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A cross-sectional study to assess the health-related quality of life of patients on haemodialysis in Chennai

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Abstract

Background End-stage renal disease (ESRD) poses a significant burden globally and in India. However, access to treatment remains limited due to resource and cost constraints. This study aimed to evaluate the health-related quality of life (HRQoL) and economic burden among haemodialysis patients.

Methods A descriptive cross-sectional study using European Quality of life, EQ-5D-5L, to measure health-related quality of life across 5 domains, i.e. mobility, self-care, usual activities, pain/discomfort and anxiety/depression, was administered, across three settings—government dialysis centre, private dialysis centre and charity based dialysis centre. The health utility values were also calculated. Also, the costs incurred in dialysis were done.

Results The mean (± SD) age of the participants was 55 (± 11) years, the majority of the participants were male (*n* = 61), 80% (*n* = 64) of the participants were employed before and 40% of them had lost a job, due to the morbidity of the disease. Upon analyzing the EQ-5D-5L data, it is inferred that all five domains were the same across all three set-ups. The direct cost incurred on the haemodialysis ranged from INR.600 to INR.3500 per month, and the indirect cost ranged fromINR.50 to INR. 3000, which is borne by the participants, in about 70% of the cases. Chief Minister Health Insurance Scheme was found to be extremely useful, wherein only 30% (*n* = 25) of the study participants (*n*=81) were insured beneficiaries.

Conclusion HRQoL was moderately impaired, and treatment posed substantial financial hardship among hemodialysis patients. Expanding access to decentralized and community-based care models could help address the challenges of regular treatment and lost productivity.

Keywords Quality of life, Kidney, EQ5D5L, Haemodialysis, HRQOL, QOL, Nephrology, Renal diseases, CKD, Dialysis

Introduction

End-stage renal disease (ESRD) is a severe and debilitating condition characterized by the irreversible loss of kidney function, leading to the accumulation of waste products in the body and a range of associated complications. ESRD contributes around 7% to the global burden of non-communicable diseases each year [1]. It has also emerged as a leading cause of death particularly in developing countries with constrained healthcare resources and limited access to renal replacement therapies. Over 1

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million people die of ESRD annually in low- and middle-income countries (LMICs) [2].

In India, about 0.22 million of new ESRD cases are diagnosed every year, resulting in an additional burden of Indian Rupees (INR) 32 Million on the health expenditure on dialysis every year. There are about 4950 dialysis centres in India. With the growing incidence, the existing infrastructure is not adequate to meet the dialysis requirements of patients. The cost of each dialysis is approximately more or less than INR.2000. Besides the direct cost, there are other indirect costs such as travel and loss of wages for patients or family members associated with this. Considering the disease burden and out-of-pocket expenditure, haemodialysis has been strengthened by a public–private partnership program as a cost-effective approach (NHM, Pradhan Mantri National Dialysis Programme, National Health Portal of India) [3].

Patients with ESRD require long-term haemodialysis (HD). Considering the access, financial costs and unmet demands of renal transplantation, HD remains the mainstay treatment option. The patient had to go to a dialysis centre two to three times per week, for maintenance of HD [4]. Patient's dependency on the health care system, dialysis staff and their caregivers increases.

With improvement in dialysis care, the longevity of the patient improves. However, the chronicity of the illness, associated with morbidity, makes them feel negative and depressive, taking a toll on their quality of life. With deteriorating health and loss of income, patients with ESRD would have to be extremely reliant on family support, especially for their financial needs and medical caregiving support.

ESRD gradually incapacitates the patient's ability to work in a job, with a detrimental effect on their financial income as well, which in turn impacts their marital status, families and social activities. Besides other disease-specific measures, their health-related quality of life is considered to be an equally essential indicator for patients with ESRD [5]. However, there are lack of studies specifically examining the impact of ESRD on patients' HRQoL in Tamil Nadu, India. The present study aims to measure the health-related quality of life (HRQoL) among ESRD patients undergoing haemodialysis and also to estimate the cost for the expenditure incurred (both direct and indirect) on a single visit for the dialysis and related costs in Tamil Nadu.

Methods

Study design

A descriptive cross-sectional study was conducted among patients undergoing dialysis at selected centres in Chennai.

Study setting

The study was conducted among patients undergoing dialysis at five major approved and registered dialysis centres in Chennai. The selection of these centres was majorly based on the feasibility in terms of access and permission. The dialysis centres were as follows:

- Public health care facility, Government Hospital, Madhavaram, Chennai.
- Private Facility, KC Hospitals, Avadi, Tiruvallur.
- Charitable facility, Sri Jain Medical Relief Society, Chennai.

Study participant selection

Eighty-one patients with ESRD undergoing dialysis, registered from the records of the dialysis centre, were randomly selected and were enrolled for the study. All the relevant information was collected from the participants.

Study tool

Besides collecting basic demographic details, modified Kuppuswamy scales 2021 [6] were used to compute the socio-economic status of the participants.

The main objective, HRQoL of the participants is measured using EQ-5D-5L [7]. EQ-5D-5L is the descriptive measure that measures and values the health state of an individual across five dimensions. The five dimensions are mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension would be rated by the individual as five levels, similar to the Likert rating, levels 1 to level 5: Level 1, no problems; Level 2, slight problems; Level 3, moderate problems; Level 4, severe problems; and Level 5, extreme problems. The patient is asked to indicate his/her health state by ticking the box next to the most appropriate statement in each of the five dimensions. This decision results in a 1-digit number that expresses the level selected for that dimension. The digits for the five dimensions can be combined into a 5-digit number that describes the patient's health state.

For costing purposes, a brief self-designed, validated proforma was used. The direct cost and indirect cost, incurred by the ESRD patients, who underwent HD, were computed using this proforma.

Data collection

The tool was digitized in the Kobo toolbox, Version, 2021.3.4 [8], and a test run was done in a mock interview and checked for its precision, validity and totality. The Kobo collect mobile app was used for the data collection. As HD took 3–4 h, participants had adequate time to participate and complete the interview. The digital tool inherently ensured various checks, for the complete

collection of data from the patients; thus, no part of the question can be skipped; also, the collected data was checked at the end of each interview if it was complete in all aspects.

Data analysis plan

Data collected was analyzed using Microsoft Excel 2019 and IBM SPSS statistical software, trial version 26. A general description of the participants will be provided based on age, gender and other socio-economic factors. Categorical variables were summarized as numbers, in the results sections. The EQ-5D-5L, descriptive health state values of the patients were provided across subgroups of socio-demographic variables (such as age, gender, socio-economic status, disease status, dialysis frequency and disease status). The EQ-5D-5L is a standardized measure used to assess the health state values of patients across different socio-demographic variables, such as age, gender, socio-economic status, disease status, dialysis frequency and disease status. These health state values are computed as EQ-5D-5L index values, also known as utility values.

To reproduce the value sets, a standardized protocol developed for India, using composite time trade-off and discrete choice experiments, was adapted. These methods help capture the preferences and trade-offs individuals make when evaluating different health states [9].

To measure the utility value, a readily available SPSS syntax is used, developed for India by Jyani et al. [9]. The syntax provides a set of commands that facilitate the calculation of the utility value based on the EQ-5D-5L index values.

The quality-adjusted life year (QALY) is calculated by multiplying the utility value obtained from the EQ-5D-5L assessment and the number of years since diagnosis of ESRD. This calculation allows for a quantitative estimation of the impact of the patient's health state on their overall quality of life (QALY).

The Shapiro–Wilk test is used to check the normality of the distribution of EQ-VAS scores (Visual Analog Scale), EQ-5D-5L index values and QALY. This test assesses whether the data follows a normal distribution. Depending on the results of the normality check, parametric or non-parametric tests are employed to compare the data sets across different socio-demographic categories. Parametric tests, such as *t*-tests or ANOVA, are used when the data is normally distributed, while non-parametric tests, such as the Mann–Whitney *U* test or Kruskal–Wallis test, are used when the data does not follow a normal distribution.

By employing these methods and tests, insights into the health state values of patients across different socio-demographic variables and making informed comparisons between different subgroups can be drawn.

Ethics

Approval of the Institutional Ethics Committee from The TN Dr M.G.R. Medical University, Guindy, Chennai, was obtained. A patient information sheet (PIS) describing the risks and benefits of participating in this study was provided and explained. Written informed consent was obtained from the eligible study participants. A participant ID was provided to each study participant for anonymity. The study was conducted according to Good Clinical Practice (GCP) guidelines, in compliance with Indian Council of Medical Research (ICMR) ethical guidelines.

EQ-5D approval

The study/project titled, "A cross-sectional study to assess the health-related quality of life (HRQoL) of patients on dialysis in Chennai" had been registered under EQ-5D-5L registry, and necessary permissions had been sought vide Registration ID: 47965.

Results

Socio-demographics and ESRD-related variables

Age, gender, marital status, place of residence, number of household members, employment status, ESRD history, dialysis: status, frequency and history and distance from the dialysis centre of the participants are listed in Table 1 below.

The mean (± SD) age of the participants was 55 (± 11) years, and the majority of the participants were male and were from Urban areas, as the study was conducted in a major metropolitan city, Chennai. Eighty percent of the participants had claimed to have been working before (except for aged patients, students, housewives and retired personnel). Of these participants, only 31% were able to continue their job, due to the morbidity of the illness, 69% had an income lesser than INR.46,129 belonging to the lower middle and lower economic strata. About 37% of the participants had to travel more than 5 km to reach the dialysis centre, and about 90% of these participants had caregivers by their side, during dialysis, and these caregivers were their spouses, daughters and mothers. About 50% of the female ESRD patients were visiting the centres alone without caregivers.

Socio-economic status

For the computation of the socio-economic status (SES), the updated modified Kuppuswamy socio-economic scale, 2021, was used, as the study was carried out during this period. It is inferred that the median income, as per the updated modified Kuppuswamy

Table 1 Distribution of socio-demographic and ESRD-related variables

Socio-demographic variable		*n* = 81	Percent
Age-wise groups of the participants (in years)	18–30	3	4%
	31–40	8	10%
	41–50	19	23%
	51–60	29	36%
	61–70	20	25%
	71–80	2	2%
Gender	Male	61	75%
	Female	20	25%
Place of residence	Urban	45	56%
	Rural	4	5%
	Others	32	40%
Marital status	Married	75	93%
	Unmarried	6	7%
Number of household members	(Lives alone) 0	1	1%
	1	1	1%
	2	5	6%
	3	13	16%
	4	26	32%
	5	18	22%
	6	8	10%
	> 6	9	11%
Current employment status	Employed	25	31%
	Unemployed	56	69%
Are you primary earning member of the family?	Yes	30	37%
	No	51	63%
If no, who is the primary earning member head of the family?	Spouse	13	16%
	Children	32	40%
	parent	3	4%
	In-law	1	1%
	Sibling(s)	1	1%
	Others	1	1%
Occupation (past/current)	Senior officials / manager	1	1%
	Professionals	1	1%
	Technicians / associate professionals	7	9%
	Clerks	3	4%
	Skilled workers/sales/marketing	32	40%
	Agricultural/fisheries	2	2%
	Plant/machine operators	3	4%
	Elementary occupation	10	12%
	Unemployed/quit job	2	2%
	Retired	1	1%
	Stay at home	17	21%
	Students	2	2%
First diagnosis of CKD	Less than a year	9	11%
	1–2 years	9	11%
	2–5 years	52	64%
	5–10 years	12	15%
	> 10 years	1	1%

Table 1 (continued)

Socio-demographic variable		*n* = 81	Percent
Time lapse from the first diagnosis to the start of first dialysis	Less than 1 month	24	30%
	1–6 months	16	20%
	6 months–1 year	9	11%
	> 1 year–2 years	8	10%
	> 2 years–5 years	14	17%
	> 5 years–10 years	7	9%
	> 10 years	3	4%
First dialysis—type	Haemodialysis	77	95%
	Peritoneal dialysis	4	5%
First dialysis line	Central venous line	63	78%
	AV fistula	14	17%
	Peritoneal catheter	4	5%
Frequency of dialysis	2 per week	50	62%
	3 per week	30	37%
	Once fortnightly (2 in a month)	1	1%
Have you registered for kidney transplant?	No	68	84%
	Yes	13	16%
Distance between the residence and dialysis centre?	Up to 1 km	16	20%
	> 1 to 2 km	12	15%
	> 2 to 3 km	15	19%
	> 3 to 5 km	8	10%
	> 5 to 10 km	14	17%
	> 10 to 15 km	7	9%
	> 15 to 30 km	5	6%
	> 30 to 50 km	3	4%
	> 50 km	1	1%
Failed AV fistula	Yes	5	6%
	No	76	94%

Table 2 Socio-economic status using modified Kuppuswamy scale

SES Index	Number of participants	
	n	(In percent)
Upper (I) 26–29	6	(7%)
Upper middle (II) 16–25	29	(36%)
Lower middle (III) 11–15	26	(33%)
Upper lower (IV) 5–10	18	(22%)
Lower (V) < 5	2	(2%)

socio-economic scale of the majority of the Indian population is INR.37387/- the SES of the participants computed and graded as follows in Table 2 below.

EQ-5D-5L

As the "Test for Normality" for VAS (p value ~ 0.05), EQ index – Utility Scores (p value < 0.05) and QALY (p value < 0.05), using "Shapiro–Wilk test", showed that the distribution is non-normal, median (IQR) for VAS, utility scores and QALY is expressed in Table 3 below. Also, as the distribution is non-normal, non-parametric tests like Wicoxon test, Mann–Whitney U test and Kruskal–Wallis test were used to determine the statistical significance, based on the number of categories, to check the level of significance between categories under each socio-demographic variable.

When the EQ-5D-5L domain-specific scoring levels of the patients were analyzed, it was inferred that all five domains—mobility, self-care, ability to perform usual activities, pain/discomfort, anxiety and depression across all three set-ups—government dialysis centre, charity institution and private dialysis centre—were

Table 3 EQ 5D 5L VAS / index values and QALY measures against socio-demographics

		VAS Score		EQ5D5L index values		QALY	
	n	**Median (IQR)**	***p* value**	**Median (IQR)**	***p* value**	**Median (IQR)**	***p* value**
Total participants[a]	81	60 (40, 70)	< 0.001	0.789 (0.488, 0.903)	< 0.001	2.039 (0.401, 4.025)	< 0.001
Gender[b]							
Male	61	60 (40, 70)	0.255	0.824 (0.488, 0.941)	0.518	2 (0.517, 4.158)	0.73
Female	20	60 (48, 70)		0.766 (0.482, 0.876)		2.404 (0.00, 3.662)	
Age (in years)[c]							
18–30	3	75 (60, 0)	0.026	0.984(0.790, –)	0.121	1.581 (0.000,)	0.607
31–40	8	45 (40, 63.75)		0.466(0.242, 0.869)		1.705(0.366, 4.506)	
41–50	19	60 (40, 70)		0.669(0.216, 0.886)		1.3372 (0.000, 3.61)	
51–60	29	65(50, 75)		0.850(0.612, 0.969)		2.5602 (0.000, 5.322)	
61–70	20	42.5(30, 60)		0.787 (0.517, 0.85)		2.4793 (1.4284, 3.921)	
71–80	2	55(40, 0)		0.024 (− 0.738, 0)		− 1.083 (− 2.953, 0)	
Median income (in INR)[b]							
< = 37,387	51	60 (40, 70)	0.101	0.715 (0.392, 0.903)	0.122	1.3372 (0, 3.645)	0.09
> 37,387	30	60 (47.50, 76.25)		0.844 (0.562, 0.936)		2.5289 (1.521, 5.794)	
Frequency of dialysis[c]							
Once a week	1		0.456		0.109		0.05
Twice a week	50	60 (40,68)		0.836 (0.493, 0.932)		1.93121 (0, 3.547)	
Thrice a week	30	60 (40,70)		0.7793 (0.22, 0.84)		2.2587 (0.540, 4.948)	
Duration of diagnosis[b]							
Less than equal to 5 years	57	60 (40, 69)	0.175	0.789(0.464, 0.907)	0.95	1.3372 (0, 2.727)	0.000
More than 5 years	24	60 (40, 75)		0.805 (0.507, 0.898)		5.325 (3.543, 6.823)	
Place of residence[c]							
Urban	46	60 (40, 71.25)	0.743	0.493 (− 0.434)	0.706	0.987 (− 1.302)	0.006
Rural	3	60 (40, 70)		0.727 (0.497, 0.88)		0.764 (2.901)	
Semi urban	32	60 (10, 0)		0.836 (0.41, 0.916)		3.166 (1.408, 5.175)	
Duration of dialysis[c]							
≤ 1 year	30	55 (40, 68.50)	0.096	0.682 (0.491, 0.95)	0.721	0.888 (0, 3.781)	0.006
2–3 years	26	50 (40, 60)		0.813 (0.349, 0.862)		1.984 (0.643, 2.762)	
4–5 years	16	64 (40, 70)		3.547 (0.871, 3.911)		3.547 (0.871, 3.911)	
> 5 years	9	70 (62.50, 77.50)		0.849 (0.647, 0.927)		6.293 (4.389, 10.249)	
Type of facility[c]							
Charity	25	65 (47.5, 85)	0.042	0.837 (0.683, 0.926)	0.38	1.696 (3.199)	0.000
GH	26	50 (40, 60)		0.704 (0.142, 0.916)		0.663 (2.577)	
Private	30	60 (40, 68.50)		0.727 (0.481, 0.889)		0.629 (1.837)	

[a] Wilcoxon test

[b] Mann–Whitney *U* test

[c] Kruskal–Wallis test

p value significant at 0.05

almost found to be the same with level 2, viz., with slight problems, excepting the self-care in private dialysis centre are at level 3, viz., moderate problems in washing/dressing, which could be attributed to the fact that charity institution and the government dialysis centres that were included in our study were not taking in patients if they were severely ill.

Figure 1 depicts the EQ 5D 5L measures, measuring mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The data shows that the majority of respondents reported the highest number of responses in level 1 and is descending across levels 1 to 5.

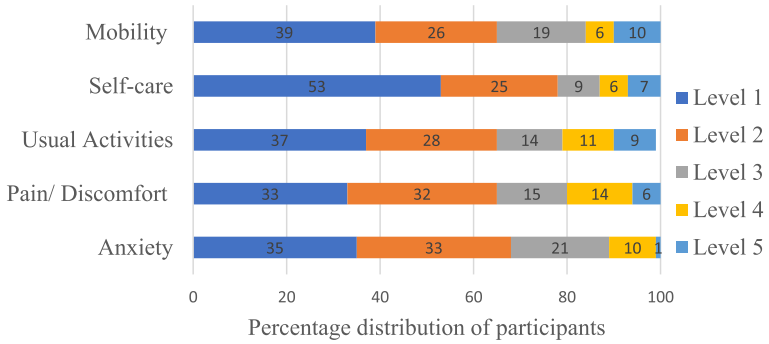

Fig. 1 EQ 5D 5L reported measure. Five dimensions (5D): mobility, self-care, usual activities, pain/discomfort and anxiety/depression; five levels (5L): Level 1, no problems; Level 2, slight problems, Level 3, moderate problems; Level 4, severe problems; and Level 5, extreme problems

Costing

For costing purposes, the patients undergoing dialysis at all three set-ups were compared. The direct cost incurred on the haemodialysis ranged from INR.600 to INR,3500 per month for the government setup and private dialysis centre respectively, and the indirect cost ranged from INR.50 to INR>3000, which is borne by the participants, in approximately at least 70% of the cases. Chief Minister's Comprehensive Health Insurance Scheme (CMHIS) was found to be extremely useful to 30% ($n=25$) of the participants, those who were insured. CMHIS helps in the reimbursement of the dialysis charges for the patients, who undergo dialysis at the government hospital [10]. Next to the public health care setting, patients preferred charitable institutions over private hospitals, as they are relatively cheaper. However, the charitable institutions were not willing to take up ESRD patients who were not otherwise found to be stable, hemodynamically or otherwise, as they were not greatly equipped to handle any crisis.

Discussion

The study provides important insights into the health-related quality of life of patients undergoing haemodialysis in Chennai, India. The mean age of the study participants was 55 years with a standard deviation of 11 years. Most of the participants in the study were male (75%) [11–13]. Other Indian studies have found that the most affected age group for ESRD was between 30 and 60 years old, which was consistent with the study where close to 70% of patients were within that age range. Studies have also shown that end-stage renal disease disproportionately impacts working-age males between the ages of 30 and 60 years old [11].

All the five domains (mobility, self-care, usual activities, pain, anxiety/depression), as measured by the EQ-5D-5L, were similar across the three dialysis centres included in the study. This suggests that the quality of dialysis, as provided across the dialysis centres, viz., government, private facilities and charitable institutions is perceived to be the same and had no significant impact on patients' perceived health-related quality of life.

A majority of patients (62%) received haemodialysis twice per week, compared to other Indian studies; 56% of patients needed dialysis twice weekly [9], whereas a study done by S Sethi et al. found that most of the patients received dialysis three times per week [11].

Only 40% of previously working participants were able to continue their jobs due to illness. This was higher than anticipated reports based on other literature [14]. In total, 82% of participants reported being unable to work due to their condition, making them non-earning members of their families. This could explain the high percentage of unemployed participants (63%) in this study.

About 65% of participants travelled more than 5 km to reach a dialysis centre, suggesting the need for improved access to care, and 88% were also accompanied by caregivers—most commonly spouses and mothers for male and young adult patients respectively. Compared with their male counterparts, about 50% of the females were visiting the centres alone without caregivers. ESRD places a significant burden on both caregivers and healthcare systems.

The overall median (IQR) health utility index value using EQ-5D-5L was found to be 0.789 (0.488, 0.903), and the EQ-VAS median score was 60 with an interquartile range of 30 indicating a relatively good perceived health-related QoL. For a study done in Palestine among ESRD patients undergoing HD, the median index value score was 0.41, and the EQ-VAS median score was 50 [15].

The overall median (IQR) quality-adjusted life years (QALY) computed from the utility index values due to dialysis in the study was 2.039 (0.401, 4.025). Patients who had been diagnosed with ESRD more than 5 years had a median QALY of 5.325 (3.543, 6.823) years and

had been undergoing dialysis for more than 5 years had a higher QALY of 6.293 (4.389, 10.249) years.

Dialysis being the first lifesaving option for people being diagnosed with end-stage kidney disease, 49% of the patients had their dialysis done in a period of a month or within 1–6 months from their diagnosis. Dialysis being the mainstay treatment, complementing the quality of dialysis services, the patients who have been diagnosed for more than 5 years and had started dialysis early had better QALY. However, these are not statistically significant as the sample size is relatively smaller, for intergroup correlations.

In this study, 84% of the patients have not been registered for a kidney transplant, but this is not satisfactory or hopeful when seen from a cost-effective point; as reported from a study done in Iran, which compared the cost-effectiveness between cadaver kidney transplantation, living person kidney transplantation and chronic dialysis, it was found kidney transplantation from a cadaver treatment method was more cost-effective than the other two kidney transplant method (transplant from living person and cadaver) and is also relatively far better than the chronic dialysis [16]. Transplantation was found to be 5–14 times superior to chronic dialysis [13], thus needs to be made available for ESRD patients in India.

The study reveals that 95% of the participants had undergone haemodialysis and the remaining 5% had peritoneal dialysis. Studies reported though there is not much significant difference in terms of quality of life for people choosing between peritoneal dialysis (PD) and hemodialysis (HD), but based on expenses, PD has a lesser financial burden compared to HD.

A study done by T Masina et al. found that the direct costs of HD were high compared to PD. Regarding morbidity and mortality, PD was no less good than HD [14]. The rate of PD is relatively lesser in India; as stated by one of the nephrologists, during our hospital visit, PD it needs to be the first option, over HD as it preserves the vascularity.

This study is the first to study the health-related quality of life of end-stage kidney disease using the EQ-5D-5L tool, in India. There are three studies done with the same tool where two are from the USA, respectively, and another one from Japan. The two US studies were on end-stage renal disease patients, and the one done in Japan was on chronic kidney disease patients [17]. Herein, using the EQ-5D-5L tool, the highest problem was noted in pain and discomfort (67%) followed by anxiety/depression (65%), usual activity (63%) and mobility (61%) with the lowest in self-care (47%). According to the systematic review done by Zhou et al., among the 5 dimensions, the self-care dimension was the one reported with the highest problem among chronic kidney patients [17].

A multiethnic study done among Asian patients found that old patients reported a higher quality of life compared to young patients in all aspects except for physical health, which was in contrast with ours, where middle-aged patients had a similar or worse quality of life than the young [16].

In a cross-sectional study done in a tertiary hospital in Singapore, the EQ-5D-5L used in this study had valid and sensitive health utility measures for assessing ESRD patients [18].

The tool EQ-5D-5L used different patient characteristics, survey locations, the use of country-specific value sets and other factors. The health preferences of patients living in different countries are affected by their social environment, living standards and health systems. Therefore, the EQ-5D-5L value sets estimated based on residents' preferences for health states vary across countries or regions. However, it appears that the EQ-5D-5L would lead to more favourable cost-effectiveness results than the SF-6D when they are used to quantify health benefits in economic evaluations. Another study which was done on renal transplant recipients shows that the HRQOL items assessed by the SF-36 instrument show a higher positive correlation to the EQ-5D-5L score than to the kidney disease-specific QOL [19]. In SF-36 subdomains, the physical health aspects of QOL, such as physical functioning, daily functioning and bodily pain, show a stronger correlation with the EQ-5D-5L score than do those related to psychological and social health, which showed a limited correlation. The limited correlation between them can be due to the domain that addresses mental health which is anxiety and depression. So, it is inferred that SF 36 is better for assessing the societal and mental aspects of renal disease or transplant patients, whereas EQ-5D-5L is a better tool to see the health utility and cost-effectiveness of the medical care [19].

It had been reported that HD patients have poorer HRQoL than cancer patients and are being alienated [20]. This has to be given due importance; preventive health services should be strengthened through NCD services.

Limitations of the study

The current study offers valuable insights into the quality of life for ESRD patients undergoing haemodialysis in Chennai, India. However, interpreting the findings should require due diligence, by acknowledging certain limitations. The relatively small and potentially biased sample limits generalizability. The cross-sectional design and reliance on a single tool restrict understanding causal relationships and the broader QoL with this population. Self-reported data on the employment details and costing parameters would need further cross-verification and scrutiny.

Additionally, cost-effectiveness comparisons need more nuanced analysis. While highlighting important needs, these limitations pave the way for future research with larger, representative samples, longitudinal designs and diverse measurement tools to refine understanding and guide interventions for improving the QoL of ESRD patients in India.

Recommendations

The study reveals significant gaps in care and support for ESRD patients in India. Despite the availability of dialysis, patients face challenges in maintaining employment, dealing with long travel distances to access dialysis facility and managing treatment costs. Decentralized care models could reduce travel burdens, and social support initiatives for transportation or home-based care might help patients continue working and receive family support. The study emphasizes the need for expanded access to dialysis and increased social support, particularly for working-age patients with long commutes, to maintain their employment and quality of life. Special provision can be made for the patients for their employability and making them economically productive. Addressing these issues through community-based programs and policy efforts could improve outcomes. A multipronged approach addressing both physical and social determinants of health is needed to enhance renal replacement therapy and the quality of life for ESRD patients in India. Further research on coordinated, patient-centred care models is recommended to find sustainable solutions for managing this condition. The Chief Minister's Health Insurance Scheme (CMHIS) has been effectively utilized, but it is limited to individuals below the poverty line (with an annual income of less than INR 70,000). Furthermore, financial aid/relief can be provided for severely ill patients with ESRD, as prolonged dialysis incapacitates these individuals, and about half of their lifetime is expended on undergoing dialysis and from the recovery following dialysis.

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Additional information/ disclosures
Human subjects: Consent was obtained from all participants in this study. Institutional Ethics Committee, The Tamil Nadu Dr MGR Medical University, Chennai, issued approval vide ref no. ECMGR0309193.
Animal subjects: All authors have confirmed that this study did not involve animal subjects or tissue.

Conflict of interest
In compliance with the ICMJE uniform disclosure form, all authors declare the following: Payment/services info: This study was awarded a grant of USD 70 (= INR 7500/-) under the Tamil Nadu State Council for Science and Technology, Chennai, vide Project Code MS-363.

Financial relationships
All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. Other relationships: All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

Authors' contributions
Karthikeyan Pandiyambakkam Rajendran: conceptualization, methodology, original draft preparation, data curation, data analysis; Rakesh Anbazhagan, Sridevi Rajamohan and Suresh Ramalingam: visualization, investigation; Srinivas Govindarajulu: supervision, validation, writing—reviewing and editing.

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Availability of data and materials
The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
Approval of the Institutional Ethics Committee from The TN Dr M.G.R. Medical University, Guindy, Chennai was obtained. A patient information sheet (PIS) describing the risks and benefits associated with participation in this study was provided and explained. Informed consent from the eligible study participants, was also obtained. A Participant ID was provided to each study participant for anonymity and the study was conducted according to GCP guidelines, in compliance with ICMR ethical guidelines.

Consent for publication
Informed consent was obtained from all individual participants included in the study. Participants were informed that the data would be used in research publications in a way that protects their anonymity. Identifying information has been removed from all data that could link it back to individual participants. All participants gave consent to the data being used for publication in this manner.

Competing interests
The authors declare that they have no competing interests.

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