ORIGINAL ARTICLE

QUALITY OF LIFE AMONG PATIENTS UNDERGOING HAEMODIALYSIS IN JAKARTA, INDONESIA

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ABSTRACT

Haemodialysis is a continuous treatment provided to patients with chronic kidney disease as a replacement for renal function. It is important to assess the quality of life among these patients. The aim of this study was to evaluate quality of life among patients on haemodialysis using an Indonesian version of the KDQoL-SF24 questionnaire. This is a cohort observational study that included 145 haemodialysis patients in a haemodialysis centre in Jakarta, Indonesia. A translated and validated version of the KDQoL-SF24 was used in this survey. The participants in this study had lower mean scores than the standard form in the following 6 components: burden of kidney disease (44.22±33.23), cognitive function (74.94±20.32), sleep (57.07±24.15), patient satisfaction (60.11±18.56), role-physical (26.21±44.01), emotional well-being (69.19±24.25) and role-emotional (40.69±49.18). A significant relationship was found between sexual function, physical functioning, role emotional and age among haemodialysis patients ($P < 0.05$). Based on the overall health rating from the KDQoL-SF24, the mean and standard deviation for the 21- to 30-year-old age group was lower than the standard form. The burden of kidney disease, cognitive function, sleep, patient satisfaction, role-physical, emotional well-being and role-emotional component scores were low for haemodialysis patients in Indonesia compared to the standard form. Additionally, age significantly affected sexual function, physical functioning and role-emotional.

Keywords

Patients on Haemodialysis, Quality of Life, KDQoL-SF24, Indonesia

INTRODUCTION

Chronic kidney disease (CKD) is a global public health problem with an increasing prevalence, and CKD is associated with the incidence of kidney failure, poor prognosis and high costs¹. The prevalence of CKD increases with the increasing number of elderly people and the incidence of diabetes mellitus and hypertension¹. CKD patients in the fifth stage or with a glomerular filtration rate of less than 15 ml/min have no kidney function¹.

Haemodialysis is a treatment to replace renal function that must be performed continuously in these patients^{2,3}. One of the purposes for continuous treatment or haemodialysis among patients with end-stage renal disease is to increase quality of life⁴. One of the instruments used to assess the quality of life among haemodialysis patients is the Kidney Disease Quality of Life-Short Form 24 (KDQoL-SF24). This instrument is valid and available on the RAND health website. The instrument has an English language version and has been translated into other languages. If a translated version is not available in the desired language, then the instrument must be translated into the desired language, and a pilot study is required to assess and reliability for that version.

In the KDQoL-24, there are 24 questions in 4 categories: health (11 questions), kidney disease (3 questions), effects of kidney disease on daily life (8 questions) and satisfaction with care (2 questions). The website also provides manual scoring guidelines to determine the quality of life or respondents.

The prevalence of diabetes, metabolic risk factors and other indicators of renal disease provided an increased understanding of the burden of kidney disease in Australia, and this understanding is applicable worldwide⁵.

MATERIALS AND METHODS

Study Location: This study was carried out in a haemodialysis centre in Jakarta, Indonesia (Cempaka Putih Islamic Hospital Jakarta, Indonesia).

Study participants and design

The study included diabetic and/or hypertensive patients who underwent haemodialysis. Universal sampling was used to select 145 patients who were undergoing haemodialysis in Jakarta, Indonesia. A cohort prospective study was conducted in this HD centre.

Inclusion criteria

- 1) All haemodialysis patients who had diabetes and/or hypertension
- 2) Patients ≥ 18 years

Exclusion criteria:

- 1) Patients < 18 years of age
- 2) Cancer patients
- 3) Pregnant patients
- 4) Patients with HIV/AIDS
- 5) Patients with systemic lupus erythema

Ethical Clearance

Ethical approval was granted by a medical committee from the Faculty of Medicine Indonesia. The study reference number is 728/UN2.F1/ETIK/2015.

Data Collection and Handling

The researcher met the patients and explained the background and purpose of the research. Patients who signed the informed consent form were included. The KDQoL-SF24 was translated into the Indonesian language by a certified translator and was validated among 23 haemodialysis patients. The

validated questionnaire was used to evaluate quality of life among 145 patients.

RESULTS

To assess the health-related quality of life (HRQOL) of haemodialysis patients in Indonesia, the KDQoL-SF24 Indonesian version was not found on the RAND website. Therefore, a pilot study had to be performed before assessing HRQOL using the Indonesian version of the KDQoL-SF24 questionnaire among haemodialysis patients in this HD centre. The alpha Cronbach value was approximately 0.7 after analysing pilot study data from 23 haemodialysis patients in this HD centre.

Reliability Analysis of Pilot Study

Table 1 shows Cronbach's alpha for the 4 domains of the Indonesian version of the KDQoL-SF24 questionnaire (your health, your kidney disease, effect of your kidney disease on your daily life and satisfaction with care). The overall Cronbach's alpha value was 0.684.

Table 1: Reliability Analysis

Component	No of Each Component	Cronbach's Alpha
Your Health	36	0.663
Your Kidney Disease	22	0.667
Effects of Your Kidney Disease on Your Daily Life	19	0.688
Satisfaction with Care	3	0.613
Overall	80	0.684

Figure 1 illustrates the demographic characteristics of the 145 patients included in the study; 85 patients were male and 60 patients were female.

Figure 1 Prevalence of Haemodialysis Patients by Sex among the KDQoL-24 Assessment Participants

Figure 2 shows the age distribution of the 145 patients included in the KDQoL-SF24 assessment in the HD centre in Jakarta, Indonesia. The largest

number of patients was found in the fifth group (42 patients).

Figure 2 Prevalence of Haemodialysis patients by Age among the Participants in the KDQoL-24 Assessment

Scoring of KDQoL-SF24

Table 2 shows the mean and standard deviation of each component of the KDQoL-SF24 questionnaire for haemodialysis patients in the HD centre in Jakarta, Indonesia and the manual standard of the KDQoL-SF. The burden of kidney disease, cognitive function, sleep, patient satisfaction, role-physical,

emotional well-being and role emotional component scores were lower than the standard form. The mean score and standard deviation for the overall health rating were higher than the manual standard of the KDQoL-SF, as shown in Table 2.

Table 2: Scoring of the KDQoL-SF24 Questionnaire for 145 Indonesian Patients

Component	Number of Components	Score of Each Component (Mean±SD)	Standard Form (Mean±SD)
Symptom/problem	12	72.53±29.30	71.21±16.77
Effects of kidney disease	8	70.92±27.65	57.30±24.53
Burden of kidney disease	4	44.22±33.23*	49.62±30.27
Work status	2	60.79±36.57	25.26±37.82
Cognitive function	3	74.94±20.32*	79.11±19.75
Quality of social interaction	3	76.69±24.85	76.65±18.71
Sexual function	2	65.52±12.15	69.30±36.17
Sleep	4	57.07±24.15*	60.68±28.61
Social support	2	69.08±33.59	64.61±27.73
Dialysis staff encouragement	2	86.03±17.49	69.90±23.13
Patient satisfaction	1	60.11±18.56*	71.38±22.04
Physical functioning	10	59.66±39.40	51.83±29.73
Role-physical	4	26.21±44.01*	32.46±39.68
Pain	2	61.40±28.77	
RAND scoring			60.40±30.11
SF-36tm scoring			57.60±29.7
General health	5	61.45±27.40	
RAND scoring			42.88±24.32
SF-36tm scoring			43.87±24.75
Emotional well-being	5	69.19±24.25*	69.54±20.36
Role-Emotional	3	40.69±49.18*	57.76±43.90
Social function	2	66.12±27.29	63.57±29.77
Energy/fatigue	4	56.84±27.29	45.89±24.06
Overall health rating	80	62.18±33.86	59.37±19.54

*Low

Table 3 shows the correlation between sex and KDQoL-SF24 scores for each component among haemodialysis patients in a HD centre in Jakarta, Indonesia.

Table 3: KDQoL-SF24 Scores for Each Component Based on Sex Among Haemodialysis Patients in a HD Centre in Jakarta, Indonesia

Score Component	Indonesia Median (Scores)		P*
	Males (n=68)	Females (n= 60)	
Symptom/problem	950	900	0.25
Effects of kidney disease	600	600	0.70
Burden of kidney disease	200	175	0.97
Work status	150	150	0.41
Cognitive function	240	220	0.18
Quality of social interaction	240	220	0.46
Sexual function	150	150	0.19
Sleep	220	230	0.48
Social support	166.66	133.33	0.60
Dialysis staff encouragement	175	175	0.38
Patient satisfaction	50	50	0.88
Physical functioning	552	650	0.07
Role-physical	0	0	0.40
Pain	135	135	0.39
General health	300	300	0.37
Emotional well-being	340	320	0.10
Role-Emotional	0	0	0.74
Social function	150	125	0.40
Energy/fatigue	220	220	0.21

* *Man-Whitney U Test*

No significant relationship was found between each component of the KDQoL-SF24 and sex among the haemodialysis patients in the HD centre in Jakarta, Indonesia, as shown in Table 3. There was a significant correlation between sex and question 14h (part of the symptom/problem component), question 15g (part of the kidney disease component), question 20 (part of the work status component), question 3d, 3e, and 3h (part of the physical functioning component), question 4c (part of the role-physical component) and question 11c (part of the general health component) among diabetic and/or hypertensive patients who underwent haemodialysis in a HD centre in Jakarta, Indonesia.

Table 4 shows the correlation between age and the KDQoL-24 score for each component among

haemodialysis patients in a HD centre in Jakarta, Indonesia. Significant relationships were found between sexual function, physical functioning, role-emotional and age among haemodialysis patients in a HD centre in Jakarta, Indonesia, as shown in Table 4. A significant relationship between age and questions of each component of the KDQoL-24 was also found in the HD centre in Jakarta, Indonesia. A significant correlation was shown between age and question 15d (part of the effects of kidney disease component), questions 20 and 21 (part of the work component), question 16a, 16b (part of the sexual function component), question 3c, 3h, 3i (part of the physical functioning component), question 4d (part of the role physical component), question 11b (part of the general health component), and question 5b (part of the role-emotional component).

Table 4: KDQoL-SF24 Score for Each Component Based on Age Among Haemodialysis Patients in a HD Centre in Jakarta, Indonesia

Score Component	Indonesia Median (Scores)					p*
	≤ 40 (N=18)	41-50 (N=30)	51-60 (N=42)	61-70 (N=40)	>70 (N=15)	
Symptom/problem	975	950	887	950	975	0.80
Effects of kidney disease	587.5	625	600	600	550	0.37
Burden of kidney disease	162.5	162.5	200	200	150	0.80
Work status	85	150	120	150	160	0.06
Cognitive function	230	240	240	200	240	0.19
Quality of social interaction	220	240	240	220	220	0.61
Sexual function	150	100	150	150	150	0.03*
Sleep	245	225	230	220	200	0.50
Social support	183.33	133.33	132.32	166.66	133.33	0.19
Dialysis staff encouragement	175	175	175	175	200	0.86
Patient satisfaction	66.66	50	50	50	50	0.69
Physical functioning	500	551	600	650	850	0.003
Role-physical	100	50	0	0	0	*
Pain	135	135	135	135	155	0.13
General health	325	325	300	300	275	0.83
Emotional well-being	370	320	340	320	320	0.43
Role-Emotional	150	0	0	0	0	0.87
Social function	137.5	150	137.5	125	125	0.03*
Energy/fatigue	230	240	210	200	220	0.71
						0.29

* Kruskal-Wallis Test

Table 5 shows the correlation between the clinical outcome and the overall health rating based on the KDQoL-SF24 score among haemodialysis patients in the HD centre in Jakarta, Indonesia. No significant relationship was found between clinical outcome and overall health rating based on the KDQoL-SF24 among haemodialysis patients

in a HD centre in Jakarta, Indonesia, as shown in Table 6.

Table 6 shows the mean and standard deviation of each component of the KDQoL-SF24 questionnaire between the study and the standard form among haemodialysis patients in a HD centre in Jakarta, Indonesia based on sex.

Table5: Scores of Overall Health Ratings by the KDQoL-SF24 Tool Based on Clinical Outcomes in a HD Centre in Jakarta, Indonesia

Component	Mean±SD / Median (Total Scores)		P*
	Survival	Death	
Indonesia	5042.14 ± 806.40	4570 ± 798.14	0.08

**Independent Sample T-Test*

Table 6: Overall Health Rating by the KDQoL-SF24 Tool Based on Sex

Component	Mean ± SD		Standard Form (Mean±SD)
	Male	Female	
Indonesia	62.55 ± 33.73	70.92 ± 27.65	59.37±19.54

The mean ± standard deviation of the males and females in the HD centre in Jakarta was greater than that of the standard form, as shown in Table 6. This finding indicates that the quality of life of these haemodialysis patients was good.

Table 7 shows the mean and standard deviation of each component of the KDQoL-SF24 questionnaire between the study and the standard form among haemodialysis patients in the HD centre in Jakarta, Indonesia based on age.

Table 7: Overall Health Rating by the KDQoL-SF24 Tool Based on Age

Country	Mean ± SD								Standard Form (Mean±SD)
	≤ 20	21-30	31-40	41-50	51-60	61-70	>70		
Indonesia	76.56 ± 25.96	50.26 ± 34.43 *	63.62 ± 34.92	63.40 ± 33.25	62.36 ± 33.35	61.55 ± 33.65	61.91 ± 35.75	59.37 ± 19.54	

** The value is lower than the KDQoL-SF Manual Standard*

There were 7 groups based on patient age (≤ 20, 21-30, 31-40, 41-50, 51-60, 61-70 and > 70 years). The mean and standard deviation of the second group of patients (21-30 years) among haemodialysis patients in a HD centre in Jakarta, Indonesia were lower than those of the standard form, as shown in Table 7. The lower scores showed that the quality of life of this group was not good.

DISCUSSIONS

The overall Cronbach's alpha for the Indonesian version of the questionnaire used in this study was 0.7. This finding is similar to results from a previous study in Thailand, where Cronbach's alpha was approximately 0.6-0.7, either for each component or for the overall KDQoL-36 Thailand version ⁶. The KDQoL-SF24 is part of the KDQoL-36, while the KDQoL-36 contains more questions than the KDQoL-SF24. Some questions from the KDQoL-36 questionnaire were not available.

In Jakarta, Indonesia, the mean (SD) scores regarding burden of kidney disease, cognitive function, sleep, patient satisfaction, role-physical, emotional well-being and role-emotional

were lower than those of the KDQoL-SF Manual Standard. In this centre, haemodialysis was a physical and emotional burden for the patients. This finding is similar to the findings of Fukura et al., who reported a much greater burden of kidney disease among ESRD patients treated by haemodialysis in Japan than among those in the United States. These patients feel frustrated due to spending much of their time on the treatment of this disease, and they feel like a burden on their families ⁷.

In this study, sleep disorder was identified as one of the problems among diabetic and/or hypertensive patients who underwent haemodialysis in Indonesia. Sleep disorder was one of the measurements used to determine quality of life in these patients. The continuous activity of haemodialysis might be one of the contributing factors. Parvan et al. revealed that 83.3 % of patients on haemodialysis had poor sleep quality ⁸. Another study conducted by Chang & Yang reported that more than half (57.1 %) of 275 haemodialysis patients enrolled in the research had poor sleep quality (PSQI > 6) ⁹. These are similar to the findings of our study.

Role-emotional and physical factors are components that can also determine the quality of life of diabetic and/or hypertensive patients who undergo haemodialysis. The disease and the continuous treatment that they will receive are the factors that affect their emotional and physical function. Some haemodialysis patients cannot accept their condition as renal failure patients, and although they may be young and full of energy, they are frustrated due to their condition. For others who do not have more energy to survive due to age may be more positive emotionally as they have a better emotional state in terms of accepting their condition and encouraging themselves to survive. Other patients will have problems due to the severity of the disease. According to the study by Mingardi et al., diabetic patients who underwent haemodialysis had lower scores in terms of physical functioning¹⁰.

In this study, sex did not influence the overall quality of life among haemodialysis patients. Some significant relationships were found between age and some questions, including one question each from symptom/problem: effects of kidney disease, work status, role-physical and general health components. In addition, there were three questions from the physical functioning category with a significant relationship with age. Zyoud et al. revealed a significant positive association between HRQOL and male sex among patients on haemodialysis¹¹. Another study conducted in Malaysia discovered that quality of life among haemodialysis patients was positively influenced by male sex¹².

As mentioned above, sexual function, physical functioning, and role-emotional were significantly correlated with age among diabetic and/or hypertensive individuals who underwent haemodialysis in a HD centre in Jakarta, Indonesia. For analysis between components of the KDQoL-SF24 and age groups of patients, patients were grouped by age before conducting the analysis, and the group of patient's aged ≤ 40 years was the first group.

This study also found some significant relationships between age and some questions, including one question from the effects of kidney disease, role-physical, general health and role-emotional components; two questions from the work status and sexual function components; and three questions from the physical functioning component among diabetic and/ or hypertensive patients undergoing haemodialysis in a HD centre in Jakarta, Indonesia.

According to Bohlke et al., age had a significant influence on physical functioning among patients on dialysis in southern Brazil, as measured by the KDQoL-SF 36¹³. Another study also found that haemodialysis patients were less active than

healthy sedentary controls, and this difference was more pronounced among older patients¹⁴. For the association between age and emotional function among haemodialysis patients, the Santos study revealed no correlation between age and the following dimensions: role of emotions and mental health¹⁵. This finding is different from our results.

Ramalingam et al. reported a moderate level of depression among haemodialysis patients¹⁶. Other studies concluded that the physical component of quality of life (QoL) and functional health decreased with age and depressive symptoms and increased with cognitive abilities¹⁷¹⁸.

Health-related quality of life (QoL) is an important measure of how a disease affects a patient's life¹⁹. The QoL domains include physical, psychological, and social functioning and general satisfaction with life²⁰¹⁹. Once patients with ESRD start to receive HD, they must face the chronic stress related to restrictions on their time, the economical and vocational costs related to treatment, functional limitations, dietary constraints, and possible adverse effects of medications²¹¹⁹. Numerous studies have demonstrated that patients on haemodialysis had a lower QoL than healthy individuals²²²³¹⁹. In another study, Zyoud et al., revealed that older age was associated with lower HRQOL¹¹.

Haemodialysis can affect a patient's sexual activity. Patients may feel tired, bored and disappointed due to their disease. Martin-Diaz et al. reported that 47 % of the haemodialysis patients who were involved in the study did not have any kind of sexual activity²⁴. Another study reported that the production of testosterone naturally declines and that the older age of the dialysis population is associated with a reduction in testosterone activity. Thus, this may exacerbate the effects of chronic kidney disease²⁵.

CONCLUSION

An assessment using the KDQoL-SF24 among haemodialysis patients in a HD centre in Jakarta, Indonesia showed that the scores corresponding to the burden of kidney disease, cognitive function, sleep, patient satisfaction, role-physical, emotional well-being and role-emotional were low. Significant relationships were found between sexual function, physical functioning, role-emotional and age among haemodialysis patients in a HD centre in Jakarta, Indonesia. From the overall health rating of the KDQoL-SF24, the mean scores of patients aged 21-30 years in Jakarta, Indonesia were lower than those of the standard form.

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