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Original Research Article

Palliative care needs and health-related quality of life among patients with end-stage kidney disease on haemodialysis in a tertiary care hospital in Mumbai: a cross-sectional study

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ABSTRACT

Background: End-stage renal disease (ESRD) is associated with substantial symptom burden, impaired health-related quality of life (HRQoL), and unmet palliative care needs. Despite the growing recognition of supportive care in nephrology, evidence from India remains limited. This study assessed HRQoL and palliative care needs among patients undergoing maintenance hemodialysis (MHD) and explored their relationship with symptom burden.
Methods: A hospital-based cross-sectional study was conducted between June 2022 and January 2023 among 236 adults receiving MHD at tertiary care teaching hospitals in Mumbai, India. Palliative care needs were assessed using the palliative outcome scale-symptoms renal (POS-S Renal), while HRQoL was measured using the EuroQol five-dimensional five-level questionnaire (EQ-5D-5L) with the Indian value set. Sociodemographic and clinical data were collected through structured interviews and medical record review. The relationship between palliative care needs, symptom burden, and HRQoL was examined using correlation.
Results: Participants had a median age of 64.5 years, and 63.6% were male. The median POS score was 16.0 (IQR: 12.0-23.0), indicating considerable unmet palliative care needs. Family anxiety, information needs, practical support, and symptom-related concerns were among the most prominent issues. The mean number of symptoms reported was 15.04±5.06, with dry mouth (91.5%), itching (83.1%), dry skin (82.2%), and fatigue being the most common symptoms. The median EQ-5D-5L utility score was 0.78, with older patients reporting poorer HRQoL. Higher POS scores were significantly associated with greater symptom burden and lower HRQoL.
Conclusions: Patients receiving MHD experience substantial symptom burden, unmet palliative care needs, and reduced HRQoL. Early integration of multidisciplinary palliative care into routine nephrology services may improve symptom management, address supportive care needs, and enhance patient-centred outcomes.

Keywords: End-stage renal disease, Maintenance hemodialysis, Palliative care needs, Health-related quality of life, EQ-5D-5L, Symptom burden

INTRODUCTION

Chronic kidney disease (CKD) is a major public health problem worldwide, with an estimated global prevalence of 9.1%, affecting approximately 697.5 million people.[1,2] ESRD represents the final stage of CKD and requires renal replacement therapy (RRT) in the form of haemodialysis (HD), peritoneal dialysis (PD), or kidney transplantation to sustain life. Owing to the limited availability of donor organs for transplantation, dialysis remains the most commonly used modality of RRT. In India, HD is the predominant form of dialysis and is generally performed twice weekly, whereas PD is usually carried out at home by patients multiple times per day.

Although dialysis effectively replaces certain kidney functions and prolongs survival, ESRD remains an incurable condition associated with substantial morbidity and mortality. Older patients, in particular, experience a higher burden of complications, poorer survival, and increased healthcare utilization compared with younger patients.[3-5] Furthermore, both the disease itself and the dialysis procedure contribute to a wide range of distressing symptoms, including fatigue, pruritus, dry skin, sleep disturbances, muscle cramps, anxiety, and depression, all of which adversely affect patients' daily functioning and well-being.[6,7] Consequently, HRQoL among patients undergoing dialysis is often significantly compromised.

With advances in medical care leading to improved survival, the focus of ESRD management has gradually shifted beyond merely extending life expectancy toward improving patients' QOL. Since dialysis is a lifelong therapeutic intervention for many patients, assessment of QOL has become an important outcome measure. Various instruments are available for evaluating QOL among dialysis patients, including generic and disease-specific tools. Although the kidney disease quality of life (KDQOL-SF™) instrument is widely used, it primarily provides generic scores and does not quantify health states in terms of utility values. Therefore, utility-based instruments such as the EuroQOL 5-Dimensional 5-Level (EQ-5D-5L) questionnaire are increasingly preferred because they quantify health states and provide utility scores that reflect patients' perceived health status and satisfaction.

In addition to impaired QOL, patients with ESRD frequently experience unmet supportive and palliative care needs. Palliative care aims to improve HRQoL by preventing and alleviating suffering through the early identification, assessment, and management of physical, psychological, social, and spiritual problems associated with life-threatening illnesses.[9] Recognizing the importance of supportive care in ESRD, the Kidney disease: improving global outcomes (KDIGO) initiative recommended the integration of palliative care throughout the entire course of ESRD management, irrespective of whether patients are receiving dialysis.[10]

Symptom assessment and management constitute the cornerstone of palliative care, and previous studies have demonstrated that palliative care interventions can reduce symptom burden and psychological distress while facilitating patient-centred decision-making and reducing unnecessary healthcare utilization.[11-14] The concept of palliative care needs is multidimensional, encompassing physical, psychological, emotional, informational, practical, social, and spiritual domains.[17] Studies among patients with both malignant and non-malignant illnesses, including ESRD, have consistently reported substantial unmet needs across these domains.[17,18] Identification of such needs is therefore essential for planning comprehensive and patient-centred renal care services.

To assess palliative care needs in patients undergoing MHD, the POS-S renal serves as a validated disease-specific instrument that evaluates symptom burden as well as broader supportive care concerns. Owing to its established validity and reliability, it is particularly suitable for identifying the multidimensional palliative care needs of patients with ESRD receiving dialysis.

Recently, the Indian value set for the EQ-5D-5L instrument has become available, enabling more accurate estimation of utility scores and health-state preferences among Indian patients. However, data on QOL and palliative care needs among dialysis patients in the Indian setting remain limited. Therefore, this study was conducted to assess the QOL of patients undergoing dialysis using the EQ-5D-5L questionnaire, evaluate their palliative care needs using the POS-S Renal instrument, and determine the factors associated with these outcomes.

METHODS

Study setting and participants

A hospital-based cross-sectional study was conducted from June 2022 to January 2023 among patients receiving MHD attending the palliative care outpatient department (OPD) of tertiary care teaching hospitals in metropolitan Mumbai, Maharashtra, India. These hospitals provide specialized nephrology and palliative care services to a large population of patients with CKD and ESRD.

Adult patients undergoing MHD who fulfilled the following eligibility criteria were included in the study: diagnosed with ESRD and receiving MHD; on regular hemodialysis for a minimum duration of three months; aged 18 years and above; and capable of understanding and responding to the study questionnaire. Patients with severe cognitive impairment, inability to communicate, acute medical instability, or other serious illnesses likely to interfere with study participation were excluded.

Sociodemographic and clinical characteristics

Data on sociodemographic characteristics were collected using a structured questionnaire and included age, sex, education, marital status, occupation, socioeconomic status, and living arrangements. Clinical information such as primary renal diagnosis, duration of dialysis, dialysis frequency, and associated comorbidities was obtained from patient interviews and medical records.

Assessment of palliative care needs

Palliative care needs were assessed using the POS-S renal, a validated disease-specific adaptation of the POS developed for patients with advanced kidney disease.[19-24]

The instrument assesses multidimensional aspects of palliative care, including physical symptoms, psychological and emotional concerns, spiritual well-being, information needs, and practical support requirements. Higher scores indicate greater symptom burden and unmet palliative care needs.

HRQoL

HRQoL was measured using the EuroQol five-dimensional five-level questionnaire (EQ-5D-5L), a widely used generic preference-based instrument for assessing health status among patients with chronic diseases, including those receiving dialysis.[29-31] The instrument evaluates five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension consists of five response levels ranging from no problems to extreme problems. Health states were converted into utility scores using the recently developed Indian EQ-5D-5L value set. Utility scores range from values below zero (health states considered worse than death) to 1.0, representing perfect health.

Data collection

Participants were recruited consecutively during their visits to dialysis units and palliative care OPDs. Purpose and procedures of the study were explained to all eligible participants before enrolment. Written informed consent was obtained from each participant before data collection.

Data were collected through face-to-face interviews conducted by trained investigators using a pretested structured questionnaire. Participants who experienced difficulty reading or completing the questionnaire independently were assisted by the investigators, who administered the questions in a neutral and standardized manner. Each interview required approximately 15-20 minutes to complete. Clinical information was verified from medical records whenever necessary.

Ethical considerations

Written informed consent was obtained from all participants. Confidentiality and anonymity of the collected information were maintained throughout the study. Participation was voluntary, and participants were informed of their right to withdraw from the study at any point without affecting their treatment or care.

Statistical analysis

Data were entered into Microsoft excel and analyzed using R (v4.2.2). Continuous variables were summarized as mean and SD/median and interquartile range, depending on the distribution of the data. Categorical variables were expressed as frequencies and percentages.

Associations between quality-of-life scores, palliative care needs, and participant characteristics were assessed using appropriate statistical tests. Independent t test or Mann-Whitney U test was used for comparison between two groups, while one-way analysis of variance (ANOVA) or Kruskal-Wallis test was used for comparisons involving more than two groups. Correlation between continuous variables was examined using Pearson's or Spearman's correlation coefficients, as appropriate. A $p<0.05$ considered statistically significant.

RESULTS

Sample characteristics

A total of 236 MHD patients were enrolled in this study and were divided into two groups according to age: 118 younger patients (age <65 years) and 118 older patients (age ≥65 years). Table 1 presents the socio-demographic and clinical characteristics of participants of the two age groups. Briefly, the median age of the patients was 64.5 years (54.0, 70.0); 63.6% of patients were male, and more than two-thirds of patients had an education level below secondary and high school education. Most of the patients were married (83.1%) and living with families (92.8%). The majority of younger patients (72.9%) and older patients (99.2%) were retired or unemployed. The monthly household income of 28% of patients was less than 5,000 CNY.

Palliative care needs

Table 2 shows total and item-specific scores of POS and the comparison between the younger and older groups. Total median POS score was 16.0 (12.0, 23.0), and older patients had higher median scores than younger patients ($p<0.01$). From the overall sample, item of family anxiety had the highest median score, followed by information needs, support, practical matters, other symptoms, and wasted time. Apart from the items of information needs and wasted time, median scores for each item of the POS were higher in older patients than in younger patients, and differences were statistically significant ($p<0.05$).

Symptom burden

The mean total number of symptoms in MHD patients was 15.04±5.06, and was greater in older patients than in younger patients (16.02±5.10 versus 14.07±4.86, $p<0.01$). Table 3 presents the 10 most common symptoms, in descending order, commencing with dry mouth (91.5%), itching (83.1%), and dry skin (82.2%). Most importantly, the symptom of feeling tired or lacking energy (86.4%) was also common in older patients. The overall median symptom severity score was 59.0 (52.0, 71.0), and was higher in the older group than the younger group (61.0 versus 55.5, $p<0.01$). Table 4 shows the top five scores for symptom severity. The highest median severity score for each symptom was dry mouth, followed by itching and dry skin. There were significant differences in other symptoms between the two groups ($p<0.05$), except for the symptom of dry skin.

Correlations of palliative care needs with symptom burden and HRQoL

The overall median HRQOL score was 0.78 (0.61, 0.78), and the median score was lower in older patients than in younger patients (0.71 versus 0.78, p<0.01). Relationship of palliative care needs with symptom burden and HRQoL in MHD patients shown in Table 5. Results revealed that both total and item-specific POS scores positively correlated with overall symptom burden score (p<0.05) and overall symptom severity score (p<0.01), and negatively correlated with HRQoL (p<0.01).

Table 1: Socio-demographic and clinical characteristics of participants in the two groups.

Variables	Total (n=236) (%)	Age <65 years (n=118) (%)	Age ≥65 years (n=118) (%)
Age (in years)	64.5 (54.0, 70.0)	54.0 (45.0, 60.0)	70.0 (68.0, 76.0)
Gender			
Male	150 (63.6)	78 (66.1)	72 (61.0)
Female	86 (36.4)	40 (33.9)	46 (39.0)
Education level			
Illiterate and primary schooling	107 (45.3)	41 (34.7)	66 (55.9)
Secondary schooling	64 (27.1)	39 (33.1)	25 (21.2)
High school and above	65 (27.5)	38 (32.2)	27 (22.9)
Marital status			
Married	196 (83.1)	100 (84.7)	96 (81.4)
Single	11 (4.7)	10 (8.5)	1 (0.8)
Divorced, separated, or widowed	29 (12.3)	8 (6.8)	21 (17.8)
Living status			
Living alone	17 (7.2)	8 (6.8)	9 (7.6)
Living with spouse, families	219 (92.8)	110 (93.2)	109 (92.4)
Employment status			
Retired/unemployed	203 (86.0)	86 (72.9)	117(99.2)
Employed	33 (14.0)	32 (27.1)	1 (0.8)
Monthly household income (in INR)			
<5,000	66 (28.0)	30 (25.4)	36 (30.5)
5,000-10,000	107 (45.3)	51 (43.2)	56 (47.5)
>10,000	63 (26.7)	37 (31.4)	26 (22.0)
Primary cause			
Glomerulonephritis	67 (28.4)	37 (31.4)	30 (25.4)
Diabetic nephropathy	61 (25.8)	28 (23.7)	33 (28.0)
Hypertensive nephropathy	60 (25.4)	27 (22.9)	33 (28.0)
Others	48 (20.3)	26 (22.0)	22 (18.6)
Duration of MHD since diagnosis (years)			
<1	48 (20.3)	23 (19.5)	25 (21.2)
1-5	85 (36.0)	38 (32.2)	47 (39.8)
>5	103 (43.6)	57 (48.3)	46 (39.0)

*Data are M (P_{25}, P_{75}) or n (%). MHD=maintenance hemodialysis.

Table 2: Palliative care needs and age-based comparisons.

Items	All sample (n=236)	Age<65 years (n=118)	Age≥65 years (n=118)	Z	P
Total	16.0 (12.0, 23.0)	14.0 (10.0, 20.0)	19.0 (13.0, 25.0)	4.06	<0.001
Pain	1.0 (1.0, 2.0)	1.0 (0.0, 2.0)	1.0 (1.0, 2.0)	2.62	0.009
Other symptoms	2.0 (1.0, 2.0)	2.0 (1.0, 2.0)	2.0 (1.0, 3.0)	3.29	0.001
Patient anxiety	1.0 (0.0, 2.0)	1.0 (0.0, 2.0)	1.0 (0.8, 2.0)	2.03	0.042
Family anxiety	3.0 (2.0, 4.0)	2.5 (1.8, 4.0)	4.0 (2.0, 4.0)	2.61	0.009
Information needs	2.0 (2.0, 3.0)	2.0 (1.0, 3.0)	2.0 (2.0, 4.0)	1.74	0.081
Support	2.0 (1.0, 3.0)	1.0 (1.0, 3.0)	3.0 (2.0, 3.0)	3.71	<0.001
Depression	1.0 (0.0, 2.0)	1.0 (0.0, 2.0)	1.0 (0.0, 2.0)	2.37	0.018
Self-worth	1.0 (1.0, 2.0)	1.0 (1.0, 2.0)	1.0 (1.0, 3.0)	2.49	0.013
Wasted time	2.0 (0.0, 2.0)	2.0 (0.0, 2.0)	2.0 (0.0, 2.0)	0.19	0.850
Practice matters	2.0 (0.0, 4.0)	2.0 (0.0, 4.0)	4.0 (0.0, 4.0)	3.58	<0.001

*Data are M (P_{25}, P_{75}). Comparison of 2 groups based on the total scores and the scores for each item of the POS. Statistical significance was evaluated by the Mann-Whitney analysis of variance test.

Table 3: Top ten most common symptoms and age-based comparisons.[a]

Symptoms	All sample n=236)	Age<65 years (n=118)	Age≥65 years (n=118)	χ^2	P value
Dry mouth	216 (91.5)	104 (88.1)	112 (94.9)	3.50	0.062
Itching	196 (83.1)	97 (82.2)	99 (83.9)	0.12	0.729
Dry skin	194 (82.2)	102 (86.4)	92 (78.0)	2.90	0.089
Feeling tired or lack of energy	192 (81.4)	90 (76.3)	102 (86.4)	4.02	0.045
Trouble staying asleep	178(75.4)	85 (72.0)	93 (78.8)	1.46	0.226
Worrying	168 (71.2)	78 (66.1)	90 (76.3)	2.98	0.085
Feeling anxious	159 (67.4)	76 (64.4)	83 (70.3)	0.95	0.331
Trouble falling asleep	158 (66.9)	77 (65.3)	81 (68.6)	0.92	0.356
Feeling irritable	147 (62.3)	71 (60.2)	76 (64.4)	0.45	0.502
Muscle cramps	129 (54.7)	58 (49.2)	71 (60.2)	2.89	0.089
Difficulty becoming sexually aroused	129 (54.7)	70 (59.3)	59 (50.0)	2.07	0.150
Decreased interest in sex	129 (54.7)	68 (57.6)	61 (51.7)	0.84	0.360

*Data are n (%), number and percentage of patients who reported the symptom. [a] Common symptoms reported using the Dialysis Symptom Index (DSI): top ten of 30 symptoms. For comparisons of common symptoms between the two groups, statistical significance was evaluated by the chi-square analysis of variance test.

Table 4: Top five scores for symptom severity and age-based comparisons[a].

Symptoms	All sample (n=236)	Age<65 years (n=118)	Age≥65 years (n=118)	Z	P value
Dry mouth	3.0 (3.0, 4.0)	3.0 (2.0, 4.0)	4.0 (3.0, 4.0)	2.39	0.017
Itching	3.0 (2.0, 4.0)	3.0 (2.0, 3.0)	3.0 (2.0, 4.0)	2.02	0.043
Dry skin	3.0 (2.0, 4.0)	3.0 (2.0, 3.0)	3.0 (2.0, 4.0)	0.04	0.965
Feeling tired or lack of energy	3.0 (2.0, 4.0)	3.0 (2.0, 4.0)	3.0 (2.0, 4.0)	2.84	0.005
Trouble staying asleep	3.0 (2.0, 4.0)	3.0 (1.0, 4.0)	3.0 (2.0, 5.0)	2.24	0.025

*Data are M (P_{25}, P_{75}). [a] Symptom severity reported using the dialysis symptom index (DSI): top five of 30 symptoms; values denote the median severity of individual symptoms. For comparisons of symptom severity between the two groups, statistical significance was evaluated by the Mann-Whitney analysis of variance test.

Table 5: Correlation analysis of palliative care needs with symptom burden and HRQoL.

Palliative care needs	Overall symptom burden score	Overall symptom severity score	HRQoL
Total	0.66**	0.79**	-0.70**
Pain	0.51**	0.57**	-0.47**
Other symptoms	0.45**	0.63**	-0.49**
Patient anxiety	0.60**	0.67**	-0.61**
Family anxiety	0.16*	0.38**	-0.33**
Information needs	0.33**	0.38**	-0.27**
Support	0.40**	0.41**	-0.39**
Depression	0.59**	0.63**	-0.63**
Self-worth	0.55**	0.66**	-0.68**
Wasted time	0.23**	0.22**	-0.15**
Practice matters	0.44**	0.53**	-0.48**

*Data are r values. Statistical significance was evaluated using Pearson's correlation test, *p<0.05, **p<0.01.

DISCUSSION

Palliative care needs among patients receiving MHD

The present study demonstrated that patients undergoing MHD experience substantial palliative care needs, highlighting the multidimensional burden associated with ESRD. Despite advances in dialysis care and improved survival, patients continue to report unmet physical, psychological, social, and informational needs. Similar observations have been reported among patients with chronic and life-limiting illnesses, emphasizing the importance of integrating palliative care into routine renal care services.[15,20]

A considerable proportion of participants reported unmet needs related to symptom management, family concerns, information regarding illness and treatment, and practical difficulties encountered during the course of their disease. The chronic nature of ESRD and the demanding schedule of dialysis treatment can significantly affect patients' daily activities, emotional well-being, and social functioning, thereby increasing their supportive care requirements. Studies have shown that multidisciplinary palliative care interventions can improve symptom control, emotional health, and overall QOL among patients with serious illnesses.[15,33,34]

The symptom burden observed in the present study was substantial and consistent with previous literature among hemodialysis patients.[8] Commonly reported symptoms included fatigue, sleep disturbances, pruritus, dry mouth, and musculoskeletal discomfort. These symptoms not only affect physical functioning but also contribute to psychological distress and reduced QOL. Previous studies have similarly reported that symptom burden among dialysis patients remains high despite ongoing treatment.[8,37-39]

Effective symptom management remains a cornerstone of palliative care. In addition to pharmacological interventions, supportive approaches such as counselling, cognitive behavioural therapy, physical activity programmes, and other non-pharmacological interventions may help address the complex physical and emotional challenges faced by patients undergoing long-term dialysis.[15,40-42]

Family and caregiver concerns

An important finding of the study was the prominence of concerns related to family anxiety and caregiver burden. Family members play a central role in supporting patients receiving MHD and often experience considerable emotional, physical, and financial strain. Similar findings have been documented in previous studies involving patients with advanced chronic illnesses.[20,43]

The ongoing demands of treatment, frequent hospital visits, uncertainty regarding prognosis, and caregiving responsibilities can adversely affect caregivers' QOL and psychological well-being. Previous research has demonstrated that palliative care interventions addressing both patient and caregiver needs can reduce caregiver burden and improve overall family well-being.[45,46] These findings reinforce the need for family-centred approaches in the care of patients with ESRD.

Unmet informational and practical needs

Apart from symptom-related concerns, participants frequently reported unmet informational and practical needs. The complexity of ESRD management often necessitates continuous information regarding disease progression, treatment options, self-care practices, and prognosis. Similar observations have been reported in studies involving patients with both malignant and non-malignant conditions.[20,32,36]

The time commitment associated with MHD represents another important challenge. Regular dialysis sessions restrict personal, occupational, and social activities, often leading to disruption of normal daily life. This burden may be particularly relevant among economically productive individuals who face difficulties balancing employment and treatment requirements.

Financial concerns also emerged as an important practical issue. The cumulative costs associated with dialysis treatment, medications, transportation, nutritional requirements, and loss of income can place considerable strain on patients and their families.[49] Furthermore, patients with functional limitations may require additional assistance with routine daily activities, further increasing dependency and supportive care needs.[50]

These findings underscore the importance of adopting a comprehensive and interdisciplinary model of care that addresses not only physical symptoms but also informational, psychosocial, and practical concerns throughout the disease trajectory.

The present study also demonstrated a significant relationship between palliative care needs, symptom burden, and HRQoL. Patients experiencing a higher burden of symptoms reported greater unmet supportive care needs and poorer QOL. Similar associations have been observed in previous studies among individuals with chronic neurological and other life-limiting conditions.[32] This highlights the need for early integration of palliative care within nephrology services to ensure holistic management of patients with ESRD.

Limitations

The findings of this study should be interpreted in light of certain limitations. First, the study was conducted among patients receiving MHD attending palliative care services in selected tertiary care hospitals in metropolitan Mumbai, which may limit the generalizability of the findings to other healthcare settings. Second, patients receiving alternative treatment modalities such as PD, renal transplantation, or conservative kidney management were not included; therefore, their palliative care needs may differ and warrant further investigation.

Third, although the POS-S Renal is a validated and widely accepted instrument for assessing palliative care needs among patients with kidney disease, some domains of supportive care may not be fully captured. Finally, the cross-sectional design limits the ability to establish causal relationships between symptom burden, palliative care needs, and QOL. Longitudinal studies are required to better understand changes in these outcomes over time.

CONCLUSION

Patients with ESRD undergoing MHD experience a considerable symptom burden and substantial palliative care needs. Higher unmet needs were associated with poorer HRQoL and greater symptom burden. These findings support the early integration of palliative care into routine nephrology practice. A multidisciplinary approach addressing physical, psychological, social, informational, spiritual, and practical concerns may help improve overall QOL and enhance patient-centred care among individuals receiving long-term dialysis.

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