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Psychological Morbidity, Burden, and Quality of Life Among Caregivers of Dialysis Patients: A Cross Sectional Study in a Tertiary Care Hospital, Kanchipuram District

Niranjan Babu Mudduluru*1, Sirisha Stephen2, Musharaf Shaik3

^{1,3}Department of Pharmacognosy, Seven Hills College of Pharmacy, Tirupati, A.P., India ²Department of Pharmacy Practice, Seven Hills College of Pharmacy, Tirupati, A.P., India

Corresponding Author Dr. M. Niranjan Babu

Professor, Department of Pharmacognosy, Seven Hills College of Pharmacy, Tirupati, A.P., India – 517561, Contact: 7702484513, Email: principal.cq@jntua.ac.in

INTRODUCTION

Chronic renal failure (CRF) refers to progressive and irreversible kidney dysfunction that impacts a significant number of people globally, posing substantial public health challenges associated with morbidity and mortality rates. Hemodialysis stands as the predominant treatment for CRF worldwide [1]. However, the challenges and limitations of dialysis often lead to various psychological issues among patients [2]. These include feelings of melancholy, anxiety, low self-esteem, dependency, fatigue, infertility, sexual dysfunction, bone complications, anemia, and frequent hospitalizations due to cardiovascular and gastrointestinal problems. Long-term hemodialysis also affects family members, causing them psychological, social, and cultural challenges [3].

As dialysis patients age [4], they face increased risks of physical, cognitive, and emotional decline [5]. This decline is exacerbated by underlying conditions such as diabetes, hypertension, cardiovascular risks, pulmonary and skeletal issues, and multiple metabolic disturbances [6], which impair their mobility and self-care abilities. Therefore, elderly dialysis patients require comprehensive care from healthcare professionals, spouses, parents, siblings, friends, and dedicated volunteers who provide emotional support [7].

Family serves as the primary source of care for dialysis patients, upon whom many depend. Family caregivers play a crucial role for elderly individuals, with approximately 36 million people worldwide providing unpaid care to a 65-year-old family member, predominantly spouses or adult children. These caregivers typically dedicate over 20 hours per week to caring for elderly relatives [8]. According to the 2000 World Health Report, health promotion programs aim to extend lifespan and alleviate symptoms of mortality and disease, with a focus on enhancing happiness. Quality of life is intricately linked to conditions that threaten physical and mental health.

The anguish and challenges faced by hemodialysis patients hinder their daily activities and ability to perform routine tasks [9]. This suffering ranges from temporary psychological and physical discomfort to profound sadness, progressing through stages from severe



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disappointment to indifference [10]. Chronic diseases impact both patients and their primary caregivers. Caregivers of hemodialysis patients often experience feelings of being overwhelmed as they support their loved ones, spending considerable time on caregiving tasks, which can lead to exhaustion and burden.

Studies, such as those by Mehrer-Imhof et al., have shown that the quality of life of caregivers significantly influences the well-being of patients. Habibzade et al. found that 52% of caregivers reported moderate to low quality of life, with 60% expressing dissatisfaction with their self-care. Additionally, 85% of caregivers felt that social support was inadequate, and 67.5% lacked recreational activities. Several studies have highlighted how disease progression in patients affects caregivers' physical well-being, which in turn impacts the health and quality of life of patients.

Given the challenges faced by caregivers of patients with chronic illnesses, including the prolonged course of kidney failure and complications associated with hemodialysis, there is a critical need to assess the emotional and psychological well-being of caregivers, who are at higher risk for these issues.

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 included 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.



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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		

The table displays demographic and socioeconomic characteristics of caregivers and patients across several categories, including age group, gender, marital status, education, and occupation. Caregivers predominantly fall within the age ranges of 31-40 and 41-50 years, whereas patients span a broader spectrum from younger to older age groups, with a notable concentration in the 31-60 age brackets.

Regarding gender, there are more female caregivers compared to male caregivers, while among patients, there is a higher representation of males. Marital status indicates that a significant majority of caregivers are married, whereas patients exhibit a diverse range including unmarried, divorced, separated, and widowed individuals.



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Educationally, caregivers display varying levels of education, with a substantial proportion having completed up to the 10th and 12th grades. Patients' educational distribution mirrors that of caregivers.

In terms of occupation, the majority of caregivers are employed across sectors such as business, skilled and unskilled work, and administration. In contrast, a larger proportion of patients are not employed.

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 the severity scoring from PHQ-9, the majority of caregivers experienced mild depression (105), followed by moderate (55) and minimal depression (51). Assessing PHQ-15 severity, low severity was observed in 137 cases, medium severity in 65 cases, minimal severity in 47 cases, and four cases exhibited high severity. Regarding the Family Burden Interview Schedule (FBIS) scores among caregivers, a higher number showed moderate burden (71.5%), followed by severe burden.

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



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CONCLUSION

This study examined caregivers at a tertiary care hospital's dialysis unit to evaluate their burden, psychological well-being, and quality of life concerning maintenance hemodialysis patients. The results indicated that caregivers of hemodialysis patients face considerable challenges, exhibit lower quality of life, and suffer from anxiety and depression. The research highlighted elevated levels of depression, somatic symptoms, and burden, particularly among women and individuals aged 35-60. Moreover, it revealed a significant negative correlation between quality of life and burden.

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