

Quality of Life and its Associated Factors among Patients Undergoing Dialysis in a Tertiary Care Hospital, Puducherry, South India - A Cross-Sectional Analytical Study

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Abstract

Background: Assessment of Quality of Life (QOL) among patients undergoing dialysis has become important with the increase in demand. Patients undergoing dialysis have limited mobility, deranged family and social life and decreased financial autonomy, all of which affect their quality of life. Hence, the study aims to assess QOL and its associated factors along with their out of pocket expenditure for seeking care.

Methods: A cross-sectional analytical study was conducted among 140 patients undergoing dialysis in a tertiary health care hospital in South India. Data on Socio-demography, history of co-morbid condition and duration and type of dialysis were collected before the start of the procedure. QOL was assessed using World Health Organization Quality of life (WHOQOL-BREF) Questionnaire. Out of Pocket Expenditure (OOPE) was assessed using a pre-tested structured questionnaire with the recall period of past 1 month (expenditure incurred during OPD, follow up, duration they spend in JIPMER for treatment during each visit, food, wages lost, travel expenditure to reach JIPMER and any other medical and non-medical cost). Domain scores and total expenditure were summarized as median (IQR).

Results: Quality of Life scores reported in Physical domain, Psychological domain, Social domain, Environment Domain were 13(6-19), 19(13-25), 56 (44-75), 13(6-19) respectively. Total cost incurred per month for a patient undergoing dialysis in INR was 4300 (2400-7200).

Conclusion: Patients undergoing dialysis had low QOL in all four domains in spite of a longer life. The direct non-medical costs incurred by the patients were huge.

Keywords: Chronic kidney disease; End stage renal disease; Out of pocket expenditure; Quality of life

Introduction

According to Global Burden of disease 2015, the burden of Chronic Kidney Disease (CKD) has increased by 32% since 2005. In total, it is estimated that 5 – 10 million people die annually due to kidney disease [1]. Thus, CKD is considered to be an important

cause of morbidity and mortality worldwide leading to impaired quality of life. Though dialysis is one of the first technological innovations in medicine to allow a patient with end stage renal failure to live longer, patients on dialysis have huge impairment in their quality of life due to limited mobility, deranged family and social life, decreased financial autonomy and other systemic complications related to the cardiovascular system, lack of production of red blood cells and abnormal bone health [2]. In India, care

for kidney diseases represents the greatest challenge in achieving Universal Health Coverage [3]. The Global Burden of Disease reveals the increased burden of kidney diseases, and hence an increased demand for dialysis. Currently, about 2.4 million people are undergoing dialysis worldwide [2]. In India around 1,30,000 patients were receiving dialysis which was increasing rapidly [4]. With the increase in demand, there is an appreciable increase in the average cost of the procedure. Yet, the issue of OOPE has not been addressed till date [5].

Quality of life (QOL) is a multifaceted concept. Present trend towards assessing the QOL in chronic diseases is considered to be an important research tool [6]. World Health Organisation (WHO) defines Quality of life as “the 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.” In this study the QOL of patients undergoing dialysis was assessed using World Health Organization Quality of Life-BREF (WHOQOL-BREF). In this context, we aimed to assess the QOL of the patients undergoing dialysis using WHOQOL-BREF tool and to determine the various socio-demographic and co-morbid conditions of the patients that affect their QOL. We also measured the Out-Of-Pocket Expenditure (OOPE) incurred by the patients undergoing dialysis in a publicly funded tertiary care hospital.

Methodology

A hospital based cross-sectional study was conducted between February and December 2019 among the patients undergoing dialysis in a tertiary care centre, Puducherry. The centre has a separate dialysis OPD, where the dialysis clinic is conducted every week. On an average around 50 patients undergoing dialysis visit weekly. During the study period, the total number of patients undergoing dialysis in the centre was 146. Among them, patients undergoing peritoneal dialysis was 46 and haemodialysis was 100. Patients aged >18 years who spoke Tamil or English and undergoing dialysis (Peritoneal/ Haemodialysis) for more than 3 months were included in the study. Patients having severe cognitive impairment were excluded. As all patients undergoing dialysis at JIPMER were included in the study, Universal sampling technique was adopted for the study purpose. The total number of patients interviewed was 140, six of them does not met inclusion criteria hence they were excluded.

Study Procedure

A semi-structured data collection performa was used to collect data regarding socio-demographic details (age, gender, marital status, residence, education, employment and family income), details of the disease condition (duration of illness, duration of dialysis, type of dialysis and history of co-existing disease) and out of pocket expenditure per visit with recall period of past one month (expenditure incurred during OPD consultation, duration they spend in JIPMER for treatment during each visit, food cost, wage lost, travel expenditure to reach JIPMER and amount spent for dialysis) after obtaining consent. WHOQOL-BREF Questionnaire was used to assess the Quality of Life (QOL) [7]. It was self-administered. However, for the participants who were unable to read, questions were asked by the investigator and responses noted. The questionnaire had 26 questions covering four domains (physical, psychological, social and environmental); however, the first two questions assess the overall perception of QOL of the individual. The responses were recorded in a 5-point Likert scale in positive direction. The raw score is calculated and transformed to a 0-100 scale using a transformation formula as per the manual of WHOQOL-BREF. Higher score reflects a better QOL.

Statistical Analysis

Data were entered in EpiData version 3.03 and the analysis was done using IBM SPSS version 19 (Statistical Package for the Social Sciences). The scores for each domain were summarized as median (IQR). Mann Whitney U test and Kruskal Wallis test were used to test the association between socio-demographic characteristics and the domains. The OOPE for the patients were summarized as Median (IQR).

Results

QOL Assessment

Of the 146 patients undergoing dialysis during 2019, six did not meet the inclusion criteria. Among the remaining 140 patients, above two-thirds (65%) of them were undergoing haemodialysis. About 59% of them were in the age group of 35-60 years and a higher proportion were unemployed (65%). The most common co-existing conditions reported were hypertension (97%) and anaemia (31%) (Table 1).

Characteristics	Frequency (n)	Percentage (%)
Age group (in years)		
18-34	48	34.3
35-60	83	59.3
>60	9	6.4
Gender		
Male	96	68.6
Female	44	31.4
Residence		
Urban	60	42.9
Rural	80	57.1
Marital status		
Married	95	67.9
Unmarried	45	32.1
Education		
Primary	NIL	
Secondary	70	50.0
Higher secondary	25	17.9
Graduate and above	45	32.1
Occupation		
Self - employed / business	13	9.3
Unemployed	91	65.0
Homemaker	22	15.7
Daily / monthly waged	14	10.0
Income (In Rupees)		
<=10000	113	80.7
>10000	27	19.3
Duration of illness		
<=5 years	95	67.9
>5 years	45	32.1
Duration of Dialysis		
<=5 years	128	91.4
>5 years	12	8.6
Type of Dialysis		

Peritoneal dialysis	48	34.3
Haemodialysis	92	65.7
History of co-existing disease*		
Hypertension	136	97.1
Anaemia	43	30.7
Diabetes	30	21.4
Heart diseases	12	8.6
COPD	7	5.0
Others [†]	17	16.8
*Multiple responses considered [†] Others - chronic liver disease, Hepatitis B & C, Stroke, HIV		

Table 1: Demographic characteristics of study population undergoing dialysis in tertiary health care centre, Puducherry (N=140).

QOL scores in the entire domain were not normally distributed. Thus the median (IQR) scores for each domain shown are as follows: Physical domain - 13 (6-19), Psychological domain - 19 (13-25), Social domain - 56 (44-75), Environmental domain - 13 (6-19). it was found that women had significantly lesser score in both psychological (p value= 0.001) and environmental domain (p value=0.011). urban population had significantly higher median (IQR) score in all the domains except environmental domain (Table 2).

Variables	Physical Median (IQR)	Psychologica Median (IQR)	Social Median (IQR)	Environmental Median (IQR)
Overall score	13 (6-19)	19 (13-25)	56 (44-75)	13 (6-19)
Age group (in years) [†]				
18-34	13 (8-19)	19 (6-25)	56 (44-75)	13 (6-19)
35-60	13 (6-19)	19 (13-25)	56 (44-75)	13 (6-13)
>60	19 (6-19)	19 (19-28)	50 (44-81)	13 (6-22)
Test statistics	1.9	2.5	0.1	3.1
P value	0.370	0.270	0.960	0.209
Gender[‡]				
Male	13 (6-19)	19 (19-25)	56 (44-75)	13 (6-19)
Female	13 (6-19)	13 (6-19)	50 (44-75)	6 (6-13)
Test statistics	-1.6	-3.8	-0.9	-0.9
P value	0.107	0.001*	0.350	0.011*
Residence[‡]				
Urban	13 (13-19)	19 (19-31)	56 (50-81)	13 (6-19)
Rural	13 (6-19)	19 (6-24)	50 (44-75)	13 (6-13)
Test statistics	-2.6	-3.8	-2.8	-1.7
P value	0.008*	0.001*	0.005*	0.086
Marital status[‡]				

Married	13 (6-19)	19 (13-25)	56 (44-81)	13 (6-13)
Unmarried	19 (13-19)	19 (6-25)	56 (44-75)	13(6-19)
Test statistics	-2.6	-0.3	-0.13	-1.6
P value	0.009*	0.767	0.896	0.109
Education[†]				
Upto 10 std	13 (6-19)	19 (6-25)	50 (44-75)	6 (6-13)
Higher secondary	13 (13-19)	19 (6-25)	50 (44-65)	13 (6-16)
Graduate and above	19 (13-19)	19 (16-31)	56 (47-94)	13 (13-19)
Test statistics	12.2	8.2	7.7	18.1
P value	0.002*	0.160	0.021*	0.001*
Occupation[†]				
Self-employed / business	13 (6-19)	25 (22-31)	56 (47-87)	13 (13-19)
Unemployed	13 (6-19)	19 (13-25)	56 (44-75)	13 (6-13)
Homemaker	9.5 (6-19)	19 (6-19)	50 (25-61)	6 (6-13)
Daily/ Monthly waged	19 (13-19)	19 (6-31)	75 (44-84)	16 (11-25)
Test statistics	5.1	9.3	9.2	12.8
P value	0.160	0.025*	0.164	0.005*
Income[‡]				
<=10000	13 (6-19)	19 (9-25)	50 (44-75)	13 (6-13)
>10000	19 (13-19)	19 (13-31)	75 (56-100)	19 (13-25)
Test statistics	-2.2	-1.0	-3.7	-3.3
P value	0.020*	0.306	0.000*	0.001*
Duration of illness[‡]				
<= 5 years	13 (6-19)	19 (6-25)	56 (44-75)	13 (6-13)
>5 years	13 (13-19)	19 (13-28)	50 (44-81)	13 (6-19)
Test statistics	-1.8	-1.5	-0.1	-0.44
P value	0.071	0.125	0.862	0.663
Duration of dialysis[‡]				
<= 5 years	13 (6-19)	19 (13-25)	56 (44-75)	13 (6-13)
>5 years	16 (8-19)	19 (8-31)	65 (45-81)	16 (8-25)
Test statistics	-0.9	5.8	-1.0	-2.0
P value	0.364	0.561	0.302	0.040*
Type of dialysis[‡]				
€Peritoneal dialysis	13 (13-19)	19 (19-25)	50 (44-56)	6 (6-13)
Haemodialysis	13 (6-19)	19 (6-25)	56 (44-81)	13 (6-19)

Test statistics	-1.0	-1.0	-3.2	-2.0
P value	0.283	0.293	0.001*	0.042*
*statistically significant, †Kruskal Wallis test, ‡Mann Whitney U test				

Table 2: Association of socio-demographic factors and various domains of WHOQOL-BREF among the patients undergoing dialysis in tertiary health care centre, Puducherry (N=140).

Graduates had significantly higher score in physical domain (p value=0.002), social domain (p value=0.021) and environmental domain (p value=0.001). We also found that participants with income more than Rs. 10,000/- per month have higher median score in all the domains psychological domain. (Table 2)

Out of Pocket Expenditure Assessment

We found that in this study 80.7% of the population were covered under insurance schemes such as Tamil Nadu Chief Minister Comprehensive Health Insurance Scheme (CMCHIS) and Puducherry BPL scheme. About 16% of the population were under paying category. Rest of the patients were ‘staff dependents’, i.e., relatives of employers working in the institution. The Median (IQR) of total health care expenditure for past 1 month was INR 4300 (2400-7200) (Table 3).

Reason for expenditure	Median (IQR) (in INR)	Minimum-maximum value (in INR)
Direct medical cost*		
Medicine	275 (0-500)	0-5200
Dialysis	0	6496-14868
Total	300 (0-700)	0-15468
Direct non-medical cost#		
Food	240 (0-480)	0-3000
Transport	1440 (570-2910)	72-12000
Rental room	0	0-8000
Attender expenditure	0 (0-575)	0-9400
Total	2580 (1200-4750)	72-21200
*Direct medical cost = medicine+dialysis cost #Direct non-medical cost = Food+transport+rentalroom+attender expenditure		

Table 3: Cost incurred per month among the patients undergoing dialysis in tertiary health care centre, Puducherry (N=140).

Discussion

Quality of life is a broad concept influenced by various components. Though dialysis is an innovative technology that helps patient with CKD live longer, it has greater impact on one’s QOL. Thus, in this study efforts were made to address QOL of the patients undergoing dialysis in a tertiary care hospital. The two major risk factor of CKD are diabetes and hypertension. WHO states that in Western countries, diabetes and hypertension accounts for over 2/3rd of the cases of CKD. Developing countries like India also reports 40-60 % of CKD cases due to diabetes and hypertension. Thus, it contributes to the major burden [8]. The present study also reveals that around 97% of the study population were hypertensive. By addressing the two major risk factors of ESRD, level of morbidity can be controlled to a certain extent. Also, there is an increasing trend in the prevalence of kidney failure among the younger age group i.e., the working population. This negatively impacts the quality of life of an individual or the community by affecting the socio-economic status [9]. We also found, 35% of the population were in the age group of 18-34 years and 65% of the study population were unemployed because to their life-changing events inspite of dialysis which could lead to financial crisis [10].

Assessment of QOL in present study using WHO QOL-BREF questionnaire reports a comparatively higher median (IQR) score in social domain, however, the overall QOL of the patients undergoing dialysis was impaired. A similar study by Joshi et al, (2016) in Nepal, reported QOL of the patients were impaired in all domains of which, environmental domain had a better score [11]. The difference might be due the study population as it included only the patients undergoing haemodialysis. Family income was the most important factor reported in our study that affects QOL which is similar to a literature [12]. Thus, addressing this issue by the government is the need of the moment.

In the current study, QOL in the physical domain among patients undergoing haemodialysis, was found to be higher among old age people, males, people residing in urban area, those having a better educational status, employment and socio-economic status. It was also, higher among those who had duration of illness and dialysis for more than 5 years. A similar study conducted by Utsav Joshi et al reported similar results except for the association of age category with physical domain [11]. A study conducted in Karnataka by Parthasarathi et al, reported that QOL of the haemodialysis patients had a lower score compared to transplant patients, general population, and asthma patients [13]. The difference in results may be due to the younger age group where the psychological domain might have a higher influence. In psychological domain, the score was found to be significantly lower among females, people who were in rural area and homemakers. The study conducted by Utsavi et al, also showed similar results in psychological domain.

In social domain, a significantly higher score was observed among people living in rural area, graduates, higher income group and the patients undergoing haemodialysis. Similar results were seen in the study which was conducted by Lemos et al, where it was stated that education and family income were the main factors that had greater impact on QOL of the patients [12]. However, the difference seen among the residence and the patients undergoing dialysis, may be due to the reason that study was conducted during the pre-dialysis phase. Current study was conducted among the patients undergoing dialysis at present. In environmental domain, there was significantly higher score among males, patients who had good education, patients who were working, the patients who had duration of illness of more than 5 years and the patients undergoing haemodialysis. Similar study by Masina et al [14] and all other studies also showed better environmental score than all the domains. But in current study environmental domain had the least score. Though majority of the participants were covered with insurance, the median (IQR) amount spent on total health care expenditure in the past 1 month was INR 4300 (2400-7200) which implies, though the treatment is free of cost the direct non-medical expenditure for the patients was enormous.

Similar study had been conducted in Kerala by C Bradshaw et al, (2018) to evaluate the healthcare expenditure among the patients undergoing dialysis. The study concluded that they have spent 88% of their household expenses as catastrophic expenditure [8]. The cost spent as shown in that study was more when compared with current study and the difference may be attributed to the study setting where it was not publicly funded. In conclusion QOL of the patients were impaired in all four domains. We also found that the patients undergoing dialysis has enormous economic burden, even though the provision of care was free of cost. The strength of the study was conducted by the single investigator fluent in the local language. The study done in the hospital based setting might be the limitation but the patients undergoing dialysis can be only assessed in the hospital setting than in community.

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