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“It’s basically ‘have that, or die’” – a qualitative study of UK older patients’ choices between dialysis and conservative kidney management.

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Title

“It’s basically ‘have that, or die’” – a qualitative study of UK older patients’ choices between dialysis and conservative kidney management.

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Running head: UK older patients’ choices between kidney failure treatments: a qualitative study.

Abstract

Rationale & Objective: Kidney failure is most common amongst older people, many of whom live with multiple long-term conditions and frailty. Kidney replacement therapy aims to prolong life and manage symptoms. Conservative kidney management (CKM) aims to optimise quality of life without dialysis. This study aimed to describe how UK older patients understand and decide between dialysis and CKM.

Design: Qualitative study using semi-structured interviews.

Setting and participants: Purposive recruitment from three UK units, of adults receiving specialist kidney care, with eGFR<20 and aged over-80-years irrespective of comorbidity, or over-65 if living with two additional long-term conditions or frailty. Patients were purposively sampled to maximise clinicodemographic variation and recruitment was continued until no new major themes were arising in the analysis.

Analytical Approach: Interviews were transcribed verbatim and analysed using inductive thematic analysis and constant comparative techniques.

Results: Eight men and seven women with a median age of 81 (range 65-90), and a median eGFR of 12 were interviewed. Three themes were identified: (i) 'Do dialysis or die', where not having dialysis was equated with death; (ii) The 'need' for dialysis, where haemodialysis was perceived as the default treatment; and (iii) Weighing-up quality and quantity of life, relating to the trade-offs made between treatment benefits and burdens. Participants appeared unlikely to recognise the uncertain survival benefits of dialysis.

Limitations: Our study took place in England and all the participants were white British. As culture and faith can play a large part in decisions involving life and death, our findings may not be applicable to those in other communities. Participants were recruited from three centres, limiting the breadth of approaches to kidney failure management.

Conclusions: For older people who face short lives irrespective of treatment for kidney failure, unfamiliarity with treatment options, the desire to live, and the 'do or die' notion conspire to cast haemodialysis as inevitable, regardless of whether this is the most appropriate treatment. To best enable shared decision making, clinicians should present kidney failure treatment options in an accurate and balanced way, and respect and support

older people who are deciding whether to have CKM or dialysis. This includes articulating uncertainty, and supporting patients to made trade-offs in relation to what is important to them.

Strengths and limitations of this study

- Rigorous qualitative methods
- Inclusion of older people who had not started kidney replacement therapy
- Participants sampled from just three centres
- All participants were white British

Index words:

kidney failure; chronic kidney disease; shared decision-making; older people; health literacy; health communication

Plain-language summary:

Older people living with kidney failure often have a limited range of treatment options, with few being well enough to receive a transplant. Instead, they either start dialysis or have “conservative kidney management” (CKM). CKM involves care that focuses on managing the symptoms of kidney failure and maintaining quality of life in the absence of dialysis. The relative ability of dialysis and CKM to make older people live longer and feel better is uncertain. This study aimed to describe how older patients understand and decide between dialysis and CKM, as evidence suggests they may not be fully supported to make informed decisions between these treatments.

We interviewed 15 older people, aged 65 to 90 years with low kidney function, about their decision-making regarding future treatments for kidney failure. We analysed the interviewees’ responses and generated three themes to explain the decision making process.

First, having had the difficult realisation that their disease would likely cause an early death, many appeared to believe that they had to ‘do dialysis or die’. Some thought that going on dialysis would give them a normal life expectancy, whereas others believed that it may not extend their lives by much.

Second, many people felt that they didn’t have any real choice about the treatment they would have. They assumed that they would start dialysis in a hospital when ‘needed’ and were unaware that they could choose dialysis at home or CKM.

Third, where interviewees had considered options for treatment, there was a ‘weighing up’ of pros and cons, with trade-offs made between quality of life and length of life. If dialysis was to extend their life expectancy beyond that with CKM, their life had to be of reasonable quality. Some viewed a life on dialysis as ‘not worth living’ while others thought that they would accept dialysis because they had a ‘life worth living’. Sometimes these trade-offs were finely balanced, making the decisions especially difficult.

Many participants appeared to have decided without receiving enough information to make the right choice for themselves. For example, most appeared unaware that dialysis might not prolong life, and believed that CKM was the same as having no treatment.

Prolonging life is not the only goal for patients who must be supported when deciding between a range of treatment options based on individual preferences. Clinicians should present kidney failure treatment options in an accurate and balanced way, and respect and support older people who are deciding whether to have CKM or dialysis. This includes articulating uncertainty, and supporting patients to make trade-offs in relation to what is important to them.

Our study took place in England and all the participants were white British. As culture and faith can play a large part in decisions involving life and death, our findings may not be applicable to those in other communities.

Introduction

The highest incidence of kidney failure is seen amongst people aged 65 years and over[1], and current services are likely to be overwhelmed with increased demand in the near future.[2] Guidelines advocate treatment planning for those at risk of kidney failure[3], including shared decision-making between peritoneal dialysis and haemodialysis, conservative kidney management (CKM), and transplantation.

The presence of two or more long-term health problems is the norm for older people living with kidney failure[4] and the majority experience frailty.[5] The impact of medication management, medical visits, laboratory tests, lifestyle changes, and monitoring can easily exceed individuals' capacity to cope.[6] Only 1% of over-75-year-olds with kidney failure receive transplants[7], making dialysis a destination, rather than a bridging therapy, for most older people. The majority of older people who initiate kidney replacement therapy start in-centre haemodialysis[1], despite evidence that this may be the most intrusive option.[8] The comparative survival and quality of life benefits of dialysis and CKM remain unclear, but appear to be diminished as people age and develop frailty and additional health conditions.[9] A systematic review showed survival amongst older people with kidney failure (of median age 77 years) was 73% at one year in those treated with dialysis, and 71% in those receiving CKM.[10] At two years, survival was 62% for those receiving dialysis, and 44% for CKM.

The guiding principle of shared decision-making is to align treatments with a patient's preferences, goals, and prognosis. However, there appears to be variability and flaws in decision support for people approaching kidney failure. These include: approaches to care that favour haemodialysis over other treatments; poorly timed and inadequate information; unfavourable power dynamics between patients and clinicians; and insufficient consideration and support for emotional aspects and impact.[11,12] Whilst there are data examining treatment decision making for older people with kidney failure, including from the UK[13], only a handful of studies have examined decisions between dialysis and CKM from the perspective of those yet to start treatment.[14-19] These studies indicate that older people facing kidney failure experience a low awareness and understanding of CKM[17,18], inadequate accounting for values and goals[18], and that some patients feel they have no choice but to pursue dialysis.[14] Little work has looked at how older people with kidney failure comprehend and interpret the unclear comparative benefits and burdens of dialysis which have become clearer over the last decade[9], and how people factor in their understanding and expectations of available treatments when deciding which to pursue. This qualitative study was developed to update and obtain a more in-depth understanding of the choices made between dialysis and CKM than is available from the existing literature – exclusively considering older people with kidney failure who have not started KRT. These data were collected as part of a programme of work exploring preferences for kidney failure treatments.[20] The findings are expected to inform how to better support older people living with kidney disease, ensuring treatment choices fit with what is important to them.[21]

Methods

Design

The presented analysis was conducted as part of an exploratory sequential mixed-methods[22] study, examining the treatment preferences of older patients deciding between dialysis and CKM.[23] Semi-structured interviews were used to examine patients' perceptions of the treatment options for kidney failure, and how decisions between these options were made. Reporting is in accordance with the Consolidated Criteria for Reporting Qualitative research (COREQ – see supplementary materials).[24]

Participants

English-speaking patients receiving specialist CKD care were eligible if they had an eGFR <15ml/min/1.73m^2, were aged over 80 years irrespective of comorbidity, or were aged over 65 years if they had a Davies comorbidity score ≥2[25] or a World Health Organization (WHO) performance status score of ≥3.[26-28] Individuals were excluded if they had ever received outpatient dialysis or a transplant. Patients were recruited from three hospitals situated between the North and Southwest of England: two transplanting centres each providing care to approximately 600 dialysis recipients, and a non-transplanting centre with approximately 200 dialysis recipients. Both larger centres provided subspecialist CKM multidisciplinary care, whilst the smaller centre provided CKM within general nephrology services.

Data collection

Patients were purposively sampled to maximise variation in age, sex, ethnicity, clinically documented treatment plan and socioeconomic background. Local clinical teams assessed eligibility and informed potential participants of the study either by telephone, or at the time of a routine hospital visit. Potential participants were provided with an information leaflet and invitation letter. Clinical teams emailed the research team with the contact details of people who expressed willingness to take part. Unless these potential participants called ahead or returned the provided slip to decline, BH telephoned them to organise interviews. Written consent, planned treatment, and sociodemographic information (age, gender, ethnicity, years of full-time education, WHO performance status, and occupation) were collected at the time of interviews. One interview was conducted with each participant between September 2018 and July 2019 in patients' homes by BH, a white, male, trainee kidney specialist in his late-30s. This was BH's first experience of qualitative research, conducted as part of his PhD, which included formal training in qualitative research and interviewing skills. No other people were present during interviews. Clinical teams provided patients' clinically documented treatment plan, latest eGFR, list of comorbid conditions, and cause of kidney failure. An Index of Multiple Deprivation was calculated using participants' postcodes.[29]

An initial topic guide was developed using the literature and piloted with patient input. Following initial analysis, an enhanced topic guide was used in the second and third hospital sites, which was adapted during the concurrent analysis process to enable further exploration of initial themes and patterns in the data (supplementary file). Transcript review and interview coaching was provided by JC, LS, RLM and LR. Unless directly asked (this happened once), BH did not disclose his medical training and described himself as a "researcher". Interviews were audio-recorded using an encrypted digital voice recorder, and handwritten field notes taken. Interviewees received £20 vouchers to compensate for their time. Recruitment was continued until no new major themes were arising in the analysis, at which point sufficient information power[30] was considered to be available to support the findings. Participants were not sent their transcripts nor involved in analysis.

Data analysis

Recordings were transcribed verbatim and managed with QSR NViVo 11 software.[31] Transcripts were analysed inductively, using thematic analysis[32] and constant comparative techniques, originating in Grounded Theory.[32] Initial coding was completed by BH. Starting with 'open' coding, concepts and meanings within interviews were identified from patients' views and experiences. The first three interview transcripts were line-by-line coded and discussed at face-to-face researcher meetings before the fourth interview was conducted. Codes and interviews were discussed and compared, with abstract consideration of wider meaning, alongside reorganisation and recoding, and thematic development.[33] LS and LR subsequently coded two interviews each, and a selection of transcripts were also read independently by JC, FC and RLM and discussed as a team to refine the coding framework and interpretation. BH wrote three in-depth descriptive accounts on subsets of interviews, which were shared and discussed at alternate-monthly research meetings, and ultimately formed into a final analytical account. Seeking of negative cases (those that appear to contradict explanations in the data) was part of the purposive recruitment strategy and constant comparative approach. Negative cases were used to explicate initial analytical findings, add richness to the analysis, and generate further thematic exploration. Analysis and recruitment were conducted in parallel, and discontinued when no new themes were identified.[34]

Patient and public involvement

A panel of people with lived experience of kidney failure and their family members were involved from inception in study design and oversight, including development of patient-facing materials, the interview topic guide, and data interpretation. MS co-authored the manuscript and wrote the plain language summary.

The study was granted ethical approval by the Surrey NHS Health Research Authority (IRAS ID 278956, Protocol number 17/SC/0070, REC reference 18/LO/1179).

Results

Participants

Thirty-three individuals were approached to take part, of whom 15 (45%) were interviewed. Of the 18 (55%) who did not take part, seven returned paper slips declining participation, and four had a family member call to decline. Reasons offered for non-participation included being too busy (2), memory problems (1), deafness (2), being away (1), having started dialysis (1), and being in hospital (2). The remaining individuals did not offer a reason.

Interviews lasted a median of 63 minutes (range 29 – 84). Participant characteristics are presented in Table 1. Eight men and seven women took part, with a median age of 81 years (range 65-90), and a median eGFR of 12. Ten participants had diabetes mellitus as a cause of kidney disease, three had vascular/ hypertensive disease, and two had nephrectomy for cancer. All described their ethnicity as white British. Clinically documented treatment plans were available for each participant, with seven preparing for in-centre haemodialysis, two for peritoneal dialysis, and the remaining six for CKM. No participants were active on the transplant waiting list. Two participants voiced uncertainty about their clinically documented plan, one of whom was considering CKM instead of haemodialysis; another peritoneal dialysis instead of CKM.

Illustrative quotes are provided in italics, including divergent views and negative cases, where relevant. All participants were assigned a pseudonym. Quotes are marked with the participant's pseudonym, age, and clinically documented treatment plan in the following format: (name; age in years; abbreviated treatment plan: haemodialysis – HD, peritoneal dialysis – PD, conservative kidney management – CKM). For example Alice, an 85 year old woman planning for peritoneal dialysis: (Alice;80s;PD).

Findings

Participants described how they prepared for kidney failure in the face of a life-changing diagnosis and an unpredictable future. For most, recognition that kidney failure was impending appeared to have been seminal, transforming a minimally intrusive disease into one influencing life and death. Many recalled intensely negative experiences, typically triggered during consultations where treatments for kidney failure were first discussed. Those who were diagnosed late in the disease course, e.g. Jeremy, who learned of his kidney disease when his eGFR was in the low 20s, described especially intense feelings of *“shock”*:

> *My first thoughts about this thing were absolute shock. Despair really.* (Jeremy;80s;HD)

However, even participants who had years of preceding chronic kidney disease monitoring, e.g. Betty, who had type two diabetes mellitus, and understood that her *“kidneys were at risk”*, expressed surprise when the prospect of kidney failure was raised. For some, this appeared to reflect that the fact, or implications, of declining kidney function had not been successfully communicated. However, accounts also suggested that kidney failure was understood as a separate, more severe condition, rather than an advanced stage of chronic kidney disease. This appeared bound-up with the concept that kidney failure without dialysis was akin to death, establishing a ‘*do or die*’ paradigm (Theme 1): the perspective that dialysis must be initiated, or life would end. Related to this was a depiction of dialysis as ‘*needed’* (Theme 2), reflecting the consequence of *‘do or die’*, alongside unfamiliarity with CKM as a treatment option, and apparent norms framing dialysis as the default treatment. Meanwhile, participants almost universally discussed the inevitability of their death and anticipated burdens from dialysis. They appeared to intuitively *‘weigh up’* (Theme 3) the quality and quantity of life consequences of futures with and without dialysis.

Theme 1: ‘Do dialysis or die’

Individuals did not typically reflect on their treatment plan as reflecting a decision from a set of options, including CKM. Rather, initiation of kidney replacement therapy was depicted as life-sustaining, and a decision to decline dialysis was depicted as turning down the longer life dialysis would bring. This view was clearest amongst individuals anticipating dialysis initiation, who largely depicted negligible life expectancy without dialysis. Three participants – all preparing for dialysis – framed a decision to decline dialysis as actively shortening life, akin to suicide or euthanasia: “*letting somebody else kill you*” (Jeremy;80s;HD). For some, declining dialysis appeared to reflect the acceptance of death from kidney failure:

> *I knew that doing nothing, I would become progressively worse so- Shorten your life in other words.* (Derrick;80s;HD)

Many participants appeared to consider prognosis as unpredictable. Some described this in terms of risk or fate, "*It's just as long as it is*" (David;60s;HD). Others appeared to make prognostic estimates influenced by their age, comorbidities, and life experiences. Participants' expectations varied greatly – ranging between those who felt they were at the very end of life, "*I'm on my last legs*" (Sally;80s;CKM), and others anticipating decades: "*if it's 40 years, it's ok*" (David;60s;HD). Some participants appeared to expect that dialysis would return life expectancy to what it would have been without kidney disease. For these individuals, the perceived survival benefit of dialysis appeared to revolve around how long they expected to live in the *absence* of kidney failure:

> *Well, I don't know. I mean something else could happen. I could have a heart attack. You don't know what your end's going to be.* (Brian;70s;PD)

The accounts of participants planning for dialysis did not tend to include speculation about the effects of their choice upon the kind of End-of-Life experiences that might ensue, and the concept of dialysis discontinuation appeared universally unfamiliar.

> [Interviewer] *Have you ever thought about whether people stop dialysis having started it?*
> [Participant] *No I've never heard of anybody not doing it.* (Jeremy;80s;HD)

Seven participants – including five of the six preparing for CKM – made less stark survival comparisons when comparing futures with and without dialysis. Some reported that the additional benefit to survival from dialysis initiation may be slight, given their age or other illnesses. Some individuals simultaneously held the '*do or die*' paradigm, and the concept that dialysis may not extend their life by long:

> *It's basically 'have that or die'… [but] if you do have the dialysis what are they going to gain me, an extra six months, or a year?* (Joe;70s;HD)

In summary, this first theme captured how participants depicted that they were offered dialysis, perceived as a treatment to prolong life. The magnitude and framing of this potential survival benefit appeared to be associated with participants' willingness to accept that they could choose not to pursue dialysis.

Theme 2: The ‘need’ for dialysis

Initiation of kidney replacement therapy following kidney failure often appeared as a *fait accompli*. Many participants recalled having been told years or decades before that they would eventually require dialysis, with initiation widely referred to in depictions of certain futures, including directive terms, such as “*having to*” or “*needing to*” start dialysis. Treatment for kidney failure often appeared to be synonymous with in-centre haemodialysis, and familiarity with, knowledge, and understanding of this (often referred to simply as “*dialysis*”) appeared to surpass that of peritoneal dialysis, CKM and transplantation. Indeed, that there were alternatives to haemodialysis appeared to have come as a surprise to several participants who had been visiting the kidney clinic for many years:

> *From the start then I knew that in twenty years I’d probably be on dialysis… I didn’t know the second, third options [peritoneal dialysis and CKM] were there. I assumed on dialysis.* (Brian;70s;PD)

All other participants receiving or expecting to receive CKM recognised dialysis as having been an option, but portrayed themselves as having declined it, rather than as having made an active choice to pursue palliative care. Even those expecting CKM often appeared to have limited understanding of what it would involve, depicting a ‘status quo’ option, rather than the introduction of a new treatment or framework for care provision:

> *You might as well go the normal route [die without starting dialysis] and take what’s coming to you.* (Betty;80s;CKM)

Where the concept of CKM was discussed by those preparing for dialysis, it was typically presented as a ‘do nothing’ option:

> *We were talking dialysis, and to see what all the options are, I said “what if I don’t do anything about it, you know?”* (Derrick;80s;HD)

A minority of participants recalled being informed that one or more potential treatments were impossible for them, with some recalling how they had been restricted to just one option. Transplantation was widely perceived as unattainable, though few recalled being informed of this by their clinical team. Three of the younger participants described themselves as awaiting review of their eligibility for transplantation. For those who perceived themselves as ineligible, age was widely advanced as the reason:

> *They started talking about "have you thought about what your treatment's going to be eventually" and I said "well, I suppose having a transplant possibly". "Oh no, no, no" he said, "too late for that, too late for that, at your age", he said, "I wouldn't recommend a transplant, you know, you'll have to go on dialysis".* (Brian;70s;PD)

A minority of participants alluded to the idea that their future treatment remained undecided or could change. For some, this appeared to reflect an understanding that future declining health might influence their attitude towards dialysis. Other individuals preparing for dialysis discussed temporising or avoiding the decision to prepare for dialysis, but presented this as compatible with its inevitable initiation:

> *If it comes to it, I might have it at home or I might even not bother, because I'm not as good as I was.* (Beryl;80s;CKM)

> *I know the dialysis is going to come, but I don't want to think about it, you know?* (David;60s;HD)

In summary, this second theme captured how many participants appeared to conceive of dialysis as an inevitability, unless they declined initiation, or died from a competing cause before reaching the putative dialysis initiation point.

Theme 3: Weighing-up quality and quantity of life

A 'weighing up' of pros and cons was universal, where individuals described selecting their treatment from several options. The assumed extension to life provided by dialysis needed to be of acceptable quality, and participants' capability to live and undertake activities independently appeared to be critically important:

> *If it's going to give me a reasonable quality of life, then it will keep me going. If I didn't think that I would have a reasonable quality of life, then I would take the option of nothing.* (Muriel;60s;HD)

Participants appeared to consider the routine of dialysis as unpleasant. Intrusion into daily life was consistently cited as negative, and some participants were concerned life would become "*centred around*" (Brian;70s;PD) treatment. The time used for dialysis was frequently portrayed as "*wasted*" (multiple participants). Few anticipated feeling better after initiation:

> *You have to get transported to hospital and back again. So, you can imagine you leave home about eight o'clock in the morning and you'd be lucky if you got home at six o'clock at night. Well, that would be fun, wouldn't it? (laughs)* (Betty;80s;CKM)

Only one participant suggested a positive aspect of dialysis beyond its influence upon survival and symptom control – anticipating social interaction as part of treatment:

> *If I go to the hospital, if nothing else there's going to be a nurse or a tea lady to have a chat with. Company.* (Muriel;60s;HD)

Some appeared to consider the orchestration of home dialysis and associated equipment as an intrusion that they were not willing to accept. For those expecting to start dialysis, the negative aspects tended to be framed as justified:

> *I know it's a drag going to hospital three times a week, but at least I'm here to do it.* (Derrick;80s;HD)

Older, frailer, and largely unpartnered participants spoke of a decline in their ability to partake in pleasurable activities, and adaptation to changes in capability. The concept of a complete or "*good life*" (Clive;80s;CKM) was pervasive. However, rather than considering their current life "*not worth living*" (Derrick;80s;HD), for participants who were preparing for CKM, it was a putative future life on dialysis that was considered unacceptable. For this group, the negative aspects of dialysis were framed as dominant, even where a longer life was anticipated, were they to start it:

> *Ok so you're going to have a longer life, but what life is it?* (Clive;80s;CKM)

For some, the trade-offs between their anticipated future on dialysis and one without appeared closely balanced. This seemed to fuel uncertainty about whether their planned treatment was right for them, or an expectation that they might not undertake their clinically documented plan:

> *I do have great reservations as to whether any of it's needed and whether it's actually worth the while? This is only a temporary respite and that you're going to die anyway... All seems quite a horrible process, and as I say, I think it's a bit of a last-ditch thing, you know, to keep you running for a little bit longer.* (Joe;70s;HD)

In summary, this third theme captured how all participants appeared to weigh-up the positive and negative aspects of futures with and without dialysis, allowing them to evaluate their anticipated treatment, and compare this with alternatives.

Discussion

To our knowledge, this is the first UK study to look at treatment decisions between dialysis and CKM, exclusively amongst older people with kidney failure who have not started KRT. We examined how individuals comprehended and interpreted the comparative benefits and burdens of dialysis.[9] We found that treatment plans were made in the context of participants having already accepted the serious nature of their condition and the possibility of death as a result. Few participants appeared familiar with the uncertain survival benefits of dialysis. For many, a future without dialysis did not appear to be perceived as a real option; replaced with a '*do or die*' Hobson's choice.[14] Unfamiliarity with home therapies and CKM appeared to render haemodialysis the default treatment that would eventually be "needed" for life to continue. Meanwhile, participants considered the life they expected to live when appraising treatments, and readily made trade-offs between their benefits and burdens.

To decline dialysis appeared to be a viable option only to those who perceived that the presumed survival benefit might be outweighed by the burdens of treatment. Choosing CKM appeared to involve going against the grain – 'opting-out' from dialysis.[35-40] In keeping with the literature[15,16,35,36,41,42], there was no evidence that our participants actively opted for palliative care. Rather, they rejected a *future* life on dialysis.[43] Critically, this did not indicate that they considered their *current* life intolerable.

It has been shown in patients of all ages that kidney failure treatment preferences reflect trade-offs[44] between anticipated benefits – principally survival on dialysis[15,16,45] and the influence upon independence, daily life, responsibilities, and interests.[11,12,19,42,46] However, the trade-offs that older people make are likely to differ from those made by younger, potentially transplantable people living different occupational, social and familial lives.[11] Furthermore, whilst kidney replacement therapy is plainly life-prolonging for those whose survival is dominated by their kidney disease, the comparative survival and quality of life benefits of dialysis and CKM remain unclear for many older people.[9] Some who initiate dialysis will die close to – or even before – the point that they would have died, had they never started. Those at the highest risk of competing mortality – the oldest and those living with major comorbidities – are most likely to prepare for or receive treatment that does not prolong their lives.[9] Conflation between CKM and '*no treatment*'[13,17,18,47-50] or death[14,16,40] may undermine individuals' freedom to make trade-offs between the uncertain comparative benefits and burdens of dialysis and CKM. Meanwhile, which treatment an individual prepares for and initiates profoundly influences their experience of living and dying with kidney failure. For example those who choose dialysis appear more likely to be hospitalised and to die in hospital than others who opt for CKM.[9] However, participants opting for dialysis did not appear to have been supported to consider the implications of their decision upon, for example, where or how they might die. Exaggerated impressions of the survival implications between dialysis and CKM are likely to lead some to prepare for dialysis, despite CKM being a better fit for their preferences to minimise treatment intrusion.

It has been shown before that patients may be left to deduce which treatment options are available to them[11,35] and are not always provided with the information or support needed to ensure their treatments fit their preferences.[51,52] Our study portrays a one-dimensional system of decision-making, where the trade-offs bound up in a potentially longer life with dialysis, and a potentially shorter life without, did not appear to have been successfully facilitated. It may appear that little progress has been made since earlier studies suggested deficiencies in decisional support.[13] This raises the question as to whether clinicians believe and feel able to convey the uncertain survival benefits of dialysis and highlights the need to develop ways of helping patients to weigh up the benefits and burdens of treatments.

Older people facing the prospect of kidney failure are likely to benefit from tailored approaches to decision-support. This must reflect where they are in the life course and what a future with kidney failure might look like for them. The three themes identified in this study provide clues as to how their care might be adapted. Clinicians will need training and resources to successfully convey uncertainty, support the weighing-up process around factors of importance to the individual, and challenge the idea that dialysis is the default. Consistency across clinical teams and over time is challenging[53] and CKM services must be available and sufficient.[13] How CKM is depicted and conceived appears central. Framing CKM more accurately can improve patients' perceptions.[17] Driven by the perceived need to offer "*positive alternatives to dialysis*" (Davison et al., 2015[54], pg.453) efforts have been made to define and standardise CKM.[55] This is important, given that access to and models of kidney supportive care are inconsistent[56,57] – meaning that in some places, a choice to not pursue dialysis does not lead to receipt of CKM. However, fully establishing CKM as a viable alternative to dialysis may require patients and clinicians to be persuaded that the 'do or die' paradigm is a fallacy born from envisaging dialysis as 'needed' to prevent death. If this were to be true, CKM *could never be received,* since those who 'need' but don't start dialysis would just die. Whilst patients and clinicians may *perceive* that the choice is between dialysis and death, this is not the decision being made. Median survival from treatment decision-making or reaching kidney failure ranges between 20 and 67 months for dialysis and 6 to 31 months with CKM, depending upon age and other factors.[58] Individuals may need to be helped to understand that the absolute survival advantage of dialysis can be small, given their shorter prognosis. This will require prognostic honesty, perhaps with the sharing of absolute survival estimates, and is most likely to be successful if decision-support involves routine discussion and documentation of individual's goals for treatment of kidney failure. Living longer is rarely the sole determinant of treatment choice.[20] Individuals who are supported to contextualise the reasons for either dialysis initiation or for choosing CKM will be better placed to make decisions based upon their preferences.

The strengths of this study include a rigorous application of qualitative methods and broad range of clinicodemographic variation between study participants, sampled from multiple kidney centres. Including individuals who had not started kidney failure treatment ensured the findings were relevant to those making preparatory decisions. The study has limitations.

Participants were recruited from three centres, limiting the breadth of approaches to kidney failure management. The frequency and approach to CKM differs between kidney units[13,57,59], which may influence the transferability of findings. The sample size is small, though this reflects the fact that sufficient information power arose early to support the major themes. Despite efforts to recruit from diverse ethnic backgrounds, all participants were white British. Culture and faith play important roles in understanding of disease and treatment decision-making[60,61], so our findings may not be typical for members of other communities and further research with ethnically diverse groups is needed. Interview studies can only capture participants' accounts of clinical encounters. These encounters appear critically important in forming people's perceptions of their treatment options, and observation and analysis of clinician-patient interactions may help to uncover which consultation approaches work best.[62]

In conclusion, this study identified that an assumption that life will end unless dialysis is started, alongside unfamiliarity with and misperceptions regarding treatment options conspire to cast haemodialysis as the default treatment for kidney failure. The influence kidney specialists have upon patients' understanding and expectations of care means they must be trained to ensure patients can make shared, informed decisions. Clinicians must support patients to make trade-offs between the uncertain benefits and requisite burdens of dialysis and CKM. Better evidence will help. Meanwhile, redefining the 'need' as the 'reason' for dialysis initiation, and reframing the 'do or die' fallacy by sharing absolute survival predictions with dialysis and CKM might facilitate improvements in person-centred decision-making.

Disclosure Statement

FC is Chief Investigator, and JC and LR coinvestigators for the Prepare for Kidney Care Study, a randomised controlled trial comparing outcomes for older people preparing for kidney dialysis vs. CKM (https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/prepare-for-kidney-care/). LS, NIHR Career Development Fellow (CDF-2018-11-ST2-009) is funded by the NIHR for this research project. The authors have no other relationships/activities/interests related to the content of this manuscript to declare.

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Author contributions

BH designed the study and conducted interviews as part of his doctoral fellowship (PhD), supported and supervised by LR, RM, FC, JC and LS. MS joined the authorship to provide perspective from a lived experience of kidney disease and developed the plain language summary. BH conducted line-by-line coding of interview transcripts independently. RM, JC, LR and LS also independently read and coded a selection of transcripts. Preliminary findings were iteratively discussed with the study team, with consideration of wider meaning, alongside reorganisation, recoding, and thematic development. BH wrote the draft manuscript. All authors reviewed, revised, and approved the final manuscript.

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We are grateful to the staff working in the three recruiting kidney units, and the patients and family members who invited us into their lives and homes to learn about their experiences of kidney disease. Thank you also to the PPI advisors who helped with study development and data interpretation.

Supplementary materials

Topic guide for interviews

COREQ Checklist

Data sharing statement

Participants consented to their anonymised data being made available to other researchers who want to analyse the data in the future. Data are managed by the University of Bristol and applications for their use should be made to the communicating author.

Tables and figures

Table 1. Participant characteristics (n=15) * Due to rounding, percentages may not always appear to add up to 100% **One participant who had an eGFR of 25ml/min/1.73m2 at the time of interview, having been 14ml/min/1.73m2 at recruitment. Key. CKM, conservative kidney management; eGFR, estimated glomerular filtration rate; HD, haemodialysis; IMD, index of multiple deprivation; PD, peritoneal dialysis; WHO, World Health Organization

Participant characteristic (n=15)	Number (%)*
Gender	
▪ Female	7 (47)
▪ Male	8 (53)
Age	
▪ 65 – 69	2 (13)
▪ 70 – 74	1 (7)
▪ 75 – 79	2 (13)
▪ 80 – 84	5 (33)
▪ 85 – 89	4 (27)
▪ ≥ 90	1 (7)
eGFR (ml/min/1.73m^2)	
▪ <10	4 (27)
▪ 10 – 14	10 (67)
▪ ≥ 15	1 (7)**
Treatment plan	
▪ HD	7 (47)
▪ PD	2 (13)
▪ CKM	6 (40)
▪ Active on transplant waiting list	0 (0)
Major comorbidities	
▪ Type 2 diabetes	10 (67)
▪ Ischaemic heart disease	7 (47)
▪ Hypertension	5 (33)
▪ Malignancy	4 (27)
▪ Obesity	2 (13)
▪ Heart failure	1 (7)
▪ Stroke	1 (7)
▪ Other comorbidity	5 (33)
Cause of kidney disease	
▪ Type 2 diabetes	10 (67)
▪ Hypertension and/or vascular disease	3 (20)
▪ Removal of kidney cancer	2 (13)
WHO performance status	
▪ 0	0 (0)
▪ 1	5 (33)
▪ 2	2 (13)
▪ 3	8 (53)
▪ 4	0 (0)
Years of full-time education	
▪ 0 – 5	1 (7)
▪ 6 – 10	6 (40)
▪ 11 – 15	6 (40)
▪ 16 – 20	2 (13)
IMD	
▪ 1 – 2	4 (27)
▪ 3 – 4	3 (20)
▪ 5 – 6	6 (40)
▪ 7 – 8	1 (7)
▪ 9 – 10	1 (7)

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The UNPACK Study – Interview Topic Guide, Phase 1 Qualitative Interviews (patient, family member or both)

- Check they received **UNPACK Phase 1 Interviews, Patient information sheet**
- Explain interview and duration, including audio-recording
- Negotiate whether interview will be individual, or two-person (patient/family member)
- Confirm that patient is happy for their healthcare to be discussed with family member
- Obtain informed consent
    - Capacity assessment:
        - Ask whether they would like to continue to an interview
        - Ask what they understand would happen if they declined an interview
        - Reiterate that this decision will not impact care
        - Check for further questions
    - Complete **UNPACK Phase 1 Qualitative Interviews, Consent Form** ☐

Interview - Start audio recorder [date of recording ______________]

- *"The point of these interviews is to help me to understand what is important to people when thinking about treatments for kidney disease. How do these 'important things' influence what treatments are chosen? Who and what else is involved?*
- *There are no right or wrong answers – I'm interested in your experiences, thoughts and ideas. Whatever you say will be useful to me – I'm here to learn from you.*
- *You can stop the interview or change the subject at any point – please just say."*

Tell me a little about yourself…

- *Still working/used to work as?*
- *How so you spend your time?*
- *Hobbies/interests?*

When kidney problems first diagnosed?

- *What happened?*
- *Since?*
- *Now?*
- *Expectations?*

What discussions about future have happened?

- *With whom?*
    - *Kidney team*
    - *Family/friends*
    - *GP*
    - *Other patients?*
- *What discussed?*
- *Why were they had?*
- *Were decisions made?*
    - *How?*
    - *Who?*

What (RRT) treatments have been discussed?

- *Initial feelings about these?*
- *Feelings about them now?*
- *Understanding of what is involved?*
- *Who and how did you learn about them?*
- *Likelihood of needing?*
- *Transplantation?*
- *Thoughts about receiving dialysis?*
    - *Effects on self*
    - *Others*
- *Thoughts about receiving conservative care?*
    - *Self*
    - *Others*

What do you think might be the advantages/ disadvantages of planning now, vs. waiting to see?

Do you feel like you have a plan?

- *If not, why not, would you want one?*
- *If so, how/when?*
- *Process: gradual/one off?*
- *Did you feel like there were alternatives?*
- *Who there? Who chose?*
- *Is this how you usually make decisions?*

Have you thought about end of life care?

- *Have you talked? Who? How?*
- *How might these plans influence?*

Have you thought about loss of capacity?

- *What plans made?*
- *Lasting power of attorney?*

- *Would you like to receive updates about this research?* ☐
- *Copy of transcript?* ☐
- *Check I have all Information I need… age* ☐ *sex* ☐ *ethnicity* ☐ *marital status* ☐ *who you live with* ☐
- **Thanks. Stop and pack audio recorder.**

Manuscript: “It’s basically ‘have that, or die’” – a qualitative study of UK older patients’ choices between dialysis and conservative kidney management.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Data collection “Page 7 Line 12”
2. Credentials	What were the researcher’s credentials? E.g. PhD, MD	Data collection “Pg 7 L13”
3. Occupation	What was their occupation at the time of the study?	Data collection “Pg 7 L12”
4. Gender	Was the researcher male or female?	Data collection “Pg 7 L12”
5. Experience and training	What experience or training did the researcher have?	Data collection “Pg 7 L13”
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Data collection “Pg 7 L7” .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Data collection “Pg 7 L24”
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	No. Further information available in the linked open-access thesis.

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods “Pg 12 L12” And Data analysis “Pg 8 Line 4-5”
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants “Pg 12 L20 onwards” and Data collection “Pg 13 Line 2 onwards”
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Data collection “Pg 7 Line 3 onwards”
12. Sample size	How many participants were in the study?	Data collection “Pg 7 Line 28-29”, Results “Pg 9 Line 3”
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Results “Pg 9 Line 4”
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data collection “Pg 7 Line 11”
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Data collection “Pg 7 Line 14”
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results “Pg 9 Line 8 onwards”
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Additional file and Data collection “Pg 7 Line 19”
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No. Data collection “Pg 7 Line 11”
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Data collection “Pg 7 Line 26”

20. Field notes	Were field notes made during and/or after the inter view or focus group?	Data collection “Pg 7 Line 27”
21. Duration	What was the duration of the inter views or focus group?	Results “Pg 9 Line 8”
22. Data saturation	Was data saturation discussed?	Data analysis “Pg 8 Line 18” and Data collection “Pg 7 Line 28-29”
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. Data collection “Pg 7 Line 30”
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Data analysis “Pg 8 Line 11-12”
25. Description of the coding tree	Did authors provide a description of the coding tree?	Data analysis “Pg 8Line 8-9””
26. Derivation of themes	Were themes identified in advance or derived from the data?	Data analysis “Pg 8 Line 15-18”
27. Software	What software, if applicable, was used to manage the data?	Data analysis “Pg 8 Line 2”
28. Participant checking	Did participants provide feedback on the findings?	Data collection “Pg 7 Line 30” and Data analysis “Pg 8 Line 23”
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes – See Results, Findings p10 onwards
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes – See Results, Findings p10 onwards
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes – See three themes presented in plain English summary, abstract and results sections
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No minor themes were described

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Title

“It’s basically ‘have that, or die’” – a qualitative study of older patients’ choices between dialysis and conservative kidney management.

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Running head: Older patients’ choices between kidney failure treatments: a qualitative study.

Abstract

Objectives: Older people with kidney failure often have a limited range of treatment options, with few being well enough to receive a transplant. Instead, they either start dialysis or have “conservative kidney management” (CKM). CKM involves care that focuses on managing the symptoms of kidney failure and maintaining quality of life in the absence of dialysis. The relative ability of dialysis and CKM to make older people live longer and feel better is uncertain. This study aimed to describe how older patients understand and decide between dialysis and CKM, as evidence suggests they may not be fully supported to make informed decisions between these treatments.

Design: Qualitative study using semi-structured interviews, analysed using inductive thematic analysis and constant comparative techniques.

Setting: Three UK specialist kidney units.

Participants: Adults with eGFR<20 and aged over-80-years irrespective of comorbidity, or over-65 if living with two additional long-term conditions or frailty. Participants were purposively sampled to maximise clinicodemographic variation and recruitment was continued until no new major themes were arising in the analysis.

Results: Eight men and seven women with a median age of 81 (range 65-90), and a median eGFR of 12 were interviewed. Three themes were identified: (i) ‘Do dialysis or die’, where not having dialysis was equated with death; (ii) The ‘need’ for dialysis, where haemodialysis was perceived as the default treatment; and (iii) Weighing-up quality and quantity of life, relating to the trade-offs made between treatment benefits and burdens. Participants appeared unlikely to recognise the uncertain survival benefits of dialysis.

Our study took place in England and all the participants were white British. As culture and faith can play a large part in decisions involving life and death, our findings may not be applicable to those in other communities. Participants were recruited from three centres, limiting the breadth of approaches to kidney failure management.

Conclusions: For older people who face short lives irrespective of treatment for kidney failure, unfamiliarity with treatment options, the desire to live, and the ‘do or die’ notion conspire to cast haemodialysis as inevitable, regardless of whether this is the most

appropriate treatment. To best enable shared decision making, clinicians should present kidney failure treatment options in an accurate and balanced way, and respect and support older people who are deciding whether to have CKM or dialysis. This includes articulating uncertainty, and supporting patients to made trade-offs in relation to what is important to them.

Strengths and limitations of this study

- Rigorous qualitative methods
- Inclusion of older people who had not started kidney replacement therapy
- Participants sampled from just three centres
- All participants were white British

Index words:

kidney failure; chronic kidney disease; shared decision-making; older people; health literacy; health communication

Introduction

The highest incidence of kidney failure is seen amongst people aged 65 years and over[1], and current services are likely to be overwhelmed with increased demand in the near future.[2] Guidelines advocate treatment planning for those at risk of kidney failure[3], including shared decision-making between treatment options. The presence of two or more long-term health problems is the norm for older people living with kidney failure[4] and the majority experience frailty.[5] The impact of medication management, medical visits, laboratory tests, lifestyle changes, and monitoring can easily exceed individuals' capacity to cope.[6] Only 1% of over-75-year-olds with kidney failure receive transplants.[7] This means that most older people who start dialysis will continue it until they die. The majority start in-centre haemodialysis[1], despite evidence that this may be the most intrusive option[8] and the availability of peritoneal dialysis, provided at home. Conservative kidney management (CKM) describes care focused on managing the symptoms of kidney failure and maintaining quality of life in the absence of dialysis. The comparative survival and quality of life benefits of dialysis and CKM remain unclear, but appear to be diminished as people age and develop frailty and additional health conditions.[9] A systematic review showed survival amongst older people with kidney failure (of median age 77 years) was 73% at one year in those treated with dialysis, and 71% in those receiving CKM.[10] At two years, survival was 62% for those receiving dialysis, and 44% for CKM.

The guiding principle of shared decision-making is to align treatments with a patient's preferences, goals, and prognosis. However, there appears to be variability and flaws in decision support for people approaching kidney failure. These include: approaches to care that favour haemodialysis over other treatments; poorly timed and inadequate information; unfavourable power dynamics between patients and clinicians; and insufficient consideration and support for emotional aspects and impact.[11,12] Whilst there are data examining treatment decision making for older people with kidney failure, including from the UK[13], only a handful of studies have examined decisions between dialysis and CKM from the perspective of those yet to start treatment.[14-19] These studies indicate that older people facing kidney failure experience a low awareness and understanding of CKM[17,18], inadequate accounting for values and goals[18], and that some patients feel they have no choice but to pursue dialysis.[14] Little work has looked at how older people with kidney failure comprehend and interpret the unclear comparative benefits and burdens of dialysis which have become clearer over the last decade[9], and how people factor in their understanding and expectations of available treatments when deciding which to pursue. This qualitative study was developed to update and obtain a more in-depth understanding of the choices made between dialysis and CKM than is available from the existing literature – exclusively considering older people with kidney failure who have not started KRT. These data were collected as part of a programme of work exploring preferences for kidney failure treatments.[20] The findings are expected to inform how to better support older people living with kidney disease, ensuring treatment choices fit with what is important to them.[21]

Methods

Design

The presented analysis represents the qualitative component of an exploratory sequential mixed-methods[22] study, examining the treatment preferences of older patients deciding between dialysis and CKM. Semi-structured interviews were used to examine patients' perceptions of the treatment options for kidney failure, and how decisions between these options were made. The findings were used to design a quantitative study (a discrete choice experiment) published separately.[23] Reporting is in accordance with the Consolidated Criteria for Reporting Qualitative research (COREQ – see supplementary materials).[24]

Participants

English-speaking patients receiving specialist CKD care were eligible if they had an eGFR <15ml/min/1.73m^2, were aged over 80 years irrespective of comorbidity, or were aged over 65 years if they had a Davies comorbidity score ≥2[25] or a World Health Organization (WHO) performance status score of ≥3.[26-28] Individuals were excluded if they had ever received outpatient dialysis or a transplant. Patients were recruited from three hospitals situated between the North and Southwest of England: two transplanting centres each providing care to approximately 600 dialysis recipients, and a non-transplanting centre with approximately 200 dialysis recipients. Both larger centres provided subspecialist CKM multidisciplinary care, whilst the smaller centre provided CKM within general nephrology services.

Data collection

Patients were purposively sampled from general nephrology clinics in the main and peripheral kidney units of the three hospitals to maximise variation in age, sex, ethnicity, clinically documented treatment plan and socioeconomic background. Local nephrology teams (doctors and nurses reviewing the patients) assessed eligibility and informed potential participants of the study either by telephone, or at the time of a routine hospital visit. Potential participants were provided with an information leaflet and invitation letter. Clinical teams emailed the research team with the contact details of people who expressed willingness to take part. Unless these potential participants called ahead or returned the provided slip to decline, BH telephoned them to organise interviews. Written consent, planned treatment, and sociodemographic information (age, gender, ethnicity, years of full-time education, WHO performance status, and occupation) were collected at the time of interviews. One interview was conducted with each participant between September 2018 and July 2019 in patients' homes by BH, a white, male, trainee kidney specialist in his late-30s. This was BH's first experience of qualitative research, conducted as part of his PhD, which included formal training in qualitative research and interviewing skills. No other people were present during interviews. Clinical teams provided patients' clinically documented treatment plan, latest eGFR, list of comorbid conditions, and cause of kidney failure. An Index of Multiple Deprivation was calculated using participants' postcodes.[29]

An initial topic guide was developed using the literature and piloted with patient input. Following initial analysis, an enhanced topic guide was used in the second and third hospital sites, which was adapted during the concurrent analysis process to enable further exploration of initial themes and patterns in the data (supplementary file). Transcript review and interview coaching was provided by JC, LS, RLM and LR. Unless directly asked (this happened once), BH did not disclose his medical training and described himself as a "researcher". Interviews were audio-recorded using an encrypted digital voice recorder, and handwritten field notes taken. Interviewees received £20 vouchers to compensate for their time. Recruitment was continued until no new major themes were arising in the analysis, at which point sufficient information power[30] was considered to be available to support the findings. Participants were not sent their transcripts nor involved in analysis.

Data analysis

Recordings were transcribed verbatim and managed with QSR NViVo 11 software.[31] Transcripts were analysed inductively, using thematic analysis[32] and constant comparative techniques, originating in Grounded Theory.[32] Initial coding was completed by BH. Starting with 'open' coding, concepts and meanings within interviews were identified from patients' views and experiences. The first three interview transcripts were line-by-line coded and discussed at face-to-face researcher meetings before the fourth interview was conducted. Codes and interviews were discussed and compared, with abstract consideration of wider meaning, alongside reorganisation and recoding, and thematic development.[33] LS and LR subsequently coded two interviews each, and a selection of transcripts were also read independently by JC, FC and RLM and discussed as a team to refine the coding framework and interpretation. BH wrote three in-depth descriptive accounts on subsets of interviews, which were shared and discussed at alternate-monthly research meetings, and ultimately formed into a final analytical account. Seeking of negative cases (those that appear to contradict explanations in the data) was part of the purposive recruitment strategy and constant comparative approach. Negative cases were used to explicate initial analytical findings, add richness to the analysis, and generate further thematic exploration. Analysis and recruitment were conducted in parallel, and discontinued when no new themes were identified.[34]

Patient and public involvement

A panel of people with lived experience of kidney failure and their family members were involved from inception in study design and oversight, including development of patient-facing materials, the interview topic guide, and data interpretation. MS co-authored the manuscript and wrote the plain language summary.

The study was granted ethical approval at all sites by the Surrey NHS Health Research Authority (IRAS ID 278956, Protocol number 17/SC/0070, REC reference 18/LO/1179).

Results

Participants

Thirty-three individuals were approached to take part, of whom 15 (45%) were interviewed. Of the 18 (55%) who did not take part, seven returned paper slips declining participation, and four had a family member call to decline. Reasons offered for non-participation included being too busy (2), memory problems (1), deafness (2), being away (1), having started dialysis (1), and being in hospital (2). The remaining individuals did not offer a reason.

Interviews lasted a median of 63 minutes (range 29 – 84). Participant characteristics are presented in Table 1. Eight men and seven women took part, with a median age of 81 years (range 65-90), and a median eGFR of 12. Ten participants had diabetes mellitus as a cause of kidney disease, three had vascular/ hypertensive disease, and two had nephrectomy for cancer. All described their ethnicity as white British. Clinically documented treatment plans were available for each participant, with seven preparing for in-centre haemodialysis, two for peritoneal dialysis, and the remaining six for CKM. No participants were active on the transplant waiting list. Two participants voiced uncertainty about their clinically documented plan, one of whom was considering CKM instead of haemodialysis; another peritoneal dialysis instead of CKM.

Illustrative quotes are provided in italics, including divergent views and negative cases, where relevant. All participants were assigned a pseudonym. Quotes are marked with the participant's pseudonym, age, and clinically documented treatment plan in the following format: (name; age in years; abbreviated treatment plan: haemodialysis – HD, peritoneal dialysis – PD, conservative kidney management – CKM). For example Alice, an 85 year old woman planning for peritoneal dialysis: (Alice;80s;PD).

Findings

Participants described how they prepared for kidney failure in the face of a life-changing diagnosis and an unpredictable future. For most, recognition that kidney failure was impending appeared to have been seminal, transforming a minimally intrusive disease into one influencing life and death. Many recalled intensely negative experiences, typically triggered during consultations where treatments for kidney failure were first discussed. Those who were diagnosed late in the disease course, e.g. Jeremy, who learned of his kidney disease when his eGFR was in the low 20s, described especially intense feelings of *"shock"*:

> *My first thoughts about this thing were absolute shock. Despair really.* (Jeremy;80s;HD)

However, even participants who had years of preceding chronic kidney disease monitoring, e.g. Betty, who had type two diabetes mellitus, and understood that her *"kidneys were at risk"*, expressed surprise when the prospect of kidney failure was raised. For some, this appeared to reflect that the fact, or implications, of declining kidney function had not been successfully communicated. However, accounts also suggested that kidney failure was understood as a separate, more severe condition, rather than an advanced stage of chronic kidney disease. This appeared bound-up with the concept that kidney failure without dialysis was akin to death, establishing a '*do or die*' paradigm (Theme 1): the perspective that dialysis must be initiated, or life would end. Related to this was a depiction of dialysis as '*needed'* (Theme 2), reflecting the consequence of *'do or die'*, alongside unfamiliarity with CKM as a treatment option, and apparent norms framing dialysis as the default treatment. Meanwhile, participants almost universally discussed the inevitability of their death and anticipated burdens from dialysis. They appeared to intuitively *'weigh up'* (Theme 3) the quality and quantity of life consequences of futures with and without dialysis.

Theme 1: 'Do dialysis or die'

Individuals did not typically reflect on their treatment plan as reflecting a decision from a set of options, including CKM. Rather, initiation of kidney replacement therapy was depicted as life-sustaining, and a decision to decline dialysis was depicted as turning down the longer life dialysis would bring. This view was clearest amongst individuals anticipating dialysis initiation, who largely depicted negligible life expectancy without dialysis. Three participants – all preparing for dialysis – framed a decision to decline dialysis as actively shortening life, akin to suicide or euthanasia: "*letting somebody else kill you*" (Jeremy;80s;HD). For some, declining dialysis appeared to reflect the acceptance of death from kidney failure:

> *I knew that doing nothing, I would become progressively worse so- Shorten your life in other words.* (Derrick;80s;HD)

Many participants appeared to consider prognosis as unpredictable. Some described this in terms of risk or fate, "*It's just as long as it is*" (David;60s;HD). Others appeared to make prognostic estimates influenced by their age, comorbidities, and life experiences. Participants' expectations varied greatly – ranging between those who felt they were at the very end of life, "*I'm on my last legs*" (Sally;80s;CKM), and others anticipating decades: "*if it's 40 years, it's ok*" (David;60s;HD). Some participants appeared to expect that dialysis would return life expectancy to what it would have been without kidney disease. For these individuals, the perceived survival benefit of dialysis appeared to revolve around how long they expected to live in the *absence* of kidney failure:

> *Well, I don't know. I mean something else could happen. I could have a heart attack. You don't know what your end's going to be.* (Brian;70s;PD)

The accounts of participants planning for dialysis did not tend to include speculation about the effects of their choice upon the kind of End-of-Life experiences that might ensue, and the concept of dialysis discontinuation appeared universally unfamiliar.

> [Interviewer] *Have you ever thought about whether people stop dialysis having started it?*
> [Participant] *No I've never heard of anybody not doing it.* (Jeremy;80s;HD)

Seven participants – including five of the six preparing for CKM – made less stark survival comparisons when comparing futures with and without dialysis. Some reported that the additional benefit to survival from dialysis initiation may be slight, given their age or other illnesses. Some individuals simultaneously held the '*do or die*' paradigm, and the concept that dialysis may not extend their life by long:

> *It's basically 'have that or die'… [but] if you do have the dialysis what are they going to gain me, an extra six months, or a year?* (Joe;70s;HD)

In summary, this first theme captured how participants depicted that they were offered dialysis, perceived as a treatment to prolong life. The magnitude and framing of this potential survival benefit appeared to be associated with participants' willingness to accept that they could choose not to pursue dialysis.

Theme 2: The ‘need’ for dialysis

Initiation of kidney replacement therapy following kidney failure often appeared as a *fait accompli*. Many participants recalled having been told years or decades before that they would eventually require dialysis, with initiation widely referred to in depictions of certain futures, including directive terms, such as “*having to*” or “*needing to*” start dialysis. Treatment for kidney failure often appeared to be synonymous with in-centre haemodialysis, and familiarity with, knowledge, and understanding of this (often referred to simply as “*dialysis*”) appeared to surpass that of peritoneal dialysis, CKM and transplantation. Indeed, that there were alternatives to haemodialysis appeared to have come as a surprise to several participants who had been visiting the kidney clinic for many years:

> *From the start then I knew that in twenty years I’d probably be on dialysis… I didn’t know the second, third options [peritoneal dialysis and CKM] were there. I assumed on dialysis.* (Brian;70s;PD)

All other participants receiving or expecting to receive CKM recognised dialysis as having been an option, but portrayed themselves as having declined dialysis, rather than as having made an active choice to pursue CKM. Even those expecting CKM often appeared to have limited understanding of what it would involve, depicting a ‘status quo’ option, rather than the introduction of a new treatment or framework for care provision:

> *You might as well go the normal route [die without starting dialysis] and take what’s coming to you.* (Betty;80s;CKM)

Where the concept of CKM was discussed by those preparing for dialysis, it was typically presented as a ‘do nothing’ option:

> *We were talking dialysis, and to see what all the options are, I said “what if I don’t do anything about it, you know?”* (Derrick;80s;HD)

A minority of participants recalled being informed that one or more potential treatments were impossible for them, with some recalling how they had been restricted to just one option. Transplantation was widely perceived as unattainable, though few recalled being informed of this by their clinical team. Three participants under the age of 80 described themselves as awaiting review of their eligibility for transplantation. For those who perceived themselves as ineligible, age was widely advanced as the reason:

> *They started talking about "have you thought about what your treatment's going to be eventually" and I said "well, I suppose having a transplant possibly". "Oh no, no, no" he said, "too late for that, too late for that, at your age", he said, "I wouldn't recommend a transplant, you know, you'll have to go on dialysis".* (Brian;70s;PD)

A minority of participants alluded to the idea that their future treatment remained undecided or could change. For some, this appeared to reflect an understanding that future declining health might influence their attitude towards dialysis. Other individuals preparing for dialysis discussed temporising or avoiding the decision to prepare for dialysis, but presented this as compatible with its inevitable initiation:

> *If it comes to it, I might have it at home or I might even not bother, because I'm not as good as I was.* (Beryl;80s;CKM)
>
> *I know the dialysis is going to come, but I don't want to think about it, you know?* (David;60s;HD)

In summary, this second theme captured how many participants appeared to conceive of dialysis as an inevitability, unless they declined initiation, or died from a competing cause before reaching the putative dialysis initiation point.

Theme 3: Weighing-up quality and quantity of life

A 'weighing up' of pros and cons was universal, where individuals described selecting their treatment from several options. The assumed extension to life provided by dialysis needed to be of acceptable quality, and participants' capability to live and undertake activities independently appeared to be critically important:

> *If it's going to give me a reasonable quality of life, then it will keep me going. If I didn't think that I would have a reasonable quality of life, then I would take the option of nothing.* (Muriel;60s;HD)

Participants appeared to consider the routine of dialysis as unpleasant. Intrusion into daily life was consistently cited as negative, and some participants were concerned life would become "*centred around*" (Brian;70s;PD) treatment. The time used for dialysis was frequently portrayed as "*wasted*" (multiple participants). Few anticipated feeling better after initiation:

> *You have to get transported to hospital and back again. So, you can imagine you leave home about eight o'clock in the morning and you'd be lucky if you got home at six o'clock at night. Well, that would be fun, wouldn't it? (laughs)* (Betty;80s;CKM)

Only one participant suggested a positive aspect of dialysis beyond its influence upon survival and symptom control – anticipating social interaction as part of treatment:

> *If I go to the hospital, if nothing else there's going to be a nurse or a tea lady to have a chat with. Company.* (Muriel;60s;HD)

Some appeared to consider the orchestration of home dialysis and associated equipment as an intrusion that they were not willing to accept. For those expecting to start dialysis, the negative aspects tended to be framed as justified:

> *I know it's a drag going to hospital three times a week, but at least I'm here to do it.* (Derrick;80s;HD)

Older, frailer, and largely unpartnered participants spoke of a decline in their ability to partake in pleasurable activities, and adaptation to changes in capability. The concept of a complete or "*good life*" (Clive;80s;CKM) was pervasive. However, rather than considering their current life "*not worth living*" (Derrick;80s;HD), for participants who were preparing for CKM, it was a putative future life on dialysis that was considered unacceptable. For this group, the negative aspects of dialysis were framed as dominant, even where a longer life was anticipated, were they to start it:

> *Ok so you're going to have a longer life, but what life is it?* (Clive;80s;CKM)

For some, the trade-offs between their anticipated future on dialysis and one without appeared closely balanced. This seemed to fuel uncertainty about whether their planned treatment was right for them, or an expectation that they might not undertake their clinically documented plan:

> *I do have great reservations as to whether any of it's needed and whether it's actually worth the while? This is only a temporary respite and that you're going to die anyway... All seems quite a horrible process, and as I say, I think it's a bit of a last-ditch thing, you know, to keep you running for a little bit longer.* (Joe;70s;HD)

In summary, this third theme captured how all participants appeared to weigh-up the positive and negative aspects of futures with and without dialysis, allowing them to evaluate their anticipated treatment, and compare this with alternatives.

Discussion

This UK study looked at treatment decisions between dialysis and CKM, exclusively amongst older people with kidney failure who have not started KRT. We examined how individuals comprehended and interpreted the comparative benefits and burdens of dialysis.[9] We found that treatment plans were made in the context of participants having already accepted the serious nature of their condition and the possibility of death as a result. Few participants – irrespective of their age or levels of comorbidity – appeared familiar with the uncertain survival benefits of dialysis. For many, a future without dialysis did not appear to be perceived as a real option; replaced with a '*do or die*' Hobson's choice.[14] Those opting for dialysis did not appear to have been fully supported to consider the implications of their decision upon their remaining lives, including where or how they might die. Unfamiliarity with home therapies and CKM appeared to render haemodialysis the default treatment that would eventually be "needed" for life to continue. Meanwhile, participants considered the life they expected to live when appraising treatments, and readily made trade-offs between their benefits and burdens.

To decline dialysis appeared to be a viable option only to those who perceived that the presumed survival benefit might be outweighed by the burdens of treatment. Choosing CKM appeared to involve going against the grain – 'opting-out' from dialysis.[35-40] In keeping with the literature[15,16,35,36,41,42], there was no evidence that our participants actively opted for palliative care. Rather, they rejected a *future* life on dialysis.[43] Critically, this did not indicate that they considered their *current* life intolerable.

It has been shown in patients of all ages that kidney failure treatment preferences reflect trade-offs[44] between anticipated benefits – principally survival on dialysis[15,16,45] and the influence upon independence, daily life, responsibilities, and interests.[11,12,19,42,46] The trade-offs that older people make are likely to differ from those made by younger, potentially transplantable people living different occupational, social and familial lives.[11] Longevity is rarely paramount for people with life limiting illness, who value support for themselves and loved ones, and prioritise independence, meaning, comfort, and achievement of life goals.[47,48] Whilst kidney replacement therapy is plainly life-prolonging for those whose survival is dominated by their kidney disease, the comparative survival and quality of life benefits of dialysis and CKM remain unclear for many older people.[9] Some who initiate dialysis will die close to – or even before – the point that they would have died, had they never started. Those at the highest risk of competing mortality – the oldest and those living with major comorbidities – are most likely to prepare for or receive treatment that does not prolong their lives.[9]

Conflation between CKM and '*no treatment*'[13,17,18,49-52] or death[14,16,40] may undermine individuals' freedom to make trade-offs between the uncertain comparative benefits and burdens of dialysis and CKM. That a 'non-choice' can arise from the misperception of less invasive care as 'doing nothing' has long been recognised in cancer[53] where patients can be steered towards anticancer treatment, irrespective of likely treatment benefit.[54] Meanwhile, which treatments individuals prepare for and initiate profoundly influences their experience of living and dying. For example those who choose dialysis appear more likely to be hospitalised and to die in hospital than others who opt for CKM.[9] Exaggerated impressions of the survival implications between dialysis and CKM are likely to lead some to prepare for dialysis, despite CKM being a better fit for their preferences to minimise treatment intrusion.

It has been shown before that people with kidney disease may be left to deduce which treatment options are available to them[11,35] and are not always provided with the information or support needed to ensure their treatments fit their preferences.[55,56] Our study portrays a one-dimensional system of decision-making, where the trade-offs bound up in a potentially longer life with dialysis, and a potentially shorter life without, did not appear to have been successfully facilitated. It may appear that little progress has been made since earlier studies suggested deficiencies in decisional support.[13] This raises the question as to whether clinicians believe and feel able to convey the uncertain survival benefits of dialysis and highlights the need to develop ways of helping patients to weigh up the benefits and burdens of treatments.

Older people facing the prospect of kidney failure are likely to benefit from tailored approaches to decision-support. This must reflect where they are in the life course and what a future with kidney failure might look like for them. The three themes identified in this study provide clues as to how their care might be adapted. Clinicians will need training and resources to successfully convey uncertainty, support the weighing-up process around factors of importance to the individual, and challenge the idea that dialysis is the default. Consistency across clinical teams and over time is challenging[57] and CKM services must be available and sufficient.[13] How CKM is depicted and conceived appears central. Framing CKM more accurately can improve patients' perceptions.[17] Driven by the perceived need to offer "*positive alternatives to dialysis*" (Davison et al., 2015[58], pg.453) efforts have been made to define and standardise CKM.[59] This is important, given that access to and models of kidney supportive care are inconsistent[60,61] – meaning that in some places, a choice to not pursue dialysis does not lead to receipt of CKM. However, fully establishing CKM as a viable alternative to dialysis may require patients and clinicians to be persuaded that the 'do or die' paradigm is a fallacy born from envisaging dialysis as 'needed' to prevent death. If this were to be true, CKM *could never be received,* since those who 'need' but don't start dialysis would just die. Whilst patients and clinicians may *perceive* that the choice is between dialysis and death, this is not the decision being made. Median survival from treatment decision-making or reaching kidney failure ranges between 20 and 67 months for dialysis and 6 to 31 months with CKM, depending upon age and other factors.[62] Individuals may need to be helped to understand that the absolute survival advantage of dialysis can be small, given their shorter prognosis. This will require prognostic honesty, perhaps with the sharing of absolute survival estimates, and is most likely to be successful if decision-support involves routine discussion and documentation of individual's goals for treatment of kidney failure. Living longer is rarely the sole determinant of treatment choice.[20] Individuals who are supported to contextualise the reasons for either dialysis initiation or for choosing CKM will be better placed to make decisions based upon their preferences.

The strengths of this study include a rigorous application of qualitative methods and broad range of clinicodemographic variation between study participants, sampled from multiple kidney centres. Including individuals who had not started kidney failure treatment ensured the findings were relevant to those making preparatory decisions. The study has limitations. Participants were recruited from three centres, limiting the breadth of approaches to kidney failure management. The frequency and approach to CKM differs between kidney units[13,61,63], which may influence the transferability of findings. The sample size is small, though this reflects the fact that sufficient information power arose early to support the major themes. Despite efforts to recruit from diverse ethnic backgrounds, all participants were white British. Culture and faith play important roles in understanding of disease and treatment decision-making[64,65], so our findings may not be typical for members of other communities and further research with ethnically diverse groups is needed. Interview studies can only capture participants' accounts of clinical encounters. These encounters appear critically important in forming people's perceptions of their treatment options, and observation and analysis of clinician-patient interactions may help to uncover which consultation approaches work best.[66]

In conclusion, this study identified that an assumption that life will end unless dialysis is started, alongside unfamiliarity with and misperceptions regarding treatment options conspire to cast haemodialysis as the default treatment for kidney failure. The influence kidney specialists have upon patients' understanding and expectations of care means they must be trained to ensure patients can make shared, informed decisions. Clinicians must support patients to make trade-offs between the uncertain benefits and requisite burdens of dialysis and CKM. Better evidence will help. Meanwhile, redefining the 'need' as the 'reason' for dialysis initiation, and reframing the 'do or die' fallacy by sharing absolute survival predictions with dialysis and CKM might facilitate improvements in person-centred decision-making.

Disclosure Statement

FC is Chief Investigator, and JC and LR coinvestigators for the Prepare for Kidney Care Study, a randomised controlled trial comparing outcomes for older people preparing for kidney dialysis vs. CKM (https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/prepare-for-kidney-care/). LS, NIHR Career Development Fellow (CDF-2018-11-ST2-009) is funded by the NIHR for this research project. The authors have no other relationships/activities/interests related to the content of this manuscript to declare.

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Author contributions

BH designed the study and is responsible for the overall content as guarantor. He conducted interviews as part of his doctoral fellowship (PhD), supported and supervised by LR, RM, FC, JC and LS. MS joined the authorship to provide perspective from a lived experience of kidney disease. BH conducted line-by-line coding of interview transcripts independently. RM, JC, LR and LS also independently read and coded a selection of transcripts. Preliminary findings were iteratively discussed with the study team, with consideration of wider meaning, alongside reorganisation, recoding, and thematic development. BH wrote the draft manuscript. All authors reviewed, revised, and approved the final manuscript.

Competing interests

FC is Chief Investigator, and JC and LR coinvestigators for the Prepare for Kidney Care Study, a randomised controlled trial comparing outcomes for older people preparing for kidney dialysis vs. CKM (https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/prepare-for-kidney-care/). LS, NIHR Career Development Fellow (CDF-2018-11-ST2-009) is funded by the NIHR. The authors have no other relationships/activities/interests related to the content of this manuscript to declare.

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Supplementary materials

Topic guide for interviews

COREQ Checklist

Data sharing statement

Participants consented to their anonymised data being made available to other researchers who want to analyse the data in the future. Data are managed by the University of Bristol and applications for their use should be made to the communicating author.

Tables and figures

Table 1. Participant characteristics (n=15) * Due to rounding, percentages may not always appear to add up to 100% **One participant who had an eGFR of 25ml/min/1.73m2 at the time of interview, having been 14ml/min/1.73m2 at recruitment. Key. CKM, conservative kidney management; eGFR, estimated glomerular filtration rate; HD, haemodialysis; IMD, index of multiple deprivation; PD, peritoneal dialysis; WHO, World Health Organization

Participant characteristic (n=15)	**Number (%)***
Gender	
▪ Female	7 (47)
▪ Male	8 (53)
Age	
▪ 65 – 69	2 (13)
▪ 70 – 74	1 (7)
▪ 75 – 79	2 (13)
▪ 80 – 84	5 (33)
▪ 85 – 89	4 (27)
▪ ≥ 90	1 (7)
eGFR (ml/min/1.73m^2)	
▪ <10	4 (27)
▪ 10 – 14	10 (67)
▪ ≥ 15	1 (7)**
Treatment plan	
▪ HD	7 (47)
▪ PD	2 (13)
▪ CKM	6 (40)
▪ Active on transplant waiting list	0 (0)
Major comorbidities	
▪ Type 2 diabetes	10 (67)
▪ Ischaemic heart disease	7 (47)
▪ Hypertension	5 (33)
▪ Malignancy	4 (27)
▪ Obesity	2 (13)
▪ Heart failure	1 (7)
▪ Stroke	1 (7)
▪ Other comorbidity	5 (33)
Cause of kidney disease	
▪ Type 2 diabetes	10 (67)
▪ Hypertension and/or vascular disease	3 (20)
▪ Removal of kidney cancer	2 (13)
WHO performance status	
▪ 0	0 (0)
▪ 1	5 (33)
▪ 2	2 (13)
▪ 3	8 (53)
▪ 4	0 (0)
Years of full-time education	
▪ 0 – 5	1 (7)
▪ 6 – 10	6 (40)
▪ 11 – 15	6 (40)
▪ 16 – 20	2 (13)
IMD	
▪ 1 – 2	4 (27)
▪ 3 – 4	3 (20)
▪ 5 – 6	6 (40)
▪ 7 – 8	1 (7)
▪ 9 – 10	1 (7)

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University of BRISTOL

The UNPACK Study – Interview Topic Guide, Phase 1 Qualitative Interviews (patient, family member or both)

- Check they received **UNPACK Phase 1 Interviews, Patient information sheet**
- Explain interview and duration, including audio-recording
- Negotiate whether interview will be individual, or two-person (patient/family member)
- Confirm that patient is happy for their healthcare to be discussed with family member
- Obtain informed consent
  - Capacity assessment:
    - Ask whether they would like to continue to an interview
    - Ask what they understand would happen if they declined an interview
    - Reiterate that this decision will not impact care
    - Check for further questions
  - Complete **UNPACK Phase 1 Qualitative Interviews, Consent Form** ☐

Interview - Start audio recorder [date of recording ______________]

- *"The point of these interviews is to help me to understand what is important to people when thinking about treatments for kidney disease. How do these 'important things' influence what treatments are chosen? Who and what else is involved?*
- *There are no right or wrong answers – I'm interested in your experiences, thoughts and ideas. Whatever you say will be useful to me – I'm here to learn from you.*
- *You can stop the interview or change the subject at any point – please just say."*

Tell me a little about yourself…

- *Still working/used to work as?*
- *How so you spend your time?*
- *Hobbies/interests?*

When kidney problems first diagnosed?

- *What happened?*
- *Since?*
- *Now?*
- *Expectations?*

What discussions about future have happened?

- *With whom?*
  - *Kidney team*
  - *Family/friends*
  - *GP*
  - *Other patients?*
- *What discussed?*
- *Why were they had?*
- *Were decisions made?*
  - *How?*
  - *Who?*

What (RRT) treatments have been discussed?

- *Initial feelings about these?*
- *Feelings about them now?*
- *Understanding of what is involved?*
- *Who and how did you learn about them?*
- *Likelihood of needing?*
- *Transplantation?*
- *Thoughts about receiving dialysis?*
  - *Effects on self*
  - *Others*
- *Thoughts about receiving conservative care?*
  - *Self*
  - *Others*

What do you think might be the advantages/ disadvantages of planning now, vs. waiting to see?

Do you feel like you have a plan?

- *If not, why not, would you want one?*
- *If so, how/when?*
- *Process: gradual/one off?*
- *Did you feel like there were alternatives?*
- *Who there? Who chose?*
- *Is this how you usually make decisions?*

Have you thought about end of life care?

- *Have you talked? Who? How?*
- *How might these plans influence?*

Have you thought about loss of capacity?

- *What plans made?*
- *Lasting power of attorney?*

- *Would you like to receive updates about this research?* ☐
- *Copy of transcript?* ☐

- *Check I have all Information I need… age* ☐ *sex* ☐ *ethnicity* ☐ *marital status* ☐ *who you live with* ☐

- **Thanks. Stop and pack audio recorder.**

Manuscript: "It's basically 'have that, or die'" – a qualitative study of UK older patients' choices between dialysis and conservative kidney management.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Data collection "Page 7 Line 12"
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Data collection "Pg 7 L13"
3. Occupation	What was their occupation at the time of the study?	Data collection "Pg 7 L12"
4. Gender	Was the researcher male or female?	Data collection "Pg 7 L12"
5. Experience and training	What experience or training did the researcher have?	Data collection "Pg 7 L13"
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Data collection "Pg 7 L7" .
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Data collection "Pg 7 L24"
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	No. Further information available in the linked open-access thesis.

Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods "Pg 12 L12" And Data analysis "Pg 8 Line 4-5"
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants "Pg 12 L20 onwards" and Data collection "Pg 13 Line 2 onwards"
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Data collection "Pg 7 Line 3 onwards"
12. Sample size	How many participants were in the study?	Data collection "Pg 7 Line 28-29", Results "Pg 9 Line 3"
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Results "Pg 9 Line 4"
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data collection "Pg 7 Line 11"
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Data collection "Pg 7 Line 14"
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results "Pg 9 Line 8 onwards"
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Additional file and Data collection "Pg 7 Line 19"
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No. Data collection "Pg 7 Line 11"
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Data collection "Pg 7 Line 26"

20. Field notes	Were field notes made during and/or after the inter view or focus group?	Data collection “Pg 7 Line 27”
21. Duration	What was the duration of the inter views or focus group?	Results “Pg 9 Line 8”
22. Data saturation	Was data saturation discussed?	Data analysis “Pg 8 Line 18” and Data collection “Pg 7 Line 28-29”
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No. Data collection “Pg 7 Line 30”
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Data analysis “Pg 8 Line 11-12”
25. Description of the coding tree	Did authors provide a description of the coding tree?	Data analysis “Pg 8Line 8-9””
26. Derivation of themes	Were themes identified in advance or derived from the data?	Data analysis “Pg 8 Line 15-18”
27. Software	What software, if applicable, was used to manage the data?	Data analysis “Pg 8 Line 2”
28. Participant checking	Did participants provide feedback on the findings?	Data collection “Pg 7 Line 30” and Data analysis “Pg 8 Line 23”
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes – See Results, Findings p10 onwards
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes – See Results, Findings p10 onwards
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes – See three themes presented in plain English summary, abstract and results sections
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	No minor themes were described