

BURDEN AMONG CAREGIVERS OF PATIENTS RECEIVING MAINTENANCE HEMODIALYSIS IN DIALYSIS CENTRES FUNCTIONING UNDER A HUB-AND- SPOKE MODEL: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Maintenance hemodialysis (MHD) imposes a considerable psychosocial and economic burden not only on patients but also on the family members who care for them. Government-supported dialysis programmes delivered through a hub-and-spoke public-private partnership model have expanded access to dialysis close to patients' homes, but the burden experienced by caregivers within this delivery model has not been well characterised. **Objective:** To assess the level of burden among caregivers of patients undergoing MHD at government-supported centres functioning under a hub-and-spoke model, and to identify sociodemographic and clinical factors associated with caregiver burden. **Methods:** In this cross-sectional observational study, 698 caregivers attending peripheral dialysis centres linked to a hub hospital were enrolled. Caregiver burden was assessed using the 22-item Zarit Burden Interview (ZBI), categorised as little-or-no (0-22), mild-to-moderate (23-44), moderate-to-severe (45-66), and severe (67-88) burden. Sociodemographic and clinical variables of both patients and caregivers were recorded and tested for association with burden category using the chi-square test, with $p < 0.05$ considered significant. **Results:** Of 698 caregivers, 419 (60.0%) were male and 279 (40.0%) female; 61.2% were spouses of the patient. Moderate-to-severe or severe burden was present in 377 caregivers (54.0%). Caregiver burden showed a statistically significant association with dialysis vintage ($p < 0.001$), with the proportion of moderate-to-severe/severe burden rising from 26.2% in caregivers of patients on dialysis for under 1 year to 80.4% in those on dialysis for more than 3 years. A significant association was also observed with caregiver gender ($p = 0.016$), female caregivers reporting greater burden than male caregivers. No significant association was found with caregiver age, relationship to the patient, or household income ($p > 0.05$). **Conclusion:** Roughly one in two caregivers of patients on MHD at hub-and-spoke dialysis centres experienced moderate-to-severe burden, closely tracking dialysis vintage and caregiver sex. These observations suggest that caregiver-directed psychosocial and financial support should be considered an integral, longitudinally-scaled component of chronic dialysis care programmes.

KEYWORDS: Caregiver burden; hemodialysis; hub-and-spoke model; Zarit Burden Interview; chronic kidney disease; dialysis vintage.

INTRODUCTION

Chronic kidney disease (CKD) is a growing global health burden, and maintenance hemodialysis (MHD) remains the most widely used form of renal replacement therapy for patients who reach ESRD without access to transplantation.^[1] While dialysis prolongs survival, it converts a fatal illness into a chronic condition that demands lifelong, thrice-weekly commitment from the patient and, almost invariably, from an informal family

caregiver who arranges transport, manages fluid and dietary restrictions, coordinates medications, and provides emotional support.^[2]

The concept of caregiver burden — the physical, emotional, social, and financial strain experienced by those who care for a chronically ill relative — has been extensively studied in dementia and oncology populations, and increasingly in hemodialysis cohorts.^[3]

Caregivers of hemodialysis patients have consistently been shown to carry a heavier burden than caregivers in many other chronic disease settings, related to the rigidity of the dialysis schedule, the unpredictability of intercurrent illness, and the financial strain of prolonged treatment.^[4,5] Unaddressed caregiver burden has downstream consequences for the patient as well, including reduced treatment adherence, caregiver burnout, and, in extreme circumstances, withdrawal of care.

In India, several states have adopted a hub-and-spoke model of dialysis delivery, in which a small number of tertiary hub hospitals provide oversight and complex care while a larger network of peripheral (spoke) centres — often run through public–private partnerships — deliver free or subsidised dialysis close to patients' homes. This model has substantially improved geographic access to dialysis for economically disadvantaged patients, but it also disperses the caregiving burden across a heterogeneous network of centres with varying levels of on-site psychosocial support. Whether caregiver burden in this specific service-delivery model mirrors that reported from single-centre hospital-based cohorts elsewhere is not established.

We undertook this cross-sectional study to assess the level of burden among caregivers of patients undergoing MHD at government-supported peripheral dialysis centres functioning under a hub-and-spoke model, and to identify the sociodemographic and clinical correlates of that burden.

MATERIALS AND METHODS

Study design and setting

This was a cross-sectional observational study conducted among caregivers of patients undergoing MHD at dialysis centres functioning under a hub-and-spoke public–private-partnership model in Telangana, India. Dialysis was provided free of cost to patients, with the Hub hospital providing clinical oversight to the network of peripheral-spoke centres.

Participants

A caregiver was defined as the family member or attendant primarily responsible for the non-medical care of a patient on MHD, including assistance with transport to and from dialysis, medication administration, dietary and fluid management, and financial support, for a minimum duration of 3 months. One caregiver was enrolled per patient. Convenience sampling was used to enrol 698 caregivers 25 peripheral dialysis centres.

Data collection instrument

Caregiver burden was assessed using the 22-item Zarit Burden Interview (ZBI), a widely validated self-report instrument in which each item is scored on a 5-point Likert scale (0 = never to 4 = nearly always), yielding a total score ranging from 0 to 88.⁶ Consistent with established cut-offs, scores were categorised as little-or-

no burden (0–22), mild-to-moderate burden (23–44), moderate-to-severe burden (45–66), and severe burden (67–88).⁷ Sociodemographic data recorded for the caregiver included age, gender, relationship to the patient, monthly household income, and duration of caregiving. Patient-related variables recorded included age, gender, comorbidities, native kidney disease, and dialysis vintage.

Statistical analysis

Categorical variables are presented as frequencies and percentages, and continuous variables as mean $\pm$ standard deviation or median (range) as appropriate. The association between sociodemographic and clinical variables and ZBI burden category was assessed using the chi-square test. A two-sided *p*-value <0.05 was considered statistically significant. Data were analysed using IBM SPSS Statistics, version 27.

Ethical considerations

The study was approved by the Institutional Ethics Committee of Gandhi Medical college and was conducted in accordance with the principles of the Declaration of Helsinki. Written informed consent was obtained from all participating caregivers prior to enrolment.

RESULTS

Patient characteristics

A total of 698 patients on MHD and their corresponding primary caregivers were included. Among patients, 372 (53.3%) were male and 326 (46.7%) were female. The majority (445, 63.8%) were in the 40–60 year age group, followed by the 21–40 year (111, 15.9%) and >60 year (126, 18.1%) groups; only 16 (2.3%) were under 20 years of age. The commonest reported comorbidity was diabetes mellitus (326 patients), followed by hypertension (252), cardiovascular disease (168), and cerebrovascular disease (72); comorbidities were not mutually exclusive. Diabetic kidney disease was the leading attributed cause of native kidney disease (245, 35.1%), followed by hypertensive nephrosclerosis (214, 30.7%), chronic interstitial nephritis (102, 14.6%), chronic glomerulonephritis (42, 6.0%), and other/undetermined causes (95, 13.6%). With regard to dialysis vintage, 114 patients (16.3%) had been on MHD for less than 1 year, 333 (47.7%) for 1–3 years, and 251 (36.0%) for more than 3 years (Table 1).

Table 1: Patient characteristics (n=698).
*Comorbidities were not mutually exclusive; percentages do not sum to 100.

Patient characteristic	n (%)
Gender	
Male	372 (53.3)
Female	326 (46.7)
Age group (years)	
<20	16 (2.3)
21–40	111 (15.9)
40–60	445 (63.8)
>60	126 (18.1)
Comorbidities*	
Diabetes mellitus	326 (46.7)
Hypertension	252 (36.1)
Cardiovascular disease	168 (24.1)
Cerebrovascular disease	72 (10.3)
Native kidney disease	
Diabetic kidney disease	245 (35.1)
Hypertension	214 (30.7)

Chronic interstitial nephritis	102 (14.6)
Chronic glomerulonephritis	42 (6.0)
Others	95 (13.6)
Hemodialysis vintage	
<1 year	114 (16.3)
1–3 years	333 (47.7)
>3 years	251 (36.0)

Caregiver characteristics

Among the 698 caregivers, 419 (60.0%) were male and 279 (40.0%) female. The largest age group was 40–59 years (362, 51.9%), followed by 20–39 years (272, 39.0%) and 60–65 years (64, 9.2%). The spouse was the primary caregiver in 427 cases (61.2%), followed by offspring (186, 26.6%), sibling (71, 10.2%), and parent (14, 2.0%). Monthly household income was below INR 5000 in 276 (39.5%) caregivers, INR 5000–10 000 in 226 (32.4%), INR 10 000–20 000 in 122 (17.5%), and above INR 20 000 in 74 (10.6%). The mean duration of caregiving was 2.5 years, ranging from 3 months to 6 years (Table 2).

Table 2: Caregiver characteristics (n=698).

Caregiver characteristic	n (%)
Gender	
Male	419 (60.0)
Female	279 (40.0)
Age group (years)	
20–39	272 (39.0)
40–59	362 (51.9)
60–65	64 (9.2)
Relationship to patient	
Spouse	427 (61.2)
Offspring	186 (26.6)
Sibling	71 (10.2)
Parent	14 (2.0)
Monthly household income (INR)	
<5000	276 (39.5)
5000–10000	226 (32.4)
10 000–20000	122 (17.5)
>20000	74 (10.6)
Duration of caregiving, mean (range)	2.5 years (3 months–6 years)

Distribution of caregiver burden

On the ZBI, 83 caregivers (11.9%) reported little-or-no burden, 238 (34.1%) mild-to-moderate burden, 318 (45.6%) moderate-to-severe burden, and 59 (8.5%)

severe burden. Overall, 377 caregivers (54.0%) experienced moderate-to-severe or severe burden (Table 3).

Table 3: Distribution of caregiver burden on the Zarit Burden Interview (n=698).

ZBI burden category	Score range	n (%)
Little or no burden	0–22	83 (11.9)
Mild to moderate burden	23–44	238 (34.1)
Moderate to severe burden	45–66	318 (45.6)
Severe burden	67–88	59 (8.5)

Factors associated with caregiver burden

Dialysis vintage showed a strong, statistically significant association with caregiver burden category ($p < 0.001$).

The proportion of caregivers with moderate-to-severe or severe burden increased progressively with dialysis vintage — from 26.2% (30/114) in patients on MHD for

less than 1 year, to 42.6% (145/333) in those on MHD for 1–3 years, to 80.4% (205/251) in those on MHD for more than 3 years. Caregiver gender was also significantly associated with burden ($p=0.016$): female caregivers more often reported moderate-to-severe or

severe burden (181/279, 64.9%) than male caregivers (196/419, 46.8%). Patient gender, caregiver age, relationship to the patient, and household income were not significantly associated with caregiver burden category (all $p>0.05$) (Table 4).

Table 4: Association between patient and caregiver variables and Zarit Burden Interview category (n=698).

Variable	No/little 0–22 n(%)	Mild–mod 23– 44 n(%)	Mod–severe 45–66 n(%)	Severe 67–88 n(%)	P value
Patient gender					
Male (372)	44 (11.8)	104 (28.0)	191 (51.3)	33 (8.9)	0.25
Female (326)	39 (12.0)	134 (41.1)	127 (39.0)	26 (8.0)	0.25
Dialysis vintage					
<1 year (114)	32 (28.1)	44 (38.6)	18 (15.8)	9 (7.9)	<0.001
1–3 years (333)	48 (14.4)	147 (44.1)	121 (36.3)	24 (7.2)	<0.001
>3 years (251)	3 (1.2)	47 (18.7)	179 (71.3)	26 (10.4)	<0.001
Caregiver gender					
Male (419)	40 (9.5)	184 (43.9)	165 (39.4)	31 (7.4)	0.016
Female (279)	43 (15.4)	54 (19.4)	153 (54.8)	28 (10.0)	0.016
Caregiver age					
20–39 (272)	19 (7.0)	98 (36.0)	125 (46.0)	29 (10.7)	0.880
40–59 (362)	56 (15.5)	121 (33.4)	169 (46.7)	25 (6.9)	0.880
60–65 (64)	8 (12.5)	19 (29.7)	24 (37.5)	5 (7.8)	0.880
Relation to patient					
Parent (14)	2 (14.3)	5 (35.7)	9 (64.3)	2 (14.3)	0.371
Spouse (427)	65 (15.2)	148 (34.7)	206 (48.2)	15 (3.5)	0.371
Sibling (71)	4 (5.6)	14 (19.7)	31 (43.7)	29 (40.8)	0.371
Offspring (186)	12 (6.5)	71 (38.2)	72 (38.7)	13 (7.0)	0.371
Household income (INR)					
<5000 (276)	20 (7.2)	114 (41.3)	108 (39.1)	25 (9.1)	0.391
5000–10000 (226)	31 (13.7)	82 (36.3)	96 (42.5)	24 (10.6)	0.391
10 000–20000 (122)	18 (14.8)	31 (25.4)	62 (50.8)	7 (5.7)	0.391
>20000 (74)	14 (18.9)	11 (14.9)	52 (60.8)	3 (4.1)	0.391

DISCUSSION

In this cross-sectional study of 698 caregivers drawn from a hub-and-spoke network of government-supported dialysis centres, just over half of caregivers (54.0%) experienced moderate-to-severe or severe burden on the Zarit Burden Interview. This figure sits within the broad range reported from other hemodialysis caregiver cohorts, though direct comparison is limited by differences in instruments, cut-offs, and study settings. A tertiary-centre study from Nepal using the same instrument reported that 43.1% of caregivers experienced moderate-to-severe burden,^[7] while a study from Iran using the Novak and Guest Caregiver Burden Inventory reported extreme burden in 74.2% of caregivers.^[9] and another Iranian study reported that just over half of caregivers had a moderate-to-low quality of life.^[10] Taken together, these findings reinforce that clinically significant caregiver strain is a near-universal feature of long-term hemodialysis care across widely different health systems, rather than an artefact of any single care-delivery model.

The relationship of caregivers to patients in our cohort was predominantly spousal (61.2%), a pattern that closely mirrors the 56.1% reported by Chhetri and Baral

in a Nepalese tertiary-care cohort.^[7] This consistency across settings likely reflects the practical reality of hemodialysis caregiving: it is typically assumed by the person living in closest daily proximity to the patient — most often a spouse — rather than being distributed across the wider family.

The strongest and most consistent correlate of caregiver burden in our cohort was dialysis vintage, with moderate-to-severe or severe burden rising from roughly a quarter of caregivers of patients on dialysis for under a year to over four-fifths of caregivers of patients on dialysis for more than three years ($p<0.001$). This is a biologically and socially plausible finding: the demands of thrice-weekly dialysis are cumulative rather than static, and caregivers of long-vintage patients must additionally absorb the physical decline, comorbidity accrual, and vascular-access complications that typically accompany prolonged dialysis exposure, alongside the sustained opportunity cost to their own employment and income. This observation is consistent with a broader literature linking longer caregiving duration to greater strain, and underscores caregiver burden as a moving target that should be periodically reassessed rather than screened for only at dialysis initiation.

Female caregivers in our cohort reported significantly greater burden than male caregivers ($p=0.016$), a finding that parallels earlier reports from Nepal and Iran describing disproportionate strain among female caregivers of hemodialysis patients.^[8,9] This pattern has generally been attributed to the layering of caregiving duties onto pre-existing domestic and income-generating responsibilities that many female caregivers continue to shoulder, as well as to gender differences in the coping strategies adopted in response to chronic caregiving stress.^[9,11] In our study, caregiver burden was not significantly associated with caregiver age, relationship to the patient, or household income. Instead, dialysis duration and caregiver gender appeared to be more useful factors for identifying caregivers at risk of higher burden.

These findings carry practical implications for dialysis programmes delivered through hub-and-spoke and similar decentralised public-private-partnership models. Because peripheral centres in such networks are typically staffed for the technical delivery of dialysis rather than for structured psychosocial support, caregivers — particularly those of long-vintage patients and female caregivers — may be systematically under-recognised and under-supported. Embedding brief, periodic caregiver-burden screening (for example, using a short-form ZBI) into routine dialysis-vintage milestones, and linking flagged caregivers to counselling, peer-support groups, or medical social work, could be a low-cost addition to existing hub-hospital oversight structures.

Limitations

This study has few limitations that warrant a cautious interpretation of these observational, single-network findings. First, the cross-sectional design precludes any causal inference regarding the relationship between dialysis vintage, caregiver gender, and burden; longitudinal follow-up of caregivers across the dialysis trajectory would be needed to establish temporality. Second, caregiver burden was assessed at a single time point and may not capture fluctuation related to intercurrent patient illness, hospitalisation, or seasonal financial stress. Third, potential confounders such as caregiver employment status, education, presence of co-caregivers, and pre-existing caregiver comorbidity were not captured and could not be adjusted for. Fourth, as data were drawn from a single hub-and-spoke network in Telangana, generalisability to other health systems and dialysis-delivery models should be made cautiously. Finally, convenience sampling, rather than formal random sampling, may have introduced selection bias. These limitations are typical of pragmatic, network-wide observational surveys of this kind and should be weighed accordingly rather than treated as detracting from the descriptive value of the findings.

CONCLUSION

In this cross-sectional survey of caregivers of patients on maintenance hemodialysis at government-supported hub-

and-spoke dialysis centres, moderate-to-severe or severe caregiver burden was observed in just over half of caregivers, and rose steeply with dialysis vintage; female caregivers appeared to be disproportionately affected. These observations suggest that caregiver-directed psychosocial and financial support strategies, tailored to dialysis vintage and caregiver gender, merit consideration as a routine component of chronic dialysis-care programmes, alongside continued efforts to expand geographic access to dialysis itself.

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Conflict of Interest

None declared.

Source of Support

Nil.

Author Contributions

AM — conception, data collection, analysis, manuscript drafting; MY — supervision, critical revision; SP — supervision, critical revision: all authors approved the final manuscript.

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