KI REPORTS
KIReports.org
CLINICAL RESEARCH

Perceptions of Illness Severity, Treatment Goals, and Life Expectancy: The ePISTLE Study

Check for updates

Hannah K.S. Beckwith[1,2], Anamika Adwaney[1], Maura Appelbe[1], Helen T. Gaffney[1], Peter Hill[1], Dihlabelo Moabi[1], Virginia L. Prout[1], Emma Salisbury[1], Phil Webster[1], James A.P. Tomlinson[1] and Edwina A. Brown[1,2]

[1]Imperial College Renal and Transplant Centre, Hammersmith Hospital, London, United Kingdom; and [2]Department of Renal Medicine, Imperial College London, London, United Kingdom

Introduction: A better understanding of factors influencing perceived life expectancy (PLE), interactions between patient prognostic beliefs, experiences of illness, and treatment behavior is urgently needed.

Methods: Case-notes at 3 hemodialysis units were screened: patients with ≥20% 1-year mortality risk were included. Patients and their health care professionals (HCPs) were invited to complete a structured interview or mixed-methods questionnaire. Four hundred eleven patient notes were screened. Seventy-seven eligible patients were approached and 51 were included.

Results: Patients predicted significantly higher life expectancies than HCPs ($P < 0.0001$). Documented cognitive impairment, gender, or increasing age did not affect 1- or 5-year PLE. PLE influenced priorities of care: one-fifth of patients who estimated themselves to have >95% 1-year survival preferred "care focusing on relieving pain and discomfort," compared with nearly three-quarters of those reporting a ≤50% chance of 1-year survival. Twenty of 51 (39%) patients believed transplantation was an option for them, despite only 4 being waitlisted at the time of the interview. Patients who thought they were transplant candidates were significantly more confident they would be alive at 1 and 5 years and to want resuscitation attempted. Cognitive impairment had no effect on perceived transplant candidacy. A high symptom burden was present and underrecognized by HCPs. High symptom burden was associated with significantly lower PLE at both 1 and 5 years, increased anxiety/depression scores, and treatment choices more likely to prioritize relief of suffering.

Conclusion: There is a disparity between patient PLE and those of their HCPs. Severity of symptom burden and beliefs regarding PLE or transplant candidacy affect patient treatment preferences.

Kidney Int Rep (2021) **6,** 1558–1566; https://doi.org/10.1016/j.ekir.2021.02.032
KEYWORDS: perceived life expectancy; prognosis; risk communication; shared decision making; symptom burden
© 2021 International Society of Nephrology. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Mortality in end-stage kidney disease is high: approximately 50% of patients die within 5 years of starting renal-replacement therapy.[1] This is a worse unadjusted survival than several solid-organ cancers,[1] and yet nephrologists rarely discuss estimates of life expectancy with patients undergoing dialysis.[2]

Prognosis plays an integral role in medical decision making and enables patients to prioritize other areas of their lives that are unrelated to their medical care. Prognosis communication is a fundamental component of practice within oncology,[3] but individuals with noncancer chronic disease often have unrealistically optimistic prognosis expectations.[4] This is significant, because PLE may influence health care choices—for example, whether to prioritize survival time or to maximize quality of life—and has implications for service delivery at a broader level.

Previous studies have shown that patients who overestimate their long-term prognosis tend to opt for more aggressive treatment measures and life-extending therapy.[2,5–7] Effects of this on an individual can include higher morbidity, increased hospital stays, and a reduction in general well being. Alongside this, there are consequences of individual treatment choices on the wider health care system: a better understanding of factors influencing PLE and the interactions between patient prognostic beliefs, experiences of illness, and treatment behavior is urgently needed.

Correspondence: Hannah Beckwith, 2nd fl ICTEM, Imperial College London, Hammersmith Campus, Du Cane Road, London W12 0NN. E-mail: hannah.beckwith@nhs.net

Received 27 November 2020; revised 8 February 2021; accepted 15 February 2021; published online 3 March 2021

Along with being associated with high levels of mortality, patients with end-stage kidney disease often suffer from numerous persistent symptoms.[8] The deleterious effects of symptoms on quality of life and functional status has been well documented.[9–12] Despite this, there is often poor symptom recognition by HCPs caring for patients with advanced kidney disease.[13,14] Patient-reported outcome measure surveys have been recommended as a method to enhance patient care and the Integrated Palliative Outcome Score (IPOS) renal symptom survey has been validated for use in patients with advanced kidney disease.[13] The impact of symptom burden on PLE has not been researched and is an area of unmet research need.

Cognitive impairment is common in patients with chronic disease, but to date all studies exploring PLE have excluded patients with cognitive impairment, undermining the applicability of their results.[4,15–17] Cognitive impairment is particularly prevalent in patients with end-stage kidney disease, affecting as many as 70% of patients undergoing hemodialysis, a rate 3 times higher than for age-matched control subjects.[18–21] Whether cognitive impairment influences PLE is not yet known, and the inclusion of patients with cognitive impairment in prognosis studies is vital in generating relevant and valid findings.

This study aims to compare perceptions of prognosis, transplant candidacy, symptom burden, and goals of care between seriously ill patients undergoing hemodialysis and HCPs. It is the first reported study that includes patients with cognitive impairment as well as the first study performed outside of North America, and we seek a better understanding of factors influencing PLE and treatment choices.

MATERIALS AND METHODS

Design

Case-record screening of all patients receiving maintenance hemodialysis in 3 of the 8 hemodialysis units at Imperial College Healthcare NHS Trust, London, United Kingdom was undertaken and a validated mortality risk score calculated.[22] All patients with a ≥20% 1-year mortality risk score were deemed seriously unwell and approached to take part in the study. Patients, the named nurse, and the lead doctor were all asked to take part in a structured interview or to independently complete a mixed-methods questionnaire. Completion of ≥2 of these questionnaires formed a patient pack and was anonymized for entry into the study. Ethical approval was granted (18/LO/1386) and the study was registered on clinicaltrials.gov (NCT04225416).

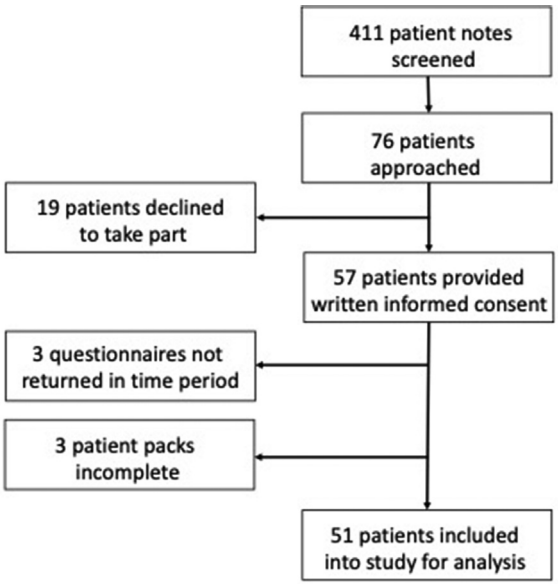


Figure 1. Flow chart of patient recruitment.

Setting and Participants

Four hundred eleven patient records were screened between November 14, 2018 and March 13, 2020. Ninety eligible patients with an estimated 1-year mortality risk ≥20% were identified, and 76 of these patients were approached before March 13, 2020. At this point, because of COVID-19, all research-based activities at our institution were suspended.

Fifty-seven patients provided written informed consent to take part in the study (response rate 75%). Nineteen patients declined and 6 were subsequently excluded (3 questionnaires were not returned in the permitted time period and 3 patient packs were incomplete). Fifty-one patients were included in the study for analysis (Figure 1). Because of the potential effects of the pandemic on confounding perceptions of mortality, the decision was made to stop further recruitment in March 2020.

Interview and Questionnaire Content and Validity

Eligible participants were given the option of completing a structured interview or completing a mixed-methods questionnaire (Supplementary Material). Seven (14%) patients chose to complete the questionnaire themselves and 44 (86%) patients preferred a structured interview, where an interviewer went through the listed questions with them.

The questionnaire was designed based on previous studies[2,15,23] and was composed of 40 multiple choice and short answer questions. To quantify patient PLE, patients were asked "How confident are you that you will be alive in 1 year?" and "How confident are you that you will be alive in 5 years?" A visual analog scale

Table 1. Patient demographics

Characteristic	Eligible participants recruited, $n = 51$	Eligible participants who did not wish to take part or who were excluded, $n = 25$	P value
Sex, *n* (%)			
Male	35 (69)	12 (48)	0.13 (NS)
Female	16 (31)	13 (52)	
Ethnicity, *n* (%)			
White (%)	29 (57)	5 (20)	0.003[a]
Nonwhite (%)	16 (31)	20 (80)	
Not documented (%)	6 (12)	0	
Age, yr, mean (SD)	73.5 (9.75)	69 (13.3)	0.11 (NS)
≤50	0	2	
51–60	5	6	
61–70	15	4	
71–80	16	6	
≥80	15	7	
Length of time on HD, months, mean (range)	57.6 (3–276)	94.0 (7–252)	0.02[b]
<6	2	0	
6–12	6	1	
13 months to 5 yrs	31	6	
>5 yrs	12	18	
Presence of diabetes mellitus, *n* (%)	23 (45)	10 (40)	0.81 (NS)
Presence of ischemic heart disease, *n* (%)	26 (51)	10 (40)	0.47 (NS)
Presence of peripheral vascular disease, *n* (%)	13 (25)	4 (16)	0.40 (NS)
Previous cerebrovascular event, *n* (%)	11 (22)	5 (20)	1.00 (NS)
Cognitive impairment, *n* (%)			0.37 (NS)
Patient concerns	22 (43)	N/A	
Confirmed	11 (22)	3 (12)	
Assistance required when walking, *n* (%)	29 (57)	16 (64)	0.62 (NS)

HD, hemodialysis; N/A, not applicable; NS, not significant; SD, standard deviation.
[a] $P \leq 0.01$.
[b] $P \leq 0.05$.

was provided with "Not very confident" at one end of the scale and "Very confident" at the other. Patients were directed to mark a cross on the line for both of these scales. Visual analog scale instruments are well validated in multiple clinical settings and particularly useful when levels of numerical literacy may influence participant responses.[23,24] It is for this reason that we chose to use a visual analog scale rather than other probability-based methods to assess patients' expectations of survival. Measurements were recorded and the percentage confidence calculated (from 0%–100%).

To measure prioritization of longevity or relief of suffering, participants were asked "If you were seriously unwell, would you prefer treatment to extend life, even if it meant more pain and discomfort, or to relieve pain and discomfort, even if it meant not living as long?" To assess symptom burden, we included the IPOS-Renal Symptom survey, a validated patient-reported outcome measure questionnaire for symptom assessment in advanced kidney disease.[13] Named hemodialysis nursing staff and the patient's nephrologist were also asked to complete a similar questionnaire for each patient. When both the named nurse and nephrologist provided an estimate for PLE, the mean of both values was recorded.

Data Analysis

Data analysis was performed using GraphPad Prism software (version 7.03; GraphPad Software, Inc., La Jolla, CA) and SPSS software (version 21; IBM Inc., Chicago, IL). Normality of distribution of data 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 (standard deviation [SD]) and compared using the unpaired t test. Simple linear regression was used to analyse the association between symptom burden and anxiety/depression scores. The 2-tailed Fisher exact test was used to compare categorical data between 2 groups. To compare >2 groups: if Gaussian distribution, an ordinary 1-way analysis of variance and the Holm–Sidaks multiple comparison tests were used; if non-Gaussian distribution, a Kruskal–Wallis test and the Dunn multiple comparisons test were used. $P < .05$ was considered statistcailly significant.

RESULTS

Patient Demographics

Patient demographics are shown in Table 1. Thirty-five of 51 (69%) patients were male, the mean age was 73.5 years (SD 9.75), and the mean length of time on dialysis was 58 months (range 3–276). There was a high presence of comorbidities among patients recruited to the study. Over half ($n = 26$) had ischemic heart disease and just under half ($n = 23$) had diabetes mellitus. While the formal assessment of functional status was not carried out for the purpose of this study, 57% ($n = 29$) of the study cohort required assistance when walking. Patients who did not want to take part in the study were more likely to be nonwhite ($P = 0.003$) and to have been on dialysis for a longer period of time ($P = 0.01$). There was no difference between age, sex, the presence of comorbidities, cognitive impairment, or need for assistance when walking between the 2 groups.

Perceptions of Illness Severity and Life Expectancy

A predicted 1-year mortality risk of ≥20% was required for patient recruitment. Despite this, 37%

Table 2. Comparisons of estimates of survival between patients and their health care professionals

	Health care professional estimate of survival						
Patient estimate of survival	**≥90%, *n* (%)**	**61–89%, *n* (%)**	**40–60%, *n* (%)**	**11–39%, *n* (%)**	**≤10%, *n* (%)**	**Unknown, *n* (%)**	**Total, *N* (%)**
At 1 year, *n* (%)							
≥90%	1 (2)[a]	5 (10)	5 (10)	3 (6)	5 (10)		19 (37)
61–89%		3 (6)[a]	4 (8)	3 (6)	3 (6)		13 (25)
40–60%		1 (2)	2 (4)[a]	6 (12)	1 (2)		10 (20)
11–39%		1 (2)		2 (4)[a]	1 (2)	1 (2)	5 (10)
≤10%				2 (4)	1 (2)[a]		3 (6)
Unknown			1 (2)				1 (2)
Total	1 (2)	10 (20)	12 (24)	16 (31)	11 (22)	1 (2)	51 (100)
At 5 years, *n* (%)							
≥90%	1 (2)[a]		5 (10)	5 (10)	2 (4)		13 (25)
61–89%		2 (4)[a]		3 (6)	1 (2)		6 (12)
40–60%			1 (2)[a]	3 (6)	5 (10)		9 (18)
11–39%			1 (2)	5 (10)[a]	5 (10)	1 (2)	12 (24)
≤10%			1 (2)	2 (4)	7 (14)[a]		10 (20)
Unknown			1 (2)				1 (2)
Total	1 (2)	2 (4)	9 (18)	18 (35)	20 (39)	1 (2)	51 (100)

Data portrayed using the format developed by Wachterman et al.[2]
[a]Indicates agreement between patients and health care professionals.

($n = 19$) thought they had a ≥95% chance of being alive at 1 year, and a quarter of patients felt they had a ≥95% likelihood of being alive at 5 years (Table 2). HCPs were significantly less optimistic, with only 1 HCP recording a ≥90% likelihood of the patient being alive at 1 or 5 years.

Patients predicted significantly higher life expectancies than health care professionals. The median HCP-predicted chance of 1-year survival was 34% versus a median patient prediction of 78% ($P < 0.001$). For 5-year survival, findings were equally discrepent, with HCPs predicting a median chance of survival of 18.5% and patients predicting a median of 48% ($P < 0.001$). There were no significant differences in estimates of life expectancy between nurses and doctors ($P = 0.75$ at 1 year and $P = 0.23$ at 5 years).

Twenty-two patients (43%) reported concerns with their memory and 11 (22%) patients had a formal diagnosis of cognitive impairment recorded. Diagnosis of cognitive impairment was clinically based and not all participants in the study were screened. Of note, only 6 of 11 formally diagnosed patients reported concerns with their memory. Documented cognitive impairment or memory loss did not affect 1- or 5-year prognostic expectations, neither did gender, increasing age, or time on dialysis.

To ensure the COVID-19 pandemic had not confounded self-reported perceptions of mortality before recruitment terminating, we compared self-reported PLE of patients recruited before January 1, 2020 ($n = 43$) and after ($n = 8$). We found no significant difference between 1- and 5- year prognostications in these groups ($P = 0.22$ and $P = 0.47$, respectively).

Treatment Goals

PLE influenced priorities of care in our cohort. Only 4 of 19 patients who thought their chance of 1-year survival would be ≥95% (21%) preferred "care focusing on relieving pain and discomfort" compared with 11 of 14 (71%) of those who thought their chance of survival was ≤50%.

Patients were significantly more likely to consider themselves transplant candidates than their nephrologists ($P < 0.001$, Table 3). Overall, 20 of 51 (39%) patients believed transplantation was an option for them, despite only 4 being waitlisted at the time of interview. Patients who believed transplantation was an option for themselves were significantly younger (median age 66.5 vs. 78.0 years, $P = 0.007$) and there was marked inter-center variation (range 12.5%–52% of patients recruited at each center). Ethnicity had no effect on transplant candidacy beliefs ($P = 0.52$). Patients who thought they were on the transplant list were significantly more confident they would be alive at both 1 year (median perceived likelihood of survival 99.5% vs. 63.5%, $P < 0.001$) and 5 years (median perceived likelihood of survival 83.5% vs. 33.5%, $P = 0.002$). Documented

Table 3. Perceived transplant candidacy

	Health care worker response		
Patient response[a]	**Yes, *n* (%)**	**No, *n* (%)**	**Total, *n* (%)**
Yes, *n* (%)	4 (8)	16 (31)	20 (39)
No, *n* (%)		28 (55)	28 (55)
Don't know, *n* (%)		3 (6)	3 (6)
Total, *n* (%)	4 (8)	47 (92)	51 (100)

Data portrayed using the format developed by Wachterman et al.[2]
[a]Assesed by the question "Do you think kidney transplantation would be an option for you?"

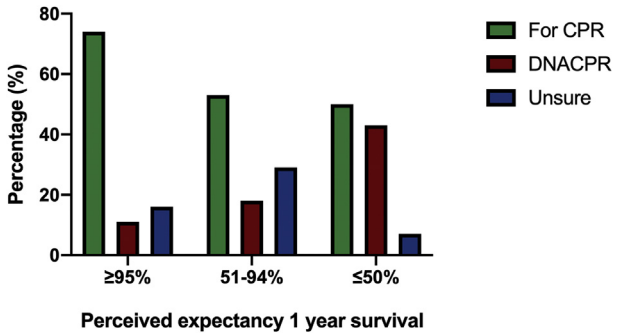


Figure 2. Influence of perceived life expectancy on resuscitation wishes. A lower perceived expectancy of 1-year survival was associated with an increased likelihood of desire to not undergo resuscitation, but this did not reach statistical significance. CPR, cardiopulmonary resuscitation; DNACPR, do not attempt cardiopulmonary resuscitation.

cognitive impairment or memory loss had no effect on expectations of transplant candidacy ($P = 0.09$).

Interestingly, in this study, many patients did not want to discuss their wishes regarding care towards the end of life (EoL); however, there was a significant center effect. Overall, 14 (27%) patients recalled talking about their EoL care plans with an HCP; however, this represented 8% of patients from center 1, 39% from center 2, and 63% of recruited patients from center 3, demonstrating marked intercenter variability. We found no difference between PLE of those patients who recalled discussing EoL care plans and those who did not ($P = 0.40$ at 1 year and $P = 0.17$ at 5 years). Despite the intercenter variability of EoL care plan discussions, we found no center differences with respect to PLE at 1 year ($P = 0.79$), at 5 years ($P = 0.12$), perceived transplant candidacy ($P = 0.08$), or wish to be resuscitated ($P = 0.74$). Of participants who did not recall discussing EoL care plans, only 9 of 37 (24%) wanted to discuss these plans further. There was no significant difference between those participants who wanted to discuss EoL care plans and those who did not; specifically age (median 66.8 vs. 73.5 years, $P = 0.06$), PLE ($P = 0.80$), ethnicity ($P = 0.44$), sex ($P = 0.44$), or currently practicing a religion ($P = 0.71$).

Overall, 30 (59%) of participants in this study wanted to be resuscitated. Five of 14 (36%) patients who had discussed their EoL care plans with a member of staff did not want to be resuscitated compared with 7 of 37 (19%) patients who had not. This did not reach statistical significance ($P = 0.27$). There was a tendency for patients who had a lower PLE to not want resuscitation attempted, but this did not reach statistical significance (Figure 2). In contrast, patients who thought transplantation would be an option for them were significantly more likely to want to be resuscitated (16/20 vs. 14/31, $P = 0.02$).

Accuracy of PLE

To date, 21 of 51 patients recruited to this study have died (41%). Thirty-five (69%) patients have 12 months of follow-up data: 14 (40%) died within 1 year of participating in the study. As reported earlier, 19 of 51 patients thought they had a ≥95% chance of being alive at 12 months. Of the patients who were highly optimistic of 1-year survival, 6 of 19 (32%) have died; 5 of 16 (31%) within 1 year of follow-up. In contrast, 11 of 51 patients did not expect to be alive at 12 months (PLE <50%) and 7 of 11 (64%) of this cohort have died (6/11, 55% within 1 year of follow-up). HCPs were significantly less optimistic of 1-year survival and predicted that 31 of 51 (61%) had a <50% chance of being alive at 12 months. Fourteen of these 31 patients (45%) have died, 12 of 28 (43%) within 12 months of follow-up.

Patient and HCP perception of mortality risk were calculated (100 − "perceived % chance of being alive at 12 months"). Perceived mortality risk was then compared to the 1-year all-cause mortality risk calculated using the Floege risk model[22] (Figure 3). Patients' perceptions of mortality risk tended to be lower than calculated values, whereas HCPs overestimated mortality risk. Compared with observed 1-year mortality in this cohort (40%), both patients and the risk assessment tool[22] underestimated mortality risk (median perceived risk 23% and 29%, respectively), whereas HCPs overestimated mortality risk (median 67%).

Symptom Burden

Completion of the IPOS renal symptom score demonstrated a high symptom burden among patients that was underrecognized by HCPs (median total score 18 vs. 10, $P < 0.001$).

A high symptom burden (total score ≥21) was associated with a significantly lower PLE at both 1 and 5 years ($P = 0.02$ and $P = 0.03$; Figure 4). Alongside this, a higher symptom burden correlated with increased anxiety scores ($P < 0.001$) and increased depression scores ($P < 0.001$).

The presence of a high symptom burden also influenced individual treatment choices. Patients with a symptom score ≥21 were significantly more likely to choose treatment that focused on relief of suffering as opposed to treatment that would be considered life extending ($P = 0.04$). Participants with a high symptom burden were also significantly less likely to want cardiopulmonary resuscitation ($P = 0.02$). The presence of cognitive impairment had no effect on symptom scores, neither did length of time on dialysis.

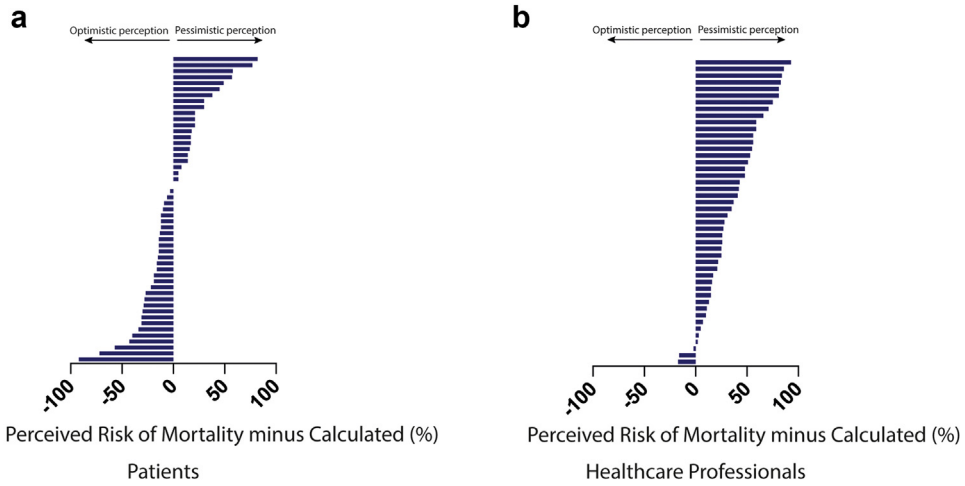


Figure 3. Comparison of perceived and calculated 1-year all-cause mortality risk by (a) patients and (b) health care professionals. Perceived mortality risk was subtracted from calculated 1-year all-cause mortality risk.[22] Patients' perceptions of mortality risk tended to be lower than calculated values, whereas health care professionals overestimated mortality risk compared with the calculated values.

DISCUSSION

This is the first study to explore PLE that has not excluded patients with known cognitive impairment. It is also the first study to explore PLE outside of North America. We have found a significant mismatch between prognostic expectations of patients and their HCPs. Factors that influence prognostic expectations include a high symptom burden and beliefs surrounding transplant candidancy, with PLE shaping subsequent treatment choices in this study.

The high prevalence of cognitive impairment among patients with end-stage kidney disease is well known,[25] and the observed rate of 22% seen in this study is similar to that reported elsewhere.[26,27] Interestingly, nearly twice as many patients in this cohort had concerns about their memory but had not received a formal diagnosis of cognitive impairment, perhaps suggesting an underdiagnosis of mild cognitive impairment in many dialysis patients. Importantly, we found that cognitive impairment had no influence on PLE, perceived transplant candidacy, or self-reported symptom burden. Findings from this study suggest that clinicians should be encouraged to talk about prognosis, treatment choices, and the impact of illness with all hemodialysis patients who wish to engage, including those with known cognitive impairment.

As with existing studies,[2,7,15,28–31] we found that recruited patients were significantly more optimistic of their PLE than their clinicians. Unlike in previous studies, we found no relationship between gender and increasing age in predicting a lower PLE.[32] Earlier studies have shown that self-rated life expectancy is a predictor for mortality in the unselected older general population, independent of health risk status.[32–34] However, all patients recruited to this study had a predicted 1-year mortality risk of >20% (that is, a similar health risk status), yet PLE varied widely, suggesting other extrinsic factors than disease or diagnosis itself influence PLE. Fried et al.[16] conducted a study whereby patients with cancer, chronic obstructive pulmonary disease, and congestive heart failure were serially interviewed over 12 months, and demonstrated little revision in prognostic expectations over time, despite disease progression. Interestingly, they also found that patients' estimates of PLE were unrelated to underlying diagnosis. Together this would suggest that it is not underlying disease risk but overall perceived health status that is affecting PLE. We found that in a cohort of individuals with similar health risk status, a high symptom burden negatively influences

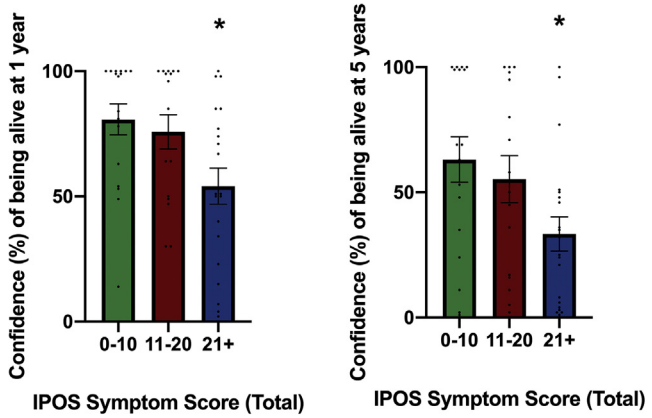


Figure 4. A high symptom burden correlates negatively with perceived life expectancy at 1 and 5 years but increased anxiety and depression scores. (a) High symptom scores (≥21) are associated with significantly less confidence of being alive at 1 year (scatterplot shows individual values, mean, and standard error of the mean). (b) High symptom scores (≥21) are associated with significantly less confidence of being alive at 5 years (scatterplot shows individual values, mean, and standard error of the mean).

PLE. This suggests it may be the lived experience of dialysis and end-stage kidney disease that has the highest effect on perceived morbidity and mortality. It would be interesting to conduct serial interviews with patients undergoing hemodialysis as they proceed along their dialysis (and transplant) journeys to explore whether perceived prognosis changes over time depending on symptom burden or if it is affected by treatment modality.

We found that compared with the calculated mortality risk patients tended to underestimate and HCPs tended to overestimate mortality risks. The mortality risk calculator developed by Floege et al.[22] was based on incident patients (within 6 months of dialysis initiation), whereas patients in this study were prevalent dialysis patients, with a mean vintage of 58 months. We chose the Floege et al.[22] model mainly for pragmatic reasons: it is easy to use and score, and is also derived from a European cohort. We wanted to include seriously ill patients in our study, so we recruited patients with a predicted mortality rate of ≥20%. The observed 1-year mortality rate seen in our cohort was higher (40%) than the median calculated risk prediction (29%), suggesting that the Floege et al.[22] model underestimates mortality in prevalent dialysis patients. This is of interest as the original study noted that for incident dialysis patients, the risk prediction consistently overestimated the observed 1-year mortality.[22] Routine use in clinical practice of mortality risk prediction scores may help to support EoL care. While in our study clinicians overestimated 1-year mortality risk, they identified 61% of high-risk patients who died within 12 months. Combining PLE (both patient and HCP) with mortality risk prediction scores offers the opportunity to identify significantly unwell hemodialysis patients who may benefit from additional input and advance care planning.

The particularly high symptom burden we found in stable outpatient hemodialysis patients was concerning, particularly because the majority of symptoms were underrecognized but were causing participants significant distress. We found that a high symptom burden was associated with significantly lower PLE at both 1 and 5 years. Previous work has shown that self-rated health influences PLE[32] and mortality.[33] It is possible that a high symptom burden results in lower self-rated health. The two may, however, be independent risk factors for increased mortality, and it would be interesting to look at this in more detail in future work. We also found that patients with a high symptom burden had increased psychological distress, highlighting the importance of eliciting and relieving coexist morbidity where possible.

The influence of PLE on treatment priorities is notable. We have shown that PLE may influence patients to make health choices and priorities that they might not otherwise had made had their PLE been more in alignment with observed survival. Patients who thought they had a reduced chance of 1-year survival (<50%) were more likely to prefer care focusing on relieving pain and discomfort. Perceptions of transplant candidacy also affected PLE, with patients who thought they were on the transplant list significantly more likely to predict higher PLE. Our findings are in keeping with earlier research,[2,5,6] but this is the first study outside of North America to replicate these results. We also found that patients who believed transplantation was an option for them were more likely to be younger and dialysing at certain hemodialysis centers. This suggests an opportunity for intervention: improved communication about potential transplant candidacy may help reduce the discordance in PLE seen between patients and their HCPs.

Previous studies exploring perceived prognosis in patients on hemodialysis have all been based in North America,[2,7,29–31] where palliative care and nephrology are often viewed as distinct and opposing care options.[35] Practice in the United Kingdom has changed significantly over the last 2 decades, with a greater acceptance and desire for symptom control and palliative care input in patients with advanced kidney disease.[36–38] The importance of improved risk communication with patients has also been widely recognized and embraced.[39,40] In contrast to the North American studies, where between 0% and <10% of patients with end-stage kidney disease recalled discussing life expectancy or EoL wishes with their clinician,[2,30] nearly 30% of patients in this study recalled discussing EoL care plans with a HCP, with significant center variability. Of note, in those who did not recall this discussion, we found a significant proportion of patients who did not want to discuss advanced care planning with their health care team. This has been seen in other specialties[41–43] and highlights that while early advance care planning is to be encouraged and promoted (and that we still have a long way to go in the United Kingdom), not all patients will wish or be able to engage with the process and recognizing this, so as not to cause undue distress, is equally important. It is also possible that discussions were had with these participants but consciously or unconsciously they were unable to recollect them.

Strengths of this study are that it is a multisite study, with centers having different practices regarding EoL discussions. The study also risk-stratified patients for inclusion and did not exclude patients with known cognitive impairment. By giving the option of a

questionnaire or interview, this study also encouraged increased participation from participants who might choose not to engage in an interview or who were unable to complete a questionnaire independently. The response rate of 74% is similar to that reported in other studies exploring PLE.[7,15] Clinicians' predictions of prognosis are frequently inaccurate,[44] and therefore we felt that it was important to include a validated risk model in determining recruitment of participants to our study. Limitations of the study include the sample size; we originally planned to recruit 60 patients, but research cessation locally meant we were unable to recruit further, and in addition we feel that once these restrictions have been lifted the effects of the pandemic may influence survivor's PLE and confound existing results. Studies on PLE on in-center hemodialysis patients before and after the COVID-19 pandemic may not be comparable for quite some time. The findings of the study may also not be extrapolatable to patients who are undergoing home hemodialysis or peritoneal dialysis. It would be interesting to explore prognostic expectations in both these cohorts of patients. Finally, although PLE was associated with treatment choices and symptom scores, we could not establish a causal relationship.

It would be impossible in the current environment not to acknowledge the effect that COVID-19 has had on our seriously ill hemodialysis population. As clinicians and caregivers, it has made us focus on patient prognosis and EoL care in a way not seen before. This study has shown that in-center hemodialysis patients are more optimistic than their caregivers about PLE and are making treatment decisions less focused on quality of life if their PLE is higher. It is important that caregivers have frank discussions with their patients about prognosis, treatment options, and symptom burdens to enable them to make life and health care choices in a fully informed manner.

DISCLOSURES

All the authors declared no competing interests.

ACKNOWLEDGEMENTS

Infrastructure support for this study was provided by the National Institute for Health Research Imperial Biomedical Research Centre. Results presented in this paper have not been published previously in whole or part, except in abstract format. The study is registered on clinicaltrials.gov (NCT04225416).

AUTHOR CONTRIBUTIONS

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

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Patient questionnaire.

REFERENCES

1. Naylor KL, Kim SJ, McArthur E, Garg AX, McCallum MK, Knoll GA. Mortality in incident maintenance dialysis patients versus incident solid organ cancer patients: a population-based cohort. *Am J Kidney Dis*. 2019;73:765–776.
2. Wachterman MW, Marcantonio ER, Davis RB, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Intern Med*. 2013;173:1206–1214.
3. Bernegger G, Musalek M, Rehmann-Sutter C. An alternative view on the task of prognosis. *Crit Rev Oncol Hematol*. 2012;84(suppl 2):S17–S24.
4. Hole B, Salem J. How long do patients with chronic disease expect to live? A systematic review of the literature. *BMJ Open*. 2016;6, e012248.
5. Phillips RS, Wenger NS, Teno J, et al. Choices of seriously ill patients about cardiopulmonary resuscitation: correlates and outcomes. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Am J Med*. 1996;100:128–137.
6. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*. 1998;279:1709–1714.
7. O'Hare AM, Kurella Tamura M, Lavallee DC, et al. Assessment of self-reported prognostic expectations of people undergoing dialysis: United States Renal Data System Study of Treatment Preferences (USTATE). *JAMA Intern Med*. 2019;179:1325–1333.
8. Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP. CKD in elderly patients managed without dialysis: survival, symptoms, and quality of life. *Clin J Am Soc Nephrol*. 2015;10:260–268.
9. Thong MS, van Dijk S, Noordzij M, et al. Symptom clusters in incident dialysis patients: associations with clinical variables and quality of life. *Nephrol Dial Transplant*. 2009;24:225–230.
10. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. *Kidney Int*. 2006;69:1621–1625.
11. Kimmel PL, Emont SL, Newmann JM, Danko H, Moss AH. ESRD patient quality of life: symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *Am J Kidney Dis*. 2003;42:713–721.
12. Merkus MP, Jager KJ, Dekker FW, De Haan RJ, Boeschoten EW, Krediet Rt. Quality of life over time in dialysis: the Netherlands Cooperative Study on the Adequacy of Dialysis. NECOSAD Study Group. *Kidney Int*. 1999;56:720–728.
13. Raj R, Ahuja K, Frandsen M, Murtagh FEM, Jose M. Validation of the IPOS-renal symptom survey in advanced kidney disease: a cross-sectional study. *J Pain Symptom Manage*. 2018;56:281–287.

14. Feldman R, Berman N, Reid MC, et al. Improving symptom management in hemodialysis patients: identifying barriers and future directions. *J Palliat Med*. 2013;16:1528–1533.
15. Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc*. 2003;51:1398–1403.
16. Fried TR, Bradley EH, O'Leary J. Changes in prognostic awareness among seriously ill older persons and their caregivers. *J Palliat Med*. 2006;9:61–69.
17. Kraai IH, Vermeulen KM, Luttik MLA, Hoekstra T, Jaarsma, Hillege HL. Preferences of heart failure patients in daily clinical practice: quality of life or longevity? *Eur J Heart Fail*. 2013;15:1113–1121.
18. O'Lone E, Connors M, Masson P, et al. Cognition in people with end-stage kidney disease treated with hemodialysis: a systematic review and meta-analysis. *Am J Kidney Dis*. 2016;67:925–935.
19. Murray AM. Cognitive impairment in the aging dialysis and chronic kidney disease populations: an occult burden. *Adv Chronic Kidney Dis*. 2008;15:123–132.
20. Sarnak MJ, Tighiouart H, Scott TM, et al. Frequency of and risk factors for poor cognitive performance in hemodialysis patients. *Neurology*. 2013;80:471–480.
21. Kurella Tamura M, Yaffe K. Dementia and cognitive impairment in ESRD: diagnostic and therapeutic strategies. *Kidney Int*. 2011;79:14–22.
22. Floege J, Gillespie IA, Kronenberg F, et al. Development and validation of a predictive mortality risk score from a European hemodialysis cohort. *Kidney Int*. 2015;87:996–1008.
23. Allen LA, Yager JE, Jonsson Funk M, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *JAMA*. 2008;299:2533–2542.
24. Gigerenzer G, Edwards A. Simple tools for understanding risks: from innumeracy to insight. *BMJ*. 2003;327:741–744.
25. Kurella M, Chertow GM, Luan J, Yaffe K. Cognitive impairment in chronic kidney disease. *J Am Geriatr Soc*. 2004;52:1863–1869.
26. Kurella Tamura M, Larive B, Unruh ML, et al. Prevalence and correlates of cognitive impairment in hemodialysis patients: the Frequent Hemodialysis Network trials. *Clin J Am Soc Nephrol*. 2010;5:1429–1438.
27. Murray AM, Tupper DE, Knopman DS, et al. Cognitive impairment in hemodialysis patients is common. *Neurology*. 2006;67:216–223.
28. Shah S, Blanchard M, Tookman A, Jones L, Blizard R, King M. Estimating needs in life threatening illness: a feasibility study to assess the views of patients and doctors. *Palliat Med*. 2006;20:205–210.
29. Saeed F, Sardar MA, Davison SN, Murad H, Duberstein PR, Quill TE. Patients' perspectives on dialysis decision-making and end-of-life care. *Clin Nephrol*. 2019;91:294–300.
30. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010;5:195–204.
31. Gilman EA, Feely MA, Hildebrandt D, et al. Do patients receiving hemodialysis regret starting dialysis? A survey of affected patients. *Clin Nephrol*. 2017;87:117–123.
32. Kobayashi LC, Beeken RJ, Meisel SF. Biopsychosocial predictors of perceived life expectancy in a national sample of older men and women. *PLoS One*. 2017;12, e0189245.
33. Siegel M, Bradley EH, Kasl SV. Self-rated life expectancy as a predictor of mortality: evidence from the HRS and AHEAD surveys. *Gerontology*. 2003;49:265–271.
34. Kim JH, Kim JM. Subjective life expectancy is a risk factor for perceived health status and mortality. *Health Qual Life Outcomes*. 2017;15:190.
35. Richards CA, Hebert PL, Liu C-F, et al. Association of family ratings of quality of end-of-life care with stopping dialysis treatment and receipt of hospice services. *JAMA Netw Open*. 2019;2:e1913115.
36. Gunda S, Thomas M, Smith S. National survey of palliative care in end-stage renal disease in the UK. *Nephrol Dial Transplant*. 2005;20:392–395.
37. Okamoto I, Tonkin-Crine S, Rayner H, et al. Conservative care for ESRD in the United Kingdom: a national survey. *Clin J Am Soc Nephrol*. 2015;10:120–126.
38. Brown EA, Chambers EJ, Eggeling C. Palliative care in nephrology. *Nephrol Dial Transplant*. 2008;23:789–791.
39. Zipkin DA, Umscheid CA, Keating NL, et al. Evidence-based risk communication: a systematic review. *Ann Intern Med*. 2014;161:270–280.
40. Thomson R, Edwards A, Grey J. Risk communication in the clinical consultation. *Clin Med (Lond)*. 2005;5:465–469.
41. Barnes K, Jones L, Tookman A, King M. Acceptability of an advance care planning interview schedule: a focus group study. *Palliat Med*. 2007;21:23–28.
42. Carrese JA, Mullaney JL, Faden RR, Finucane TE. Planning for death but not serious future illness: qualitative study of housebound elderly patients. *BMJ*. 2002;325:125.
43. Fleming J, Farhuhar M. Cambridge City over-75s Cohort (CC75C study collaboration), Brayne C, Barclay S. Death and the oldest old: attitudes and preferences for end-of-life care–qualitative research within a population-based cohort study. *PLoS One*. 2016;11:e0150686.
44. White N, Reid F, Harris A, Harries P, Stone P. A systematic review of predictions of survival in palliative care: how accurate are clinicians and who are the experts? *PLoS One*. 2016;11:e0161407.