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# End-of-life care decisions for haemodialysis patients – ‘We only tend to have that discussion with them when they start deteriorating’

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## Abstract

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**Background** Haemodialysis patients receive very little involvement in their end-of-life care decisions. Issues relating to death and dying are commonly avoided until late in their illness. This study aimed to explore the experiences and perceptions of doctors and nurses in nephrology for involving haemodialysis patients in end-of-life care decisions.

**Methods** A semi-structured qualitative interview study with 15 doctors and five nurses and thematic analysis of their accounts was conducted. The setting was a large teaching hospital in Wales, UK.

**Results** Prognosis is not routinely discussed with patients, in part due to a difficulty in estimation and the belief that patients do not want or need this information. Advance care planning is rarely carried out, and end-of-life care discussions are seldom initiated prior to patient deterioration. There is variability in end-of-life practices amongst nephrologists; some patients are felt to be withdrawn from dialysis too late. Furthermore, the possibility and implications of withdrawal are not commonly discussed with well patients. Critical barriers hindering better end-of-life care involvement for these patients are outlined.

**Conclusions** The study provides insights into the complexity of end-of-life conversations and the barriers to achieving better end-of-life communication practices. The results identify opportunities for improving the lives and deaths of haemodialysis patients.

## Introduction

In recent years, there has been an international commitment to improve the quality and safety of health care in different contexts to ensure patients achieve the best possible health-related outcomes.<sup>1–3</sup> Quality improvement initiatives have focused on a number of domains of clinical practice to design or redesign care processes to enable patients and their families to achieve a ‘good death’.<sup>4–6</sup> This has resulted in the publication of a number of guidelines in the USA<sup>7,8</sup> and the UK<sup>9,10</sup> on how to deliver end-of-life care for people with conditions such as end-stage renal disease (ESRD).

Global estimates suggest the incidence and prevalence of ESRD are increasing.<sup>11–15</sup> Annual mortality rates for ESRD are 20–25%,<sup>16</sup> exceeding deaths from several cancers.<sup>17,18</sup> A number of studies<sup>19–22</sup> highlight there has been a significant increase in the number of people with ESRD who tend to be older ( $\geq 65$  years), have complex health-care needs, multiple comorbidities and are more likely to die from disease complications. Formal recommendations to enable timely palliative care for renal patients have been developed and implemented in some countries.<sup>14,23,24</sup> There is also evidence<sup>25–29</sup> which indicates that end-of-life discussions about preferences of care with haemodialysis patients are infrequently initiated by their health-care team. One study<sup>30</sup> estimates more than 50% of haemodialysis patients, who are living with ESRD, are not involved in those decisions. Emerging evidence confirms that patients want to talk about end-of-life and be given more information, at an earlier point in their illness,<sup>27–29,31,32</sup> yet issues relating to death and dying are rarely considered until a medical crisis occurs.<sup>27,29,30</sup> Some patients incorrectly believe they can be kept alive indefinitely on haemodialysis and do not view themselves as living with a terminal illness or understand that dialysis may extend life, but it might not improve their quality of life.<sup>18,28</sup>

Involving patients in their health and treatment options is recognized as a central pillar of patient-centred care and best practice in several

national and international nephrology guidelines.<sup>23,33–35</sup> As a growing body of evidence suggests that the quality of end of life for these patients is less than optimal, it is imperative that patients are engaged to identify their goals of care and preferences.<sup>29,36–38</sup> Experts in end-of-life care advocate earlier advance care planning, allowing patients to avoid unwanted life-sustaining therapies and to be better prepared for death.<sup>8,25,39–41</sup> Advance care planning is a structured and formal way of ensuring that family members and health-care professionals are informed of the patient’s preferences for subsequent care if they are unable to express a view.<sup>22,28,42,43</sup> The process of advance care planning involves identifying the patient’s preferences and goals for future care through reflection and discussions with a health-care professional that take into account the patient’s values, psychological, ethical and social perspectives.<sup>22,28,42–44</sup>

Haemodialysis patients and their carers rely heavily on health-care professionals as a source of information and support.<sup>18,24,45</sup> With an ageing and growing dialysis population,<sup>20,21,46,47</sup> complex patients with a higher incidence of comorbidities will increasingly use nephrology services.<sup>48,49</sup> We explored the experiences of doctors and nurses around end-of-life decisions and their approaches for discussing end-of-life care with patients in a large nephrology and transplant unit in the UK. We report identified barriers for having end-of-life care discussions with patients and opportunities for improving existing communication practices in nephrology care.

## Method

Twenty semi-structured interviews were conducted with health-care professionals involved in the delivery of care to patients with ESRD. Individual interviews were chosen to avoid the discomfort of discussing sensitive issues in a group situation.<sup>50–52</sup> A purposive stratified sample of doctors and nurses was recruited to ensure a wide representation of participants from different grades of professional standing. A snowball

sample was used to gather participants through the identification of an initial subject who was used to provide the names of others. This methodology takes advantage of the social networks of identified respondents, providing an escalating set of potential contacts.<sup>51–54</sup>

### Data collection

All interviews were undertaken by SL, then a medical student, using a semi-structured topic guide that included important topics to be addressed, in all interviews, as well providing a flexible guide of open-ended questions to explore experiences and attitudes, and allow participants to volunteer issues pertinent to them.<sup>51,52,55</sup> The interview guide was developed through a literature review followed by construct validation with a steering group, comprising a nephrologist, a nephrology specialist nurse, and healthcare professionals and researchers from the UK and Canada with expertise in end-of-life decision making and shared decision making. The guide consisted of four broad topics: information giving about prognosis; discussion about advance care planning; discussion about withdrawal from dialysis; and improving end-of-life care. Interviews were audio-recorded and transcribed.

### Analysis

Data were analysed using thematic analysis.<sup>56,57</sup> This method of analysis is essentially a process of categorizing data according to a thematic framework (or coding scheme), and key themes are summarized.<sup>52,58</sup> Four transcripts were independently coded by ACS and SL; subsequently, themes were compared and agreed between them and a coding framework with definitions was developed. SL subsequently applied and successively iterated the thematic framework to all data using the qualitative software package, NVivo8 (Manufactured by QSR International, Melbourne, Australia).<sup>59</sup> We stopped data collection once theoretical saturation was achieved, that is, when respondents were not providing any further fresh insights.

### Ethical considerations

Ethical review was sought and granted from Cardiff University School of Medicine Research Ethics Committee (SMREC reference number: 11/48). Informed consent was obtained from all participants in this study in line with benchmarks for best practice in ethical conduct in research.<sup>60–63</sup> To obtain informed consent, all prospective participants were informed verbally and in writing about the likelihood, magnitude and duration of harm or benefit of participation in the study. They were informed that their participation in this study was voluntary and participants were free to withdraw from the study at any time. Transcripts were anonymized.

### Results

Twenty participants including seven consultants (i.e. Attendings), four specialist registrars (i.e. Fellows), four junior doctors (i.e. Residents) and five senior registered nurses were interviewed. The demographic characteristics of the participants are summarized in Table 1. Interviews lasted between 28 and 70 minutes (mean = 47 minutes).

Four key themes emerged from the data, including uncertainties of prognosis, the use of advance care planning in practice, limitations of dialysis withdrawal practices and barriers to achieving better end-of-life care (Table 2). We present the key findings for each theme.

#### Uncertainties of prognosis

##### *Prognosis is not routinely given*

The length of time that a patient can expect to live following a diagnosis of ESRD is rarely discussed. Doctors perceive that they clearly signpost to patients that their life is likely to be shortened, although all doctors said specific time frames are not routinely given to patients. Whilst population-based estimates are available, responding doctors indicated that usual practice is to give life-expectancy information if directly asked by a patient.

**Table 1** Table of demographic and professional characteristics of doctors and nurses interviewed

Characteristic	Doctors	Nurses
Sex		
Female	7	5
Male	8	0
Age (years)		
Mean	37	45
Range	26–53	38–53
Years of practice in total		
Mean	13	24
Range	1.75–29	16–33
Years of practice in nephrology		
Mean	9	20
Range	0.3–26	15–26

Demographic and professional characteristics of study doctors and nurses.

They're not given a prognosis unless they actively seek it out. (Consultant 7)

Life expectancy is usually discussed when it becomes clear a patient is declining, and in their last few weeks of life.

We only tend to have that discussion with them [about prognosis] when they start deteriorating. (Consultant 3)

Reasons given for not opening discussions about life expectancy included the difficulty of estimating prognosis and a belief that patients did not want or need to know about prognosis.

#### *Difficulty of estimating prognosis*

Due to the complexity and individuality of each patient, doctors described the difficulty of trying to put a figure on the amount of time a person has left to live, admitting that it was something they felt they could not always predict.

Although you know their life is going to be shorter, you can't say for that individual what their exact prognosis is going to be. (Consultant 2)

#### *Patients may not want or need to know about prognosis*

Doctors and nurses felt that patients may not want or need to know about their prognosis. It was suggested that giving prognoses may be

overloading patients with too much information, and an unnecessary burden that may in fact harm patients, by causing them to become depressed.

I just think to give them that [prognosis] when they don't really need that. They've got enough to cope with to think they're going to be on a treatment – a long-term treatment, a chronic treatment – until they die. And a lot of them don't want to know. (Nurse 2)

However, it was noted that whilst patients may not be given a prognosis, receiving dialysis causes patients to 'become aware of their own mortality', having seen others die around them.

#### The use of advance care planning in practice

##### *Advance care planning is rarely carried out*

Many participants (9/15 doctors, 5/5 nurses) expressed that advance care planning is carried out for a small proportion of patients. Some doctors described advance care planning as something they were likely to avoid, and as an issue that nobody thinks about. Reasons given for why advance care planning is rarely carried out included the difficulty of bringing up the topic of end-of-life, a lack of experience, a lack of policy, a focus on acute medical issues and a lack of understanding of legalities.

A lot of it is too little too late. You see a patient going down-hill and then you're in a big rush to try and sort everything out. (Consultant 3)

As a consequence of a lack of advance care planning, decisions are sometimes made when patients are too ill to participate.

However, others thought that advance care planning is in fact accomplished and that whilst it may be 'ad hoc' and 'not very formal', it is adequate for patient needs.

##### *Initiating end-of-life discussions upon patient deterioration*

For the majority of participants, discussions regarding end-of-life are initiated when an individual becomes very unwell; patient deterioration was the main trigger identified for initiating such conversations.

**Table 2** Themes and subthemes identified from interviews

Themes	Subthemes	Exemplar quote
Uncertainties of prognosis	Prognosis is not routinely given	'They're not given a prognosis unless they actively seek it out'
	Difficulty of estimating prognosis	'Although you know their life is going to be shorter, you can't say for that individual what their exact prognosis is going to be'
	Patients may not want or need to know about prognosis	'I just think to give them that [prognosis] when they don't really need that. They've got enough to cope with to think they're going to be on a treatment, a long-term treatment, a chronic treatment, until they die. And a lot of them don't want to know'
The use of advance care planning in practice	Advance care planning is rarely carried out	'A lot of it is too little too late. You see a patient going down-hill and then you're in a big rush to try and sort everything out'
	Initiating end-of-life discussions upon patient deterioration	'It's a difficult discussion. It's easier to just let people slowly carry on and deteriorate, and they never bring it up. That's the easiest way out of it. It's a lot of effort. . . it's a lot harder to bring up these discussions'
Limitations of withdrawal practices	Over-dialysis of patients	'People say we'll try dialysis, we'll see how it goes and if they're really ill on it, we'll stop but they don't seem to stop'
	Variation in end-of-life care practices	'There are some doctors who are very reluctant to withdraw and then there are others who I think are more confident and feel confident to approach a patient and say, look we should withdraw'
	Lack of talking about withdrawal before patient deterioration	'We talk about why we're going to start it but we don't talk about why we're going to stop it, or what might be the reasons why we would want to stop it'
	Patients have a limited understanding of dialysis withdrawal	'If you suggest that [dialysis withdrawal] and explain that they're not going to survive without dialysis, it does seem to come as quite a shock'
Barriers to achieving better end-of-life care	An awareness of the role of other colleagues and communication	'Probably they ask them these questions in clinic but I don't know'
	Responsibility and culture	'It is not knowing whose role it is and sort of passing the buck and maybe thinking, oh someone else has already spoken to them'
	Patient awareness, education and support	'With cancer patients, you associate cancers with death. . . People don't associate dialysis with death as much'

Despite recognizing the benefits of having earlier discussions with patients, doctors identified that in practice these are very difficult conversations to have, especially with patients who feel well, and those that are younger. As a consequence, end-of-life discussions are sometimes not broached until the patient has experienced significant deterioration and illness and symptom management cannot be optimized.

It's a difficult discussion. It's easier to just let people slowly carry on and deteriorate, and they never

bring it up. That's the easiest way out of it. It's a lot of effort. . . it's a lot harder to bring up these discussions. (Consultant 7)

### Limitations of withdrawal practices

#### *Overdialysis of patients*

The term 'overdialysis' was used by participants to describe prolonged, potentially unnecessary, treatment. Some participants (6/15 doctors and 4/5 nurses) expressed the opinion that patients

can be over-dialyzed even when they have very little quality of life and are no longer aware of their surroundings.

There are some patients who we dialyze when we perhaps shouldn't. (Junior 2)

In particular, it was queried whether dialyzing some patients with dementia is in their best interests.

She got admitted to hospital and then the dementia rapidly worsened, she [had] many other interconnected illnesses, infections and other things. She had no concept at all, she was still given dialysis three times a week, it was very difficult because she tended to pull out the lines... (Registrar 1)

The concept of 'hard to stop once you've started' was commonly used to describe the challenges in identifying goals of care and consequent actions.

People say we'll try dialysis, we'll see how it goes and if they're really ill on it, we'll stop but they don't seem to stop. (Consultant 3)

Despite suggesting that some patients may be over-dialyzed, doctors and nurses recognized that their perception of quality of life may be very different from that of a patient, who may want to continue dialysis for as long as possible. Furthermore, doctors emphasized that whilst it may sometimes appear patients are being over-dialyzed, those with mild dementia can decompensate significantly during intercurrent illness and then recover a reasonable quality of life; doctors endeavour to take into account fluctuations in a patient's mental state.

#### *Variation in end-of-life practices*

Doctors reported varying approaches regarding timing of withdrawal of dialysis. Doctors and nurses disclosed that the approach to a patient's withdrawal can differ significantly depending upon the team providing care to the patient.

There are some doctors who are very reluctant to withdraw and then there are others who I think are more confident and feel confident to approach a patient and say, look we should withdraw. (Nurse 2)

#### *A lack of talking about withdrawal before patient deterioration*

The majority of doctors (12/15) said they would talk about withdrawal when a patient becomes very unwell or starts to deteriorate; the possibility of withdrawal is not usually touched upon when the patient is well.

We talk about why we're going to start it but we don't talk about why we're going to stop it, or what might be the reasons why we would want to stop it. (Consultant 4)

In my experience patients don't usually make the decision to stop dialysing. But we don't ever really discuss that with them. Usually it's just sort of presumed that everyone will keep dialysing. (Junior 2)

#### *Patients felt to have a limited understanding of dialysis withdrawal*

Perhaps due to a lack of discussion about dialysis withdrawal, doctors and nurses felt that patients can have misconceptions about their possible treatment options and outcomes. Although some doctors and nurses thought that patients know they have the option to withdraw, others expressed the view that because dialysis becomes a part of a patient's everyday life they do not necessarily think that they can stop.

Once they are established on the dialysis...I don't think they are aware they can withdraw. (Registrar 3)

It was also ascertained that some patients are not aware of the implications of stopping dialysis.

If you suggest that [dialysis withdrawal] and explain that they're not going to survive without dialysis, it does seem to come as quite a shock. (Registrar 4)

#### *Barriers to achieving better end-of-life care*

##### *Awareness of the role of other colleagues and communication*

Doctors and nurses were not always informed of what information is given to patients by their colleagues and consequently may not be aware

of what conversations patients have had about end-of-life.

Probably they ask them these questions in clinic but I don't know. (Nurse 1)

I'm not sure how many patients are told, no, I'm not aware of what the nurses actually tell them. (Registrar 1)

Furthermore, patient preferences for end-of-life and registered plans of care are not consistently recorded. This was identified as a particular problem for patients admitted to hospital acutely, for whom preferences are often not known, resulting in unnecessary interventions, such as resuscitation and subsequent continuation of dialysis.

He hated being in hospital. He'd been in hospital so much he very much wanted to die at home. . . He had another bleed. . . He was seen by a locum GP and admitted to hospital. . . It was not what he wanted. . . He was admitted to MAU, he sat on a trolley overnight, a bilateral amputee. . . He didn't have a registered plan of care. . . The system just failed him completely. (Consultant 5)

A lack of documentation of patient wishes was also identified as a potential cause of problems following the transition of patient care from one team to the next.

#### *Responsibility and culture*

There is no specified person assigned the role of having end-of-life discussions; thus, some individuals hope others will take responsibility for having such conversations. This is a key contributory factor towards a lack of advance care planning.

It is not knowing whose role it is and sort of passing the buck and maybe thinking, oh someone else has already spoken to them. (Registrar 4)

Respondents indicated that raising the subject of end-of-life is not part of the culture in dialysis units, where it is an onerous discussion to have and not something doctors and nurses like talking about. Here, death was considered a taboo subject, and thus, it may not occur to people to discuss it. The focus instead lies on trying to

keep people alive, regardless of whether or not they may have come to the end of their natural life.

It's not part of the culture. . . people just don't want to bring it up. (Consultant 7)

#### *Patient awareness, education and support*

Participants advised patients do not associate ESRD with death in the same way patients diagnosed with cancer understand the life-limiting implications. They suggest this may be due to a lack of discussion in the public arena and media about this issue. Doctors felt that bringing up dying with haemodialysis patients is harder, due to the patients' lack of awareness of ESRD as a life-limiting illness.

With cancer patients, you associate cancers with death. . . People don't associate dialysis with death as much. (Consultant 7)

Furthermore, whilst robust pre-dialysis educational programmes exist, this is not always extended to patients after starting dialysis. Additionally, doctors and nurses felt that patients are not given enough personal support; in particular, there is nobody assigned the role of overseeing patients for whom dialysis is becoming less effective in managing their symptoms of advancing renal disease and may want to discuss withdrawal.

Why should we have a whole army of nurses who discuss options predialysis. . . why can't we have one person who is assigned that task of talking to patients who have considered withdrawal? Why can't we have the same mechanism in place for coming off dialysis? (Consultant 5)

## **Discussion**

Findings from this study suggest that prognosis is not routinely discussed with patients, in part due to a difficulty in estimation of prognosis and the belief that patients do not want or need this information. There is variation of end-of-life practices amongst doctors. Advance care planning is carried out in moments of crisis or when



a patient's condition has significantly deteriorated; thus, end-of-life discussions are usually initiated upon patient deterioration, and some doctors and nurses perceive patients are often withdrawn from dialysis too late. Furthermore, the possibility and implications of withdrawal are not commonly discussed with well patients.

### Relationship with the literature

Our findings are consistent with the literature,<sup>18,22,26,29</sup> in particular the issue of prognosis not being discussed in advance of patient deterioration. Previous studies have highlighted a gap in patient knowledge surrounding prognosis, particularly that they have a life-limiting illness with a high mortality rate where only 50 per cent of dialysis patients are alive three years after starting ESRD therapy.<sup>22,64</sup> Doctors and nurses in our study suggest that patients did not want to be given prognoses and that to provide such information would negatively impact on patients' well-being. Those views are in contrast to other studies involving patient surveys and interviews, which suggest that the vast majority of patients and their carers want to be given life-expectancy information, and for their clinician to provide this information without being prompted.<sup>18,28,31</sup> Doctors were uncertain about the accuracy of estimating prognosis for an individual. However, developments to aid these estimations include a clinical prediction tool for six-month mortality for patients on haemodialysis,<sup>65</sup> and a clinical score to predict six-month prognosis in elderly patients starting dialysis.<sup>66</sup>

There is growing evidence that advance care planning is valuable to patients with ESRD: it allows them to avoid unwanted medical interventions, help prepare themselves and those around them for death, achieve a sense of control and relieve burden placed on others.<sup>14,39,42,67–71</sup> However, the results of this study support previous findings that in practice patients rarely discuss end-of-life treatment preferences with their health-care team, often due to the discomfort of their health-care professionals in discussing these issues.<sup>25–28,70,72</sup> Doctors and nurses described a lack of experience and confi-

dence in when to initiate and how to conduct advance care planning. Answering 'no' to the question, 'Would you be surprised if this patient died within the next year?' can be used to prompt nephrology teams to initiate end-of-life discussions.<sup>73,74</sup> This has been used extensively as a prognostic tool by providers caring for oncology, dementia and cardiovascular patients and has proven to be a good indicator of future function.<sup>75</sup>

Effective communication is fundamental to advance care planning which is predicated on in-depth discussions between the health-care professional, patient and their family to identify the patient's values, priorities and preferences for future care.<sup>22,28,42,44</sup> The participants' accounts about a lack of discussion about end-of-life care amongst the health-care team and lack of advance care planning are akin to the wider palliative care literature which refers to a similar concept colloquially called 'conspiracy of silence'.<sup>76–78</sup> In the context of palliative care, this is described as a collusion to deprive a person of information about their condition or treatment.<sup>76–78</sup> For example, there is a clear gap in patient knowledge surrounding prognosis, particularly that they have a life-limiting illness with a high mortality rate.<sup>22,64</sup> Evidence from a number of reviews<sup>8,79–84</sup> has highlighted how 'conspiracy of silence' can result in the exclusion of patients and their families from decisions about end-of-life care.

A number of guidelines, communication frameworks, and tools<sup>7–9,71,80,85–91</sup> have been developed to support health-care professionals and other members of the team such as social care professionals to develop the confidence, skills and attributes required to communicate effectively with patients and their families about end-of-life care. Guidance on how to conduct discussions about end-of-life care is provided by Davison and Torgunrud<sup>92</sup>, who outline a patient-centred advance care planning model for ESRD to act as a guide to help doctors explore such issues with their patients.<sup>92</sup> There are other generic approaches that can be used by health-care teams to promote patient engagement with decisions about their end-of-life care; quality

indicators have been outlined by Sinuff *et al.*<sup>93</sup> in terms of goals for discussion, what should be documented, and organization or system issues that can aid successful planning. In addition, shared decision-making approaches might also assist to achieve patient engagement in decision making.<sup>33,94,95</sup>

The variation in end-of-life decision making amongst doctors elicited from the interviews is also described in the literature.<sup>22,96,97</sup> Differences in training have been identified as a factor underlying this variation;<sup>98</sup> and it is recognized that familiarity with best practice guidelines can aid nephrology doctors in feeling more prepared for end-of-life decision making and reducing variability in practices such as dialysis withdrawal.<sup>96</sup>

#### Strengths and Limitations of the study

The study provides data on an important under-researched issue. Semi-structured interviews are valuable for exploratory work to identify meanings and perspectives, allow the identification of cultural and social factors that influence patient care and can detect obstacles to change.<sup>51,52,99</sup> Although interviews were undertaken with doctors and nurses, the results are intended for consideration in conjunction with previous studies focusing on eliciting patient opinions.<sup>26–28,32,100,101</sup>

Data are from one large nephrology unit which limits generalizability to other settings. However, the frequency and consistency of emerging themes throughout the interviews indicate an opportunity for further work to determine whether these issues are relevant elsewhere. Whilst the study was carried out in the context of ESRD, the results may be transferable to other settings caring for patients with advanced disease.

It is recognized that it is difficult to eliminate bias and that researcher preconceptions shape research.<sup>102</sup> However, the validity of the findings is supported by repeated interviewing, alongside reference to the relevant literature.

Further exploratory work is needed, including observational studies of clinician–patient

interactions, and interviews with patients in the UK, to inform potential feasible interventions for improving the patient and clinician encounter around these issues. The content of current UK guidelines<sup>23</sup> informing clinical decision making about haemodialysis highlights the importance of delivering patient-centred care and enabling people in renal failure to play an active role in decisions about their treatment. Approaches that use shared decision making have been shown to enable people with kidney disease to play a central role in decisions about their treatment which gave them greater confidence and control over their illness.<sup>103</sup> Therefore, further research is needed to examine how approaches such as shared decision making can be integrated more widely into clinical practice to bring about better patient satisfaction and improved patient outcomes.

#### Recommendations for policy and practice

We have themed our recommendations broadly as better decision support for patients, better education for clinicians and better systems of care delivery. Patients and families should be supported to codesign these processes.<sup>104,105</sup>

##### *Better decision support for patients*

Patients should be given realistic information about prognosis and expectations on dialysis and how they can participate in setting goals of care and be involved in care planning. Clinicians can use prognostic tools to make estimates about when to initiate discussions around end-of-life care.<sup>65,66</sup> Further, consideration should be given to provide educational and decision support for patients once they have started dialysis. Assigning a dedicated nurse to this role for patients struggling on dialysis could minimize the risk of overtreatment. Finally, public awareness of the concept of ESRD as a life-limiting illness needs careful consideration to ensure they and their families understand the implications of their diagnosis.

### *Better education for clinicians*

Doctors and nurses could benefit from support on how to initiate advance care planning discussions with their patients. The existing patient-centred advance care planning model for ESRD could be a helpful resource for local teams to design their own systems for ensuring all patients have access to such discussions.<sup>92</sup> All practising health-care professionals should receive the appropriate preparation to achieve this pre- and post-licensure, which could support acceptance of a 'good death' as a goal of professional practice.

### *Better systems of care delivery*

Systems would need to adapt to the changes required to support the collaborative development of end-of-life planning between health-care professionals and patients and their families. Registered plans of care need to become an integral part of practice and established best practice guides such as the 'Gold Standards Framework' can support health-care teams in achieving this.<sup>106</sup> A change in the culture of dialysis units towards ensuring all patients have access to information and an opportunity to discuss end-of-life decisions is needed; this will require identification of key staff to champion, lead and encourage team members to incorporate new approaches into their everyday practice.

## Conclusion

The study provides insights into the challenges of engaging in end-of-life conversations between patients living with ESRD and their health-care providers. The variability in the practices of doctors and nurses is perhaps underpinned by a lack of awareness of available best evidence to inform discussions about prognosis. Whilst advance care planning is infrequently carried out, and end-of-life discussions are rarely initiated prior to patient deterioration, all health-care professionals involved in this study reported the need to improve this area of practice.

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## Conflict of interest

None.

## Author contributions

ACS designed the study and, together with SL, developed the coding framework. AE, SR, RS and MAM provided clinical expertise to support the analysis, particularly the contextualization of the issues identified by the research team (ACS, SL). All authors are responsible for reported research and have participated in the analysis and interpretation of data, drafting or revising, and have approved this manuscript as submitted.

## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Appendix S1.** Question Schedule.

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