

Original Article

Knowledge and Perceptions on End-of-life Care among End-stage Renal Disease Patients on Hemodialysis

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ABSTRACT. The role of end-of-life care is fundamental for end-stage renal disease (ESRD) patients, who are known to have a high morbidity and mortality rate despite being on dialysis. This requires effective communication and shared decision-making. Thus, exploring patients' knowledge and perceptions is essential to improve the gaps in delivering end-of-life care. This study aimed to describe the knowledge and perceptions of end-of-life care among ESRD patients on hemodialysis (HD). This was a cross-sectional study involving 14 outpatient HD centers in Kuantan, Malaysia. Patients were recruited from March to June 2019. A validated questionnaire was delivered via interview-based surveys by the researcher or trained interviewers. The majority of the respondents had poor knowledge of the disease and end-of-life care. However, more than 70% of the respondents felt that it was important for them to be actively involved in medical decision-making, as well as being prepared and planning for death. End-of-life needs, which included management of symptoms and psychological, social, and spiritual support, were important to most respondents. Additionally, patients with higher educational backgrounds were observed to have higher scores for both knowledge and perceptions ($P < 0.05$). The study found poor knowledge but acceptable perceptions among patients. This highlights the gaps in the current local approach in clinical practice to end-of-life care in ESRD.

Introduction

End-stage renal disease (ESRD) is associated

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with an increased risk of morbidity and mortality despite the advancements in medical technologies.^{1,2} The adjusted rate of all-cause mortality is 6.3–8.2 times greater for dialysis patients.³ The majority of the patients suffering from this life-limiting illness⁴ will undergo hemodialysis (HD) to maintain their lives.⁵ Despite dialysis, the expected improvement in the symptoms of ESRD patients is not well supported in the literature.⁶ The enduring high physical and emotional burdens of patients have

been highlighted in several studies.^{7,8}

Palliative care encompasses education, management of symptoms, advance care planning (ACP), and psychological support.⁹ The priorities are comfort and quality of life, aligned with the individual patient's preferences and goals of care. It also incorporates the transition from a conventional disease-oriented focus to rehabilitative treatment.¹⁰ These include ACP and decisions regarding cardiopulmonary resuscitation. The initiation of dialysis and its withdrawal is another unique subject in renal palliative care.¹¹

Although the concept of end-of-life care for ESRD patients has been around for many years,¹² it is lagging behind that in other terminal illnesses and has not been discussed well in routine clinical practice in Malaysia.¹³ Research on local renal palliative care is also sparse. In 2014, University Malaya Medical Centre conducted a study on 56 patients on their knowledge and attitudes toward ACP.¹³ The lack of knowledge was highlighted, along with the significant clinical impact of education on the patients' preferences and decisions regarding end-of-life care.¹³

Thus, efforts to empower end-of-life care for ESRD patients, which are presently poorly addressed, are essential. Factors related to both patients and health professionals, apart from the technical issues, play important roles in optimizing the practices of end-of-life care. Hence, identifying patients' awareness and understanding of and attitudes toward this subject is vital to establish by acceptable mutual, comprehensive care. We therefore conducted this study to describe patients' knowledge and perceptions, and other issues of end-of-life care in the local ESRD population.

Materials and Methods

This was a cross-sectional study conducted among 350 HD patients from 14 outpatient dialysis centers in Kuantan, the state capital of Pahang, Malaysia. The sample size was calculated via a simple proportion formula based on the previous studies by Davison et al and Hing

Wong et al.^{2,13} According to these studies, the level of knowledge, perceptions, and preferences was reported to be 25%, 90.6%, and 89%, respectively. The largest sample size from this calculation was 288 patients. Anticipating a nonresponse rate of 20%, the total calculated sample size was about 350 patients from a total of 653 patients on HD in Kuantan.

Data were collected from March 2019 to June 2019 via convenience sampling. The inclusion criteria were patients above the age of 18 years on regular HD. Eligible respondents were asked to complete a validated questionnaire in a structured, interview-based setting after we had obtained their written informed consent. The questionnaire was adapted and modified from a study involving patients with Stage 4 to 5 chronic kidney disease on peritoneal dialysis and HD patients at the University of Alberta, Canada.² Some modifications were made to the questionnaire in relation to the local settings. The questionnaire consisted of three sections. Section A included the sociodemographic data, and Sections B and C covered the self-reported knowledge and end-of-life perceptions, respectively. The questionnaire underwent validation through a process involving construct validity and internal consistency reliability analyses. The questions were delivered by trained interviewers and the staff of the centers as facilitators. They did not assist nor exert influence on the answers given. The study was approved by the Medical Research and Ethics Committee, Ministry of Health, Malaysia (NMRR-18-2802-42524).

Statistical Analysis

All analyses were performed using IBM SPSS Statistics version 20.0 (IBM Corp., Armonk, NY, USA). The categorical data are presented in frequencies with percentages, whereas continuous data are presented as means and standard deviation or as medians with interquartile ranges for data that were not normally distributed. Descriptive analyses were used for most of the study data. The differences in knowledge and perceptions in relation to the

background characteristics of patients were also further analyzed via Mann–Whitney *U*-tests and Kruskal–Wallis *H*-tests where appropriate. $P < 0.05$ was considered to be statistically significant.

Results

In total, 350 participants were recruited. There were no missing data, which suggested that all the questions were answered completely and there was no early termination of the interviews. The mean age was 53.4 ± 12.7 years old. The majority were above 50 years old (63.5%, $n = 222$), and 8.3% ($n = 29$) were above 70 years. Table 1 shows the socio-demographic variables. An almost equal sex distribution was observed. The majority were Malay (83.4%, $n = 292$) and Muslim (84.3%, $n = 295$). More than half ($n = 183$, 52.3%) were unemployed. Almost one-third (29.8%, $n = 104$) had an average monthly income of less than RM 1000. The majority had a to secondary school education level (59.1%, $n = 207$), and only 14.4% ($n = 50$) were graduates. About 5% had no formal education. In total, 101 (28.9%) patients independently cared for themselves, whereas more than half (58.4% or $n = 189$) admitted to being dependent on their spouses. The rest were taken care of by their children, siblings, or parents. The mean duration of dialysis was 55 ± 52.6 months. Half (50%) had been on HD for <3 years. Diabetes was found in 143 patients (40.9%), and hypertension was found in 249 patients (71.1%). These conditions were not the primary cause of ESRD. In total, 141 (40%) participants had multiple comorbidities. None of the patients was on once- or twice-weekly HD sessions, as all the study participants were recruited from outpatient centers where all dialysis sessions are scheduled on a thrice-weekly basis by default, except for a very few patients, who were not captured during the convenience sampling.

Tables 2–4 show the patients' self-reported knowledge on end-of-life care and its issues. More than half ($n = 194$, 55.6%) of the patients felt that their health would improve. Less than

50% ($n = 169$) had ever thought that other possible complications might occur. Less than 40% ($n = 139$) were aware of their right to withdraw from dialysis. More than half knew about cardiopulmonary resuscitation and mechanical ventilation [56.3% ($n = 197$) and 55.1% ($n = 193$), respectively]. However, only 14.6% ($n = 51$) knew about end-of-life care and its options. Many reported not knowing what palliative care or a hospice was (68% and 87.4%, respectively). The majority also did not know about advance medical directives and a lasting power of attorney (LPA) (70% and 89.4%, respectively). Overall, most were not familiar about end-of-life care and its options. Each response was also scored, with higher scores indicating better self-reported knowledge. The scores were between 11 and 33. The median score for patients' self-reported knowledge in this study was 20 with an interquartile range of 5.

The perceptions of end-of-life care are illustrated in Table 3. About 70% agreed that it was important for them to be prepared and plan for death, as well as to have their social, psychological, or spiritual concerns addressed by the nephrology staff. Active involvement of the family in medical decision-making was also an important aspect for the majority (76.3%, $n = 267$). The majority (73.1%, $n = 256$) felt the importance of having regular "quality of life" discussions with the staff. About 60% agreed on the importance of being informed about treatment options available, including withdrawal from dialysis. However, fewer patients (47.1%, $n = 165$) agreed about the importance of alternative ways to manage their symptoms such as traditional medicine and new treatments. This may be caused by their high dependence on the nephrology staff. The median total score of the patients' perceptions of the end-of-life care was 27, with an interquartile range of 5, which was higher than the score for knowledge. Eighty respondents scored the maximum possible for this section, indicating the importance of all the elements described to them.

There was a statistically significant difference

Table 1. Patients' background and sociodemographic characteristics.

Characteristics	Patients, <i>n</i> (%)
Age, years (mean±SD)	53.43±12.7
Age	
18–30	15 (4.3)
31–40	49 (14.0)
41–50	64 (18.3)
51–60	115 (32.9)
61–70	78 (22.3)
>70	29 (8.3)
Sex	
Male	188 (53.7)
Female	162 (46.3)
Education level	
No formal education	18 (5.1)
Primary	63 (18.0)
Secondary	207 (59.1)
Prediploma or matriculation	12 (3.4)
Diploma	31 (8.9)
Bachelor's degree	16 (4.6)
Masters or PhD	3 (0.9)
Race	
Malay	292 (83.4)
Chinese	43 (12.3)
Indian	14 (4.0)
Others	1 (0.3)
Religion	
Islam	295 (84.3)
Buddhism	33 (9.4)
Christianity	4 (1.1)
Hinduism	9 (2.6)
Others	9 (2.6)
Employment status	
Employed	82 (23.5)
Unemployed	183 (52.3)
Retired	85 (24.3)
Marital status	
Single	33 (9.4)
Married	266 (76.0)
Divorced	9 (2.6)
Single parent	42 (12.0)
Estimated average monthly family income (RM)	
<RM 500	45 (12.9)
RM 500–RM 999	59 (16.9)
RM 1000–RM 1999	124 (35.4)
RM 2000–RM 2999	55 (15.7)
RM 3000–RM 3999	31 (8.9)
RM 4000–RM 4999	13 (3.7)
RM 5000–RM 5999	5 (1.4)
≥RM 6000	18 (5.1)

Continuation of Table 1.

Duration of ESRD, months (mean±SD)	62.46±56.2
Duration of ESRD, months	
≤12	60 (17.1)
13–36	95 (27.1)
37–60	57 (16.3)
61–84	47 (13.4)
85–108	25 (7.1)
>108	66 (18.9)
Duration of hemodialysis, months (mean±SD)	55.05±52.6
Duration of hemodialysis, months	
≤12	86 (24.6)
13–36	91 (26.0)
37–60	59 (16.9)
61–84	40 (11.4)
85–108	24 (6.9)
>108	50 (14.3)
Who is the main caregiver?	
Self	101 (28.9)
Spouse	189 (58.4)
Child or children	49 (14.0)
Others	11 (3.1)
Frequency of hemodialysis per week	
1	0 (0.0)
2	0 (0.0)
3	350 (100.0)
Are you receiving sponsorship?	
Yes	269 (76.9)
No	81 (23.1)
Comorbidities	
Diabetes mellitus	143 (40.9)
Hypertension	249 (71.1)
Ischemic heart disease	18 (5.1)
Stroke	8 (2.3)
Dyslipidemia	58 (16.6)
SLE	9 (2.6)
Gout	3 (0.9)
Renal stone	1 (0.3)
ADPKD	1 (0.3)
Others	14 (4.0)
Any options for kidney transplantation?	
Yes	85 (24.3)
No	261 (74.6)
Attempted (failed)	4 (1.1)

SD: Standard deviation; RM: Malaysian ringgit; ESRD: End-stage renal disease; SLE: Systemic lupus erythematosus; ADPKD: Autosomal dominant polycystic kidney disease.

Table 2. Patients' self-reported knowledge.

Question	Patients, <i>n</i> (%)
How do you see your health in the next 12 months?	
Improving	194 (55.6)
No change	139 (39.5)
Worsening	17 (4.9)
Do you think your condition is curable?	
Yes	37 (10.6)
Unsure	155 (44.3)
No	158 (45.1)
Have you thought about what might happen with your illness in the future? (Complications such as infection, stroke, and myocardial infarction)	
No	50 (14.3)
Unsure	131 (37.4)
Yes	169 (48.3)
Do you know what end-of-life care is and its options?	
No	160 (45.7)
Unsure	139 (39.7)
Yes	51 (14.6)
Do you know what palliative care is?	
No	238 (68.0)
Unsure	88 (25.1)
Yes	24 (6.9)
Do you know what a hospice is?	
No	306 (87.4)
Unsure	27 (7.7)
Yes	17 (4.9)
Do you know that a patient has the right to withdraw from dialysis?	
No	113 (32.3)
Unsure	98 (28.0)
Yes	139 (39.7)
Do you know what cardiopulmonary resuscitation is?	
No	92 (26.3)
Unsure	61 (17.4)
Yes	197 (56.3)
Do you know what mechanical ventilation is?	
No	77 (22.0)
Unsure	80 (22.9)
Yes	193 (55.1)
Do you know what an advance medical directive (will) is?	
No	142 (40.6)
Unsure	103 (29.4)
Yes	105 (30.0)
Do you know what a lasting power of attorney is?	
No	201 (57.4)
Unsure	112 (32.0)
Yes	37 (10.6)

Table 3. Patients' perceptions of the importance of elements related to end-of-life care.

Question	Patients, <i>n</i> (%)
How important is detailed information about your medical condition to you?	
Extremely/somewhat unimportant	11 (3.1)
Unsure	60 (17.1)
Extremely/somewhat important	279 (79.7)
How important is it for you to be informed about your prognosis (i.e., how your illness will progress)?	
Extremely/somewhat unimportant	10 (2.9)
Unsure	70 (20.0)
Extremely/somewhat important	270 (77.1)
How important is it for you to be informed about treatment options such as withdrawing from dialysis?	
Extremely/somewhat unimportant	27 (7.7)
Unsure	111 (31.7)
Extremely/somewhat important	212 (60.6)
How important is it for you to have your physical symptoms (e.g., pain and nausea) to be treated by the nephrology staff?	
Extremely/somewhat unimportant	9 (2.6)
Unsure	83 (23.7)
Extremely/somewhat important	258 (73.7)
How important is it for you to be prepared and plan ahead for death?	
Extremely/somewhat unimportant	16 (4.6)
Unsure	92 (26.3)
Extremely/somewhat important	242 (69.1)
How important is it to you to have access to information on alternative ways to manage your physical symptoms (e.g., traditional medicine, new treatments, and holistic care)?	
Extremely/somewhat unimportant	47 (13.4)
Unsure	138 (39.4)
Extremely/somewhat important	165 (47.1)
How important is it to you for your family to be actively involved in medical decision-making?	
Extremely/somewhat unimportant	27 (7.7)
Unsure	56 (16.0)
Extremely/somewhat important	267 (76.3)
How important is it for your responses regarding quality of life to affect your future care?	
Extremely/somewhat unimportant	14 (4.0)
Unsure	74 (21.1)
Extremely/somewhat important	262 (74.9)
How important is it for you to discuss your quality of life regularly with the nephrology staff?	
Extremely/somewhat unimportant	15 (4.3)
Unsure	79 (22.6)
Extremely/somewhat important	256 (73.1)
How important is it for you to have your social, psychological, or spiritual concerns attended to by nephrology staff?	
Extremely/somewhat unimportant	11 (3.1)
Unsure	86 (24.6)
Extremely/somewhat important	253 (72.3)

Table 4. Total scores for patients' knowledge and perceptions of the end-of-life care.

Variables	Median	IQR
Knowledge	20	5
Perception	27	5

IQR: Interquartile range.

in the scores for knowledge for those with different educational backgrounds ($P = 0.001$). Similarly, employment status ($P = 0.044$), financial status ($P < 0.05$), and the duration of ESRD and HD ($P < 0.05$) had an impact on the knowledge. The knowledge scores increased with higher educational levels, employment, financial status, and longer duration on HD. However, age ($P = 0.124$), sex ($P = 0.986$), marital status ($P = 0.287$), and caregiver status ($P = 0.053$) did not affect the knowledge scores. The patients' perceptions differed significantly by educational background ($P = 0.004$) and caregiver status ($P = 0.004$). Patients who were independently taking care of themselves and those with a better educational background had higher scores than those in other groups.

Discussion

End-of-life care is a fundamental and integral aspect of management in ESRD.¹⁵ Several international studies have previously demonstrated the low level of familiarity with issues of end-of-life care among the ESRD population.^{2,16,17} Similarly, the level of dissemination is limited in the local population, as described by Hing Wong et al.¹³ To date, this is the second study in the country that has looked into aspects of end-of-life care among ESRD patients. Interestingly, several similarities were observed in these two local studies. Both found a similar distribution of the patients' educational background and duration on HD. Another similar finding compared with a larger study in Canada was the caregiver burden, as majority of the respondents (60%) were dependent on their spouses and family. These caregivers have been described in the literature as commonly experiencing significant physical and psychosocial burdens, especially in resource-limited places.¹⁸

Unsurprisingly, the study findings demons-

trated that most participants have poor knowledge of end-of-life care and its options, which only 15% of the study participants reported knowing. Less than one-third of them knew about advance medical directives, LPA, hospice, and palliative care. These findings are in line with the study from University Malaya Medical Centre (2014), in which three-quarters of the respondents had never heard of ACP and only 3.6% of them had prepared an advance directive.¹³ Regardless of initiatives to empower optimal renal palliative care globally, the levels of dissemination and familiarity with end-of-life care remain low in the local population.

The mortality rate among ESRD patients is higher than that in the general population, particularly in the elderly.¹⁹ The 24th report of the Malaysian Dialysis and Transplant Registry stated that the overall unadjusted 5-year survival and 10-year survival of patients on dialysis were 52% and 27%, respectively.⁵ Despite the relatively older age of patients in this study, our findings showed that <50% of patients thought about the progression of the disease. Surprisingly, more than half of the participants predicted that their health would improve. Similar findings were reported in Saudi Arabia with only 14% of patients were aware that end stage renal disease is incurable.¹⁶ This signified poor knowledge and understanding of the disease and its progression among patients. The study's findings were also similar to literature showing that the knowledge and understanding of the illness and its prognosis among ESRD patients are poorer compared with cancer patients.^{9,20} This is alarming and affects treatment expectations and the goals of care. This may also be related to many other factors, including patients' education level, the local culture, and the structure of the whole treatment program. The fact that more than half of the patients did not know that

they were able to withdraw from HD means that the likelihood of them charting their own future treatment options is lower. They are most likely to leave the decisions to the medical teams managing them.

ESRD patients have poorer access to palliative care services compared with those with other life-limiting diseases. Eneanya et al described how ESRD patients are seldom referred for palliative care, with many of them dying in acute care facilities.¹⁹ Hing Wong et al also reported that more elderly long-term HD patients experience intense care at the end of their lives, compared with cancer patients. This was shown by the longer duration spent in the intensive care unit: 47% versus 24%.¹³ Fewer dialysis patients (20%) received hospice care compared with cancer patients (55%) at the end of their lives.¹⁹ The study findings again implied poor awareness and appreciation of the hospice roles among the local ESRD population. The numbers may increase if they were made aware of the benefits of palliative and hospice care.

More than two-thirds of the respondents felt that it was important for them to be prepared and plan for death. Health professionals tend to presume that patients may not want to know their prognosis, as it may cause an unnecessary burden and depression.¹⁵ Death is regarded as a taboo subject by health professionals, and talking about the end of life is an unwanted discussion.¹⁵ The findings in this study showed that this belief is wrong. Patients want to be well-informed about their diagnosis, prognosis, and treatment options, as well as end-of-life issues. Management of symptoms and quality of life were other aspects of care perceived to be important by most patients. Therefore, this must be addressed and tackled by the managing team.

Lack of awareness and knowledge on the disease trajectories may often cause issues concerning the end of life and death to be avoided.¹⁵ Patients often do not view themselves as terminally ill and falsely assume that they will be kept alive indefinitely on dialysis.¹⁵ There has also been a failure to share prognoses

and a lack of ACP between the physician and patients, which leads to treatments that are actually against the patients' preferences.²¹ Effective communication and clear discussions to break the barriers are essential to improve the provision of end-of-life care throughout the duration of the illness. This could be established by understanding the patients' background and awareness, as well as proper attitudes and approaches to end-of-life care.

Limitations

The study was limited to predominantly Malay and English-speaking patients. Since this predominantly involved a certain ethnic group, it limits the generalizability of the findings, and it is not representative of ESRD patients in general. The delivery of the questionnaires by each interviewer may potentially have varied because of the interviewers' bias. A larger cohort may also be needed to further clarify the issue.

Conclusion

The majority of patients have poor knowledge about the end-of-life care and a poor understanding of their illness, disease trajectories, and the prognosis. However, most perceive this information to be important and are comfortable discussing issues pertaining to end-of-life care. This study serves as an important attempt to gauge the knowledge, attitudes, and communication regarding renal palliative care for more holistic management. It lays the foundation to guide further nationwide studies at a larger scale to the development of renal supportive care policies in the country.

Source(s) of Support

This study was funded by the International Islamic University Malaysia's Research Initiative Grant. The study received ethical approval from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia (NMRR-18-2802-42524).

Conflict of interest: None declared.

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