

Original Research Article

Quality of life in chronic kidney disease: a community perspective using world health organization quality of life: BREF questionnaire

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ABSTRACT

Background: The quality of life is an important assessment tool in improving the quality of care among chronic kidney diseases (CKD) especially in a palliative care setup. This study attempted to assess the quality of life of chronic kidney disease patients.

Methods: This community based cross sectional study was conducted among 140 patients who were registered at palliative clinics in Malappuram District, Kerala using a standard tool for quality of life (QOL) in Malayalam version. Domain scores were analysed across clinic epidemiological factors.

Results: Mean age of the study population was 53.99 (14.36%). Majority 73 (52.1%) were educated up to upper primary. The median duration of CKD was 4 years and ranged from 3 months to 22 years. 55.3% were undergoing dialysis 16.3% had renal transplantation. Hypertension was reported by 65% and diabetes by 50.7%. The highest score was obtained in the environmental and lowest in the psychological domain. Age below 40 years, male gender and provision of an income was associated with better QOL scores and perception scores. QOL was significantly higher in all domains among those who had undergone renal transplantation compared to those on hemodialysis.

Conclusions: The status of renal transplantation and younger age group positively affected the good quality of life. Considering the cost of renal transplantation and post-transplant survival peritoneal dialysis could be promoted in low resource settings. Secondary prevention of hypertension and diabetes should be addressed at programme level to delay nephropathy.

Keywords: Chronic kidney disease, Quality of life, Transplantation, Dialysis, Kerala

INTRODUCTION

Chronic diseases may have multiple impacts like mortality, long term morbidity, and impairment in quality of life (QOL). According to WHO, QOL is defined as individuals' perceptions 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.¹ Chronic kidney diseases are reaching epidemic proportions and as per World Health

Organization (WHO) Global burden of disease project, chronic kidney diseases (CKD) is 12th leading cause of death and 17th cause of disability. Prevalence of CKD varies across hospital and community-based settings and in presence of coexisting diseases.^{3,4,5} Burden of CKD is also different depending on availability and access to care, timing and quality of care also social support.^{6,7} It is suggested that QOL can theoretically encompass a wide range of domains and components like functional ability including role functioning, the degree and quality of social interaction, psychological well-being, somatic

sensations, happiness, life situations, life satisfaction and need for satisfaction.⁸ QOL assessment is an important tool for evaluating the impacts of treatment interventions and benefits.⁹ As renal disease management itself is in initial stages in the state, studies on quality of life in CKD were scarce. This study attempted to assess the quality of life of chronic kidney disease patients who were registered at palliative clinics and its distribution across clinical and socio epidemiological determinants.

METHODS

This community based cross sectional study was conducted among patients registered under palliative clinics of Malappuram district of North Kerala using a standard tool, from 2018 March to July. Chronic kidney disease patients above 18 years, who were not critically ill, able to speak and understand and willing to participate in the study were included. For study purpose, a patient is defined to have chronic kidney disease if he/she is having structural or functional kidney damage based on GFR or kidney markers, or having diagnosed with chronic kidney disease by a physician or a nephrologist for 3 months or more from a government or private hospital and categorized as same in palliative care register.¹⁰

The sample size was estimated as per $N=4SD^2/d^2$. Taking the highest score and SD (11.73) for QOL in hemodialysis patients from a South Indian study, sample size was taken as 100 at 20% error.¹¹

Study tool

The semi-structured pre-tested questionnaire was administered by a trained interviewer at patient's house. If the patient could not read, the questions were read out and responses were noted. Quality of life was assessed using validated Malayalam version of WHO QOL-BREF questionnaire.¹² It is a 26 item instrument— items 1 and 2 assess individual perception of QOL and general health respectively and remaining are 4 domains namely physical (7 items) psychological (6 items) social relationship (3 items) and environmental (8 items). Each item is rated by a 5-point likert scale. Higher score reflects good QOL. Data on socio demographic variables like age, sex, education, income and occupation, details of previous and present morbidities, stage of disease, treatment modality and support available were also collected. Study was conducted after getting approval from institutional ethics committee.

Statistical analysis

Data was entered into excel sheet and analyzed using SPSS16 trial version software. QOL raw scores were converted to transformation scores initially to a range of 4-20 and then into 0-100 scale for each domain. Results of descriptive analysis were presented as mean±standard deviation (SD) and proportions. Normality of data distribution was evaluated by shapiro-wilk test and Q-Q

plot. Student “t” test and analysis of variance (ANOVA) was used for other multiple-group comparisons. Pearson's correlation coefficient was used to assess the correlation between domain scores and socio demographic determinants. Multiple linear regression (Enter Model) was performed to determine predictors of good QOL score. p-value of <0.05 was considered to be statistically significant.

RESULTS

Socio demographic profile

Data was collected from 140 patients with CKD above 18 years. There were 102 males (72.9%) and 38 females (27.1%). Mean age of study population was 53.99 (14.36) years. Mean age of males was 50.3 (16.22) years and females 55.5 (13.4) years. Almost 69 (49.3%) were in 41-60 years age group. Majority 73 (52.1%) were educated up to upper primary. Majority were manual labourers (40.7%) and gulf returnees (14.3%). Other main occupation was driving (10%). 7.9% were students. Based on ration card categorization 111 (79.3%) belonged to below poverty line, including 37 patients in the economically most backward group. Rashtriya swasthya bhima yojana insurance was utilized by 31 (22.7%). At present only 16 (11.4%) patients had some income and 13 of them had undergone renal transplant. 120 (85.7%) were currently married and 57 (40.4%) belonged to the nuclear family. The socio demographic characteristics are described in (Table 1).

Table 1: Sociodemographic factors of the study population (n=140).

Variable	Categories	N	(%)
Gender	Male	102	(72.9)
	Female	38	(27.1)
Age group in years	18-40	24	(17.1)
	41-60	69	(49.3)
	>60	47	(33.6)
Education status	Up to upper primary	73	(52.1)
	Higher secondary	59	(42.1)
	Degree and above	6	(4.3)
	Illiterate	2	(1.4)
Socioeconomic status	APL	111	(69.2)
	BPL	29	(20.8)
Any source of income	Yes	16	(11.4)
	No	124	(88.5)
Marital status	Currently married	120	(85.7)
	Unmarried	20	(14.3)

Clinical profile

Median duration of CKD was 4 years and ranged from 3 months to 22 years. Median age of onset was 51 years and ranged from 12 years to 86 years. Mean age at onset was significantly lower for females (44.6±18.5) compared

to males (50.81±14.4). As per case records, diabetic nephropathy (42.1%) was the commonest cause of CKD followed by hypertensive nephropathy (22.9%). Majority of the study population were in the advanced stage of CKD, namely, stage 5 and only seven were in stage 1 reflecting the registration of advanced patients to a supporting system. All transplant patients reported good renal function except one patient. Among those in the advanced stage, 82(55.3%) were undergoing dialysis either twice or thrice per week, mainly (63.1%) from private dialysis centers. Four patients were on peritoneal

dialysis (PD) and 20 (16.3%) had undergone the renal transplant. Three of those on peritoneal dialysis were working. The remaining 36 (25.3%) were yet to start dialysis. In addition to CKD, coexisting illness was reported by 69(44.3%). Hypertension was reported by 65% and diabetes by 50.7%. Transplantation status was low in above 60 years age group. The distribution of clinical characteristics across different age groups is given in (Table 2). Stage of disease and gender proportion was not significantly different across age groups. But comorbidity and treatment status differed.

Table 2: Distribution of clinical characteristics across age groups.

Variables	Categories	18-40 yrs N (%)	40-60 yrs N (%)	>60 yrs N (%)	Level of significance
Gender	Male	13 (12.7)	52 (51)	36 (36.3)	P=0.071
	Female	11 (28.9)	17 (44.7)	10 (26.3)	
Stage of CKD	CKD stage 1	3 (33.3)	2 (22.2)	2 (44.4)	P=0.653
	CKD stage 2	2 (20)	4 (40)	4 (40)	
	CKD stage 3	2 (10)	9 (45)	9 (45)	
	CKD stage 4	2 (15.4)	7 (53.8)	4 (30.8)	
	CKD stage 5	15 (16.9)	47 (52.8)	27 (30.3)	
Treatment status	HD	9 (11)	42 (51.2)	31 (37.8)	P=0.007
	No HD	7 (18.4)	16 (42.1)	15 (39.5)	
	Transplant	8 (40)	11 (55)	1 (5)	
Presence of comorbidity	No morbidity	21 (26.9)	41 (52.6)	16 (20.5)	P=0.042
	Morbidity	4 (6.3)	28 (44.4)	31 (49.2)	

Table 3: Distribution of QOL perception scores.

Variable	Categories	Score of perception on general QOL	Level of significance	Score of satisfaction with general health	Level of significance
Gender	Male	2.62±.96	0.121	2.85±1.0	0.265
	Female	2.92±1.17		3.08±.96	
Age group in years	18-40	3.12±1.16	0.002	3.25±1.15	0.000
	41-60	2.83±.98		3.13±.95	
	>60 years	2.3±.93		2.43±1.0	
Having Income	Yes	3.56±0.814	0.00	3.56±1.2	0.008
	No	2.58±1.0		2.82±1.01	
Rx status	Not on HD	2.51±.98	0.022	2.73±1.06	0.004
	HD	2.87±1.04		2.95±1.01	
	Transplant	3.15±1.04		3.6±.88	

Quality of life perceptions

General QOL was described as either good or very good by 24.3%. Overall satisfaction with general health was satisfactory or very satisfactory for 34.3%. Mean score of response to perception on general QOL and satisfaction with general health were calculated. Mean score for satisfaction with general health was found to be higher (2.9±1.06) than perception score of general QOL (2.7±1.03) among total population and when several

factors were compared. Females had better perception scores. Considering age group, patients in younger age group had significantly better score and score gradually decreased as age advanced. Those having income had better score. When treatment status was compared, patients who were yet to start hemodialysis had poorest score and those who had kidney transplantation had highest score. The score distribution across different clinic epidemiological factors and group comparison with their significance level are given in Table 3. By

regression also, these factors showed significant association.

Quality of life domain scores

We analyzed the final transformed domain score in 0-100 scale. Mean scores, median score and 95% CI of four domains namely physical, psychological, social and environmental were calculated. Highest score was obtained in environmental domain reflecting the general good standard of living in the state and lowest in the psychological domain, which belongs to category of low QOL and others domains represented moderate QOL. The distribution of domain scores is described in Table 4.

Quality of life and clinico epidemiological factors

We analyzed how quality of life domains scores varied across socio demographic factors like age group, sex, socio economic status, current income status, marital status and treatment status. All scores were significantly high among those below 40 years (p=0.001). Men had slightly better scores in all domains but not statistically significant (p>0.05). Physical and psychological domains scores were higher among BPL card holders. Social domain was better for APL group. Environmental domain scores were similar among BPL and APL. But those who had some means of income had significantly better quality of life scores in domains except psychological domain. The findings of analysis of quality of life domain scores among different clinico epidemiological determinants and significance level are given in Table 5.

Table 4: Distribution of quality of life scores among study population.

Domains	Mean score±SD	Median score	95% confidence interval
Physical	46.3±13.39	45.72	(44.08,48.51)
Psychological	41.9±13.4	40.00	(39.68,44.12)
Social	45.06±13.46	45.32	(42.83,47.28)
Environmental	48.1±10.29	48.00	(46.39,49.80)

Quality of life score and treatment status

We further analyzed how kidney disease profiles affected the quality of life. QOL scores and stage of the disease were not related. Those who were having the disease for more than 5 years had better scores in all domains except the psychological domain. Current treatment status also influenced the scores. Quality of life was significantly higher in all domains among those who had undergone renal transplant as given in (Table 5). Those who had some other chronic diseases other than diabetes and hypertension had significantly poorer scores in physical and psychological domains. We tried to find predictors for good QOL domain scores and perception scores by multi linear regression. Gender was not a predictor of QOL. Age group, provision of income, treatment status were significant predictors as described in Table 6 and 7.

Table 5: Domain scores across clinico epidemiological determinants.

Determinant	Physical domain (Mean±SD)	Psychological domain (Mean±SD)	Social Domain (Mean±SD)	Environmental domain (Mean±SD)	P-value
18-40 yrs	55.0±13.18	50.67±13.5	49.1±14.6	52.58±11.59	<0.001
41-60 yrs	46.77±12.48	45.6±13.5	42.6±13.6	48.5±10.18	
>60 yrs	41.41±13.4	41.41±13.46	37.1±10.54	45.23±9.017	
Male	47.07±12.69	45.77±13.2	41.99±13.67	48.46±9.88	All domains p>0.05
Female	44.57±13.4	43.16±13.94	41.68±13.4	47.16±10.29	
BPL	46.9±13.3	45.2±13.8	40.98±13.6	48.0±10.48	All domains p>0.05
APL	44.1±13.4	44.32±11.9	45.42±12.47	48.4±9.7	
Income present	58.14±14.4	51.83±16	50±17.7	55.13±9.6	All domains p<0.05 except psycho p=0.06
No income	44.74±12.56	43.96±12.9	40.81±12.6	47.11±10.1	
HD	43.9±11.3	42.7±12.8	39.9±12.6	46.6±9.8	<0.001
No HD	45.4±14.9	43.6±12.9	41.26±13.2	47.4±10.9	
Transplant	58.1±12.5	57.3±10.5	51.2±13.9	55.4±8.0	

Table 7: Linear regression analysis of relation between domain scores and clinico epidemiological determinants.

Variable	Physical domain		Psychological domain		Social domain		Environmental domain	
	β	p	β	p	β	p	β	p
Gender	-0.099	0.199	-0.094	0.251	-0.020	0.806	-0.066	0.425
Age group	-0.246	<0.01	-0.149	<0.01	-0.236	< 0.05	-0.160	0.06
Having Income	-0.270	<0.01	-0.153	<0.01	-0.175	< 0.05	-0.215	<0.01
Rx status	0.251	<0.01	0.264	< 0.05	0.205	<0.01	0.209	< 0.05

Table 6: Linear regression analysis of relation between perception and clinico epidemiological factors.

Variable	Perception on general QOL		Perception on satisfaction with health	
	β	P	β	P
Gender	0.126	117	0.075	0.35
Age group	-0.174	<0.05	-0.195	<0.05
Having Income	-0.283	<0.01	-0.194	<0.05
Rx status	0.198	<0.05	0.221	<0.01

Correlation between quality of life and clinico epidemiological variables

Significant negative correlation was observed between age and all domains scores. ($r=-0.369$, $p=0.000$) for physical domain, ($r=-0.265$, $p=0.002$) for psychological domain ($r=-0.317$, $p=0.000$) for social and ($r=0.230$, $p=0.006$) for environmental domain. Positive correlation was observed between education and domain score with coefficients ($r=0.270$, $p=0.001$) for physical domain, ($r=0.204$, $p=0.016$) for psychological domain ($r=0.229$, $p=0.003$) for social domain and ($r=0.221$, $p=0.009$) for environmental domain. Duration of CKD had significant positive correlation with all domain scores except physical domain. Duration of hemodialysis had no correlation with QOL scores. Haemoglobin values were positively correlated with physical domain ($r=0.211$, $p=0.047$). The stage of disease was positively correlated with psychological domain ($r=0.169$, $p=0.046$) and negatively with other domains.

DISCUSSION

Assessment of QOL in CKD is important as it is a long-standing disease with limited treatment facilities in low resource setting. In our study, CKD patients were of low socio-economic background and supported by regional palliative care clinics for frequent hemodialysis mainly from private clinics and for rejection suppressant drugs. Proportion of females were less among transplant group. The quality of life score was lower for females, better for those in young age groups and those who had undergone

renal transplant. In a study by Carrero et al using same scale, nearly two thirds of the case group members were males, nearly half were seen at a private clinic and women more often seemed to donate and were less likely to receive kidney transplants when compared with men as observed.¹³ As in our study, Lemos et al using another scale observed that women had poorer QOL and younger age had better QOL.¹⁴ Similar to our finding, they too observed that quality of life improved with provision for income. Another study by Tuzun et al using WHO QOL BREF too pointed that Socio-economic status significantly affected quality of life in chronic diseases.¹⁵ In a prospective study by Mujais et al and Indian study by Aggarwal HRQOL decreased in proportion to grade of disease, age and in presence of comorbidities as our some findings.^{16,17}

According to Sathvik et al the quality of life of hemodialysis patients, in comparison to renal transplant patients, was significantly lower in all the four WHOQOL-BREF domains and female hemodialysis patients showed significantly lower quality of life than male patients in the psychological and environmental dimensions of WHOQOL-BREF.¹¹

As observed in a multi centric study by Joshi et al patients with chronic kidney disease on dialysis had overall low QOL scores in all four domains, but higher scores compared to our study and they observed lowest score in physical domain unlike our observation.¹⁸ Age, ethnicity, employment status, income, and duration on hemodialysis were the other factors observed as affecting one or more domains of QOL in their study. Low-income status and increased duration on hemodialysis were the negative predictors of QOL of patients on maintenance hemodialysis. They found significant negative correlation between age and physical domain as observed by us. A significant positive correlation was also observed between educational level and psychological domain, income and physical domain, income and social domain and income and environmental domain duration of illness and psychological domain and duration of illness and environmental domains. Age was a negative predictor and education a positive predictor for all domains in our study also. Pereria et al studied QOL of elderly CKD patients in particular and observed psychological domain as worst demanding special planning in care.¹⁹ A positive correlation between comorbidities and complications and an inverse correlation between the number of

complications and QOL was also n among elderly people with chronic kidney disease in a Brazilian study.¹⁹

Many authors from different regions compared hemodialysis and peritoneal dialysis patients and were of the opinion that PD improved quality of life.²⁰ On the contrary one south African study observed higher symptom burden in PD patients compared to hemodialysis.²¹ A systematic review comparing both treatment modalities was also inconclusive on the benefit of PD.²² In our study we could find only 4 patients on peritoneal dialysis and they belonged to those having an income and in better QOL but it is a limited number to make comments.

A systematic review suggested that patients with kidney transplants may experience better rates of life participation compared with patients receiving dialysis.²³ A recent study by McAdams et al suggested even in frailty– the phenotype of decreased physiological reserve patients had better HRQOL in post-transplant.²⁴ But a 5 year follow up study of transplant suggested continuous need for improvement as the progress in QOL was in kidney specific domains only and still lower than general healthy population.²⁵

CONCLUSION

Majority of chronic kidney disease patients were young adults or middle aged and males in their productive age group. Despite having no steady income, all of them continue haemodialysis without interruption. The low proportion of renal transplants are on supportive drugs. Their quality of life was poor in all domains. The status of renal transplant and younger age group positively affected the good quality of life. Considering the huge demand for high cost renal care, we have to delay development of diabetic and hypertensive nephropathy by meticulous management of diabetes mellitus and hypertension and by adding renal screening component to NPCDCS programme. Considering the cost of renal transplantation and post-transplant survival peritoneal dialysis could be promoted in low resource settings. Studies on long term quality of life are to be evolved. Pre-evaluation and continuous monitoring of the quality of life could be used to assess the effectiveness of renal care strategies.

Recommendations

As non communicable diseases like diabetes and hypertension are highly prevalent in the state, its better management and enhanced awareness of complications among public is very much needed. And the national programme should include renal disease control activities which can be high risk screening for nephropathy and periodic specialist clinics. Treatment facilities and treatment support systems should be strengthened at government level.

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