptable to the patient and interviewer and in a suitable quiet area. We used a topic guide to shape the interviewing process; there was ongoing adaptation of the guide based on new information gleaned from preceding interviews. After the first four interviews, initial themes for the interviews were discussed between KG and MG. The remaining interviews were then completed by KG and SS with the revised topic guide. KG completed the first five interviews and SS completed the remaining five interviews. Each interview lasted between 30 and 40 min. Audiorecordings of the interviews were transcribed verbatim by a transcription company, which had the facility to provide secure downloading of audio files and guaranteed confidentiality. Once the transcribed interviews were returned, the transcripts were checked against the audio recordings for accuracy and to remove any identifying material.

Data analysis

We analysed the collected data thematically using inductive analysis. We undertook six phases of thematic analysis, which included familiarisation with the data, where the interview transcripts were read and reread. Phase II involved initial 'coding'. We developed initial ideas for codes from the first two interviews, producing an initial coding framework which was discussed within our research team. Coding continued with subsequent interviews and codes were reviewed and combined into larger categories and themes (phase III). The categories and emerging themes (phase IV) were reviewed, checking how they fit together and how they related to the phenomena of interest—bereavement and impact of mortality. The first five interviews were coded independently by two researchers (SS and KED) to ensure a quality check of early analysis. SS and KED conducted a further five interviews and data from these 10 interviews allowed for deep exploration of the identified themes. The themes were then refined and named (phase V). Analysis continued with writing up (phase VI) and checking that the interpretations reached were reflective of all of the interviews.^{13,14}

Patient and public involvement

Prior to ethics submission, KG approached four patients on long-term haemodialysis to discuss the design of the study, types of questions we would ask during the semistructured interview process and how they would feel about being interviewed while on dialysis. The types of interview questions were developed by patients' previous

Table 1 Participant characteristics

	Male (n=4)	Female (n=6)
Age range	52–85	42–88
Mean	70.25	66.5
Months on dialysis at time of interview (average)	75.75	102.3
Ethnicity		
White	3	6
African/Caribbean	1	0
Cause of renal failure		
Renal calculi	0	1
APKD	0	2
Kidney atrophy	0	2
Type II diabetes	0	1
Renal cell carcinoma	1	0
Obstructive nephropathy	1	0
Hypertension	1	0
Nephrotic syndrome	1	0
Domicile		
Lives with partner	4	1
Lives alone	0	3
Warden accommodation	0	1
Single with two children	0	1

APKD, adult polycystic kidney disease.

experience of a fellow patient's death, for example witnessing a patients' death on dialysis or how and when patients' were told about a death and if they were comfortable talking about the subject matter. Three out of four patients found that talking about death was acceptable and all had experienced the death of a fellow patient. All patients who participated provided feedback which was incorporated into the design, topic guide and conduct of the study.

RESULTS

We approached all eligible participants, two declined and the remainder were interviewed. The characteristics of participants who enrolled in the study are shown in [table 1](#).

Four core themes emerged from the interviews. These were (1) patients' relationship to haemodialysis, (2) how patients define the haemodialysis community, (3) patients' views on death and bereavement and (4) patients' expectations around death in the dialysis community. Each of the core themes and subthemes are detailed below.

Patients' relationship to haemodialysis

Acceptance of dialysis

Participants described haemodialysis as a big commitment which impacted their lives considerably, including

their diet, relationships and social life; however, the benefits of attending outweighed the risk of not attending in their view.

Well first of all I found it very difficult, because I was doing more or less a full seven days a week, suddenly three mornings were taken out, so I had to rejig. (Participant 3)

It's just like, like appointments and things like that... then you think well how can I manage that, how can I get to that, how can I do that...and obviously, you come in the afternoon for a dialysis. (Participant 10)

Participants knew the risks of not attending and that there was an appreciation for the dialysis treatment they were receiving.

It's a big commitment, but it keeps me alive. (Participant 1)

I've been around for so long, I do appreciate how important to have your dialysis...I do appreciate how tenuous life is. (Participant 9)

Patients' motivation to continue dialysis

Most participants explained that haemodialysis takes up a lot of time, although most work dialysis around their life. Participants in the study approached dialysis differently, those who were retired tended to accept dialysis into their weekly routine; however, those who were of working age found it harder. Those of working age with younger families described their families and life at home as a motivating factor for attending dialysis.

My kids, if I didn't do it [dialysis] I wouldn't be around for my kids and they are everything to me...I keep going for my kids. (Participant 7)

The wife said to me, 'you're here', that's all that matters. I'm here with her, so if that's what matters... if anything happened to her, I wouldn't bother with this. (Participant 2)

How patients define the haemodialysis community

Similarity of situation

All participants reported that they felt part of a dialysis community and that they could enjoy banter, laugh and engage with others going through a similar situation. Some forged strong bonds with each other while some did not consider other patients as friends.

We are all going through the same thing and we are the only ones that know what other people are going through and they know what you're going on about. (Participant 7)

This is the community. All...everybody here knows everybody's name, you know where they come from, they know what they're doing, they know how sick they are...I have always looked forward to coming in here [dialysis]. (Participant 5)

Interestingly some participants stated early in their interviews that they did not feel part of the community but as the interviews progressed they reported ways in which they did feel part of the community. Downplaying the idea of friendship is one of the ways in which the participants were noted to be protecting themselves from the pain of loss/death.

There are people in this...in this environment where I wouldn't usually put them into the friendship section.... Most of them...I've seen a lot of them die. So I try not to get close to them. (Participant 5)

Nurses and the haemodialysis community

Not only did participants describe their own part, and that of fellow participants, in the dialysis 'community', but also strongly felt that the nurses had an impact on their haemodialysis experience and thus have an important role in the community.

I enjoy every minute on this ward because of the nurses, the staff are brilliant. (Participant 6)

I can tell you that it's the nurses who make the community. (Participant 5)

Patients see the same nursing staff several times a week and reported strong relationships with the staff. Participants mentioned that because staff knew the patients really well, this this was seen as a kind of friendship.

I've got closer relationships with the nurses than I have with patients. (Participant 8)

Patients' views on death and bereavement

Acceptance of death

Participants expressed the feeling that death is normal and expected under the circumstances of being on dialysis and having other associated conditions, such as diabetes.

We all have to go sometime. (Participant 2)

Participants seemed accustomed to the heightened risk of death in those on dialysis because of their experience on the unit. One participant explained that they did not have a feeling of guilt because they themselves could die at any point.

You can come in here [dialysis] this morning and could be dead by lunchtime, I have seen that myself. (Participant 8)

When death was expected, some participants saw the death of a fellow patient as a blessing and a relief and felt that the patient was no longer suffering.

It made me feel sad, but didn't affect me because it [death] was expected.... It's a situation where perhaps it isn't quite so sad because they've been so ill. (Participant 8)

While participants acknowledged that death was part of the cycle of life, it still was particularly difficult when younger members of the dialysis community died.

It's very sad when he died, he was really quite young. (Participant 3)

Patients preparing for the eventuality of death

Some participants commented that being on dialysis and witnessing the loss of other patients prompted them to take action. This included planning funerals, talking to their children and organising their affairs.

I thought last year, I thought I don't want to leave, how difficult it is to cope with all the fuss of arranging a funeral, so I went off to the Co-Op which we always use for our family funerals and I said I want to arrange it and pay for it now. (Participant 4)

I didn't want to leave any debt for my kids...its one debt I haven't got to worry about. (Participant 8)

But even when patients were in a position to take steps to prepare for death, there can still be resistance from family members and an unwillingness to acknowledge the need for preparations for death.

My youngest son, um, he just sort of, he didn't even want to go there. No. No, he didn't want to go there at all. So he, he sort of started off ignoring what I was saying. (Participant 1)

Patients' expectations around death in the dialysis community

Lack of information-sharing

Most participants felt that nurses could not share information about a fellow patient dying due to the issue of confidentiality and that nurses had informed them that they were not allowed to pass on this kind of news. Nurses were only prompted to mention a death if asked directly by a patient.

Well the staff don't tell you if anyone died...I don't think they are allowed, but if you ask, they will talk to you about it. (Participant 1)

It would have been nice to be told [about a patient's death] as soon as possible. (Participant 6)

Sharing of a fellow patient's death

Participants were informed of other patients' deaths in different ways; some were told immediately by the nursing staff, however others were not informed directly and found out through other patients or relatives. Generally, participants felt that the news of a fellow patient's death was not shared in a timely manner. Participants wished to be informed by the nursing staff close to the time of the death to enable them to pay their respects. For some this included the option of attending their funeral.

One of the nurses came and told me straight away [that he died] and I really appreciated her for that. (Participant 8)

I would have gone [to funeral], you know, if, if they'd told me.... I feel well I wish they'd [nurses] tell us. (Participant 4)

Participants explained that they did not necessarily need emotional support after a fellow patient died, but that knowledge of the death and information are important to them. Participants mentioned that talking about death of a fellow patient within their community was therapeutic.

It doesn't look like as if anybody needs more support...if I did feel overcome, I would go talk to the Chaplain. (Participant 3)

I've known a few people who've died. We all [patients] talk about it. (Participant 2)

Participants mentioned that the basic information that a fellow patient had died would minimise any upset and that it would be better than not knowing or trying to guess what had happened to them.

You see the empty bed, which means it's either a transplant or a death. (Participant 3)

If somebody disappears then we need to know whether they've transferred, whether they've had a transplant or unfortunately they've died. Um, and I don't think, we don't need to know any more than that, but it's just a case of it does stop people worrying and getting upset. (Participant 9)

DISCUSSION

This study reported on the impact of a patient's death within a dialysis centre on fellow patients. We found that patients were largely accepting of their limited life expectancy. The concept of a haemodialysis community was a key finding from this study. Our participants indicated that dialysis was a common denominator between them and that they understood what other participants were going through. This key finding is similar to other long-term conditions, however where communities are forged online rather than face to face.^{15 16}

Within the dialysis centre, they experienced a community which included the nursing staff as well as fellow patients on haemodialysis. Relationships developed within this dialysis community and, as such, the death of a fellow resulted in grief experiences for the survivors. If the death was not openly acknowledged, other patients were unable to grieve.

This study aimed to understand more about the patient on dialysis community; what has emerged is that it is not purely a community of patients but instead a community of patients and the dialysis nurses. The sense of community heightens the sense of loss, and understanding how these concepts of community develop among patients

on dialysis also allows us to understand the impact of death. Seeing the same nurses each week added to the 'community' feeling. There is little prior research describing the views of patients towards dialysis nurses but more on the views of care and overall satisfaction of the patient experience.¹⁷ Further work is needed to understand the ways that nurses and others contribute to the haemodialysis community. This might include an exploration of patients' views towards nurses and patients' perception of the nurses' role in their community. It would be valuable to understand how nurses who forge lifelong therapeutic relationships with patients experience their death and whether nurses themselves feel part of a haemodialysis community. These concepts have potential implications for practice including the provision of clinical supervision and support.

Our exploration of patients' attitudes to death and dying has revealed great patient insight into the life-limiting nature of end-stage renal disease (ESRD) and the inevitability of death. The age at which someone died influenced the impact of their death on the surviving patients. Surviving patients reported that they found it harder to accept the death of a 'young' person. In general, our participants voiced the belief that death was a normal part of life. A belief that aligns with Axelsson *et al's*¹⁸ study who found that patients on haemodialysis were accepting of death but fearful of how and when it would happen. However, this finding deviates from earlier qualitative research which suggested that patients on long-term haemodialysis are unaware of the life-limiting nature of ESRD especially in comparison to people's expectations of cancer.¹⁹ Knowledge of the growing literature over the last decade and an increased awareness including a public health approach to end of life care and advance care planning may explain this deviation from prior studies. A change was highlighted by Ekelund and Andersson²⁰ where patients wished for more adequate discussions on their individual life expectations. This may also be a reflection of a growing recognition among nephrology teams that patients value information about prognosis.²¹

Participants articulated a wish to have death in the unit acknowledged openly. When they saw an empty bed there was uncertainty around what had happened to their fellow patient. Patients either received a transplant, died or had their treatment regimen altered. Participants felt that if the death of a fellow patient was not communicated they were unable to acknowledge the death and grieve. Participants felt there was reluctance among staff to share this information with the community.

We found that the death of a patient on the unit did not cause survivor guilt in this group. The concept of survivor guilt is sparsely explored in the literature and it is therefore difficult to make comparisons with other patient groups. Lack of acknowledgement of a death can lead to disenfranchised grief.²² This has been identified in patients with renal diseases who experienced

the loss of a transplanted kidney.²³ The concept of disenfranchised grief is worthy of exploration so that the grief experienced in this population group can be openly recognised and acknowledged.

Strength and limitations

This study allowed for a deep exploration of a previously unexplored and important aspect of haemodialysis experience which is worthy of further exploration. Further studies would benefit from larger samples including satellite units and diverse patient groups in order to better approximate theoretical sufficiency. We emphasise that the findings from one tertiary centre may not be transferable to other cultures given the important interface between death ritual and culture.

CONCLUSION

This study establishes that grief is experienced by patients in the haemodialysis community on the death of fellow patient. Recognition of the existence of bereavement and grief within the dialysis community may be a catalyst for the provision of culturally appropriate support. As a first step, the death of a fellow patient should be acknowledged and communicated appropriately to the surviving patients on dialysis. We recognise that further exploratory work is needed to understand the experiences and perceptions of nurses around giving news of a patient's death and their own reaction to loss. Future work should also aim to improve patient experience by considering how to shape a service to address bereavement and grief among surviving patients on haemodialysis. The authors acknowledge the interface between death and culture and recommend that the findings of this study are explored in diverse patient groups.

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Topic guide

1. Haemodialysis background:

Please tell me your haemodialysis story/narrative

More specific questions if not answered:

How do you find HD?

How long have you had HD for?

What type of RRT have you had before?

Is there a plan for a kidney transplant?

What are your biggest fears about haemodialysis?

Do you like to have your HD in the same chair/bed space?

2. HD community

Tell me about the haemodialysis community

How do you view your relationships with the other patients you dialyse with?

Have you developed any friendships?

3. Bereavement

Have you ever experienced the death of a fellow patient? Empty bed vs death on the HD unit

If so, how did this affect you?

Please tell me more about this

(Survivor guilt? Bereavement reaction present)

4. Patients own feelings and engagement with treatment

How has the loss of a fellow patient affected your relationship with haemodialysis?

How does this make you feel?

Who do you share your thoughts with?

5. OKU bereavement policy

What do you think about how the unit currently informs HD patients of a death of a fellow patient?

How could/should this be done differently (if at all)?

How would you like the unit to inform your fellow patients of your death?