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Gender Differences in Experiences and Expectations of Hemodialysis in a Frail and Seriously Unwell Patient Population

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Introduction: Surprisingly few studies have explored the experiences of seriously unwell people with kidney disease on hemodialysis therapy: we conducted a mixed-methods study to investigate gender differences in illness experience, symptom burden, treatment considerations or expectations in this cohort.

Methods: Seriously unwell people on hemodialysis (1-year mortality risk of >20%) at 3 hospital-based units were invited to take part in a structured interview or to complete the same questions independently via a questionnaire. A total of 54 people took part (36 males, 18 females); data analysis was undertaken using a thematic approach.

Results: "Desire to keep living" is the most important and basic thought process when starting dialysis. Fear also predominates influencing risk assessment and decision-making. Once fear is managed, there are physical, social, practical and emotional issues to rationalize, but choice only seems possible if shared decision-making is part of the consultation.
Gender differences were seen in perceived hopes and expectations of treatment. Males were more likely to prioritize achievement of physical goals, with females prioritizing a wish to feel well. Both genders reported significantly higher symptom scores than their health care provider perceived, however this difference was more marked in females. Dialysis regret existed in >50% of participants and 6 out of 54 (11%) stated that they would have chosen no dialysis at all. Females were more likely to report feeling depressed ($P = 0.001$).

Conclusion: Different genders approach treatment decisions and prioritize treatment expectations differently. Recognizing this will allow personalized care plans to be developed and improve the experiences of seriously unwell people with kidney disease.

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As a consequence of our aging population, it is increasingly common for kidney replacement therapy to be offered to older, frailer people. As a result, there are a growing number of seriously unwell people on haemodialysis[1] who tend to have multiple comorbidities and a high care burden, meaning a greater proportion of their time is spent managing health care issues or being within a health care setting. Their perceptions of these experiences can influence subsequent behavior. Indeed, illness perception has been associated with numerous outcomes including treatment adherence, functional recovery and quality of life.[2]

Furthermore, patient experience is a key indicator of the quality of patient care received while undergoing treatment.[3] As such, the significance of patient-reported experience measures (PREMS) is becoming increasingly recognized. In contrast to patient-reported outcome measures, PREMS capture perceived experience of care throughout a treatment process. They can encompass a wide range of metrics, ranging from cleanliness of facilities to communication received, and from timeliness of assistance or transport, to access to health care professional.[4–6] Historically, routine PREM collection within renal registries has been limited,[6]

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although this is improvingdue to international collaborations such as the Standardized Outcomes in Nephrology initiative.[7-9]

The impact of gender on patient experience is an area of growing interest. Differences in general patient satisfaction between males and females was first noted over 15 years ago,[10] but it is only more recently that this has been explored in more detail.[11-15] Females consistently report fewer positive experiences and have lower scores for both physical and mental health. Nevertheless, nearly all these studies were undertaken in North America and whereas some include an unselected patient cohort, none have focused specifically on people with kidney disease.

Alongside this, although considerable literature exists on the lived experience of dialysis[16-18], very few studies have explored the experiences of seriously unwell people on hemodialysis. Axelsson and colleagues interviewed 8 severely unwell adults (5 males, 3 females) to investigate how they contextualized living with hemodialysis when nearing end of life. A second study interviewed 20 people of Latin-America heritage to explore cultural preferences among those with advanced illness,[19] but neither sought to explore treatment expectations or factors influencing high-quality care.

Recognizing an evident knowledge gap, we sought to explore the experiences of seriously unwell people while on hemodialysis, with a particular focus on gender differences. Females with advanced chronic kidney disease (defined as estimated glomerular filtration rate less than 20 ml/min per 1.73 m^2 report a higher symptom burden than males,[20] as do those newly started on hemodialysis.[21] However, further exploration in prevalent people on dialysis has not been explored, and we were keen to distill this further utilizing a qualitative approach.

We sought to explore what participants hoped to get out of treatment, what they considered "good treatment" to be and their expectations and regrets since starting dialysis. We were particularly interested to determine if gender differences existed in terms of illness experience, symptom burden, or treatment considerations and expectations. From this, we hope to be able to identify ways to improve the experiences of people with end-stage kidney disease.

METHODS

Study Design

This is a mixed methods study. In-depth structured interviews were conducted as part of the ePISTLE study (Perceptions of Illness Severity, Treatment Goals and Life Expectancy[22]). Ethical approval was granted (18/LO/1386) and the study was registered on clinicaltrials.gov (NCT04225416).

Participant Selection

Case notes of all people receiving maintenance hemodialysis at 3 hemodialysis centers at Imperial College Healthcare National Health Service Trust were screened ($n = 411$) and a validated mortality risk score for each patient was calculated.[23] Those whose 1-year mortality risk score was ≥20% were considered seriously unwell and invited to take part in the study. Ninety people were eligible and 54 chose to take part.[22] Seven participants (13%) chose to complete the questionnaire independently and 47 (87%) preferred a structured interview, using the questionnaire as the framework for discussion.

Data Collection

Interviews were conducted in a private space, during hospital hemodialysis sessions or following routine outpatient clinical review and lasted approximately 20 minutes. People receiving care from either interviewer (HB or AA) were not enrolled into the study. Participants self-reported sociodemographic information (age, sex, ethnicity and duration of renal replacement therapy). Symptom burden was assessed using the Integrated Patient Outcome Scale Symptom survey, a validated patient-reported outcomes tool[24] All interviews were transcribed verbatim at the time of interview. Participants' named nurse, and lead doctor were also asked to complete the Integrated Patient Outcome Scale Symptom survey at the time of interview.[22]

Data Analysis

A thematic analysis approach of qualitative data was used to identify key areas and themes[25] from the structured interviews and completed questionnaires. Data were analyzed without identifiers. Analysis was conducted using a standard methodological approach: inductive coding was performed to identify themes, without an a priori theoretical perspective and a table of master themes was generated. Codes were developed and confirmed by 2 trained individuals (HB and NT) who evaluated the transcripts to identify each theme. Master themes were then cross-checked with the original transcripts to ensure validity.[26] Once themes and subthemes were identified, the transcripts were labeled according to self-identified gender and age. From this, analysis of theme frequency according to gender was undertaken.

Quantitative data analysis was performed using GraphPad Prism software (version 9; GraphPad Software Inc, La Jolla, CA) and results reported using descriptive statistics. Normality of distribution of data

Table 1. Demographics of study participants

Demographics	Male (n = 36)	Female (n = 18)	P value
Age (yr) mean, (SEM)	74.4 (1.63)	71.1 (2.38)	0.25[a]
Length of time on dialysis (mo) (median, IQR)	46 (24–82)	36.5 (13–58)	0.36[b]
Ethnicity			
Black	5	3	0.07[c]
White	21	9	0.34[c]
Asian	6	3	1.00[c]
Other/not recorded	4	3	0.29[c]
Actively involved in decision to start dialysis, n (%)	23 (64)	12 (67)	0.84[c]

IQR, interquartile range; SEM, Standard error of the mean.
[a]Unpaired t-test.
[b]Mann-Whitney test.
[c]Chi-squared.

was assessed using the D'Agostino–Pearson test. Nonparametric variables were expressed as median (interquartile range) and compared using the Mann–Whitney U test. Parametric variables were expressed as mean (SD) and compared using the unpaired t test or analysis of variance. The 2-tailed Fisher exact test was used to compare categorical data between 2 groups. $P < 0.05$ was considered statistically significant.

RESULTS

Demographics

Demographics of the 54 people included in the study are shown in Table 1. Thirty-five out of fifty-four (65%) felt actively involved in the decision to start dialysis. There were no differences between the genders in terms of age, ethnicity, length of time on dialysis or involvement in the decision to start dialysis (Table 1).

Factors Considered When Starting Dialysis

Responses to the question "What factors did you consider when deciding whether to start dialysis?" were analyzed. Six master themes were identified: a strong desire to keep living, fear, decision making and choice, impact on wellbeing, social support network and a desire to achieve specific health goals. (Table 2).

Desire to Keep Living

Participants were very aware that the alternative to dialysis was death. Not only did they have an awareness of their own mortality, but many also commented on their experiences of death in their friends. The sudden absence of fellow peers on hemodialysis was noted, and some had also witnessed death occur within the dialysis unit. As such, the possibility of their own death and a strong desire to keep living was frequently raised.

Fear

Fear was a dominant factor for some participants. Fear of the dialysis process, and once started on hemodialysis, the fear that something could go wrong. Concerns about potential end of life symptoms were raised:

Table 2. Factors considered when starting dialysis: master themes and exemplar quotes

Master theme	Subthemes	Exemplar quotes
Desire to keep living	Awareness of mortality Witness to death(s) of friends/peers	"I had always said I didn't want to do dialysis, but they said the alternative was death." Female, 87 "I've seen a lot of my friends die and they are younger than me. I feel like I'm living on borrowed time." Male, 85
Fear	Fear of dialysis process Fear of something going wrong Fear of potential end of life symptoms	"I was scared when I looked at the machine and saw blood, I went home scared." Male, 84 "If I have a problem, I can seek help from the staff and doctors here, whereas at home, I wouldn't know what to do." Male, 66 "I'm scared of drowning." Female, 77
Decision making and choice	Collation and understanding of information Formation of conclusion Perception medic(s) know best Sense that alternatives were not suitable/ I am not suitable No choice/ Directed/ Did as I was told	"I thought about home dialysis but decided it was better to go to clinic." Male, 82 "I've been able to dialysis with my sister here, with machines next to each other both times." Female, 62 "There was nothing I could do…I was told I have got to have the dialysis." Male, 84 "I just do what the doctors say. They control it." Male, 72 "I couldn't have PD as I have too much scar tissue from many operations." Male, 55
Overall wellbeing	Impact of transport/traveling on quality of life Impact of dialysis shifts on day/night cycle Potential improvements to health Desire to "feel better" Frustration at wasting time in a health care setting Symptom control	"I wanted to feel better." Female, 67 "I wish I felt better on dialysis, I think I'd be better able to cope with it. But I go home, and I go to bed." Female, 70 "Too much time is wasted in hospital and on transport. I've wasted 10 hours today here and on transport." Male, 75
Social support network	Family wishes Home circumstances precluding home-based therapies Desire to travel and see family	"My son said you must go give it a try." Male, 84 "I did a lot of it because of my sister… I know how upset she would be if I said no and died." Female. 70
Specific health goals	Mobility Wish for an operative procedure To assist through chemotherapy	"I wanted to walk." Female, 63 "I wanted my heart operation." Male, 86 "I needed dialysis as my kidneys were not fully functional and to assist me through chemotherapy." Male, 67

PD, peritoneal dialysis.

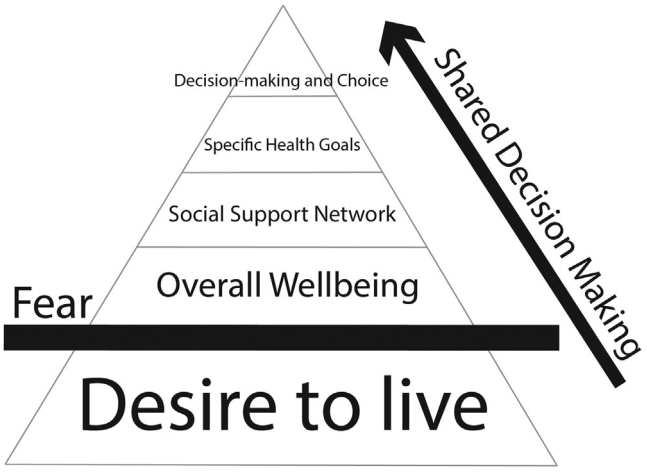


Figure 1. Hierarchy of thought processes when contemplating dialysis. When approaching factors considered when starting dialysis, we found there appears to be a hierarchy to the thought processes involved. We found "Desire to keep living" is the most important and basic factor, but "Fear" also dominated and influences risk assessment and decision-making. Once fear is managed, there are physical, social, practical and emotional issues to rationalize, but choice only seems possible if shared decision-making is part of the consultation.

breathlessness, "drowning" and pain predominated, but the visibility of blood in the hemodialysis process was also noted.

Decision Making and Choice

The process by which participants collated information and formed a decision on whether to start dialysis or which modality was explored. There was a strong perception that medic(s) know best. Many participants felt that they had no choice in the decision-making process, either because of strong direction from involved clinicians, or that their bodies had "failed" them, for example: "I couldn't have PD [peritoneal dialysis] as I have too much scar tissue from many operations." In-center hemodialysis was viewed as a "safe" option-having trained staff on hand to deal with any potential problems was extremely reassuring for this patient cohort.

Overall Wellbeing

The perceived benefit of dialysis for overall wellbeing was frequently cited as a strong driver for treatment initiation. However, for many participants, the perceived reality of dialysis contrasted heavily with their lived experiences: "hemodialysis is nothing like it was portrayed." Many started hemodialysis from a desire to feel better and with a wish for symptom control, but as the interview progressed, the negative impacts of dialysis on quality of life, circadian rhythms, and ongoing unresolved symptomatology were mentioned.

Social Support Network

The influence of a person's social support network on initiation of dialysis was wide ranging. Family wishes strongly influenced decisions to begin dialysis, but a desire to travel and see family was also highlighted. For others, who perhaps did not have the same degree of social or family support, their home circumstances precluded various home-based therapies, and for these participants, again there was less perceived freedom in their decision to begin hemodialysis.

Specific Health Goals

Finally, for some participants, achievement of specific health goals was a strong driver for starting hemodialysis. The desire for mobility was frequently mentioned, but also the need for dialysis as an adjunct (for example to assist through chemotherapy or to permit further operative procedures) was highlighted. For these participants, it appeared that the decision to begin hemodialysis was easier, there was a clear "benefit" to initiation and negative impacts of dialysis instigation were considered less important.

When considering factors cogitated when starting dialysis, there appears to be a hierarchy to the thought processes involved. "Desire to keep living" is the most important and basic factor, but fear also dominated and influences risk assessment and decision-making. Once fear is managed, there are physical, social, practical and emotional issues to rationalize, but choice only seems possible if shared decision-making is part of the consultation (Figure 1).

Gender differences were seen in the way that participants approached the decision on whether to begin hemodialysis. Themes identified were grouped into master themes which showed no significant differences in frequencies between the sexes, but unpicking subthemes further highlighted subtle differences (Figure 2a). We found males were significantly more likely to consider alternative treatment options ($P = 0.001$), whereas females were more likely to prioritize overall well-being.

Treatment Expectations

To identify treatment expectations, participants were asked both at an individual level, "what do you hope to get out of treatment," but also to consider more generally, "what does good treatment mean to you?." Answers to both these sections were combined to identify master themes for treatment expectations.

Seven master themes were identified; A desire to achieve physical goals, a sense of social normalcy, a feeling of (mental) wellbeing, expectations of care, a

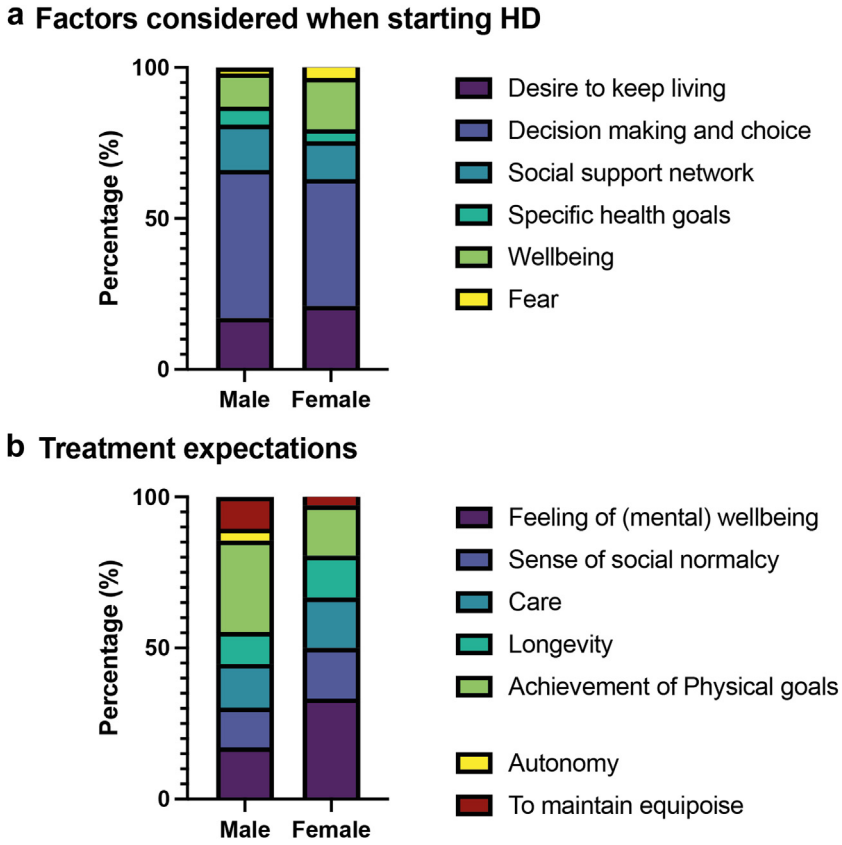


Figure 2. Gender differences seen in considerations and expectations of treatment. (a) Factors considered when starting hemodialysis. (b) Treatment expectations.

desire to maintain autonomy, equipoise and to promote longevity (Table 3).

Achievement of Physical Goals

Participants listed various physical goals as a desired outcome of treatment. Control of symptoms was prioritized highly, as was a desire to live an "active life": maintaining activity levels and to have the energy and stamina needed to complete their daily goals. Transplantation as a goal of dialysis was also frequently mentioned, despite participants in this study being selected for having a high mortality risk and very few actually being listed for transplantation at the time of study.[22]

Sense of Social Normalcy

A desire to maintain a sense of social normalcy was also frequently highlighted, with participants wishing to be able to go shopping, do activities, to see friends and travels, as well as to hold down jobs and relationships. There was a recognition that with hemodialysis, significant time had to be spent within a health care setting, but that a wish to maximize the time spent outside of health care was paramount.

Mental Wellbeing

Alongside achievement of physical goals, was a desire to feel better/well psychologically. The wish to "feel well" was emphasized by many participants. Some participants wanted to feel as though their treatment was continually progressing toward recovery, but this was not uniform.

Expectations of Care

Expectations of care varied quite significantly. Nearly all participants wanted co-ordinated, consistent and predictable care: the current fragmentation and independence of treatment teams seen across the health care system was not well received. However, while some participants were keen to be involved in, and to influence their treatment decisions, others wanted to be "looked after" and felt that the responsibility for treatment delivery very much lay with members of health care staff.

Autonomy

A wish to retain a sense of autonomy was also highlighted by participants, with concerns about "suffering" or an inability to communicate at end-of life emphasized.

Equipoise

Some participants felt that they were happy with current treatment outcomes and wanted to continue "as I am" (Male, 77 years).

Table 3. Treatment expectations: master themes and exemplar quotes

Master theme	Subthemes	Exemplar quotes
Achievement of physical goals	Specific symptom control (e.g., pain, fatigue, blood pressure, seizures, sleep) Maintaining activity levels Transplantation Mental clarity Improved energy and stamina	"I'd like to regain my muscle strength and not feel the cold so much." Male, 62 "Good treatment relieves the pain and gives maximum quality of life; it lets me move, lets me think." Male, 60 "To get a good night's sleep." Male, 82 "[To] live as active a life as possible." Male, 67
Sense of social normalcy	To maximize time spent outside of a health care setting To have a job/girlfriend To go shopping/get the bus/go to church/ go home Ability to see friends and family To travel	"I'd like to feel more normal. Like I used to feel. I feel sometimes it's so draining, and I try to be a bit upbeat." Female, 70 "Everyone thinks I'm alright but I'm not." Female, 70 "To go back to work. I'd like to do a part time job, just to keep me busy." Male, 62
Feeling of (mental) wellbeing	To feel better/well/healthy/at peace Maximizing quality of life Sense of progression toward recovery	"To feel well, not ill and miserable." Female, 85 "To get well and to lead a happy and comfortable life." Female, 61
Expectations of care	Paternalistic approach ("to be looked after") Coordinated, consistent and predictable care Safe and polite environment Good communication Responsive care/treatment Less fragmented/polarized care To get the best treatment?	"Treatment is too fragmented. At one time you used to see a single consultant. Now things are so polarized that one person cannot assist with something else." Female, 70 "It isn't up to me, it's up to the staff to do the best they can for me." Male, 66 "I don't like to discuss my personal problems in front of any others which I have to do on the dialysis unit." Female, 61
Autonomy		"[I want to] be in control of my body and what happens to it." Female, 70 "I don't want to be kept alive or on a machine if I couldn't communicate or wasn't aware of what was going on. I don't think I'd like to carry on." Male, 66 "There's no point living too long if suffering continues." Male, 60
To maintain equipoise		"To sustain my ability to carry on as I am." Male, 72 "To keep going as I am." Male, 77 "Dialysis does its job and I'm getting on with life." Male, 55 "I don't want any more…everything is alright." Male, 84
Longevity		"To make me live as long as I can." Male, 74 "A bit more time." Female, 83

Longevity

Finally, a desire for treatment to buy a "bit more time" (Female, 83 years) and to promote longevity was also highlighted, with a wish to "live as long as I can" (Male 74 years).

Overall, Gender differences were also seen in perceived hopes and expectations of treatment. Males were more likely to prioritize the wish to achieve physical goals and activities, with females prioritizing a wish to feel well, and achievement of a sense of mental wellbeing (Figure 2b).

Dialysis Regret

Participants were asked, "if you had the ability to go back in time, what form of treatment for end-stage kidney disease would you choose?." Only half (27/54) would choose the same modality, that is in-center hemodialysis whereas 6 out of 54 (11%) stated that they would have chosen no dialysis at all. No gender differences were seen ($P = 0.8$).

> "The breathing problems, fluid overload, restrictions on what you can eat, restrictions on life- you have to come to hospital three times a week, night-time shifts when you can't get a proper shift, when you get home, and you don't want to go out anywhere as you are too tired. I would have chosen no dialysis at all". Female, 55 years.
>
> "I have been doing less since I started dialysis, not more". Male, 85 years.
>
> "You think it's going to make you feel better, but I've found it really debilitating. Sometimes you have good days but a lot of the time I'm existing rather than living at the moment. This is my life now; I find it very hard. I want to forget I'm on dialysis and you can't. It's so onerous and it's 3 days a week" Female, 70 years.

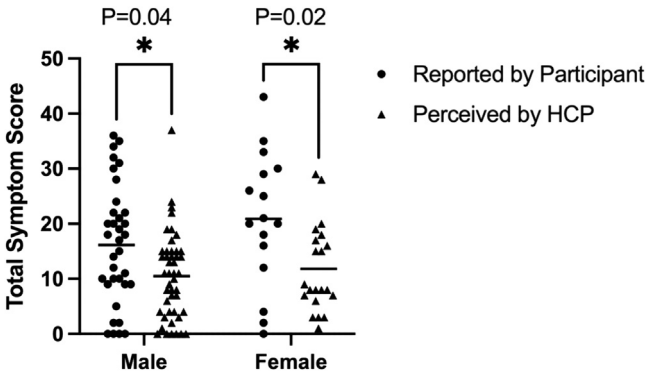


Figure 3. Comparison of total symptom score as reported by participant compared with health care provider score[a]. [a]2 way ANOVA. HCP, health care provider.

Gender Differences in Reported Symptoms

There were no statistical differences in the physical symptom scores between males and females (pain, breathlessness, weakness, nausea, vomiting, poor appetite, constipation, diarrhea, sore/dry mouth, drowsiness, poor mobility, itch, difficult sleeping, restless legs or skin changes). Females were more likely to report feeling depressed than males ($P = 0.001$), but there was no difference among reported anxiety levels ($P = 0.2$). Both genders reported significantly higher symptom scores than their health care provider perceived, however this difference was more marked in females ($P = 0.02$ vs. $P = 0.04$) (Figure 3).

DISCUSSION

This is the first study to explore treatment considerations and expectations of seriously unwell people on hemodialysis, and to consider the effect of gender on these parameters. It is also the first to describe dialysis regret within a UK population.

When deciding whether to commence dialysis therapy, we found no gender differences in themes considered, but significant differences in the way decisions were approached and prioritized. We found those who self-identified as male were more likely to take a practical approach to problem-solving, seeking alternative treatment options and hands-on solutions. In contrast, we found females were more likely to prioritize overall well-being. Recognizing that different genders approach treatment decisions and prioritize treatment expectations differently will allow for more personalized care plans to be developed.

When approaching factors considered when starting dialysis, we found there appears to a stronger emphasis on some issues leading to a hierarchy of the thought processes involved. We found "Desire to keep living" is the most important and basic factor, but "Fear" also dominated and influences risk assessment and decision-making. Once fear is managed, there are physical, social, practical and emotional issues to rationalize, but choice only seems possible if shared decision-making is part of the consultation. Shared decision-making is frequently raised as a high priority for people with kidney disease and is consistently ranked low in PREMS,[27] highlighting the real need to improve research and understanding in this area. The impact and influence of gender on patient experience and PREMS is increasingly recognized. Females consistently report fewer positive experiences of health care and lower scores for both physical and mental health.[11-15] To date, gender differences in PREMS of people with kidney disease have not been explored.

We found gender differences in reported symptoms. Both genders reported significantly higher symptom scores than their health care provider perceived, however this difference was more marked in females. Symptoms affecting people with end-stage kidney disease do not differ markedly from those reported by people living with advanced cancer or advanced heart failure.[28-31] As is seen with advanced heart failure, we found females had higher total symptom scores and were more likely to report feeling depressed than males.[28,32-34] Depressive symptoms have been shown to influence survival in people on dialysis so eliciting concerns about low mood and ensuring appropriate treatment is commenced should remain a clinical priority for renal physicians.[35-37] Of note, the symptom score does not measure the effect of symptoms, for example intrusion and impacts on daily living. Future work should ensure that this impact is appropriately captured.

Our study also explored the concept of dialysis regret. While participants were not asked using the term regret directly, we asked "if you had the ability to go back in time, what form of treatment for end-stage kidney disease would you choose?" as a proxy. We found regret existed in approximately half of all participants in this cohort. This is the first time that dialysis regret has been measured in a UK population and while initially the reported levels seem very high, they are similar to levels (61%) reported elsewhere.[38] Other studies have reported significantly lower levels of regret: 21%,[39] 8%,[40] 7.4%[41] and 7%[42]: the reason for these disparities remain unclear. This is the first study to specifically examine people on hemodialysis with a high (>20%) mortality risk, and this may have influenced perceptions and reflections of participants.

Finally, we explored expectations and experiences of treatment within this participant group and found gender differences in terms of priorities of treatment outcomes and expectations.

Males were more likely to prioritize the wish to achieve physical goals and activities, with females prioritizing a wish to feel well, and achievement of a sense of mental wellbeing. Improvements to mobility and pain have also been highlighted as patient priorities when considering expectations of treatment in other specialties.[43,44]

This study has closely examined the views and experiences of seriously unwell people on hemodialysis by ensuring that only those participants with a ≥20% mortality risk[23] were included into the study. However, all participants have been recruited from hemodialysis centers and as such, perspectives of only those who chose to start hemodialysis have been included. It would be interesting to compare and contrast the

thought processes and expectations of those who chose a supportive care pathway. There may have also been recall bias present, particularly in response to questions about dialysis initiation, given the median time on dialysis prior to study entry was over 3 years. In addition, influencing factors and treatment expectations were assessed at a single timepoint, so we were not able to assess whether treatment expectations change over time with the occurrence of significant medical and or psychosocial event. A longitudinal approach with repeated interviews could allow a more detailed assessment.

While we have examined the effects of patient gender in this study, we have not assessed the effects of physician gender and there is a suggestion that physician gender also influences attitudes toward advance care planning and decision making.[45-47] The participants in this study were looked after by 1 of 4 nephrologists, only 1 of whom is female, so we were unable to explore this area in more detail. Future work should also consider the gender of the treating nephrologist when exploring peoples' treatment decisions and priority setting. Furthermore, both of the interviewers were female, which may have also influenced results obtained.

To conclude, there are clear gender differences in the experiences and expectations of seriously unwell people on hemodialysis. Recognizing that different genders approach treatment decisions and prioritize treatment expectations differently will allow for more personalized care plans to be developed and improve the experiences of seriously unwell people on dialysis.

DISCLOSURE

EAB has the following disclosures: Baxter Healthcare: speaker, advisory board, educational grants; liberDi: advisory board; AWAK: advisory board; Vifor: speaker. All other authors declare no conflict of interest.

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AUTHOR CONTRIBUTIONS

HB and EAB participated in study conception and design. HB, AA, MA, HG, PH, DM, VP, ES, PW and JT participated in patient and health care professional recruitment. HB, NT and EAB undertook data analysis/interpretation and critical revision of the manuscript to its final form. All authors read and approved the final manuscript.

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