

Social Impact of End-Stage Renal Disease Requiring Hemodialysis among Patients with Type-2 Diabetes and Their Caregivers in Bengaluru, Karnataka

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Abstract

Introduction: Diabetic nephropathy is the leading cause of end-stage renal disease (ESRD) requiring hemodialysis. The social impact of a chronic disease like this is far reaching and often difficult to quantify. **Objectives:** To assess the social impact of ESRD among type 2 diabetics requiring hemodialysis and their caregivers. **Methods:** A cross-sectional study was carried out between February 2017 and 18 among patients with type 2 diabetes requiring hemodialysis and their caregivers, attending the dialysis unit at St. John's Medical College Hospital, Bengaluru, India. Social impact was assessed under the domains of stress (physiologic and psychologic), quality of life (QOL), cost of care, self-perceived burden, and caregiver burden. Study tools used were semi-structured interview schedule for sociodemographic data, details regarding diabetes, hemodialysis and cost of care, EuroQol-5D-3L, hemodialysis stressor scale, Cousineau Self-Perceived Burden Scale, and Caregiver Burden Scale. **Results:** A total of 160 participants were included. Majority were males (78%) between 46 and 60 years of age. Most participants experienced moderate stress due to hemodialysis (65%) and moderate self-perceived burden (47.5%). Five (10.6%) participants reported full health, while one (0.6%) reported poor health. Anxiety/depression (80.6%) was the top reported problem among all domains of QOL. Caregiver burden was moderate (53.9%). Annual median cost of direct medical expenditure was ₹258,600 (interquartile range [IQR]: 197,400–433,500) and ₹16,500 (IQR: 9,600–32,100) for nonmedical. **Conclusion:** We conclude that the social impact of ESRD among type 2 diabetics requiring hemodialysis and their caregivers was moderate. Routine counseling of patients receiving haemodialysis and support groups for patients as well as caregivers will help reduce the impact.

Keywords: Caregiver burden, chronic kidney disease, cost of care, diabetes, end-stage renal disease, hemodialysis stress, hemodialysis, quality of life, social impact, type-2 diabetes

INTRODUCTION

India is “the diabetes capital of the world” with 62.4 million Indians living with diabetes.^[1] The growing epidemic of type-2 diabetes in India is highlighted in several studies.^[2,3] Most type-2 diabetics have already developed complications at the time of diagnosis, given the long asymptomatic period of hyperglycemia.^[4]

Approximately one-third of patients with diabetes mellitus have diabetic nephropathy.^[5] Diabetic nephropathy is the leading cause of end-stage renal disease (ESRD) worldwide and is estimated that ~20% of type-2 diabetics reach ESRD during their lifetime.^[6] Clinically, kidney disease in diabetics is characterized by increasing rates of urinary albumin

excretion, starting from normo-albuminuria, progressing to micro-albuminuria, macro-albuminuria, and eventually to ESRD requiring renal replacement therapy. Hemodialysis is the most common treatment option in ESRD; however, it is considered a potential source of stress by both the patients and their caregivers.^[7]

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How to cite this article: Hanspal I, Fathima FN, Kedlaya PG. Social impact of end-stage renal disease requiring hemodialysis among patients with type-2 diabetes and their caregivers in Bengaluru, Karnataka. Indian J Community Med 2021;46:626-30.

Received: 03-12-20, **Accepted:** 02-08-21, **Published:** 08-12-21

Access this article online

Quick Response Code:



Website:
www.ijcm.org.in

DOI:
10.4103/ijcm.IJCM_995_20

Diagnosis of a chronic disease, such as diabetes or ESRD, has far reaching economic and social consequences on the individual, his/her family and the society. Social impact of a disease includes all social and cultural consequences to human populations that alter ways in which people live, work, play, relate to one another, organize to meet their needs, and generally cope as members of society.^[8] Social impact of a chronic disease is far reaching and often difficult to quantify. By means of conducting this study, we aim to assess the social impact by examining physiological and psychological stress due to hemodialysis, quality of life (QOL), and self-perceived burden among type-2 diabetics with ESRD requiring hemodialysis, burden among caregivers, and cost of care.

METHODS

The study assessed social impact under the domains of financial, inter-personal relationship, physiologic and psychological stress from the perspective of patient and his/her caregiver. A cross-sectional study was undertaken between February 2017 and 18 among patients with type-2 diabetes undergoing hemodialysis and their caregivers, attending the dialysis unit at St. John's Medical College Hospital (SJMCH), Bengaluru.

Based on a previous study,^[9] where the prevalence of stress among caregivers of patients undergoing dialysis was found to be 72.5%, with a relative precision of 10%, confidence limits 95%, and a nonresponse rate of 10%, the sample size was determined to be 160. Study participants were recruited from patients attending the dialysis unit at SJMCH between February 1, and May 31, 2017 and randomly selected using simple random sampling with replacement by the lottery method. The study was approved by the Institutional Ethics Committee of SJMCH. Written consent was obtained from all participants before enrollment.

Study tools used

Semi-structured interview schedule for sociodemographic data, details regarding diabetes and hemodialysis and cost of care for diabetes and hemodialysis; EuroQol-5D-3L:^[10] for patients' QOL; hemodialysis stressor scale:^[11] for physiologic and psychologic stress among patients; Cousineau self-perceived burden scale:^[12] for perceived burden among patients and Caregiver Burden Scale:^[13] to assess caregiver burden. A pilot study was conducted to assess utility of the study tools used in the study.

The data collected were entered in Microsoft Excel and analyzed using the standard statistical package. Sociodemographic data, stress, and perceived burden were analyzed using the descriptive statistics (means, medians, and proportions). Costs and QOL were measured as continuous variables. Chi-square, Fisher's exact, Mann-Whitney *U*, and Kruskal-Wallis tests were used to test associations between different variables and possible risk factors. $P < 0.05$ was considered statistically significant.

RESULTS

A total of 160 participants were included. Majority were male (78%) between 46 and 60 years of age. Majority (84.4%) lived in the urban areas and had nuclear families (64.4%). More than half (72%) of the study population was not gainfully employed (retired, unemployed, and homemakers). As per B.G. Prasad classification, 54.4% of the study population belonged to socioeconomic Class I. Only 22% participants were financially independent, whereas 46.9% were fully dependent on others. Less than half (41.2%) had some kind of health insurance, while a sizable majority (59%) not having any. Primary caregivers for more than half of the patients were their spouses (56.3%). Eight (5%) participants did not have a primary caregiver and they took care of themselves.

The mean age at the diagnosis of diabetes was 41.77 ± 8.11 years. Apart from diabetes, 95% of them had some kind of comorbidity (hypertension, dyslipidemia, and hypothyroidism). The duration of hemodialysis ranged between 1 and 120 months among our study participants, and majority of them travelled under 10 km to reach the dialysis unit. More than half (65.6%) received hemodialysis twice per week and 34.5% followed a thrice per week regime.

Most participants experienced moderate stress due to hemodialysis (65%). An overwhelming majority (98.1%) had some kind of complication (chronic kidney disease [CKD]-mineral bone disease, diabetic foot, neuropathy, retinopathy, and cardiac disease) over and above diabetic nephropathy; anemia (76.3%) being the most commonly noted complication.

Direct medical expenditures include cost of medication, hemodialysis, investigations, and intercurrent hospital admissions. Annual median cost of hemodialysis was ₹115,200 (inter quartile range [IQR]: 115,200–172,800), ₹48,000 (IQR: 36,000–72,000) for medications, ₹12,000 (IQR: 8000–15,600), and ₹160,000 (IQR: 100,000–360,000) for intercurrent hospital admissions. Direct nonmedical expenditures include cost of travel to and from dialysis unit as well as miscellaneous expenditure on the day of hemodialysis. The annual median cost of travel was ₹144,00 (IQR: 8,400–29,700) and annual median miscellaneous expenditures were ₹54,750 (IQR: 36,500–73,000).

QOL was poor among those participants who were unemployed (median = 9 [IQR: 7–11]). Participants who were financially fully independent (median = 7 [IQR: 6–9]) for health-care needs had a better total QOL score compared to those who were fully/partially dependent on others for finance. 10.6% participants reported full health, whereas one (0.6%) reported poor health. Anxiety/depression (80.6%) was the top reported problem among all domains of QOL.

Self-perceived burden among patients was reported as moderate by 47.5%. Severe burden was experienced by 26.9%, whereas 18.8% participants reported mild self-perceived burden. Significant associations were found

between the patient's primary caregiver ($P = 0.010$), patient's current employment status ($P < 0.001$), patient's financial dependence ($P = 0.015$), and patient's self-perception of burden on his/her caregiver [Table 1].

Caregiver burden was assessed among 152 caregivers. Almost half of the caregivers (53.9%) experienced moderate burden. Severe burden was experienced by 36.2%, whereas 3.9% participants reported mild caregiver burden. Burden among the caregivers was severe when the patient was unemployed ($P = 0.042$), patients did not have health insurance ($P = 0.002$) and when patient delayed dialysis due to any reason ($P = 0.012$) [Table 1].

DISCUSSION

Diabetes is a "silent killer," because by the time patient is diagnosed to have diabetes, he/she is already affected with complications such as diabetic nephropathy, retinopathy, and neuropathy. Anemia among CKD patients is of varied etiology and similar to anemia of chronic inflammatory disease.^[14] In our study, anemia (76.3%) was the most common complication noted, followed by diabetic retinopathy (61.3%).

Patients requiring long-term hemodialysis often have difficulty in holding a job and face financial problems. Compared to our study findings, where more than half of them were not gainfully employed, lesser proportion of participants in the study from Chennai were retired (28%) while a higher proportion were unemployed (35%) due to health status.^[15] A study from Taiwan reported that 18.3% participants were unemployed, 24.1% retired while 23.8% participants were employed.^[16]

According to the Indian CKD registry report,^[17] 42.7% patients had a monthly family income of less than ₹5000, whereas it ranged between ₹10,000 and ₹30,000 in another study.^[15] The median monthly family income among our participants of ₹39,000 (IQR: 20,000–50,000) seems to be higher compared to that in other studies. Socioeconomic status of majority of our study participants was middle class and above, probably because only those patients who can afford hemodialysis treatment attended the dialysis unit.

Threatened employment status of patient due to illness and recurrent nature of haemodialysis causes patients' families to bear hefty costs of health care, especially out-of-pocket expenditure as majority of the Indian population is not covered by health insurance. According to the Indian CKD registry, a vast majority of patients do not have access to health insurance^[17] which is in tandem with our finding of half of our participants not having health insurance. India does not have an established program to manage CKD patients, hence patients requiring hemodialysis have to fund treatment from their own resources.^[18]

According to National Health Policy-2018, the average per capita health expenditure on account of hospitalization is ₹10,351 per person per hospitalization,^[19] whereas in our study, it was higher (₹15,596.88). A study based on a large

dataset in India found that drug costs accounted for 58% of out-of-pocket expenditure on diabetes.^[20,21] The annual median cost of medication for ESRD among our participants was ₹12,000 (36,000–72,000) and the per capita cost of medication was ₹5,280.63.

Patients receiving hemodialysis are forced to follow a long-term painful treatment in addition to the numerous limitations and restrictions of lifestyle. Having to deal with a chronic illness greatly affects the QOL of patients with ESRD. Our findings suggest that QOL was significantly poorer among patients whose caregivers experienced severe to very severe caregiver burden. This emphasizes that family support and caregivers' views have great influence on the patient, both emotionally and physically. In our study, anxiety/depression (80.6%) was the top reported problem, whereas better scores were recorded in mental compared to physical component of QOL in a study that used Short Form Health Survey-12.^[22]

We found that participants who experienced increased stress due to hemodialysis increasingly felt themselves being a burden on their caregivers. Most patients on dialysis feel helpless, as they are unable to maintain their employment and sustain daily activities. With increasing severity of illness, there is an increase in the level of patients' dependency, which creates feelings of being burdened on others. This is a significant reason why substantial proportion of patients discontinue hemodialysis in an attempt to gain their independence and freedom again.^[23] It was noted in our study that participants experienced increased stress due to hemodialysis, when their caregivers also increasingly felt burdened due to caregiving. Caregivers were more likely to have negative feelings toward patients if they had no prior experience of the dialysis process. Caregivers experience stress from added responsibilities of managing patients' medical treatments, dietary requirements, clinic appointments, and psychosocial issues.^[23]

In our study, self-perceived burden was mildly present among those who faced problems in routine activities and mild to moderate among those who faced problems at work. Facing difficulties in routine activities imply increased dependence on caregivers and hence the feeling of being a burden on caregiver arises among patients receiving hemodialysis. Experiencing problems at workplace indicate reduced work efficacy, threatens the job security as well as the patient's financial independence. This is emphasized by our findings of increased self-perceived burden among those who were not employed and were fully dependent in terms of finances.

Studies have found that the sense of carer responsibilities is lower when patients are independent in activities of daily living and have less severe dialysis-linked complaints or lower comorbidity.^[24] In our study, caregiver burden was more among patients with moderate to severe stress due to hemodialysis. Other studies done to assess QOL of caregivers of patients on hemodialysis have shown that these caregivers had a slightly worse QOL as compared to the general population.^[24,25]

Table 1: Associations between variables

Hemodialysis stress			
Variable	Mild, n (%)	Moderate to severe, n (%)	
Residence*			
Urban	69 (51.1)	66 (48.9)	
Rural	6 (24)	19 (76)	
Employment status*			
Employed	29 (64.4)	16 (35.6)	
Not employed	46 (40)	69 (50)	
Family type*			
Nuclear	55 (53.4)	48 (46.8)	
Nonnuclear	20 (35.1)	37 (64.9)	
Variables	Mild, n (%)	Moderate, n (%)	Severe, n (%)
Patient's self-perceived burden			
Primary caregiver*			
Self	3 (37.5)	2 (25)	3 (37.5)
Spouse	21 (19.1)	48 (53.3)	23 (25.6)
Children	3 (6.7)	20 (44.4)	22 (48.9)
Grand-children	2 (40)	0	3 (60)
Others	3 (25)	6 (50)	3 (25)
Employment status*			
Employed	14 (31.1)	26 (57.8)	5 (11.1)
Not employed	16 (13.9)	50 (43.5)	49 (42.6)
Patient's financial dependence*			
Fully dependent	16 (21.3)	26 (34.7)	33 (44)
Fully independent	11 (22)	28 (56)	11 (22)
Partially dependent	3 (8.6)	22 (62.9)	10 (28.6)
Caregiver burden			
Employment status*			
Employed	0	29 (69)	13 (31)
Not employed	6 (5.5)	53 (48.2)	51 (46.4)
Patient has health insurance*			
Yes	6 (6.5)	40 (43.5)	46 (50)
No	0	42 (30)	18 (70)
Patient's hemodialysis delayed*			
Yes	2 (6.9)	9 (31)	18 (62.1)
No	4 (3.3)	73 (59.3)	46 (37.4)
QOL			
Variable	Total QOL score, median (IQR)		
Gender*			
Male	8 (7-10)		
Female	9 (9-11)		
Marital status*			
Currently married	8 (9-10)		
Not married	9.5 (8.25-11)		
Employment status*			
Employed	7 (6-8)		
Not employed	9 (7-10)		

Contd..

Table 1: Contd..

Patients' financial dependence*	
Fully dependent	9 (7.5-10)
Fully independent	7 (6-9)
Partially dependent	8 (7-10)
*Significant at $P < 0.05$, ^a Chi-square test, ^b Fisher's exact test, ^c MannWhitney U-test, ^d Kruskal-Wallis test. QOL: Quality of life, IQR: Interquartile range	

CONCLUSION AND RECOMMENDATIONS

Among our study participants, anxiety/depression was most reported among all domains of QOL. Annual median cost of direct medical expenditure was ₹258,600 (IQR: 197,400–433,500) and ₹16,500 (IQR: 9,600–32,100) for nonmedical. Stress was moderate among patients and both self-perceived as well as caregiver burden were moderate. Thus, we conclude that social impact of ESRD among type-2 diabetics requiring hemodialysis and their caregivers was moderate [Table 2].

Psychological stress due to hemodialysis among patients can be addressed through routine counseling, timely referrals to psychiatrist/psychologist, support group sessions moderated by dialysis staff/doctors to share experiences and difficulties. Health of caregiver directly impacts the patient outcomes, and hence, it is important to consider the caregiver's needs. Converting the informal group of caregivers in the hemodialysis waiting area into a weekly/fortnightly/monthly support group meetings will help caregivers share their burden and experiences. Iterate support from friends and family to patients and their caregivers in assistance with cleaning, personal care, grocery shopping, and transportation to the dialysis unit.

Strengths and limitations

This is the first study that has assessed the social impact of a chronic disease comprehensively and under the domains of inter-personal relationships, economic, physiologic and psychological stress from the perspective of patient and their caregivers. To the best of our knowledge, this is the first study assessing the social impact of ESRD requiring hemodialysis among patients with type 2 diabetes in Karnataka.

The limitation of this study was that the information regarding cost of care was based on recall and was self-reported by the participants. We did not find adequate record of costs in the forms of bills for intercurrent hospital admission, medicines, and investigations as the patient did not bring these along to the dialysis unit. The study purposively recruited participants from only one dialysis unit at a tertiary care hospital. However, the dialysis unit at St. John's Medical College Hospital is one of the largest, providing services to approximately 4000 patients requiring hemodialysis.

Financial support and sponsorship

Nil.

Table 2: Social impact of end-stage renal disease among patients with type-2 diabetes and their caregivers

	Domain	Result
Patient	Stress due to hemodialysis	65% moderate stress
	QOL	80.6% anxiety/depression
	Self-perceived burden	66.3% mild to moderate stress
	Expenditure	Direct medical cost: ₹258,600 (IQR: 197,400-433,500) Direct nonmedical cost: ₹16,500 (IQR: 9600-32,100)
Caregiver	Caregiver burden	90.2% moderate-to-severe burden

IQR: Interquartile range, QOL: Quality of life

Conflicts of interest

There are no conflicts of interest.

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