

The Validation of Questionnaire on End-of-Life Care Knowledge, Perceptions, and Preferences among End-Stage Renal Disease Patients on Hemodialysis

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Abstract

Introduction: End-of-life care issues for end-stage renal disease (ESRD) patients are still not fully highlighted in trials and clinical practice. Due to the inadequacy, exploring patients' knowledge, perceptions, and preferences is essential to improve the delivery of care. This was performed using questionnaires which have been a widely useful tool in medical researches. Up to date, there was no published, validated questionnaire developed in Malaysia for such purposes yet. **Objective:** This study aimed to develop and validate the questionnaire on end-of-life care knowledge, perceptions, and preferences among hemodialysis (HD) patients. **Subject and Methods:** A cross-sectional study was conducted among 92 HD patients from 14 centers. It involved four phases including (i) developing the questionnaire and pretesting, (ii) improving and editing and redistribution to respondents for the pilot study, (iii) factor analysis (FA), and (iv) internal consistency reliability testing. **Results:** The result of FA with varimax rotation performed identified three domains for the 41 items, with 10–20 items in each domain. All the 41 analyzed items had a good factor loading of more than 0.4 with the lowest value of 0.421 and were nicely fit into three respective domains: knowledge, perceptions, and preferences. Internal consistency reliability analysis Cronbach's α values were between 0.5 and 0.7 for all domains, higher than the level set for this study (0.5). **Conclusion:** The questionnaire was successfully validated and considered a useful tool in describing ESRD patients' end-of-life care knowledge, perceptions, and preferences.

Keywords: End of life, end-stage renal disease, questionnaire, validation

INTRODUCTION

End-stage renal disease (ESRD) is defined as an irreversible decline in renal function which will be fatal in the absence of renal replacement therapy.^[1] It is a life-limiting illness^[2] and majority will undergo hemodialysis (HD) treatment to maintain lives.^[3] However, the expected symptoms' improvement for ESRD patients was not well-documented in the literature.^[4] Several studies have highlighted the high burden of physical and emotional symptoms among ESRD patients.^[5,6]

Palliative care for ESRD patients integrates education, symptoms management, advance care planning, and psychological support, leading to the terminal phase of planning for the end of life.^[7] It prioritizes the comfort and quality of life aligned with patients' preferences and goals.^[8] It showed great benefits regardless of either dialysis or nondialytic pathways.^[9] Surprisingly, the role of renal

palliative care lags far behind other terminal illnesses. The inadequacies of end-of-life care in the patient management have also been described in many studies.^[9,10] It is neither well known nor optimally implemented in the routine clinical practices in Malaysia, and research on the local practice is lacking.^[11] Up to now, there was only one local, single-center study that investigated end-of-life care aspect demonstrating the low level of knowledge dissemination among patients.^[11]

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Understanding their views including awareness, values, and preferences on the end-of-life care and its related issues is an important step to identify gaps between patients' preferences and clinical practice.

Questionnaires were widely used by researchers in understanding mass thinking. Due to its feasibility and low cost in data collection,^[12] it is a readily accepted method, compared to the more invasive and long experimental study. Apart from its low cost and feasibility, its wide utilization in studies involving large number of patients was able to yield statistical analysis with bigger power compared to other methods.^[13]

The development of a questionnaire that addresses end-of-life care attributable to ESRD is vital. The aim of the study is to develop and validate the questionnaire on end-of-life care knowledge, perceptions, and preferences among ESRD patients on HD.

SUBJECTS AND METHODS

Questionnaire development

The questionnaire was adapted and modified from a study conducted in 2008 involving chronic kidney disease stage 4–5 peritoneal and HD patients at the University of Alberta, Canada. It was developed from an extensive review of the literature on vital factors, including treatment of symptoms, place of death, and advance care planning.^[14]

Some modifications were made in consideration to our local settings. The decision was made after an expert panel meeting for content validity. Content validity is to show whether items in a questionnaire covered the intended topics clearly.^[12] The questionnaires were translated into the Malay language by two health-care professionals who were fluent in both the languages.

The questionnaire consisted of the following four main domains:

- A. Background and sociodemographic data
- B. Self-reported knowledge
- C. End-of-life care perceptions
- D. End-of-life care preferences.

Section A consisted of patients' sociodemography. In Section B, patients' knowledge of the disease and its trajectory was assessed. The responses were put into 3-point Likert scale whereby responses 1, 2, and 3 were marked as 0, 1 and 2, respectively. The higher the marks indicated better knowledge and vice versa. Section C addressed patients' end-of-life care perceptions. This section also applied marking from 0 to 2, in which higher marks demonstrated better perception. A 3-point scale from "1 = very/somewhat important," "2 = unsure," and "3 = extremely/somewhat unimportant" was applied. Both Sections B and C had "unsure" answer option to avoid bias from guessing. Section D involved questions on preferences in relation to end-of-life care issues. Patients chose the preferred options outlined.

An initial pretesting among unintended population for face validity was conducted to ensure its feasibility, readability, and comprehensibility. The questionnaire was then revised, according to the inquiries and suggestions given by the respondents. The questionnaires were redistributed via convenient sampling and delivered in a structured interview-based survey. Inclusion criteria included age more than 18 years old with ESRD on HD. Patients who were unable to understand English or Malay language were excluded from the study.

Construct validity

Factor analysis (FA) was performed on the data collected to test for construct validity.^[15] It was performed by dividing into three factors because during the questionnaire development phase, three domains for FA have been identified, namely knowledge, perception, and preference.

Internal consistency reliability analysis

Internal consistency reliability analysis was tested using Cronbach's alpha (α). The Cronbach α was set at 0.5 for this current study.

RESULTS

A total of 92 patients completed the questionnaire. The validation process of the questionnaire included internal consistency and construct validity assessment. There were three domains, namely knowledge (B), perception (C), and preferences (D) with 41 items altogether.

Construct validity

Table 1 shows the result of FA with varimax rotation that identified three domains for the 41 items, with 10–20 items in each domain. All the analyzed items had a factor loading of more than 0.4, the cutoff point for a good factor loading,^[16] with the lowest value of 0.421, and were nicely fit into three respective domains.

Internal consistency reliability analysis

Table 2 shows Cronbach's α reliability analysis for the 11 items in domain knowledge, 10 items in domain perceptions, and 20 items in domain preferences. The results of the analysis indicated that Cronbach's α was between 0.5 and 0.7 for all factors, which was moderately consistent and acceptable. All the Cronbach's α values obtained were higher than the level set for this study which was 0.5.

DISCUSSION

Although the concept of end-of-life care for ESRD patients has been around for many years, it is lagging behind other terminal illnesses and was not thoroughly discussed in routine clinical practice.^[10,11] Thus, there is an urgent need to create a validated questionnaire. The questionnaire comprised four domains which were (i) patients' background and sociodemographic data, (ii) end-of-life care knowledge, (iii) end-of-life care perceptions, and (iv) end-of-life care preferences. These were adapted from a similar study conducted in Alberta, Canada, which had been

Table 1: Factor loading of each item based on factor analysis

Item number	Items	Domain		
		Knowledge	Perceptions	Preferences
1	Health in the next 12 months?	0.726		
2	Think your condition is curable?	0.747		
3	What might happen with your illness in the future?	0.537		
4	What end of life care is and its options?	0.775		
5	What palliative care is?	0.824		
6	What a hospice is?	0.421		
7	Know that a patient has the right to withdraw from dialysis?	0.536		
8	What CPR is?	0.841		
9	What mechanical ventilation is?	0.823		
10	What an advance medical directive (will) is?	0.697		
11	What LPA is?	0.699		
12	How important detailed information about medical condition to you?		0.891	
13	How important to be informed about your prognosis?		0.557	
14	How important to be informed about treatment options?		0.662	
15	How important to have your physical symptoms be treated?		0.607	
16	How important to be prepared and plan ahead?		0.842	
17	How important to have access to information on alternative ways to manage your physical symptoms?		0.731	
18	How important for family to be actively involved in medical decision-making?		0.682	
19	How important "quality of life" responses to affect future care?		0.663	
20	How important to discuss "quality of life" regularly?		0.880	
21	How important to have social, psychological or spiritual concerns attended?		0.782	
22	Who do you rely on for social and emotional support?			0.653
23	If you are physically or mentally unable to make a decision, who would you choose to make decisions about your medical care?			0.631
24	How would you normally get the information that will help to make a personal decision?			0.787
25	Do you regret the decision to start hemodialysis?			0.660
26	Why did you choose dialysis over conservative care (no dialysis)?			0.745
27	How comfortable are you in discussing end-of-life issues with family?			0.537
28	How comfortable are you in discussing end-of-life issues with your nephrology staffs?			0.748
29	Has the doctor talked to you about how much time you have to live?			0.571
30	Have you completed related documents?			0.667
31	If completed an advance medical directive, what request to be done in the case heart stopped beating?			0.800
32	Thinking of current condition, what would you want your doctor to do if you heart stopped beating?			0.889
33	If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible?			0.557
34	Where would you prefer to die?			0.552
35	During the past 12 months, have you discussed your choices concerning end-of-life care?			0.537
36	Members of the health care team you like to talk with about end-of-life issues?			0.793
37	When like to have this end-of-life conversations?			0.653
38	How often like to have your end-of-life care plan reviewed?			0.908
39	Where to have this end of life discussions?			0.685
40	What would you like to see as part of an end-of-life care program for patients dying with kidney disease?			0.623
41	What issues surrounding end of life care would you like to know more about?			0.591

Extraction method: Principal component analysis. 3 components extracted. Rotation method: Varimax with Kaiser normalization. CPR: Cardiopulmonary resuscitation, LPA: Lasting power of attorney

validated. However, modifications were made in terms of items arrangements for each domain, wordings with Malay translation to fit the local population. Its purpose was to gain understanding in the local context and identify gaps in the current practice. Both clinicians and patients unusually have distinctive priorities

and preference in viewing this subject. Therefore, establishing mutual understanding will yield a better outcome.

The three domains which undergone validation analysis were knowledge, perceptions, and preferences, containing 41 items.

Table 2: Reliability analysis with Cronbach's alpha for each domain

Item number	Items	Mean (n=92)	Standard deviation	Cronbach's alpha
1	Health in the next 12 months?	1.69	0.761	0.573
2	Think your condition is curable?	2.47	0.703	
3	What might happen with your illness in the future?	2.39	0.827	
4	What end of life care is and its options?	1.31	0.616	
5	What palliative care is?	1.16	0.464	
6	What a hospice is?	1.02	0.140	
7	Know that a patient has the right to withdraw from dialysis?	2.06	0.968	
8	What CPR is?	2.37	2.946	
9	What mechanical ventilation is?	1.92	0.891	
10	What an advance medical directive (will) is?	1.37	0.720	
11	What LPA is?	1.47	0.809	0.601
12	How important detailed information about medical condition to you?	2.98	0.140	
13	How important to be informed about your prognosis?	2.92	0.392	
14	How important to be informed about treatment options?	2.67	0.653	
15	How important to have your physical symptoms be treated?	2.86	0.448	
16	How important to be prepared and plan ahead?	2.80	0.491	
17	How important to have access to information on alternative ways to manage your physical symptoms?	2.63	0.631	
18	How important for family to be actively involved in medical decision making?	2.63	0.747	
19	How important "quality of life" responses to affect future care?	2.86	0.448	
20	How important to discuss "quality of life" regularly?	2.76	0.513	
21	How important to have social, psychological or spiritual concerns attended?	2.76	0.551	0.797
22	Who do you rely on for social and emotional support?	1.59	0.339	
23	If you are physically or mentally unable to make a decision, who would you choose to make decisions about your medical care?	1.72	0.258	
24	How would you normally get the information that will help to make a personal decision?	1.72	0.355	
25	Do you regret the decision to start hemodialysis?	1.14	0.348	
26	Why did you choose dialysis over conservative care (no dialysis)?	1.59	0.572	
27	How comfortable are you in discussing end-of-life issues with family?	1.37	0.692	
28	How comfortable are you in discussing end-of-life issues with your nephrology staffs?	1.47	0.758	
29	Has the doctor talked to you about how much time you have to live?	1.29	0.701	
30	Have you completed related documents?	3.37	0.488	
31	If completed an advance medical directive, what request to be done in the case heart stopped beating?	1.96	0.916	
32	Thinking of current condition, what would you want your doctor to do if you heart stopped beating?	1.76	0.885	
33	If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible?	2.00	0.775	
34	Where would you prefer to die?	3.50	0.931	
35	During the past 12 months, have you had a discussion about your choices concerning end-of-life care?	1.90	0.103	
36	Members of the health care team you like to talk with about end-of-life issues?	1.83	0.241	
37	When like to have this end of life conversations?	2.78	1.447	
38	How often like to have your end of life care plan reviewed?	1.47	0.857	
39	Where to have this end of life discussions?	2.45	0.730	
40	What would you like to see as part of an end of life care program for patients dying with kidney disease?	1.63	0.477	
41	What issues surrounding end-of-life care would you like to know more about?	1.35	0.457	

CPR: Cardiopulmonary resuscitation, LPA: Lasting power of attorney

The items per domain ranged from 10 to 20 items. It underwent content validity by the respective experts on subject matters and face validity in which only a few reported little difficulties. No early termination or adverse effect was recorded. Focusing on the construct validity of the developed questionnaire, FA

performed on the data collected shows that the number of factor solution was three. These findings supported the convergence and discriminant validity of the questionnaire as it fulfilled two out of three criteria on a number of factors which needed to be obtained, namely all factors obtained have eigenvalue

of >1 (not shown) and number of factors were following the number of domain identified in the development of the questionnaire. In addition, all factors' loading values were more than 0.4 and items in each domain were inter-correlated within but not with items in other domain.

It can be concluded that this questionnaire has a satisfactory internal validity whereby all the items for knowledge, perception, and preference have Cronbach's α value of more than 0.5, the value set in this study. A higher value of Cronbach's α can be achieved by increasing the number of items in each domain as described by the previous researcher that items of <10 in a section are likely to yield α value of <0.7.^[12,17] The similar trend is observed in this study whereby preference domain has the highest of the value of 0.797, followed by perception and knowledge with the α values of 0.601 and 0.573, respectively. The latter two both have 10 and 11 items and produce about a relatively similar α value. As opposed to the preference domain which consists of 20 items, the α value obtained was comparably high.

CONCLUSION

This questionnaire was successfully validated and considered as a useful tool. This is the first successfully validated questionnaire for such purpose in Malaysia. Improvement will still be necessary from time to time to ensure its relevance in relation to the evolving disease patterns.

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Conflicts of interest

There are no conflicts of interest.

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