AJKD
Original Investigation

Understanding by Older Patients of Dialysis and Conservative Management for Chronic Kidney Failure

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Background: Older adults with chronic kidney disease stage 5 may be offered a choice between dialysis and conservative management. Few studies have explored patients' reasons for choosing conservative management and none have compared the views of those who have chosen different treatments across renal units.

Study Design: Qualitative study with semistructured interviews.

Settings & Participants: Patients 75 years or older recruited from 9 renal units. Units were chosen to reflect variation in the scale of delivery of conservative management.

Methodology: Semistructured interviews audiorecorded and transcribed verbatim.

Analytical Approach: Data were analyzed using thematic analysis.

Results: 42 interviews were completed, 4 to 6 per renal unit. Patients were sampled from those receiving dialysis, those preparing for dialysis, and those choosing conservative management. 14 patients in each group were interviewed. Patients who had chosen different treatments held varying beliefs about what dialysis could offer. The information that patients reported receiving from clinical staff differed between units. Patients from units with a more established conservative management pathway were more aware of conservative management, less often believed that dialysis would guarantee longevity, and more often had discussed the future with staff. Some patients receiving conservative management reported that they would have dialysis if they became unwell in the future, indicating the conditional nature of their decision.

Limitations: Recruitment of older adults with frailty and comorbid conditions was difficult and therefore transferability of findings to this population is limited.

Conclusions: Older adults with chronic kidney disease stage 5 who have chosen different treatment options have contrasting beliefs about the likely outcomes of dialysis for those who are influenced by information provided by renal units. Supporting renal staff in discussing conservative management as a valid alternative to dialysis for a subset of patients will aid informed decision making. There is a need for better evidence about conservative management to support shared decision making for older people with chronic kidney failure.

Am J Kidney Dis. 65(3):443-450.

INDEX WORDS: Chronic kidney disease; conservative management; conservative care; supportive care; decision making; older adults; geriatric; dialysis; end-stage renal disease (ESRD); renal replacement therapy (RRT); end-of-life care; advanced care planning; qualitative.

Editorial, p. 372

In recent years, increasing numbers of adults 75 years and older started renal replacement therapy.[1-3] In England, the Renal National Service Framework recognized the important role of alternatives to dialysis in older adults with chronic kidney disease (CKD) stage 5 who have high comorbidity and frailty, and conservative care programs have been developed.[3]

The evidence base comparing dialysis and conservative management consists largely of single-center studies with methodological complexities such as selection bias, making results less generalizable. Older adults who initiate dialysis therapy are likely to live longer than those receiving conservative management, although this advantage may be small in patients with comorbid conditions, particularly cardiovascular disease and complications of diabetes.[4,5] The burden of dialysis and its effect on quality of life may outweigh the benefit of longevity for some patients.[6-9] Up to 15% of older adults with CKD stage 5 opt for conservative management,[2,7] with conservative management increasingly being recognized as an acceptable and beneficial treatment option.[5,10,11]

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Received March 31, 2014. Accepted in revised form August 1, 2014. Originally published online October 7, 2014.

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 0272-6386
http://dx.doi.org/10.1053/j.ajkd.2014.08.011

Qualitative studies have explored why patients opt for conservative management.[12-15] Some patients thought they were too old for dialysis, thought dialysis was too strenuous to undertake, felt well without dialysis, did not want to be a burden on their family, and found it difficult to travel to dialysis.[12-15] One study also identified that some patients were reluctant to think about the future.[14]

To our knowledge, no research has explored the views of patients across different renal units with different conservative management policies and practices about choosing between conservative management and dialysis. This study aimed to explore the experiences of older adults who had made a decision between different treatments for CKD stage 5 in 9 UK renal units. We also compared patient perspectives between renal units that had more or less developed conservative management pathways.

METHODS

Design and Setting

This is a qualitative study with exploratory semistructured interviews with patients recruited from 9 of the 52 adult renal units in England. Renal units refer to nephrology departments situated within acute hospitals that provide dialysis, including in-hospital hemodialysis. Units were selected using nonprobability purposeful sampling[16] to explore specific characteristics of interest, including location in England (Fig 1) and scale of conservative management delivery. The latter was estimated by responses provided to a previous UK Renal Registry survey.[17]

Participants

Staff in each renal unit identified patients 75 years or older who had an estimated glomerular filtration rate (eGFR) < 15 mL/min/1.73 m^2 or who were receiving dialysis. Participants were required to speak English fluently and were judged by their health care professionals to be sufficiently physically and mentally fit to take part in an interview. Participants then were purposively sampled by 3 stages of illness and management pathway: (1) following the decision to opt for conservative management (conservative management pathway), (2) following the decision to receive dialysis but prior to initiating dialysis therapy (predialysis pathway), and (3) following the initiation of dialysis therapy (dialysis pathway). Participants were invited to take part by post or in person by staff in the renal unit.

Interviews

Participants were interviewed face to face in their own homes, in the renal unit while receiving dialysis, or by telephone by an experienced qualitative researcher (S.T.-C.) with whom they had had no previous contact. The interviewer presented herself as an impartial nonclinical observer interested in participants' own views. All participants gave written informed consent. Interviews followed a semistructured guide that asked participants about their knowledge and understanding about management options and reasons for their management decision (Item S1, available as online supplementary material). A semistructured format was used to ensure that all participants were asked relevant questions and to allow participants the opportunity to talk about issues that were important to them.[18] Interviews were audiorecorded and transcribed verbatim. Transcripts were checked by the interviewer but not by participants. Recruitment and interviews continued until the interviewer was satisfied that the data indicated saturation.[18] Field notes taken during interviews were referred to in the analysis to aid interpretation of data.[18]

Figure 1. A map of England shows the location of the 9 renal units selected for the study.

Data Analysis

Thematic analysis[19] allowed an inductive approach to exploring the data that lessened the likelihood that findings would be influenced by the researchers' preconceptions. Transcripts were coded line by line, with codes being assigned to each meaningful segment of text. Transcripts then were compared with one another, using a constant comparison approach, to search for similarities and differences between interviews.[20] S.T.-C. independently coded 20 interview transcripts and developed an initial set of themes. NVivo 9 (QSR International) was used to facilitate coding. Initial themes were discussed with the wider research team and amended and renamed until a consensus was reached. This framework was used to code the remaining 22 transcripts. Any new data that did not fit into the existing themes were highlighted and discussed further, with subsequent amendments to the final themes. Participants did not contribute to data analysis and interpretation.

RESULTS

Participant Characteristics

Ninety participants were invited to the study and 42 were interviewed, with 14 participants in each group (Table 1). Eleven participants declined without giving a reason, 7 patients were unable to take part for health reasons, 4 participants died after being invited, and 26 did not reply. Interviews ranged from 27 to 87 (median, 47) minutes. Three conservative management participants specifically wanted to be interviewed with a family member present for support.

Characteristics among the 3 pathway groups did not differ substantially. The age range was 74 to 92

Table 1. Numbers of Patients Recruited From Each Management Pathway and Each Renal Unit

Renal Unit No.	Predialysis	Dialysis	CM Pathway	Total for Renal Unit
1	2	1	2	5
2	2	2	2	6
3	2	1	1	4
4	1	2	1	4
5	3	2	1	6
6	1	3	1	5
7	2	1	1	4
8	0	1	3	4
9	1	1	2	4
Total	14	14	14	42

Abbreviation: CM, conservative management.

(mean, 82) years. Two-thirds were men (n = 28; 67%), and most were white British (n = 38; 90%). Many participants had a partner (n = 24; 57%) with whom most lived (n = 22; 52%). Others lived alone (n = 14; 33%), with children (n = 3; 6%), with friends (n = 1; 2%), or in a care home (n = 2; 4%).

At the time of the interview, participants had been attending their renal unit for a median of 49 (interquartile range [IQR], 16.5-72) months and had either been receiving dialysis for a median of 10.5 (IQR, 8.5-18.5) months or had opted for conservative management a median of 11 (IQR, 9-31) months previously.

Renal Unit Characteristics

Results from a national survey[21] confirmed variation in the scale of conservative management delivery in the 9 units (Table 2). Three units reported <10% of patients 75 years or older receiving conservative management compared to up to 50% in the other 6 units. These 3 units also differed in the terminology for conservative management, tending to refer to it as "nondialysis." Based on these data, units were classified into units with either more (units 1, 2, 5, 6, 8, and 9) or less (units 3, 4, and 7) established conservative management pathways.

Qualitative Findings

Four themes emerged from the analysis of all interview transcripts (Fig 2).

Theme 1: Patients' Understanding of the Management of CKD

All participants had an understanding of what dialysis was. In most units, knowledge about conservative management was uncommon among patients who had not opted for conservative management.

> *"It was presumed that dialysis would work for me…. I can't remember [staff] ever suggesting or saying that there is a third option–of not having dialysis." (Male, 82, predialysis, unit 5)*

However, in units with more established conservative management pathways, some dialysis patients were aware of conservative management as an option.

> *"[The nurse] was leaving the low clearance [clinic] to go to people who were having non-dialysis, tablets and things." (Female, 76, dialysis, unit 8)*

There was a difference between patients on conservative management and others in whether dialysis was viewed as inevitable or as a choice. Patients on conservative management reflected that at first they had been guided toward dialysis, but had reviewed their decision later.

> *"Well initially, because you think that's the right way to go, you're on the dialysis track. So you're going that way, everybody's going that way…. At some stage the conservative management comes into play—and it's when you realize that the dialysis is perhaps not the best track, but something has to tell you that…what told me was [friends' negative experience of dialysis]." (Male, 82, conservative management, unit 5)*

Table 2. Scale of CM Delivery in the 9 Renal Units Sampled, Taken From a National Survey of 71 United Kingdom Renal Units

Renal Unit No.	Patients Aged ≥75 y on CM	CM Discussed With All Patients ≥75 y?	Dedicated Staff Time for CM Patients?	CM Guideline?	Staff Training in Delivering CM?	Dedicated CM Clinics?	Funding for CM?	Terminology Used to Refer to CM
8	40%-49%	Yes	Yes	Yes	Yes	Yes	Yes	CC
2	40%-49%	Yes	Yes	Yes	Yes	No	No	SC
1	20%-29%	Yes	Yes	Yes	No, in prep	Yes	No	CM
6	20%-29%	Yes	Yes	Yes	Yes	No	No	CM
9	20%-29%	Yes	Yes	No	No	Yes	No	CM
5	10%-19%	Yes	Yes	No	Yes	No	No	CC
7	1%-9%	Yes	No	No, in prep	Yes	No	No	CM (nondialysis)
3	1%-9%[a]	Yes	No	Yes	No	No	No	Nondialysis care
4	1%-9%	Yes	No	No	No	No	No	Not for dialysis

Abbreviations: CC, conservative care; CM, conservative management; prep, preparation; SC, supportive care.
[a]At the time of recruitment, renal unit 3 reported that they only had 1 CM patient recorded on their system.

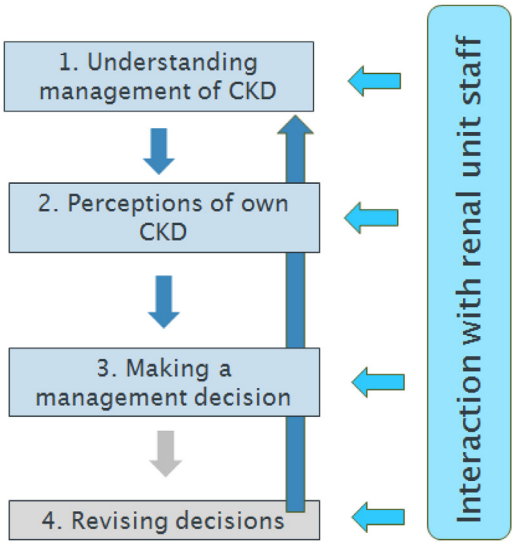

Figure 2. A thematic map of the 4 themes identified from the analysis of 42 interviews. The diagram indicates how interaction with staff fed into patients' conceptualization of the process between understanding chronic kidney disease (CKD) and making (and occasionally revising) a management decision for their own CKD.

Theme 2: Patients' Perceptions of Their Own CKD

Most predialysis and conservative management patients believed they had no CKD symptoms, with many associating any symptoms they had with their age or other comorbid conditions.

> *"[The GFR] was about 8.1 but I feel ok, my appetite is good and I sleep well. I still drive my car and so forth so there's no problem there." (Male, 76, conservative management, unit 1).*

A lack of symptoms seemed to be interpreted by some conservative management patients as an indication that their CKD was not serious.

> *"[Staff] wanted to put me on dialysis, nearly five months ago, but I didn't want to go on dialysis. Everything is all right, you know, I don't have to go on dialysis." (Male, 81, conservative management, unit 2)*

Other patients expected that dialysis would be recommended when eGFR was a certain level regardless of symptoms. Some patients had received conflicting messages from staff, with one describing how staff had explained an eGFR of 6 very differently.

> *"[The nurse] said 'we've given you a score of 6 [GFR].' I thought—6/10, that's not bad. Then I thought, 6 out of how many? She said '6/100 that's how poorly you are' and that brought me down to earth. [Later in interview] It went from 6 to 5 and the doctor said, 'don't worry, it's alright,' she says, 'I've got a patient on 4, been on 4 for years and she's still alive, don't worry.'"(Male, 87, conservative management, unit 9)*

Another, who had been told about dialysis and conservative management mentioned that a doctor from another hospital had stressed the need for dialysis.

> *"I saw a specialist down at [other hospital] and he said 'well it's down to ten.' He said 'put it like this, if you came in here now there'd be a good chance that you wouldn't be going home again'… that would have really worried some people." (Female, 87, conservative management, unit 1)*

Theme 3: Patients' Experiences of Making a Management Decision About Their CKD

Patients opting for different treatments appeared to hold contrasting beliefs about the potential advantages of dialysis. Some dialysis and predialysis patients believed that dialysis could extend their lives. Some patients from units with a less established conservative management pathway reported that they had been told they would live for several years on dialysis.

> *"[The Consultant] said, 'well it looks as if you will probably have six years [on dialysis].'" (Male, 82, dialysis, unit 3).*

In contrast, conservative management patients, from units with more established conservative management pathways, believed that dialysis did not guarantee longer life.

> *"I decided that I didn't want dialysis. I'm told that's not terribly unusual and I was told that if you say yes to dialysis, you don't necessarily live any longer anyway." (Male, 84, conservative management, unit 9)*

Many conservative management patients believed that they would have a better quality of life without dialysis.

> *"It did occur to me that [on dialysis] you were, sort of, living for tomorrow, for your next treatment, for tomorrow, for your next treatment. And it made me think, well, I wonder if it's better to live as best you can and let time take its course." (Male, 82, conservative management, unit 5)*

In contrast, some predialysis patients believed that dialysis could offer them a better quality of life or help them maintain their current quality of life.

Conservative management and dialysis patients discussed the time spent receiving dialysis differently. Conservative management patients saw this time as a "waste," whereas others thought that it was similar to how they would usually spend their time.

> *"I don't want to waste a week of my life all the time when I can be at home, enjoying myself. I mean, to me, I'm going to lose my life if I'm going to have to be on dialysis." (Female, 82, conservative management, unit 7)*

> *"I'm 81 so it don't matter to me, I thought four hours out of your life twice a week, what difference does it make? I would only be sat watching the television anyway."(Female, 81, dialysis, unit 7)*

Transport to dialysis was a major concern and a reason for some not to have dialysis when home dialysis was not an option.

> *"I can't drive and I live out of town so it's relying on hospital transport and I mean you could be waiting hours…. I just couldn't cope with it." (Female, 82, conservative management, unit 7)*

Several patients had family support that made it possible for them to undertake dialysis. Some conservative management patients indicated that they did not want to be a burden on others or the health care system by having dialysis and thought it was unreasonable when they had already reached old age.

> *"At 80, there is a lot of younger people that could benefit from dialysis which, you know, what's the good of dialysis when you reach 80 years old?" (Male, 82, conservative management, unit 5)*

Participants described the direct influence of staff on their decision making. Many patients discussed how staff had explicitly recommended dialysis, even in units with more established conservative management pathways.

> *"[The staff] said 'it's up to you, you've got the choice. You can have dialysis or you can have the other thing…if you want not to have dialysis it's your choice but you've got to realize that it is going to kill you…but if you're on dialysis you could last for ten, fifteen, twenty years'." (Male, 76, dialysis, unit 2)*

In other units with more established conservative management pathways, participants were more inclined to report discussions with staff about conservative management as a real alternative to dialysis.

> *"They went to great lengths to tell us that we could opt in or out of the dialysis and that there was an alternative to dialysis, which is this [conservative management] care path." (Husband of a 74-year-old woman on conservative management in unit 8)*

Theme 4: Patients' Experiences of Revising Management Decisions

Conservative management patients were aware that they could change their decision to be on the conservative management pathway and move to dialysis. Two dialysis patients reported that they had previously changed their mind, initially choosing conservative management because they felt well but then opting for dialysis when unwell.

> *"I said at the time no [to dialysis] and then within a fortnight I'd changed my mind. Because my health wasn't very good at all." (Male, 88, dialysis, unit 4)*

In 3 of the 14 interviews with conservative management patients, participants described how they would have dialysis if they "had to have it" or if they "got really ill," although this was not usually discussed until late in the interview (Box 1). This suggested that conservative management was conceptualized by some patients as a temporary management strategy that might change with deteriorating health.

Revising decisions from conservative management to dialysis appeared to be linked to participants having little or no discussion about the illness trajectory or death and dying. Conservative management patients from units with more established conservative management pathways appeared to have discussed the future with staff more than patients from other units. This included talking about how their CKD would progress and setting up advanced care planning.

> *"I don't think it's an agonising death…they said 'you could suddenly start to feel very ill…and then ultimately probably go into a coma and just disappear.' Which doesn't sound pleasant but it's not that bad to worry about." (Male, 75, conservative management, unit 1).*

Box 1. A Discussion Thread Taken From One Interview With a Patient Choosing Conservative Management

Thread begins:

Interviewer: "One of the nurses told us that you had decided not to have dialysis?"

Patient: "No. She said that if I did change my mind—you know—but—I don't think I will, definitely not."

Later in interview:

Interviewer: "And [nurse] said to you more recently that you're able to change your mind if you decide you want to have dialysis?"

Patient: "Oh yes."

Interviewer: "And what do you think about having that option still available?"

Patient: "Well it's nice, I think, that it's there; whether I'll ever take it up, I don't know—but—in a way, I suppose it's a comfort that I could go back, you know, if I was really ill."

Later still in interview:

Interviewer: "Yes, so do you think that—you might change your mind then, if you got—if you got more symptoms from it or got quite ill?"

Patient: "Well yes, if I got really ill and I wouldn't be having any—type of life anyway, would I? If I was that ill, you know, so there wouldn't be that much choice."

Note: The patient was an 82-year-old woman on the conservative management pathway, treated by unit 7.

DISCUSSION

In this study, patients with chronic kidney failure (eGFR < 15 mL/min/1.73 m^2) who chose different treatments held contrasting beliefs about what dialysis can offer. There was a divide between conservative management and dialysis/predialysis patients in whether they expected that they would live longer on dialysis therapy and whether their quality of life would get better or worse. These beliefs appeared to be influenced by the information provided by renal staff, particularly whether patients were aware of conservative management as an option. While most acknowledged the severity of their CKD, some conservative management patients perceived it as asymptomatic and less serious than other comorbid conditions. Only some patients choosing conservative management had spoken to staff about illness trajectory or death.

Some conservative management patients felt too old for dialysis, were worried about being a burden,

and were concerned about traveling to dialysis, as previously reported.[12-15] As in other studies, patients reported little or no discussion about advanced care planning and feeling well without dialysis.[14] Feeling well seemed to lead some patients to think their CKD was not serious, which influenced their management decision. A lack of lay-expert dialogue regarding illness trajectory and advanced care planning had led some initially to express a preference for conservative management but then change their decision when they became unwell. Thus, patients who have not made a firm decision about treatment should not be labeled as conservative management because they require further support with decision making and may require preparation for dialysis.

Our results confirm that conservative management patients may choose quality of life over longevity.[15,22,23] Patients held contrasting beliefs about whether dialysis would extend life, indicating the importance of patient expectations, as well as priorities.

This study has identified the influence that renal staff have on decision making. Patients from different units reported being given different information that presented conservative management in a more or less positive light. Patients from units with a more established conservative management pathway were more likely to know what conservative management was, to have been given more information about it, and, for those who had chosen it, to have discussed the consequences of their decision in more detail. However, patient numbers in this study were small and this should be explored in further research.

This is the first qualitative study to explore patients' views of choosing between dialysis and conservative management across several renal units in the United Kingdom. The 9 renal units displayed diversity in terms of both patients' treatment decisions and service delivery and had either more or less established conservative management pathways.

Although qualitative results cannot be generalized to other populations, data gathered can sensitize clinicians and researchers to important issues and offer conceptual transferability.[18] Although interviews run the risk of obtaining socially desirable responses,[18] the interviewer presented herself as an impartial observer who had no link to the renal unit. Moreover, patients mentioned negative aspects of the care they had received, suggesting they felt able to speak freely.

Dialysis, predialysis, and conservative management patients differed in their physical and mental health, both within and between groups. The choice between dialysis and conservative management is most relevant to older adults who are frail with other comorbid conditions. However, despite purposeful sampling, some interviewees were not frail and were experiencing minimal problems from their comorbid conditions. For these patients, it was unsurprising that less emphasis had been placed on conservative management as an option by renal unit staff. It also should be noted that patients, having made their decision, inevitably would be biased in reporting their experiences of their chosen pathway.

The categorization of units into groups representing units with either a more or less established conservative management pathway was relatively crude and is a key limitation of the study. Inevitably there was some overlap in policy and practice between the 2 groups. However, the categorization was helpful to look at general trends that could be explored further.

Patients in units with a more or less well-established conservative management pathway reported receiving different information. Having fewer resources dedicated to conservative management may reflect a general trend in a unit to encourage dialysis. However, it also may reflect less experience in providing conservative management care. Units that encourage an active approach to discussing conservative management with suitable patients are likely to offer a choice and more detailed information and discussion about both options.

Research is needed that compares the outcomes of a conservative management and dialysis pathway for similar patients to help clarify which types of patients may benefit from conservative management. The development of decision aids that present evidence and information about all treatment options, including conservative management, in an impartial way may help support staff in promoting informed decision making. Other research has developed specific examples of these.[24]

It was interesting to note that according to the renal unit records, some patients had opted for conservative management several months prior to interview. These patients may have chosen conservative management prior to kidney function reaching stage 5. In addition, some patients initially had opted for conservative management when well and changed their minds when they experienced symptoms. Both situations suggest that the label of conservative management is being used for a very broad population, arguably one that is much larger and more diverse than the label conservative management would suggest.

Conservative management is an alternative to dialysis and could be strictly defined as applying to only patients who have passed the point at which dialysis would otherwise have been started. Although this time point will differ between patients and be judged differently between clinicians, a consensus based on eGFR or symptoms linked to kidney failure may be possible and would reduce the number of patients with asymptomatic CKD stage 5 being labeled as receiving conservative management. Having a more standard

approach to defining conservative management, specifying separately patients who plan to have conservative management in the future and those who are currently receiving conservative management, would provide a clearer view of the numbers of patients on this pathway and the variation between units.

Both dialysis and conservative management patients reported that they had not discussed the future with staff, and this sometimes led to a decision being revised later. Regardless of what treatment decision is made, it is important that renal staff give patients the opportunity to discuss the likely trajectory of illness, including death, dying, and advanced care planning, to promote optimal end-of-life care.[25-27]

Our results indicate that older adults with CKD stage 5 who have chosen different treatment options have contrasting beliefs about what dialysis will offer. Patients' decisions are influenced by information provided by staff in their renal units. The practice of information sharing appears to differ between units with more or less well-established conservative management pathways. It is known that conservative management can be a difficult topic to discuss, and further research to identify how best to encourage and support dialogue between health care practitioners and patients is warranted.

ACKNOWLEDGEMENTS

We thank all the patients who volunteered to take part in this study and gave their time to contribute their views. A number of clinical staff within each of the 9 renal units helped invite patients to the study, and we thank them for their enthusiasm and dedication to this task. This study was carried out as part of a larger project, Conservative Kidney Management Assessment of Practice Patterns Study (CKMAPPS). We thank members of the CKMAPPS steering group who had input into the design and delivery of this study.

Support: This project was funded by the National Institute of Health Research (NIHR) Health Services Research (HSR) Programme (project number 09/2000/36) and will be published in full in the *Health Services and Delivery Research* journal. This report presents independent research commissioned by the NIHR. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors; those of the National Health Service; the NIHR; Medical Research Council; Central Commissioning Facility; NIHR Evaluation, Trials and Studies Coordinating Centre; the HSR Programme; or the Department of Health. This study was sponsored by the University of Southampton. The study sponsor did not have any role in the study design, data collection or analysis, writing of the final manuscript, or the decision to submit this manuscript for publication.

Financial Disclosure: The authors declare that they have no other relevant financial interests.

Contributions: Research idea and study design: PR, HR, GML, FEMM, KF, FC, data acquisition: ST-C; data analysis/interpretation: ST-C, IO, GL. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. ST-C takes responsibility that this study has been reported honestly, accurately, and transparently; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

SUPPLEMENTARY MATERIAL

Item S1: The semi-structured interview guide followed during patient interviews.

Note: The supplementary material accompanying this article (http://dx.doi.org/10.1053/j.ajkd.2014.08.011) is available at www.ajkd.org

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