ORIGINAL ARTICLE

Differences in Attitude towards End-Of-Life Care among Haemodialysis Patients and their Family Members in Two Malaysian Hospitals

Kharuddin AT[a], **Osman I**[b], **Ibrahim NA**[b], **Azahar A**[b]

[a] *Department of Anaesthesiology and Intensive Care, Hospital Serdang, Selangor, Malaysia.*
[b] *Department of Anaesthesiology and Intensive Care, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Selangor, Malaysia.*

ABSTRACT

INTRODUCTION: End-of-life (EOL) care has become an important topic of discussion in those with chronic illness, especially in End Stage Renal Disease (ESRD) patients on dialysis. This study explored attitudes towards the EOL care among haemodialysis patients and compared them with the patients' family members. **MATERIALS AND METHODS:** The study was a cross-sectional descriptive study conducted in two tertiary hospitals in Malaysia. The data was collected by using a survey questionnaire from 164 participants which consisted of 82 pairs of patients and their relatives. **RESULTS:** 'Patient' and 'family' groups demonstrated differences in their preferences regarding EOL care options. Family members group favoured cardiopulmonary resuscitation (81.7% vs 41.4%) ($p < 0.001$), endotracheal intubation (80.5% vs 43.9%) ($p = 0.989$) and nasogastric tube feeding (87.8% vs 67%) ($p = 0.001$) more than patients themselves. The physician was the most nominated surrogate decision -maker by the patient (91.5%). Majority of the patients (57.3%) felt uncomfortable discussing EOL care options. There was significant correlation between duration of dialysis and patients' EOL preferences where patients less than 5 years on haemodialysis favoured CPR (55.9% vs 31.3%; $p = 0.026$), intubation (55.9% vs 35.4%) and nasogastric tube feeding (82.3% vs 56.3%; $p = 0.013$) compared to patients who had been on haemodialysis for 5 years or longer. **CONCLUSION:** This study demonstrated significant differences between the attitudes of the patients and their relatives regarding EOL care preferences.

Keywords
Attitudes, Decisions, End-of-life care, Haemodialysis

Corresponding Author
Dr Noor Airini Ibrahim
Department of Anaesthesiology and Intensive Care, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia.
E-mail : airini@upm.edu.my

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INTRODUCTION

Patients with end-stage renal disease (ESRD) have significantly increased morbidity and mortality. ESRD patients, being in the final stage of chronic kidney disease (CKD) usually succumb to the condition if untreated with haemodialysis or renal transplant.[1]

End-of-life (EOL) care is a term used to describe support for patients who are approaching death. EOL issues, especially in the care of people living with dialysis has become an important topic of discussion in society, most notably in developed countries.[2]

Despite continuing technological advancements, mortality rate among ESRD patients on dialysis remains high.[3] According to the Malaysian Dialysis and Transplant Registry 2016, 35% of deaths among ESRD patients were from cardiovascular diseases. About 19% of mortality was due to death at home, and these were believed to be due to cardiovascular events as well. Withdrawal of dialysis resulting in death only accounted for 1% of deaths since 2004.[4] This could be because the option of dialysis withdrawal was not made available to patients throughout the duration of illness, and physicians rarely discuss with their patients and relatives about advance care planning or advanced directive.

Establishing advanced directive is rarely practised in Malaysia. Decisions on EOL care when the patients' health deteriorates are often made by the family and relatives without direct involvement of the patient, whose preferences regarding EOL treatment remain unknown. The decision to limit or withdraw therapy in the intensive care unit is influenced by many factors – these include the chances of cure, overall patient functional status, quality of life, local practice variations of the attending intensivists, and the socioeconomic support.[5-7] From the patients' perspective, factors guiding such decisions include religious and ethnic beliefs, perception of illness curability, age, family support, number of children, level of education, and knowledge about cardiopulmonary resuscitation and its outcome.[8,9]

A previous study found that nursing home residents did trust their relatives, physicians, and nurses to make decisions for them, but in contrast many relatives did not know for sure what the patient themselves really wanted.[10] Another study showed that few patients and relatives had participated in conversations about EOL care and majority of them wanted to be involved in the decision-making process. However, the final decisions were usually left to the health care professionals.[11] While it is crucial to know patients' preferences on EOL decisions so that their wishes are respected, any discussion should also involve family and relatives because they would become the surrogate-decision makers when the patients could no longer participate in decision making.

The main objective of this study was to explore the attitudes towards EOL care among haemodialysis patients and to compare it with that of the family or relatives, as the latter may be involved in future EOL care decision making.

MATERIALS AND METHODS

This was a cross sectional study survey questionnaire study. It was conducted in two major tertiary hospitals in Malaysia, namely Hospital Kuala Lumpur and Hospital Serdang. A total of 164 subjects were recruited over a 6-month period in which 82 pairs of patients and their relatives were interviewed in either the nephrology ward or the nephrology clinic. Purposive sampling method was used. The inclusion criteria were ESRD patients requiring regular haemodialysis with presence of a family member or relative or spouse, and first degree relative or spouse that would be involved in the patient's EOL decision making. The exclusion criteria were mental illness, including those with intellectual disability, dementia, and psychosis, who would not have the capacity to give consent, refuse to participate, and those aged less than 18.

The study was explained to potential participants and all questions were clarified. Written consent was then obtained, and participants were assured of confidentiality. A survey questionnaire was then provided to the patients and their relatives. The same interviewer guided them on each question. The interviewer explained any word that the respondents did not understand, for example CPR, or nasogastric tube insertion. Only explanations were given, thus there was no influence on the respondents' response to the questions asked. The patients and their relatives were interviewed separately and were not allowed to hear or view each other's responses.

QUESTIONNAIRE DESIGN

The questionnaire was adapted from the previous study by Ang et al with the author's consent.[12] The questions regarding EOL care started with a scenario that required participants to imagine themselves or their loved ones becoming completely dependent in self-care. The questions explored preferences in EOL care, including the preferred place of death, the use of cardiopulmonary resuscitation, intubation, nasogastric tube feeding, use of restraints, and antibiotics.

ETHICAL ISSUES

Ethical approval was obtained from Medical Research and Ethics Committee of the Ministry of Health, Malaysia (NMRR-17-2269-38096). There were challenges for older and vulnerable respondents to answer sensitive topics such as end of life care. The interviewer provided verbal explanations to any queries during the process, aimed at enhancing a trusting relationship. The interview process was stopped if a question led to stress or uneasiness to either the patients or their relatives.

Table 1. Demographic Data of Participation

Characteristic	No. (%)	
	Patient (n=82)	Relative (n=82)
Gender		
Male	40 (48.8)	46 (56.1)
Female	42 (51.2)	36 (43.9)
Religion		
Islam	54 (65.9)	54 (65.9)
Christian	10 (12.2)	10 (12.2)
Buddhist	7 (8.5)	7 (8.5)
Hindu	10 (12.2)	11 (13.4)
Other	1 (1.2)	0 (0.0)
Education Level		
Primary and lower	15 (18.3)	5 (6.1)
Secondary	34 (41.5)	24 (29.3)
Tertiary and higher	33 (40.2)	53 (64.6)

STATISTICAL ANALYSIS

All the patients' data were recorded in Microsoft Excel and were analysed using IBM SPSS statistics version 25. p<0.05 was taken as the statistically significant value. Categorical variables were compared with Chi-square test for independent variables, or McNemar test for paired variables.

RESULTS

The median (interquartile range) age of the participants was 46 (28 to 64) years. The patients had a higher median age of 54 (39 to 69) years compared to the family group median age of 42 (23 to 61) years. The ratio of male to female participants was about 1:1. Across the board, most subjects were Malays (54% of the participants), followed by Indians (16%) and Chinese (12%). It is worth to note that most patients only had a secondary school (or below) educational level (n=49, 59.8%) whereas the majority in the relative group had tertiary education or higher (n=53, 64.6%). The rest of the demographics of the study population are shown in **Table 1.**

Of the 82 patients who participated in the study, 53.7% felt uncomfortable discussing about EOL care. The majority in the patient's group (91.5%) chose doctors instead of their own family members to be nominated as surrogate decision makers if they become non communicative.

When patients' attitudes towards EOL care were analysed by age group, significant differences were observed in their responses toward CPR and intubation. The patients who were in middle adulthood (45-65 years) were less likely to prefer CPR (p=0.309) than those in young adulthood (18-44 years) and the elderly (65 years of age or older). However, all groups were more likely to prefer minimal and non-invasive procedures such as nasogastric tube feeding, use of restraint and antibiotics administration **(Table 2).**

Table 2. Comparison of Preference on End-of-Life Care among Patients by Age Groups

Parameter	Age group (no.) [%]			p-value§
	Young adulthood* (n=20)	Middle adulthood† (n=49)	Elderly^ (n=13)	
Cardiopulmonary resuscitation				
Yes	10 (50%)	17 (35%)	7 (54%)	0.309
No/Unsure	10 (50%)	32 (65%)	6 (46%)	
Intubation				
Yes	10 (50%)	19 (39%)	7 (54%)	0.796
No/Unsure	10 (50%)	30 (61%)	6 (46%)	
Nasogastric tube feeding				
Yes	11 (55%)	33 (67%)	11 (85%)	0.029¶
No/Unsure	9 (45%)	16 (33%)	2 (15%)	
Use of restraints				
Yes	13 (65%)	49 (100%)	12 (92%)	<0.001¶
No/Unsure	7 (35%)	0 (0%)	1 (8%)	
Antibiotic use				
Yes	20 (100%)	49 (100%)	10 (77%)	<0.001¶
No/Unsure	0 (0%)	0 (0%)	3 (23%)	

*Participants aged *18-44 yr; †45–65 yr; ^>65 yr. §p-value calculated using chi-square test. ¶p-value is statistically significant.

When patients' attitudes toward end-of-life care were analysed by duration of haemodialysis, significant differences were observed in their responses toward CPR and intubation. The patients who had been on haemodialysis for 5 years or longer were less likely to prefer CPR (p=0.026) and intubation (p=0.066) compared to those which were on haemodialysis for less than 5 years. There were no significant differences observed between the two groups regarding preferences on nasogastric tube feeding, the use of restraints and antibiotics (**Table 3**).

Table 3 Comparison of Preference on End-of-Life Care by Duration of Haemodialysis

Parameter	Duration of haemodialysis		p-value§
	<5 years (n=34)	≥5 years (n=48)	
Cardiopulmonary resuscitation			
Yes	19	15	0.026¶
No/Unsure	15	33	
Intubation			
Yes	19	17	0.066
No/Unsure	15	31	
Nasogastric tube feeding			
Yes	28	27	0.013¶
No/Unsure	6	21	
Use of restraints			
Yes	33	41	0.080
No/Unsure	1	7	
Antibiotic use			
Yes	34	45	0.138
No/Unsure	0	3	

§p-value calculated using chi-square test. ¶p-value is statistically significant.

A comparison of attitudes towards EOL care between the patient and relative groups is shown in **Table 4**. Significant differences were found when patients' own preferences for EOL care were compared to that of their relatives with regards to CPR ($p<0.001$) and intubation ($p<0.001$). The relative group was more likely to opt for CPR and intubation on the patient's behalf than the patients themselves.

Table 4 Comparison of between patient's own preference and relative' ' decision for their loved ones.

Parameter	No (%)		p-value*
	Patients' preference	Relatives' decision	
Cardiopulmonary resuscitation			
Yes	34 (41.4)	67 (81.7)	<0.001¶
No/Unsure	48 (58.6)	15 (18.3)	
Intubation			
Yes	36 (43.9)	66 (80.5)	<0.001¶
No/Unsure	46 (56.1)	16 (19.5)	
Nasogastric tube feeding			
Yes	55 (67.1)	72 (87.8)	0.001¶
No/Unsure	27 (32.9)	10 (12.2)	
Use of restraints			
Yes	74 (90.2)	67 (81.7)	0.001¶
No/Unsure	8 (9.8)	15 (18.3)	
Antibiotic use			
Yes	79 (96.3)	80 (97.6)	1.000
No/Unsure	3 (3.7)	2 (2.4)	

*p-value calculated using McNemar test. ¶p-value is statistically significant.

DISCUSSION

Very few patients and their relatives have participated in conversations with their doctors about their preferences and wishes regarding EOL care. While some were quite open and wished to have the discussion, others were reluctant or indifferent towards partaking in these sensitive issues. It is indeed a challenging task for physicians to ascertain patients' EOL wishes, given the complexity of the illness and patient expectation, large variation in symptom burden, advances in life sustaining treatments and the sensitive emotional context of these conversations. We found only half of the patients (53.7%) felt comfortable in discussing EOL care issues. This conformed to a previous Malaysian study in 2016, where only 41.1% of the haemodialysis patients felt comfortable discussing death.[5] These low percentages were probably because these patients lacked knowledge about advance care planning (ACP). ACP is a process of shared decision making about future health care plans between patients, doctors, and family members, should the patients become incapable of participating in medical treatment decisions. Previous studies have suggested that patients welcome ACP and expect health professionals to initiate discussions.[13,14]

In this study, when patients were asked what they preferred for themselves if they became permanently uncommunicative and totally dependent in self-care, most patients chose less aggressive treatments which include antibiotics use (96% agreed), use of restraints (90% agreed) and nasogastric tube feeding (67% agreed). The result was comparable to a previous study done in Singapore which reported that patients predominantly opted for comfort-care at their end-of-life juncture.[12] Previous studies had shown that patients' priorities for quality care during advanced illness and at the end-of-life included expert pain and symptom management, avoiding inappropriate prolongation of the dying process, relieving burdens on loved ones, and being prepared for death.[15-17] Therefore, addressing cardiopulmonary resuscitation preferences with patients is a very important aspect to ensure patients' wishes are respected.

When analysed by age, the study found that older age was not associated with preference for CPR or intubation. These findings were consistent with previous studies demonstrating that treatment preferences in seriously ill older adults vary widely, and studies in ESRD patients found that older age was not associated with preference for CPR.[18,19] There was increasing evidence that patients older than 75 years with ischemic heart disease, those with multiple comorbidities, and those who were frail, did not benefit from renal replacement therapy. While dialysis had not shown to increase their lifespan, it also put them at a higher risk for other comorbidities.[20] Essentially, for these patients, dialysis was unlikely to improve their symptoms and may in fact negatively impact their health-related quality of life (HRQL) and functional status.[21,22]

We also found that the overall duration of haemodialysis affects patients' preferences on EOL care. Patients who had been on haemodialysis for five years or longer were less likely to prefer intubation and CPR compared to those who have been on haemodialysis for less than five years. Potential explanations for this observation include poor quality of life and previous hospitalisation experiences. Patients with advanced chronic renal disease have a high symptom burden, reporting high rates of fatigue, dyspnoea, insomnia, pain, anxiety, and depression.

These symptoms greatly affect patients' HRQL: the mean prevalence of chronic pain across multiple worldwide cohorts of haemodialysis patients was 58.6% and is often unrecognized and undertreated.[19] Patients with longer haemodialysis duration may have realised that they do not have a good quality of life, having to go to the dialysis centre three times per week coupled with restriction of fluids in their daily life. Moreover, they may have experienced a critical medical condition, or saw someone go through this experience during the previous hospitalisation which increased their knowledge on CPR and intubation. This is supported by a previous study which showed that improved knowledge about CPR resulted in increased preference for comfort-care near end-of-life.[23]

When relatives were asked to decide on behalf of their loved ones, majority of the relatives preferred CPR and intubation. This contrasted with the patients' preferences; they were less likely to opt for CPR and intubation if they became uncommunicative and totally dependent. The decision by the relatives may be borne out of the need to feel satisfied that they were trying all possible avenues for their loved ones. They may want to avoid the feeling of guilt or regret at the untimely death of their loved ones should a decision not to continue treatment be made. This study showed that family member decisions may not reliably represent the patients' own preferences and wishes. Thus, when patients were excluded from EOL decision-making, the resulting medical care they receive may run counter to their personal preference. This study affirmed that it was important for the physician to initiate EOL discussion between patients and family members so that expectations and wishes from both groups may be met.

Lastly larger scale studies would be more representative of the general haemodialysis patient group and we recommend a pilot study to produce a more reliable questionnaire for future research into this subject.

CONCLUSION

The study showed there were differences in attitudes towards EOL care between patients and relatives. Patients' wishes particularly on EOL issues may differ from that of the families making decisions for them. Therefore, we suggest early communication and discussion among haemodialysis patients, relatives, as well as the physicians in charge pertaining to EOL care issues for the best interest of both patients and relatives.

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