

Health related quality of life among end stage renal disease patients from low income country, Nepal: a cross sectional study using WHOQOL-BREF

Kamal Ranabhat

Department of Health Service, Ministry of Health and Population, Nepal

Pratik Khanal (✉ pratikkhanal@iom.edu.np)

Tribhuvan University Institute of Medicine <https://orcid.org/0000-0002-1057-5700>

Shiva Raj Mishra

World Heart Federation, Geneva, Switzerland

Anu Khanal

Tribhuvan University Institute of Medicine

Sangita Tripathi

Tribhuvan University Institute of Medicine

Mahesh Raj Sigdel

Tribhuvan University Institute of Medicine

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Abstract

Background

Little is known about the health-related quality of life (HRQOL) among end stage renal diseases (ESRD) patients in Nepal. This study examined the health-related quality of life of among the dialysis and transplant patients in Nepal.

Methods

Nepali Version of WHOQOL-BREF questionnaire was administered using face to face interviews among ESRD patients, from two large national referral centers in Nepal. The differences in socio-demographic characteristics among ESRD patients were examined using Chi-square test. The group differences in QOL were examined using Mann-Whitney U test and Kruskal-wallis tests.

Results

Of the 161 participants, 92 (57.1%) were transplant patients and 62 (42.9%) were dialysis patients. Hypertension (70.9%) was the commonest co-morbidity among ESRD patients. Dialysis patients scored significantly lower than the transplant patients in all the four domains as well as in overall perception of quality of life and general health. Ethnicity ($p = 0.020$), socio-economic status ($p < 0.001$), educational status ($p < 0.001$) and employment status ($p = 0.009$) was significantly associated with the overall QOL in ESRD patients. Across patient groups, educational status ($p = 0.012$) was positively significant with the QOL in dialysis patients while residence ($p = 0.023$), socio-economic status ($p < 0.001$), educational status ($p = 0.004$) and diabetes status ($p = 0.010$) was significantly associated with the QOL in transplant patients.

Conclusion

The overall QOL of the renal transplant recipient was higher than those of the patients on maintenance hemodialysis; this was true in all the four domains of the WHOQOL-BREF. ESRD patient with low HRQOL should be prioritized for risk modification intervention.

Introduction

The incidence and prevalence rate of end-stage renal disease (ESRD) has been rising globally, yet the burden in South Asia is not known precisely due to improper registration system[1]. However, a recent population-based study assessed the age-adjusted incidence of ESRD at 232 cases per million populations per year in South Asia. In Nepal, the estimated incidence of ESRD is around 2,900/year [2, 3].

ESRD is a global epidemic which is associated with high cost and financial burden to patients, families and health system of any country [4-6]. In Nepal, burden of ESRD is growing however only a fraction of ESRD patients receive renal replacement therapy every year [7]. ESRD treatment is costly and unaffordable for most Nepalese people[2, 8].

Assessment of QOL could be a valuable research tool in assessing the outcome of therapeutic intervention in chronic diseases [9-11]. World Health Organisation (WHO) has defined QOL as individual's perceptions of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards and concerns[9]. The ESRD is a chronic disease having negative impact on various domains of patients' lives, leading to impairment in QOL and post-transplantation outcomes [12, 13]. Globally, health related quality of life (HRQOL) has been recognized as an important tool in assessment of health and wellbeing of people receiving renal replacement therapies [14-16].

In Nepal, kidney transplantation services was introduced in Tribhuvan University Teaching Hospital (TUTH) from August 8, 2008, although kidney transplantation was legalised in 2002[17, 18]. There are currently 42 dialysis and five transplant centers in Nepal for its 29 million people. All these five transplant centers and 17 out of 42 dialysis centers are situated in the Kathmandu valley, the capital city of the country[19]. A paucity of information on the quality of ESRD services exists since the introduction of renal transplantation services in Nepal. Furthermore, limited study has been done on ESRD in Nepal and no published studies are available to compare QOL in ESRD patients receiving different renal replacement therapies. In this context, this study aimed to assess and compare QOL of dialysis and renal transplant patients in various dimensions using WHOQOL BREF. The study may support policymakers and concerned authorities to develop better interventions and programs for ESRD patients in Nepal.

Methods

Study settings

The study was conducted in dialysis patients attending Tribhuvan University Teaching Hospital (TUTH) and renal transplant patients attending National Public Health Laboratory (NPHL) under Ministry of Health and Population (MoHP). The patients who underwent renal transplant visited NPHL for the purpose of monitoring of kidney function tests as part of their follow-up. Both of these institutions are situated in Kathmandu, the capital city of Nepal.

Study design and sampling technique

A cross-sectional comparative study design was adopted to assess the HRQOL between dialysis and renal transplant patients. The NPHL was chosen for recruiting renal transplant patients while TUTH was chosen for recruiting dialysis patients for face-to-face interviews.

A total of 161 patients were recruited from the study sites in the month of October and November in 2018. The eligibility for haemodialysis patients included those receiving haemodialysis at least twice in a week for three months or more while for transplant patients included those who had undergone transplant for six months or more. Other eligibility for the study participants were those at least 18 years of age and were able to provide written consent. Patients who had serious health complications and mental health disorders were also excluded from study as these conditions hamper the HRQOL of patients.

Data collection measures

The data collection tool was questionnaire containing three sections. These included (i) socio-demographic information; (ii) information related to kidney specific disease and (iii) HRQOL of the study participants.

The socio-demographic information included age (continuous; 20-30, 31-40, 41-50, >50 years), sex (male and female), residence (urban and rural), socio-economic status (lower, middle and upper) , ethnic group (*Brahmin/Chhetri, Janajati* and others), marital status (ever married, unmarried), employment (unemployed and employed), education (illiterate, up to 10 years of schooling and higher education), food habit (vegetarian and non-vegetarian) and perceived family support (full, partial and no support). The socio-economic status of the study participants was measured using "Kuppuswamy's socio-economic status scale for Nepal[20]. It is measured on the basis of literacy level, type of occupation and family income level per month. This tool was developed in India in 2009 in which socioeconomic status is identified based on total score: 26-29 score for upper level, (b) 16-25 score for upper middle, (c) 11-15 score for lower middle, (d) 5-10 score for upper lower and (e) <5 score for lower level. In this study, upper middle and lower middle was merged as middle while upper lower and lower were merged as lower. Similarly, clinical information related to ESRD included donor for transplant, duration of dialysis or transplant and presence of comorbidity.

The WHOQOL-BREF, a generic health- related questionnaire developed by the WHOQOL group was selected to quantify the HRQOL of ESRD patients[21]. The Nepali version of WHOQOL-BREF questionnaire has been used in cross-cultural setting by Giri et al[22]and Mishra et al[23].The WHOQOL-BREF consist of 26 items and provides a profile of scores on four dimensions of quality of life: physical health,psychological health,social relationships andenvironment health domain. The score of four domains was the outcome variable while all other variables were considered as independent variables. Higher scores represent better quality of life. The scores on the 26 item questions were measured on a scale of 4-20[21].

Data collection procedure

Data was collected by face to face interview. Research assistants (public health undergraduates) along with the first author were involved to conduct the interview at the study sites. Pre-testing of tools was carried out among ten dialysis patients attending Bir hospital located in Kathmandu. Based on pre-testing, minor changes in wording and sequence of the questions were done. Cronbach's alpha test was

computed for each domain and the value ranged from 0.60 to 0.86 indicating good internal consistency. Ethical approval for the study was obtained from Ethical Review Board of Nepal Health Research Council (Reference number: 389/2016) as well as administrative approval was taken from data collection sites. Written informed consent was taken with the participants before data collection.

Data analysis

The data was entered in EpiData version 3.1 and data was transported to IBM SPSS version 21.0 for analysis. Descriptive analysis included calculation of frequency, percentage, mean and median for presentation of socio-demographic, ESRD-related and WHOQOL-BREF scores. Chi-square test was used for assessing difference in categorical variables while Mann-Whitney U test and Kruskal-wallis one-way analysis of variance tests were used for comparing QOL across socio-demographic and clinical characteristics since the QOL score was not normally distributed. The level of significance was maintained at 5% with $p < 0.05$ considered as statistically significant.

Results

Demographic characteristics of study participants

Among 161 participants, 92 (57.1%) were transplant patients and remaining 69 (42.9%) were dialysis patients. In this study, 54.7% were 18-40 years of age, 75.2% were male and 47.3% belonged to *Aadibasi/Janajati* ethnic group. The mean age (\pm SD) of the study participants was 40.66 ± 12.02 years. Most of the participants (58.4 %) belonged to middle socioeconomic status, 12.4% were illiterate and 50.3% were unemployed. Nearly two third (65.8%) participants mentioned that they got full support from their family in care and psychological support while one in ten participants didn't get any support from their family (Table 1).

The age of the patients in the dialysis group was significantly higher than the transplant group ($p < 0.01$) and there was significant difference in education status ($p = 0.021$) and employment status ($p = 0.020$) across two patient groups. However, there was no significant difference according to sex, residence, socio-economic status, ethnic group, marital status, food habit and perceived family support in the patient groups (Table 1).

Table 1 Socio-demographic characteristics of the study participants (n=161)

Characteristics	Total (n=161) n (%)	Dialysis (n=69) n (%)	Transplant (n=92) n (%)	P-value
Age (years)	(40.66±12.02)	43.57±13.02	38.47±10.77	<0.01
20-30	36 (22.4)	14 (20.3)	22 (23.9)	
31-40	52 (32.3)	17 (24.6)	35 (38.0)	
41-50	40 (24.8)	15 (21.7)	25 (27.2)	
>50	33 (20.5)	23 (33.3)	10 (10.9)	
Sex				0.958
Male	121 (75.2)	52 (75.4)	69 (75.0)	
Female	40 (24.8)	17 (24.6)	23 (25.0)	
Residence				0.234
Urban	124 (77.0)	50 (72.5)	74 (80.4)	
Rural	37 (23.0)	19 (27.5)	18 (19.6)	
Socioeconomic status				0.061
Lower	57 (35.4)	31 (44.9)	26 (28.3)	
Middle	94 (58.4)	33 (47.8)	61 (66.3)	
Upper	10(6.2)	5 (7.2)	5 (5.4)	
Ethnic group				0.203
Brahmin/ Chhetri	57 (35.4)	21 (30.4)	36 (39.1)	
Aadibashi/Janjati	76 (47.2)	32 (46.4)	44 (47.8)	
Others	28 (17.4)	16 (23.2)	12 (13.0)	
Marital status				0.652
Unmarried	11 (6.8)	4 (5.8)	7 (7.6)	
Ever married	150 (93.2)	65 (94.2)	85 (92.4)	
Employment				0.020
Employed	80 (49.7)	27 (39.1)	53 (57.6)	
Unemployed	81 (50.3)	42 (60.1)	39 (42.4)	
Education				0.021
Illiterate	20 (12.4)	14 (20.3)	6 (6.5)	

Up to 10 years of schooling	96 (59.6)	40 (58.0)	56 (60.9)	
Higher	45 (28.0)	15 (21.7)	30 (32.6)	
Food habit				0.719
Vegetarian	6 (3.7)	3 (3.3)	3 (4.7)	
Non vegetarian	155 (96.3)	66 (96.7)	89 (95.3)	
Family support				0.513
Full	106 (65.8)	42 (60.9)	64 (69.6)	
Partial	39 (24.2)	19 (27.5)	20 (21.7)	
No support	16 (9.9)	8 (11.6)	8 (8.7)	

Clinical characteristics of the study participants

Patients with renal transplant received kidney donation mainly from their parents (31.5%), spouse (30.4%) and children (25.0%). The duration of renal replacement therapy was more than one year for 67.4% of the renal transplant patients and 53.4% for the dialysis patients. Most of the dialysis participants (97.1%) followed recommended Kidney Disease Improving Global Outcome (KDIGO) guidelines for dialysis sessions[24]. Regarding co-morbidities, 77.0% had hypertension, 20.5% had diabetes mellitus and 5% had nephrotic syndrome while 6.2% had other comorbidities (Table 2).

Table 2: Clinical characteristics related to ESRD

Characteristics	Number	Percent
Donor for transplant (n=92)		
Parents	29	31.5
Spouse	28	30.4
Siblings	23	25.0
Children	8	8.7
Others	4	4.3
Dialysis session (3.5 to 4 hour per session-KDIGO guidelines)		
Recommended	67	97.1
Not recommended	2	2.9
Duration of dialysis		
3 months to 1 year	32	46.4
More than 1 year	37	53.6
Duration of transplantation		
6 months to 1 year	30	32.6
More than 1 year	62	67.4
Type of co-morbidities[*]		
Hypertension	124	77.0
Diabetes mellitus	33	20.5
Nephrotic Syndrome	8	5.0
Others	10	6.2

multiple response

WHOQOL-BREF scores of the dialysis and transplant patients

Table 3 shows the mean score for QOL in different domains of WHOQOL-BREF. The highest mean score for QOL was found in social relationship (13.58 ± 2.14) domain and lowest mean score was found in environment domain (11.73 ± 1.89). Dialysis patients scored significantly lower than the transplant patients in terms of physical ($p < 0.001$), psychological ($p < 0.001$), social relationship ($p = 0.012$) and environmental ($p = 0.004$) domains. Similarly, the overall QOL score ($p < 0.001$), overall perception of quality of life, Q1 ($p < 0.001$) and overall perception of general health, Q2 ($p < 0.001$) was significantly lower in dialysis participants than transplant patients ($p < 0.001$).

Table 3: Mean domain score for dialysis and renal transplant patients

Type of domain	Total (n=161)	Dialysis (n=69)	Transplant (n=92)	P-value
Physical	12.03±2.16	10.61±1.99	13.09±1.61	<0.001
Psychological	12.38±2.44	10.84±1.95	13.53±2.12	<0.001
Social relationship	13.58±2.14	13.15±2.10	13.89±2.13	0.012
Environment	11.73±1.89	11.25±1.62	12.10±2.00	0.004
Perception of quality of life	3.03±0.90	2.42±0.72	3.49±0.73	<0.001
Perception of general health	3.07±0.94	2.51±0.80	3.49±0.81	<0.001
Overall QOL score	12.43±1.63	11.46±1.35	13.15±1.45	<0.001

Socio-demographic variables, ESRD characteristics and QOL Score

The mean QOL scores across socio-demographic and ESRD characteristics are presented in Figure 1. Ethnicity ($p=0.020$), socio-economic status ($p<0.001$), employment ($p=0.009$) and education ($p<0.001$) of the ESRD patients were significantly associated with the overall QOL (Additional File 1). Among ethnic groups, *Aadibasi/Janajati* had higher QOL than *Brahmin/Chhetri* and other ethnic groups. The QOL increased with the increase in socio-economic gradient and educational status. Age, sex, residence, marital status, hypertension and diabetes status was however not significantly associated ($p>0.05$) with the QOL among ESRD patients.

The mean differences in QOL scores were also assessed across dialysis and transplant patients. The findings showed that there was statistically significant difference in QOL across socio-demographic and clinical categories ($p<0.05$) with higher QOL score in transplant patients as compared to dialysis patients (Figure 1, & Additional File1).

Among dialysis patients, there was significant difference in QOL across educational status ($p=0.012$) where those with higher educational status had higher QOL. In case of transplant patients, residence ($p=0.023$), socio-economic status ($p<0.001$), education ($p=0.004$) and diabetes status ($p=0.010$) was significantly associated with QOL. Those belonging to urban location had higher QOL than participants from rural location while QOL increased with increase in socio-economic and educational status. Interestingly, those with diabetes status had higher QOL than those with no diabetes (Figure 1, & Additional File 1).

Domain wise QOL across socio-demographic and ESRD characteristics

The domain wise difference in QOL across socio-demographic and ESRD characteristics are presented in Additional File 1. Among dialysis patients, there was significant difference in QOL score among different age group across social domain ($p<0.001$) with age group 31-40 years having higher mean QOL score

than other age groups. In transplant patients, there was significant difference in QOL score in psychological domain with higher QOL score in those aged more than 50 years as compared to other age groups. In both dialysis and transplant patients, sex, ethnicity and hypertensive condition was not associated with the QOL ($p>0.05$).

In dialysis patients, residence was not significantly associated with any of the domains while in transplant patients; residence was significantly associated with social ($p=0.023$) and environment domain ($p=0.009$) with higher QOL in urban dwellers as compared to the rural dwellers. Socio-economic status was not significantly associated with QOL across all domains ($p>0.05$) in dialysis patients while it was significantly associated with QOL scores across all domains in transplant patients ($p<0.05$). Marital status was significantly associated with psychological domain ($p=0.034$) in dialysis patients with married participants having higher QOL. In transplant participants, marital status was however not associated with any of the domains. Employment status was not associated with QOL across any domains among dialysis patients ($p>0.05$) while in transplant patients, it was associated with psychological domain ($p=0.039$) with employed having more QOL than unemployed participants.

In both dialysis and transplant patients, education was significantly associated with the environment domain ($p=0.009$ and $p=0.027$ respectively) where participants with higher education had higher QOL as compared to illiterate or up to ten years of schooling. In transplant patients, educational status was also significantly associated with the psychological domain ($p=0.041$). While presence of diabetes mellitus was not significantly associated with any of the domains of QOL ($p>0.05$) in dialysis patients, it was significantly associated with psychological domain ($p=0.033$) and social domain ($p=0.006$) in transplant patients. Those with diabetes mellitus had higher QOL in these domains as compared to those who had no diabetes mellitus.

Discussion

This is the first study in our knowledge to report comparison of QOL between dialysis and renal transplant patients in Nepal. The study findings revealed significantly higher QOL score in transplant patients than dialysis patients across all domains: physical, psychological, social relationship and environment. Similarly, the overall perception regarding QOL and general health was also significantly higher in transplant patients than the dialysis patients. Previous studies conducted elsewhere also have shown impaired QOL in dialysis patients as compared to renal transplant patients [7, 25-30]. Though our study findings reinforce renal transplant as an effective renal replacement therapy for improving QOL among people with ESRD, health system in Nepal face limited and inequitable access to transplant services. Further, few nephrologists, long waiting time to receive transplant service and inadequate financial protection adds much to worry for people with ESRD[31].

The lower QOL in physical domain in dialysis patients than transplant patients can be attributed to physical pain, weakness, insomnia and hindrance to daily activities as identified in previous studies [32, 33]. A study previously done in Nepal also had pointed increased duration of hameodialysis as a

negative predictor of QOL[34]. Similarly, the reason for renal transplant patients having a higher QOL in psychological domain might be due to decrease in mental burden resulting from having to visit health facility for frequent dialysis. Similarly, the increased self-esteem and improved perception regarding own health might have contributed to good mental wellbeing among renal transplant patients[26]. A study from Nepal[3] had shown 94.3% survival rate among transplant patients after one year follow-up. Dialysis patients often face mental health problems due to their health conditions which might led to a compromised QOL as identified by previous studies[33, 35, 36]. Renal transplant patients had a higher QOL in social domain than the dialysis patients in our study. This might be due to improved health including sexual relationship, and more leisure time, allowing them to network with their family and friends. Dialysis patients, on other hand, need to engage family members or relatives during treatment which might have contributed to lower QOL as family members may not be always available. This is also evident from our findings as dialysis patients received less support from family members than the transplant patients. Further, due to pain, it is difficult for dialysis patients for social mobility and thus maintaining healthy social relationship.

Expensive treatment mainly drugs, difficulty in transportation during follow up and safety related issues might be contributing factors for lower QOL score in environment domain among dialysis patients as compared to transplant patients. The government pays hospital a fixed amount for providing haemodialysis and transplant service for the destitute through its impoverishment citizen fund established in 2016[19, 31]. However, in the absence of renal registry and fully viable health insurance system to cover expenses associated with the treatment, patients with ESRD face a major setback in living a quality life[31, 37]. Importantly, the government subsidy through the impoverished citizen fund does not cover all treatment expenses and moreover, there is a low enrollment and limited ceiling in benefit package (NPR 100,000) in health insurance[38]. In our study, even after transplant, QOL in environment domain was found comparatively lower than other domains in renal transplant. A social health protection mechanism is thus imperative to address the financial barriers not only in seeking transplant services, but also saving people with chronic diseases in falling into poverty trap.

In this study, socio-economic status was positively significantly associated with the overall QOL score among ESRD patients. While analyzing across patient groups, socio-economic status was significantly associated with the overall QOL and in all domains in transplant patients. As people with higher socio-economic status are in a better position to pay for the treatment expenses, it might have resulted in higher QOL. However, it was not the case among dialysis patients as socio-economic status was not significantly associated with the overall QOL and in any of the domains. This indicates that dialysis patients, regardless of their socio-economic status face hindrance to living a quality life.

Employment status was associated with overall QOL among ESRD patients. While analyzing separately among dialysis and transplant patients, employment was however not statistically significant with the QOL in both the patient groups. Domain wise, employment status was significantly associated with the psychological domain of QOL among transplant patients. Treatment expenses incurred during the transplant might have resulted in lower QOL in psychological domain among unemployed people. Nepal

has a large informal economy, a quarter of the population under poverty line and majority of the population under poverty either sell their assets for paying for health care especially for treatment of chronic diseases or simply stop their treatment [39, 40]. Those in the formal sector are more likely to be in a better paying capacity for their health care and thus face less financial catastrophe.

Hypertension was the commonest co-morbidity (70.9%) among ESRD patient followed by diabetes mellitus (18.9%). Similar findings have been reported in previous studies[41, 42]. But there was no influence of comorbidities on overall QOL among ESRD patients. However, while analyzing across patient groups and domains, diabetes mellitus was found to be positively associated with overall QOL and in psychological domain in transplant patients. Presence of diabetes was not associated with the overall QOL and in any of the domains among dialysis patients. A previous study has reported poor QOL scores in ESRD patients with comorbidity of diabetes [43]. In this study, majority of dialysis patients (97.1%) were undergoing thrice-a-week dialysis as recommended by KDIGO guidelines, which is higher compared to a previous study in India [7] where most of the dialysis patients were undergoing twice-a-week dialysis due to economic constraints. This may be because hospital based dialysis services for the needy are financed by the government through impoverishment citizen fund in Nepal [31, 44]. However, as said earlier, other costs such as distribution of dialysis and transplant facilities, transportation, living cost incurred due to distant health facility, and expensive drugs need to be paid out of pocket by the patients.

This study has few strengths and limitations. In this study, WHOQOL-BREF tool was used to assess QOL which has been extensively used across different segments of population in Nepal and globally, which makes it relevant for this study. Moreover, this generic tool can be applied to both healthy and diseased population. One of the limitations of this study was that it sought to compare the HRQOL between only two categories of patients i.e. dialysis and transplant and not with peritoneal and with healthy population, and such comparisons were done in a small sample of population. Moreover, the study might have encountered respondent bias due to subjective response. Further studies employing a large sample and qualitative study for exploring the in-depth experience of people with ESRD might help to generate more robust evidence regarding QOL in this population. Despite limitations, this study provides a comparative situation of QOL faced by dialysis and transplant patients and the evidence could be useful for policy makers, program managers and others stakeholders for developing an effective response towards improving the health conditions of people with ESRD. Considering the increasing burden of CKD as well as other non-communicable diseases in Nepal, it would be effective to design interventions for the reduction of behavioral, biological and environmental risk factors associated with the chronic disease outcomes.

Conclusion

This study found that overall QOL scores of renal transplant patients were significantly better than that of dialysis patients in all the four domains of the WHOQOL-BREF. The QOL was higher in social domain for both groups while it was lower in physical domain and environment health domain for dialysis and transplant patients respectively. The QOL improved significantly with increase in socio-economic gradient

in transplant patients while socioeconomic status was not associated with QOL in dialysis patients. Renal transplant services should be encouraged for people with ESRD as they have a higher QOL than the dialysis patients.

Abbreviations

CI: Confidence Interval; CKD: chronic kidney diseases; ESRD: End stage renal disease; HRQOL: health related quality of life; IOM: Institute of Medicine; KDIGO: Kidney Disease Improving Global Outcome; MoHP: Ministry of Health and Population; QOL: Quality of life; SD: Standard Deviation; TUTH: Tribhuvan University Teaching Hospital; WHO: World Health Organization

Declarations

Ethics approval and consent to participate

Ethical approval for this study was provided by the Nepal Health Research Council, Kathmandu, Nepal (Reference number: 389/2016). A written informed consent was obtained from individual participants. Confidentiality and anonymity of the participants were ensured by coding the interviews. Study participants were informed clearly about their freedom to opt out of the study at any point of time without justifying for doing so.

Consent for publication

Not applicable

Availability of data and materials

All data related to this study are included in the manuscript and additional file.

Competing interests

The authors declare that they have no competing interests.

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None

Author's contributions

KR conceived the concept and design of the study. KR, AK and ST conducted the survey. KR and PK were involved in data analysis and manuscript writing. SRM and MRS supervised the study and reviewed the manuscript. All the authors read, reviewed and read the final manuscript.

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Figures

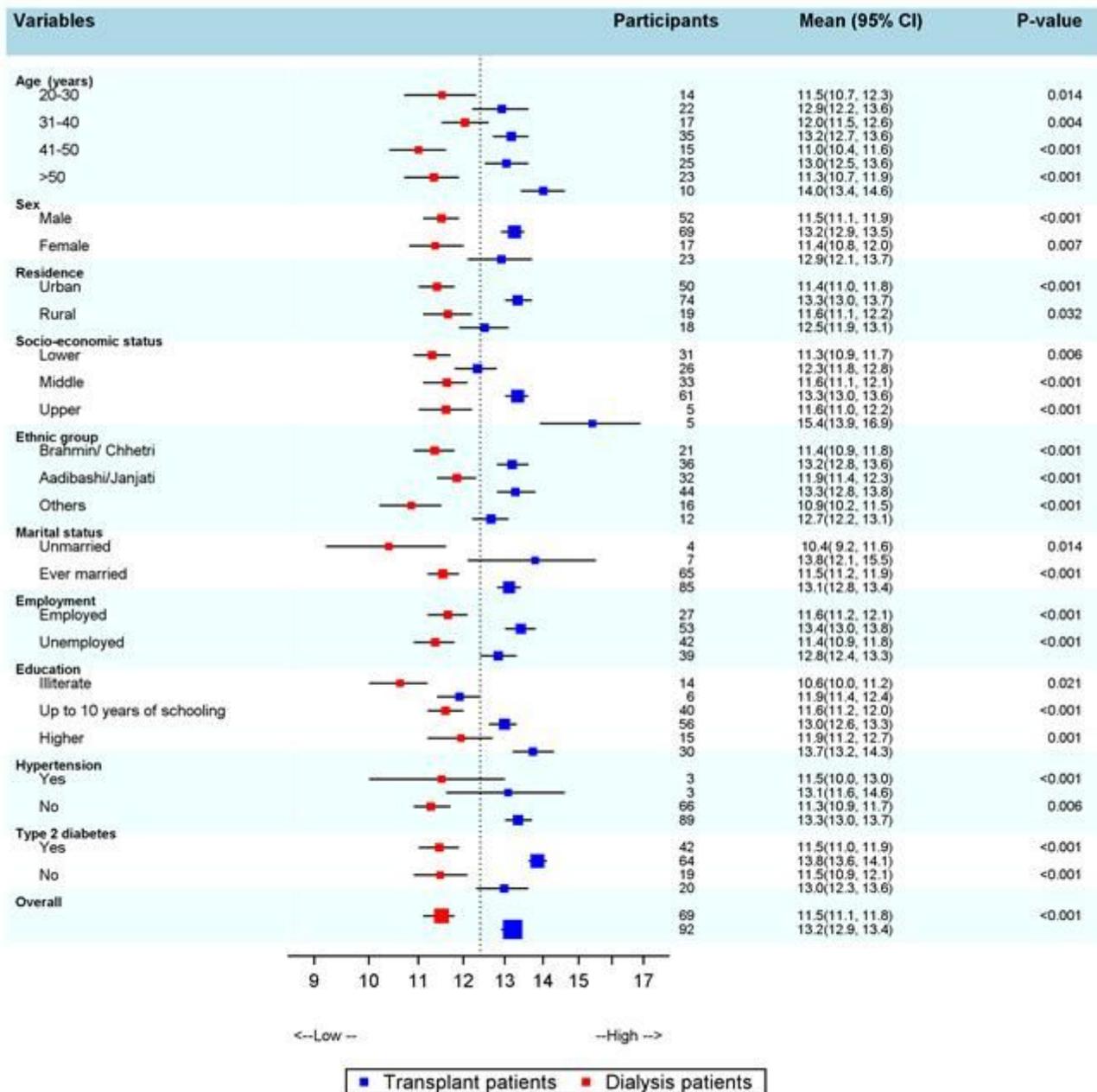


Figure 1

QOL score across socio-demographic and ESRD characteristics. The size of square is inversely proportional to the variance of the mean. The dotted vertical line shows the average QOL of the participants. P-value shows the test for difference in QOL between dialysis and transplant participants across socio demographic and ESRD characteristics. The individual estimates are shown in Additional File 1.

Supplementary Files

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