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Original Article

A cross sectional study on assessment of health related quality of life among end stage renal disease patients undergoing hemodialysis

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ABSTRACT

Background: Numerous advancements are nowadays being developed in the field of medicine to improve the clinical outcomes among chronic kidney disease patients. Though these therapies help the patients to live longer life, still their quality of life remain uncertain.

Objective: The objective of the study was to assess the health related quality of life (HRQOL) among end stage renal disease patients undergoing hemodialysis.

Methods: A cross-sectional descriptive study was conducted among 50 patients undergoing maintenance hemodialysis in a tertiary level referral hospital in Kerala. Patients who had completed at least three months of maintenance hemodialysis, and aged 18 years and above of either sex were included in the study. The socio demographic details of the patients were collected through patient and bystander interviews and from their hospital case records. HRQOL was evaluated using a standardized scale of Kidney Disease Quality of Life-Short Form questionnaire.

Results: Among HRQOL, the mean score of kidney disease component summary was higher than Mental Component Summary and Physical Component Summary (60.48 ± 11.81 , 41.83 ± 15.78 and 36.49 ± 16.30 respectively). Patients possessed better quality of life in Social support (73.54), Dialysis staff encouragement (67.56) and Quality of social interaction (67.56) and the worst scores in Role-physical (13.57) and Role-emotional (17.72) scales.

Conclusion: The study has shown that the quality of life of hemodialysis patients was highly impaired and it clearly defines how the disease state adversely affects the physical and mental status of the patient.

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1. Introduction

Chronic kidney disease (CKD) is a pathological condition that is diagnosed on the basis of the presence of proteinuria or decreased glomerular filtration rate (GFR) for a period of 3 months or more.¹ In CKD, nephrons, the functional unit of kidney becomes non functional and leads to reduction in kidney function. Though the compensatory mechanisms become activated initially, later as the disease progresses it becomes unable to cope up the increased need of kidney and results in decline of GFR. The major risk factors include diabetes, hypertension, autoimmune disease, polycystic kidney disease, drug toxicity, urinary tract abnormalities, etc.²

According to the 2010 Global Burden of Disease study, CKD was ranked 27th in the list of causes of total number of global deaths in 1990, but rose to 18th in 2010.³ Numerous advancements are nowadays being developed in the field of medicine to improve the clinical outcomes among CKD patients. Renal replacement therapies such as hemodialysis and kidney transplantation are the most accepted and available treatment options for end stage renal disease (ESRD), but these all are focusing on symptom reduction only, without considering the patient as an individual. Though these therapies help the patients to live longer life than they would have lived without the treatment, still their quality of life remain uncertain. Thus it is important to assess the health related quality of life (HRQOL) of ESRD patients undergoing hemodialysis, not only to predict the risk of morbidity and mortality, but also for keeping a check on their physical, mental and kidney disease status.⁴

WHO has defined QOL as “an individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features in their environment. Thus the assessment of health related quality of life stands as an inevitable option in the evaluation of quality and effectiveness of patient care, comparison of various treatment options, and the improvement of treatment outcomes.⁵

Many studies have been conducted for measuring the HRQOL using various generic as well as disease-specific instruments. Generic measures such as SF-36, WHO-QOL BREF questionnaire were commonly used to predict patients' outcome and to detect the changes in QOL. Later disease-specific instruments have been developed to assess aspects of HRQOL in relation to a disease of interest, which are not adequately assessed by generic measures. They focus on concerns that are more relevant to a specific illness and treatment. The Kidney Disease Quality of Life Questionnaire–Short Form (KDQOL-SF™) has become the most widely used QOL measures for CRF patients. It is a self-report tool that includes the Medical Outcomes Study Short Form-36 generic core and several multi-item scales targeted at QOL concerns of special relevance for patients with CRF.⁶

Despite a rising incidence of ESRD in India, there is still unavailability of an updated, authentic data on burden of CKD

and the impact of disease on quality of life. However, providing support and care to such patients has remained a low priority area with limited resources in terms of monetary support and availability of specialist and trained individuals. There is an urgent need to evaluate and address these issues through interdisciplinary and collaborative efforts to yield a substantial gain in quality of life of patients. Hence, the present study aims to describe various dimensions of health-related quality of life.⁷

2. Materials and methods

2.1. Study design

This cross-sectional descriptive study was carried out from 1st January–1st July 2015 that is over a period of 6 months in the dialysis unit of a tertiary level referral hospital in Kerala.

2.2. Subjects

Patients who had completed at least three months of maintenance hemodialysis, and aged 18 years and above of either sex were included in the study. The patients who had voluntarily withdrawn from dialysis and those who have any major surgical interventions in the previous three months, malignancies, tumors, cognitive impairment, dementia, active psychosis, and major hearing impairment were excluded from the study in order to prevent bias in the assessment of QOL as these may interfere with the result.

2.3. Procedure

Ethical clearance was obtained from Institutional ethical committee of Al Shifa Hospital, Kerala with no. IEC/ASH/2015/PD/16, prior to initiation of the study. During the starting period of study a total of 84 ESRD patients were undergoing hemodialysis on regular basis in the dialysis unit. The sample size was scientifically calculated and 50 patients those who satisfied the study criteria were included by convenient sampling method. The nature, type or intention of the study was explained to the participants and given at least twenty-four hours to decide whether or not to participate. A written consent was obtained from them prior to their enrollment in the study by providing them with the consent letters in the local language. The socio demographic details of the patients were collected using a semi-structured questionnaire and the details were collected through patient and bystander interviews and from their hospital case records. Bystanders were interviewed to cross check the data given by the patient mainly on details like their sleep patterns (insomnia), eating habits (whether patient is anorexic or not) and whether the patient is adherent to the dietary restrictions. Then the patients were given with the validated questionnaire, KDQOL-SF™ version 1.3, to measure the HRQOL after translating into the local language. It includes generic and disease related cores. The items that form the generic core of KDQOL-SF version 1.3 are those constructed for SF-36 version 1 (19). The results of generic core reported by two components (Mental Component Summary (MCS) and Physical Component

Summary (PCS)), are comprised of eight scales of SF-36: physical functioning, role-physical, bodily pain, general health, vitality (energy/fatigue), social functioning, mental health (emotional well-being), and role-emotion. Disease targeted items include eleven scales that relate to the kidney disease are: symptoms/problems, effects of kidney disease on daily life, burden of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement and patient satisfaction. These 11 subscales (items) make kidney disease component summary (KDCS). The range of each score scale is from 0 to 100 and higher scores show better quality of life.

The questionnaire KDQOL-SF™ was generally self-administered, and the patients mostly filled out their questionnaire at home or in dialysis department. The written information was double-checked with the patients to assure that the patients filled the questionnaire by themselves and to make sure that they completed the questionnaire properly and the HRQOL scores were obtained. Some patient had to be reminded frequently on the very next visit to ensure the returning of the filled questionnaire on time.

2.4. Statistical analysis

The collected data were compiled using Microsoft excel and were analyzed using Statistical Package for Social Sciences (SPSS) version 20.0. Descriptive statistics was used to assess the mean and standard deviation for patient demographics like age group. Chi square test was performed for comparing the mean scores of each component with socio demographic and clinical variables of the respondents. The statistical significance of the study was assessed at 5% level of significance.

3. Results

Sociodemographic characteristics of the study population are shown in Table 1. A total of 50 CKD patients participated in the study, which included 40 males and 10 females. Almost 38% of the patients were above 60 years with mean age of 51.94 ± 14.71 years. Majority had an education till high school (58%) and 10% were graduates.

Clinical characteristics of patients involved in the study are shown in Table 2. The most predominant cause of renal failure was Kidney disease (27), followed by diabetes (17 patients), hypertension (5 patients) and other disease (Alport Syndrome). Duration of dialysis extends from 1 year to more than 7 years and the mean duration was found to be 4.04 years.

From Table 3, it was found that the mean score of KDCS was higher than MCS and PCS (60.48 ± 11.81 , 41.83 ± 15.78 and 36.49 ± 16.30 respectively). Among KDCS, all scores except effect of kidney disease (46.32) and burden of kidney disease (33.50) were found to be above 50. But in MCS, except emotional well-being score (55.27), all were below 50 and in PCS none of the scores exceeded 50. The patients possessed better quality of life in Social support (73.54), Dialysis staff encouragement (67.56) and Quality of social interaction (67.56) and the worst QOL scores in Role-physical (13.57) and Role-emotional (17.72) scales.

Table 1 – Socio demographic characteristics of the study participants.

Variables	Number (%) (n = 50)
Age	
21–30	6 (12%)
31–40	4 (8%)
41–50	8 (16%)
51–60	13 (26%)
>60	19 (38%)
Gender	
Male	40 (80%)
Female	10 (20%)
Religion	
Hindu	21 (42%)
Christian	28 (56%)
Muslim	1 (2%)
Educational status	
Lower primary	7 (14%)
Upper primary	8 (16%)
High school	29 (58%)
Pre degree	1 (2%)
Degree	5 (10%)
Marital status	
Married	41 (82%)
Unmarried	7 (14%)
Divorced	2 (4%)

Table 2 – Clinical characteristics of the study participants.

Variables	Number (%) (n = 50)
<i>Causes of renal failure (previously confirmed by a medical practitioner and supported by investigations)</i>	
Type 2 diabetes mellitus	17 (34%)
Hypertension	5 (10%)
Kidney disease	27 (54%)
Others	1 (2%)
<i>Duration of dialysis in years</i>	
1 year	6 (12%)
2 years	10 (20%)
3 years	8 (16%)
4 years	11 (22%)
5 years	5 (10%)
6 years	3 (6%)
7 years and above	7 (14%)
<i>Frequency of hemodialysis</i>	
Two times weekly	28 (56%)
Three times weekly	22 (44%)
<i>Comorbidities</i>	
Type 2 DM	7 (14%)
HTN	16 (32%)
Type 2 DM + HTN	9 (18%)
Heart disease	2 (4%)
HTN + heart disease	1 (2%)
Type 2 DM + heart disease	3 (6%)
Type 2 DM + HTN + heart disease	4 (8%)
Others	8 (16%)
<i>Insurance distribution</i>	
General	5 (10%)
Karunya	34 (68%)
ESI	4 (8%)
ECHS	7 (14%)

Table 3 – Mean KDQOL-SF™ scores of respondents.

Components	Subscales	Mean ± SD
Physical Component Summary (PCS)	Physical functioning	42.14 ± 22.62
	Role-physical	13.57 ± 28.11
	Pain	49.29 ± 30.91
	General health perceptions	41.84 ± 16.13
	Total	36.49 ± 16.30
Mental Component Summary (MCS)	Emotional well-being	55.27 ± 20.83
	Role-emotional	17.72 ± 33.42
	Social function	49.24 ± 24.79
	Energy/fatigue	45.60 ± 18.58
	Total	41.83 ± 15.78
Kidney Disease Component Summary (KDCS)	Symptoms/problems	68.69 ± 17.34
	Effect of kidney disease	46.32 ± 18.20
	Burden of kidney disease	33.50 ± 19.31
	Cognitive function	61.86 ± 27.80
	Quality of social interaction	67.56 ± 27.34
	Sleep	65.20 ± 22.27
	Social support	73.54 ± 24.28
	Dialysis staff encouragement	72.85 ± 14.59
	Patient satisfaction	54.80 ± 21.98
	Total	60.48 ± 11.81

Table 4 depicts the comparison of mean scores of physical, mental and kidney disease components based on socio-demographic and clinical variables of respondents. Chi-square statistics was used to find out whether there is any association between such variables and quality of life. None of the components showed statistically significant association with the variables age, gender, marital status, duration and frequency of dialysis and insurance distribution of study population. A significant association was observed between marital status and social support ($P < 0.001$), dialysis staff encouragement ($P < 0.005$), effect of kidney disease ($P < 0.05$) and burden of kidney disease ($P < 0.05$). Insurance distribution possessed a significant association in the effect of kidney disease score ($P < 0.05$). Patients who have started hemodialysis recently (less than mean duration, i.e. <4 years) showed higher scores in most of the subscales, and they possessed significantly high scores in physical functioning (P value: 0.018), general health perceptions (P value: 0.046) and patient satisfaction (P value: 0.026) measures compared to those who are on HD for longer years. Frequency of hemodialysis showed

Table 4 – Comparing the mean scores of physical, mental and kidney disease components based on sociodemographic and clinical variables of respondents.

Variable	PCS Mean ± SD	Chi- square value	P-value	MCS Mean ± SD	Chi- square value	P-value	KDCS Mean ± SD	Chi- square value	P-value
Age									
21–30	36.56 ± 10.74	1047.50	0.756	43.09 ± 23.53	1280.00	0.341	64.53 ± 11.95	1456.25	0.191
31–40	30.94 ± 14.09			47.90 ± 15.26			62.32 ± 7.33		
41–50	42.15 ± 19.72			47.88 ± 15.50			59.38 ± 12.99		
51–60	36.02 ± 15.96			41.98 ± 14.67			59.39 ± 15.72		
>60	35.28 ± 17.39			37.43 ± 14.12			59.99 ± 13.59		
Gender									
Male	38.25 ± 17.24	32.813	0.621	42.96 ± 15.89	43.75	0.397	60.31 ± 13.67	46.88	0.478
Female	29.44 ± 9.43			37.33 ± 15.28			61.15 ± 10.80		
Marital status									
Married	37.43 ± 16.63	51.48	0.968	42.24 ± 14.58	91.64	0.267	60.30 ± 13.72	100.00	0.317
Unmarried	31.13 ± 15.32			39.28 ± 25.91			63.65 ± 9.03		
Divorced	29.69 ± 13.70			39.35 ± 23.13			56.36 ± 4.94		
Educational level									
Lower primary	38.32 ± 17.58	125.38	0.121	42.17 ± 16.67	143.40	0.138	60.94 ± 11.99	145.65	0.377
Upper primary	34.73 ± 11.25			41.86 ± 14.82			52.18 ± 6.28		
High school	30.31 ± 18.70			38.04 ± 15.40			75.08 ± 00		
Pre degree	39.38 ± 00			35.13 ± 00			58.45 ± 14.02		
Degree	34.63 ± 11.79			44.15 ± 15.52					
Duration of dialysis									
1 year	30.83 ± 19.78	221.51	0.384	33.13 ± 20.71	244.98	0.613	48.69 ± 21.81	295.23	0.282
2 years	35.5 ± 11.56			45.03 ± 18.93			62.11 ± 9.35		
3 years	41.95 ± 19.73			47.37 ± 14.46			62.87 ± 12.53		
4 years	35.19 ± 17.39			38.56 ± 13.74			63.23 ± 14.58		
5 years	28.05 ± 8.39			37.04 ± 13.05			58.66 ± 10.13		
6 years	45.47 ± 8.17			45.66 ± 11.37			68.09 ± 3.68		
7 years & above	38.39 ± 19.70			43.63 ± 19.67			57.55 ± 14.66		
Frequency of dialysis									
2 times weekly	34.80 ± 15.77	32.08	0.656	39.86 ± 17.19	40.53	0.536	56.81 ± 12.50	45.942	0.516
3 times weekly	38.64 ± 17.07			44.34 ± 13.76			65.14 ± 12.48		
Insurance distribution									
General	37.19 ± 17.72	121.30	0.180	41.28 ± 16.59	136.38	0.249	60.11 ± 12.11	150.00	0.286
Karunya	37.49 ± 13.99			40.12 ± 15.42			62.46 ± 15.87		
ESI	32.66 ± 23.68			41.75 ± 18.45			54.08 ± 7.16		
ECHS	34.62 ± 11.79			44.15 ± 15.52			58.45 ± 14.02		

a negative correlation with the energy/fatigue (P value: 0.046) measure.

4. Discussion

ESRD has a considerable impact on the functional status and quality of life (QOL) perceived by the patient. Even in relatively early stages, it may be accompanied by symptoms that affect daily life. The present study focused on the assessment of HRQOL among ESRD patients undergoing hemodialysis. Even though several standard questionnaires are available, KDQOL-SF™, a specific instrument to evaluate patients with kidney disease, was selected for determining quality of life of the study population.

The demographics obtained from the study population were slightly different from that of previous studies. Mean age of patients in our sample was 51.94 ± 14.71 years, which is much lower than the mean age of ESRD patients in developed countries and the result correlates with the study of Pezeshki and Rostami.⁸ In the current study, majority of population was found to be aged above 60 years. Results showed that the most common causes of renal failure were kidney diseases and lifestyle diseases such as DM and hypertension, which are mostly seen associated with enhancing age. This finding is not accordant with the study done by Mohammed et al.⁹ The male predominance observed in the ESRD population was similar to other studies^{10,11} and the reluctance seen in women to seek health care may be one of the reasons. 80% of study population was married, which is quiet similar to the study undertaken by Stephen et al.,¹² which suggest that it is harmony with the age group.

Even though there are variations among the results of the previous studies, most of them have shown diabetes as the leading cause of CKD. According to Pezeshki and Rostami, Abraham et al., diabetes is the leading cause followed by hypertension.^{8,11} A study conducted in Japan by Fukuhura et al., have shown glomerular nephritis to be the second leading cause of CKD.¹³ Our study result have shown kidney disease (54%) to be the leading cause among our population (which included diseases like glomerular nephritis, ADPKD, etc.) followed by diabetes (34%) and hypertension (10%).

From earlier studies it is evident that the quality of life of hemodialysis patients are highly impaired.^{8,10,11} Our results were also accordant to these studies. Despite the deterioration of the physical health status, the mental health of dialysis individuals is relatively preserved. The low physical component score clearly explains the impaired physical health status of the study population. This was explained by superior adjustment of older patients to their chronic illness. It could be easily correlated with our result since 38% of our study population comprises of patients above 60 years. Comparatively better results were obtained in disease specific items such as symptoms, cognitive function, quality of social interaction, etc. Moreover they are satisfied with the support from society, family and dialysis staff. But the disease state affected the mental component of patient negatively, especially least score obtained in role emotional subscale under MCS. The results have shown similarities with the study conducted by Bele et al.,⁷ but comparatively the QOL scores seen in our population were low.

There was no correlation between age and three components of KDQOL in general but statistically significant increase was seen with cognitive function and physical function and which correlates with Kenchaappa et al.¹⁴ Although most of the components and subscales decreased with increasing age, some scales like burden of kidney disease and patient satisfaction increased with aging. Despite lower social support of older patients, satisfaction was better in these patients, possibly because they had greater adaptation and lower expectation than younger individuals. Female gender had lower scores in several measures of HRQOL except for the social support. Gender does not seem to have significant association with the quality of life of hemodialysis patients. Duration of dialysis though not significantly associated with the QOL component measures, it showed significant association with subscales like patient satisfaction, physical functioning and general health perception. Comparatively the QOL scores were found to be higher in case of patients who are married and a significant association was observed between marital status and Social support. According to Theofilou et al. married patients seem to experience a better QOL and suggesting that better psychological and social well-being can be associated with family conditions and living with a partner.¹⁵

Being a cross sectional study most measures were self-administered questionnaires that may be influenced by fluctuations in the respondent's attention, motivation, comprehension, and response biases such as social desirability, which can potentially cause measurement error. We have not adjusted scores with general population and confounding factors were not considered such as hemoglobin level, serum albumin, KT/V, etc. Besides, we have not measured spiritual and religious dimensions that are known to influence QOL. Further follow up studies are required to understand more about HRQOL and to take measures to improve the quality of life of hemodialysis patients. Moreover, multicentered studies are essential to generalize the results.

5. Conclusion

The dialysis patients reported highly impaired HRQOL. It clearly defines how the disease state adversely affects the physical and mental status of the patient. The current therapies aim to improve the functional capacity of the patients for as long as possible, however they do not modify the progression of HRQOL of the patients. Thus HRQOL measurement gains worldwide attention as important outcome measure after the initiation of the dialysis therapy.

Conflicts of interest

The authors have none to declare.

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