

A Cross Sectional Study On Psychological Morbidity, Burden And Quality Of Life Among Care Givers of Patient Under Going Dialysis at a tertiary Care Hospital In Kanchipuram District

Date of Submission: 05-05-2024

Date of Acceptance: 15-05-2024

I. INTRODUCTION

Progressive and irreversible kidney failure is chronic renal failure (CRF). CRF affects many people worldwide, making it a public health issue that causes morbidity and mortality. Hemodialysis is the most prevalent chronic renal failure (CRF) treatment worldwide [1]. Dialysis difficulties and limits cause many psychological illnesses [2]. Patients experience melancholy, anxiety, low self-esteem, reliance, exhaustion, infertility, sexual dysfunction, bone difficulties, anaemia, cardiovascular and gastrointestinal illnesses, and frequent hospitalisations. Family members can have psychological, social, and cultural issues from long-term hemodialysis [3].

Dialysis patients are ageing [4] and at risk of physical, cognitive, and emotional decline [5] due to diabetes, hypertension, cardiovascular risk factors, pulmonary and skeletal issues, and multiple metabolic disturbances [5], which affects their mobility and self-care. Thus, elderly dialysis patients need care from health professionals, spouses, parents, siblings, friends, and emotionally committed volunteers [4].

Family is the finest source of care for dialysis patients, therefore many depend on them [6, 7]. Family carers are crucial to elderly individuals. Approximately 36 million people provide unpaid care to a 65-year-old family member, 80% of whom are spouses or adult children. Family carers typically contribute over 20 hours of weekly care to elderly individuals [8]. According to the 2000 World Health Report, health promotion programmes should increase lifespan and focus mortality and disease symptoms. In 2001, the WHO prioritised happiness [9]. Health, physical and mental health, performance, and participation all affect quality of life [10]. Quality of life is linked to diseases and conditions that threaten physical and mental health [11]. Hemodialysis patients' anguish and agony impede their everyday activity and capacity to execute daily tasks [12]. Suffering extends from temporary psychological, mental, and bodily

discomfort to severe sadness and has stages from malignant disappointment to apathy and indifference (the last stage) [13]. Chronic diseases affect patients and primary carers. Hemodialysis carers may feel overburdened because they must support their patients [14]. Carers often spend a lot of time caring for patients, causing exhaustion and burden [15].

Mehrer-Imhof et al. found that carers' quality of life affected patients' [16]. Habibzade et al. found that 52% of carers had moderate to low quality of life and 60% were partly dissatisfied with their self-care. In addition, 85% of carers thought social support was inadequate and 67.5% had no recreational activities [15]. Several studies found that disease development in patients diminished carers' physical well-being, affecting patients' health and quality of life [17-19].

Given the low quality of life in carers of patients with physical and mental diseases and the long course of kidney failure and frequent hemodialysis complications affecting patients' mental health and quality of life to varying degrees, the present study was planned to evaluate carers of hemodialysis patients, who are at a higher risk for emotional and psychological problems.

II. METHODS

This cross-sectional study was conducted over an 18-month period from November 2019 to July 2021 at the dialysis unit and Psychiatric department of Karpaga Vinayaga Institute of Medical Science & Research Centre. The study focused on caregivers of patients undergoing dialysis, with a calculated sample size of 267. Inclusion criteria comprised caregivers meeting the definition and aged over 18 years, while individuals with medical, psychiatric, or substance abuse issues were excluded. Data collection involved face-to-face interviews conducted by the principal investigator. Caregivers visiting the dialysis unit were approached, study details were explained, and informed consent was obtained prior to participation. A total of 253 caregivers consented

and participated in the study, with no exclusions. Sociodemographic information was collected using a semi-structured questionnaire, alongside assessments using instruments including PHQ-9, PHQ-15, BPRS, Family Burden Interview Schedule, and WHO QOL-BREF.

Data were entered into Microsoft Excel and analyzed using SPSS 20. Descriptive statistics such as frequencies, proportions, means, and standard deviations were employed. The Chi-

square test was used for categorical data analysis, while paired data for quantitative analysis were subjected to tests of significance. Graphical representation of data was accomplished using bar diagrams, pie charts, and other visual aids within MS Excel and MS Word. This study aimed to provide insights into the caregiving experiences and burdens among caregivers of dialysis patients, contributing valuable information for healthcare interventions and support services.

III. RESULTS

CATEGORY	CAREGIVER	PATIENT
AGE GROUP		
<10	0	5
11-20	13	33
21-30	51	31
31-40	81	51
41-50	65	46
51-60	29	49
60-70	14	29
71-80	0	7
>80	0	2
GENDER		
FEMALE	152	96
MALE	101	157
MARITAL STATUS		
MARRIED	213	89
UNMARRIED	40	16
DIVORCED	0	2
SEPARATED	0	4
WIDOW	0	13
EDUCATION		
GRADUATE	40	26
NOT EDUCATED	13	21
PRIMARY	45	51
UPTO 10 TH	60	87
UPTO 12 TH	95	68
OCCUPATION		
ADMINISTRATOR	16	0
BUSINESS	63	0
FARMER	17	0
NOT EMPLOYED	40	0
PROFFESIONAL	8	0
RETIRED	3	0

SKILLED WORKER	42	0
STUDENT	12	0
UNSKILLED WORKER	52	0

The table presents demographic and socioeconomic characteristics of caregivers and patients in various categories including age group, gender, marital status, education, and occupation. In terms of age distribution, the majority of caregivers fall within the age ranges of 31-40 and 41-50 years, while patients are spread across a wider range from younger to older age groups, with a notable proportion in the 31-60 age brackets.

In terms of gender, there are more female caregivers compared to male caregivers, whereas among patients, there is a higher representation of males. Marital status shows that a significant majority of caregivers are married, whereas

patients exhibit a broader diversity including unmarried, divorced, separated, and widowed individuals.

Looking at educational background, caregivers have varying levels of education with a notable proportion having education up to the 10th and 12th grades. Patients also show a similar educational distribution.

In terms of occupation, the majority of caregivers are employed in various sectors such as business, skilled and unskilled work, and administration, whereas patients' occupation data indicates a higher proportion of not employed individuals.

PHQ9 Severity Score		
Severity	Frequency	Percentage
Mild Depression	105	41.5
Minimal Depression	51	20.2
Moderate Depression	55	21.7
Moderately Severe Depression	42	16.6
Total	253	
PHQ15 Severity Score		
Severity	Frequency	Percentage
High	4	1.6
Low	137	54.2
Medium	65	25.7
Minimal	47	18.6
Total	253	
FBIS Category		
Severity	Frequency	Percentage
Burden	3	1.2
Moderate Burden	181	71.5
Severe Burden	69	27.3
Total	253	

Based on PHQ9 severity scoring most of the caregiver were in mild depression (105) followed by moderate (55), minimal depression (51). Based on PHQ 15 severity scoring low severity was seen in 137 cases, medium severity was seen in 65 cases minimal severity was

observed in 47 cases and four cases are observed with high severity. Among caregivers based on FBIS score moderate burden were observed more in number (71.5%) followed by severe burden and burden.

Variables	Mild Depression	Minimal Depression	Moderate Depression	Moderately Severe Depression	Total	P-Value
Married	89	30	54	40	213	
	41.8	14.1	25.4	18.8		
Unmarried	16	21	1	2	40	<0.0001*
	40	52.5	2.5	5		
Total	105	51	55	42	253	
	Burden	Moderate Burden	Severe Burden	Total		P-value
Married	2	147	64	213		
	0.9	69	30			
Unmarried	1	34	5	40		0.058
	2.5	85	12.5			
Total	3	181	69	253		
	High	Low	Medium	Minimal	Total	P-value
Married	4	121	59	29	213	
	1.9	56.8	27.7	13.6		<0.0001*
Unmarried	0	16	6	18	40	
	0	40	15	45		
Total	4	137	65	47	253	

The current study we observes moderately severe (18.8%) and moderate depression (25.4%) was seen more among caregivers who got married. Severe burden (30%) and burden (69%) was observed more in married caregivers when comparing to the unmarried group which is statistically significant at 5% level of significance. Among study group health status of married caregivers was highly affected in married (56.8%) group comparing to unmarried (40%) group.

IV. DISCUSSION

Acute diseases become chronic and impair. Chronic renal failure patients benefit from dialysis. Complex therapies require more care and lifestyle changes. Policymakers consider caring a health concern after 20 years of research. Most dialysis patients depend on their families for daily activities and medical care, therefore carers are crucial to their long-term management. Patients and carers alter therapies. Physical dependence on carers and inability to operate independently affect their social life and quality of life compared to the

general population. Carers can be traumatised by terminal illness. Carer anxiety results from uncertainty (Pelletier-Hibbert & Sohi, 2001). Friedemann and Buckwalter (2014) identified few clinically depressed carers [149]. Well-mannered carers treated their sick relative like family. It was.

Without family or community support, most carers survived. Caregiving rose for seniors. Studies show patient and social-demographic factors induce burden.

Carers 50–60 struggled. The burden falls on active workers over 35. They worried about money, marriage, job stress, changing hours, taking unpaid days off, quitting, or retiring early to improve patient care. Different age groups may have care disruptions.

Career, family, and social duties can conflict with younger and middle-aged carers. Elderly carers should identify, reduce, and fix difficulties. Senior carers are often spouses of care recipients, which increases their stress due to their proximity and emotional presence. Chronically ill

spouses and carers suffer emotionally from long marriage.

Stress raises elderly carers' 4-year mortality. The findings advise assessing high-burden senior spousal caretakers more often. Their Regularly assess care. Finding a replacement carer is vital if their health declines. Bayoumi et al. [150] found a strong negative correlation between age and carer burden. Harris et al. say young and old care similarly. However, Mukadder et al. found age lowered carer load. Major socioeconomic factors affecting load vary by study [151,152].

Most carers (71.5%, n=253) experienced mild-moderate load. Two Indian studies indicated similar loads. Financial aid and strong social ties burdened most mild-moderate caretakers, studies revealed. US and Johannesburg hemodialysis caretakers reported little difficulties 53.4% [153]. Johannesburg's private sector study reveals high-income countries' financial and social security may explain these differences. Lowered moderate-severe carer load [152].

These studies found that limited social support, older carers, low education, and poor carer and care receiver health increased perceived load [153]. Higher education, younger age, and singleness increased stress in our study. Some chronic disease carer studies found amount disparities.

a burden. Intergenerational living helped carers. Ranking 12th, 37.5%.

Environment had 36 HRQoL, psychology 56 (SD=12.89). Stress severely lowered HRQoL. Domain scores improve life. Sample HRQoL=58.2(SD=17.9). Below 75 carer QoL. We lack comparable cut-points and norms for this caring group. Ajitpal et al. evaluated Indian CKD carers.

Mental (54) and physical (54) mean scores were similar. The mean Social (62) and Environmental (59.3) scores exceeded our research population. Transportation, finance, and the environment are environmental issues [153]. Most individuals will have terrible finances, transportation, housing, and entertainment. Our analysis found 15.8% unemployment. Many experts have examined the economic impact of diseases on developing country families and made recommendations. Due to unemployment, carers reside in informal settlements with limited infrastructure and social services, reducing environmental scores. Sexuality, relationships, and support are social issues. Social ratings drop with smaller homes,

nuclear families, and extended family. Low public support for Alvarez et al.

Stress and mental disorders from caregiving. Carers receive extensive social support [154]. Marriage and social life may deteriorate with caregiving. Other research using the medical outcomes survey short form 36 (SF 36) found carers had a far lower quality of life than the general population. Burden lowers QoL regardless of evaluation technique, the study found. More compassion dropped all life domain mean scores. Source: Suri et al. Burden raised depression and QOL. Thus, caretaker burden hinders many facets of living. Research reveals caretaker load damages HD patients. Quality of life and dialysis at risk. Our study cannot show causality, but reducing caretaker strain may improve hemodialysis patient and carer quality of life.

The data shows women are burdened. Indian women care for others and may underreport their workload and rarely ask for help. The study shows intervention gender load perception discrepancies. This process impacts women more because they care for themselves and others alone. husbands who serve patients and families.

Studies show male carers are burdened more. Burden ratings include male carers. Other studies link hemodialysis patient load to function. Researchers should have checked. Care for independent ADL-performers was easier for Harris et al. [156]. The deterioration of dementia patients burdened 16% of caretakers, according to Kim et al. Research showed no damage from conventional care [157].

Carer QOL was impacted by age, therapy, and QOL. Older haemodialysis patients lost quality of life. Schulz believes patient pain and sickness, behavioural problems, functional disorders, time and care, senior carer, family relationship (particularly wife/husband), and gender (female) affect caretaker stress, sadness, and mental health. [158].

Georgianni et al. used the Hospital Anxiety and Depression Scale to cross-sectionally assess dialysis patients and carers' anxiety to depression. Another burden study by Oluseyi A. Adejumo et al. found a considerable connection between anxiety and depression in carers: 27.8% and 11.4% had high anxiety and sorrow [39].

End-stage renal illness carers in Nigeria had 31.6% more anxiety and depression than controls, 49.1% and 33.3% had mild to moderate and high burdens, and females were more affected

[160,40]. Our study found that carer stress and observing chronically ill loved ones can promote depression and anxiety. Few carers seek therapy, therefore this study helps.

Our study reveals the significant chronic burden, depression, and reduced quality of life experienced by caregivers of dialysis patients, highlighting these often-underreported challenges. Caregivers frequently prioritize the patient's health over their own, emphasizing the need for targeted support and assistance for these individuals facing significant morbidities. However, limitations arose due to the COVID-19 pandemic, preventing us from reaching our intended sample size of 267, which would have provided more robust data for analyzing caregivers' issues. Additionally, conducting the study in a tertiary healthcare setting may limit its generalizability to the broader community. Looking forward, future research could investigate the relationship between the functional status of hemodialysis patients and caregiver burden, aiding in tailored support based on illness severity. Furthermore, extending the study to include interventions for psychiatric morbidity among caregivers could be beneficial, with pre- and post-intervention evaluations enhancing coping strategies and long-term resilience. These future directions aim to improve care strategies and outcomes for caregivers navigating the challenges of chronic illness management.

V. CONCLUSION

The dialysis unit carers at a tertiary care hospital were studied to assess carer load, psychological morbidity, and quality of life among maintenance hemodialysis patients. The findings revealed that hemodialysis carers undergo significant hardship, report poor quality of life, and experience anxiety and sadness. The study identified higher levels of depression, somatic symptoms, and burden among women and individuals aged 35-60. Furthermore, quality of life showed a notable negative correlation with burden.