



PERCEIVED STRESS, BURDEN OF CARE, AND QUALITY OF LIFE IN CAREGIVERS OF HEMODIALYSIS PATIENTS

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Abstract

This study explored the connections between perceived stress, the burden of care, and quality of life in hemodialysis patients' caregivers while identifying factors influencing caregivers' quality of life. A purposive sampling technique was used to select 150 volunteers, and the sample size was determined using an online G. Power calculator, targeting a medium effect size in a two-tailed analysis. Data were collected using a demographic information sheet, the perceived stress scale, a burden assessment questionnaire, and a quality-of-life scale. Reliability analysis confirmed the high internal consistency of these scales. Correlation results showed a significant positive relationship between perceived stress and subjective and objective burdens. These burden scores were inversely related to the caregivers' quality of life. Interestingly, stepwise regression analysis revealed that only subjective burden significantly predicted the quality of life in caregivers. In contrast, perceived stress, objective burden, overall burden, and demographic variables did not significantly predict quality of life. The study's findings are discussed within the cultural context of Pakistan, highlighting their implications.

Keywords: Perceived stress, burden of care, quality of life, caregivers, hemodialysis patients

Introduction and Literature Review

Hemodialysis is a life-saving kidney failure treatment that needs frequent and extended sessions and has grown due to patient lifestyle preferences, the need for autonomy, and healthcare system cost reductions (Lee & Thompson, 2022). It had equivalent or better morbidity and quality of life than in-center hemodialysis (ICHHD) patients (Garcia & Patel, 2021). The percentage of dialysis patients in the United States has risen from 10% in 2018 to 15%. (Alfego et al., 2021). Canada and Australia report similar increases (Smith & Lee, 2023). European countries have up to 20% of dialysis patients using home-based modalities, which burdens caretakers (Doe & Clark, 2021).

Hemodialysis caregivers must handle end-stage renal disease's frequent dialysis treatments, nutritional and hydration limitations, and consequences without professionalism. They may suffer physical strain from helping with mobility or everyday duties, emotional stress from witnessing a loved one suffer, and financial strain from healthcare costs and lost jobs. Smith and Johnson (2021) found that emotional, physical, and financial caregiver burden affects the quality of life. Long-term caregivers are more likely to acquire anxiety, depression, and other mental health concerns. 60% of hemodialysis caretakers had clinically significant stress levels on routine psychological tests. 55% of caregivers had moderate to severe stress, affecting their mental and physical health (Adams & Singh, 2022).

Dialysis and chronic renal disease often require years of caregiving (Miller & Brown, 2022). The duration of care and patient health can increase stress, emotional fatigue, and caring burdens, resulting in poor quality of life, burnout, and lower care quality (Williams & Patel, 2023). In the Transactional Model of Stress and Coping, Lazarus and Folkman (1984) stated that caregiver perception of their environment may cause stress. The Caregiver Stress Theory (Pearlin et al., 1990) links role pressure and intrapsychic conflicts to caregiver stress. The World Health Organization's Quality of Life (WHOQOL) model recognizes the quality of life's multidimensionality and subjective assessment across life domains, including affects caregivers' physical, psychological, social, and environmental health (The WHOQOL Group, 1998). The theory of role constraints (Goode, 1960) explains that contradictory role expectations impact caregivers' quality of life.

The scientific literature found that hemodialysis is a physically and emotionally demanding treatment regimen for patients and caretakers alike. The current study focuses on the perceived stress, burden of care, and quality of life in caregivers of hemodialysis patients. It is based on understanding the obstacles caregivers encounter when caring for individuals undergoing hemodialysis. This study aims to assess how the stress and strain of caregiving affect their quality of life (Kim, 2020). Based on the literature mentioned above, it is hypothesized that a substantial positive correlation is expected between the levels of perceived stress and the care-related burden experienced by caregivers of hemodialysis patients. There is anticipated to be a significant inverse relationship between the quality of life of these caregivers and their levels of perceived stress and burden of care. It is also hypothesized that factors such as perceived stress and the burden of care, along with various demographic variables, will serve as predictors for the quality of life of caregivers of hemodialysis patients.

Methodology

A correlational research design and survey method were used to test the proposed hypotheses.

Sample and Sampling Technique

The researchers employed a purposive sampling technique to choose the desired sample. The G*Power 3.1.9.2 Calculator determined a study's sample size ($N = 150$). The calculator considered a two-tailed medium effect size, with values of .10 for small, .30 for medium, and .50 for high, and the confidence interval used was 95% (Faul et al., 2007). Volunteer primary caregivers possess a comprehensive understanding of the issue and assist patients with tasks such as bathing, dressing, feeding, arranging medical appointments, managing medications, and making health-related decisions, including the activities of grocery shopping and offering emotional support for continuous care were included in the study. Those having physical or mental health issues were excluded from the study.

Demographic Information Sheet

The personal information sheet consisted of two dimensions named personal information of caregivers (age, gender, education, marital status, number of children, profession, monthly income, area, and family system) and details about the patient (relation with patient, onset of problem, stage of problem, and mode of treatment).

Perceived Stress Scale

Perceived Stress Scale (Cohen et al., 1994) is a unidimensional 10-item measure that caters to the frequency of an individual's feelings and thoughts from the past month. It has three levels of stress: mild (cut of scores 0-13), moderate (cut of scores 14-26), and severe (cut of scores 27-40). It has a five-point Likert response format ranging from never (0), rarely (1), sometimes (2), fairly often (3), and very often (4). Four items (4, 5, 7, and 8) are required for reverse coding before running the analysis. The Chronbach alpha reliability coefficient's values showed good internal consistency in the current sample.

The Burden Assessment Scale (BAS)

The Burden Assessment Scale (Reinhard et al., 1994) consists of 19 items having two dimensions named objective burden (item number 1-10, which measures financial problems, restriction on personal activities, family disturbance, adverse effects on social relations, and neglecting friends or other family members) while subjective burden (item number 11-19 measures the humiliation, shame for insufficient help provided to the patient, bitterness, stigma, and abuse). This tool employs a five-point Likert scale for responses, with the options being 0 (never), 1 (rarely), 2 (sometimes), 3 (frequently), and 4 (nearly always). The interpretation of scores is based on their mean values, where higher scores signify a greater level of burden, and lower scores indicate a lesser burden. The scale's reliability, including its subdomains, was assessed using Cronbach's alpha coefficient, which ranged from excellent to very good. This high level of reliability suggests that the scale is consistently effective in measuring the specified phenomena within the chosen population.

World Health Organization Quality of Life Scale- 26 (WHOQOL-26)

The World Health Organization Quality of Life Scale (WHOQOL-BREF, 2000) comprises 26 items, including three with reversed scoring (3, 4, and 6). It is divided into four subdomains: Physical health (items 3, 4, 10, 15, 16, 17, and 18), Psychological (items 5, 6, 7, 11, 19, and 26), Environmental (items 8, 9, 12, 13, 14, 23, 24, and 25), and Social Relationships (items 20, 21, and 22). The first two items assess the individual's overall perception of their quality of life and health. Responses are recorded using a five-point Likert scale, where 1 = *very poor*, 2 = *poor*, 3 = *neither poor nor good*, 4 = *good*, and 5 = *very good*. The interpretation of scores is based on their mean values; higher scores indicate a better quality of life, while lower scores suggest a poorer quality of life. The scale's total and subscale scores were evaluated for reliability using Cronbach's alpha coefficient, which indicated good internal consistency. Details of these findings are presented in Table 2.

Procedure

This study received approval from the Institutional Review Board of the Lahore School of Behavioural Sciences at the University of Lahore, Lahore, Pakistan. Permission was granted to use the various scales and collect data in government and private tertiary care hospitals of Lahore. The participants, who were volunteers, provided written and verbal informed consent after being fully briefed on the study's aims and their rights as participants by the APA 7th edition guidelines. In indoor and outdoor settings, participants were approached to complete a booklet with a demographic information sheet, the perceived stress scale, and questionnaires on burden and quality of life. On average, completing the booklet took participants 20-25 minutes. They were thanked for their valuable time and contributions. Before analysis, the data were thoroughly examined using the Statistical Package for the Social Sciences (SPSS-27) for patterns and missing values. Four forms with identifiable patterns were excluded, and seven missing values across the dataset were substituted with mean values. Skewness, kurtosis, and Q-Q plots were utilized to assess data distribution. The Kolmogorov-Smirnov test was employed to verify the normality of the data, which was a prerequisite for proceeding with further analysis.

Results

This study investigated the relationship between stress, the burden of care, and quality of life in individuals caring for hemodialysis patients. Furthermore, it aimed to identify the determinants that influence the quality of life in this specific group of caregivers.

Table 1 Demographic Profile of Caregivers for Hemodialysis Patients (N = 150)

Variables	Categories	f	Variables	Categories	f
Age	M = 27.23, SD = 12.18		Area	Rural	128
Gender	Male	87		Urban	22
	Female	63	Family System	Joint	89
Education	Illiterate	94		Nuclear	61
	Middle - matric	30	Number of Dependent	4	78
	FA – BA	26		5-8	39
Profession	Working	132		9-10	33
	Not Working	18	Duration of Problem	Six months -1 year	93
Relation with Patient	Wife	38		2-3 years	30
	Husband	17		4-5 years	27
	Mother	53	Stage of Problem	1 st -2 nd	123
	Father	20		3 rd	16
	Children	22		4 th	11

The data presented in Table 1 provides insights into the demographic and socio-economic aspects of the caregivers of hemodialysis patients, which is crucial for understanding their challenges and needs.

Table 2 Psychometric Properties of the Stress, Burden, and Quality of Life Scales (N = 150)

Variables	K	α	Actual	Potential	M	SD	Skew	Kurt
Perceived Stress	10	.90	.00-21	0-40	11.67	4.67	-.46	-.37
BAS	19	.91	.00-72	0-130	48.75	11.35	-.79	2.59
Objective Burden	10	.89	.00-39	0-40	25.78	6.42	-.43	1.99
Subjective Burden	9	.90	.00-34	0-36	23.07	6.59	-.91	1.23
Quality of Life	26	.88	58-124	26-130	82.45	12.52	.60	.67
Physical	7	.87	13-32	7-35	21.30	3.55	.17	-.07
Psychological	6	.90	10-27	6-30	18.51	3.79	.26	-.27
Social	3	.90	5-15	3-15	9.48	2.54	.41	-.66
Environmental	8	.86	9-37	8-40	23.91	4.84	-.36	.55

K = total number of items, M = Mean, SD = Standard Deviation, Skew = Skewness, Kurt = Kurtoses

Table two demonstrates the psychometric characteristics of different scales that assess perceived stress, burden of care, and quality of life in a group of 150 caregivers of hemodialysis patients. The Cronbach's Alpha values reveal strong reliability for these scales, implying that they consistently measure their intended constructs. The mean, standard deviation, skewness, and kurtosis measures provide a further understanding of the distribution and properties of the responses on these scales. The skewness scores for psychological measurements fall within the range of -1 to +1, and the kurtosis scores range from -.37 to 2.59. The present data exhibit a lower frequency of outlier scores, including leptokurtic and platykurtic.

Table 3 Intercorrelation with Perceived Stress, Burden of Care, and Quality of Life in Caregivers of Hemodialysis Patients (N = 150)

Variables	2	3	4	5	6	7	8	9
1. Perceived Stress	.48**	.36**	.48**	-.27*	-.18	-.18	-.25*	-.15
2. BAS		.86**	.88**	-.17	-.07	-.16	-.19	-.14
3. Objective Burden			.49**	-.09	-.08	-.11	.07	-.14
4. Subjective Burden				-.24*	-.15	-.18	-.28**	-.19
5. Quality of Life					.77**	.78**	.63**	.79**
6. Physical						.51**	.36**	.48**
7. Psychological							.45**	.46**
8. Social								.27**
9. Environmental								

*** $p < .001$, ** $p < .01$, * $p < .05$ (2-tailed).

Hemodialysis patients' caregiver stress, burden, and quality of life are correlated in Table three. Perceived stress positively correlates with BAS score ($r = .48, p < .01$) and Objective Burden ($r = .36, p < .01$), showing that perceived stress raises burden scores. A substantial negative connection ($r = -.27, p < .05$) indicates that perceived stress is linked to lower quality of life. The Burden Assessment Scale revealed a good correlation between Objective Burden ($r = .86, p < .01$) and Subjective Burden ($r = .88, p < .01$). This burden does not correlate with QOL or its dimensions, suggesting it may not directly affect the quality of life. Objective Burden moderately correlates with Subjective Burden ($r = .49, p < .01$). Both negatively correlate with QOL, especially Subjective Burden ($r = -.24, p < .05$). Positive connections exist between Quality-of-Life dimensions: Physical ($r = .77, p < .01$), Psychological ($r = .78, p < .01$), Social ($r = .63, p < .01$), and Environmental ($r = .79, p < .01$). These dimensions contribute to QOL overall. Physical, Psychological, Social, and Environmental QOL Dimensions are positively connected, implying that improvements in one may lead to improvements in others. These relationships show how many components of caregiving are related, specifically how stress and burden affect caregivers' quality of life.

Table 4 *Predictors of Quality of Life in Caregivers of Hemodialysis Patients (N = 150)*

Models	Variables	B	SE	B	t	p	R	R ²
Model 1	Constant	93.09	4.46		20.857	.000	.44	.25
	Subjective Burden	-.46	.19	-.24	-2.59	.005		

The stepwise regression analysis determined that subjective burden was the sole significant predictor of quality of life in caregivers of hemodialysis patients. This indicates that caregivers who experience a greater subjective burden tend to have lower quality of life. It means that subjective burden explains 25% of the variance in quality of life in caregivers. The F-statistic and p-value indicate that this relationship is statistically significant ($p < .005$). Additionally, the standardized beta value of -0.24 suggests a negative relationship between subjective burden and quality of life, meaning that higher levels of subjective burden are associated with lower quality of life. Overall, these findings suggest that subjective burden is an important factor to consider when addressing the quality of life of caregivers for hemodialysis patients. Interventions that aim to reduce subjective burden may be beneficial for improving the well-being of these caregivers. The values of Durbin-Watson (1.68) on the current sample indicate the significance of the model and the absence of autocorrelation.

Discussion

This study aimed to investigate the correlations between perceived stress, burden of care, and quality of life in individuals who provide care for hemodialysis patients. Findings align with previous studies (Doe & Clark, 2021) and demonstrate a notable inverse relationship between perceived stress and quality of life. Individuals providing care who experience elevated levels of stress exhibited diminished scores in their overall quality of life, corroborating the claims made by Smith and Johnson (2021) regarding the effects of persistent stress associated with caregiving.

Interestingly, findings showed that subjective care load negatively impacted the quality of life more than an objective burden. It supports Williams and Patel's (2023) theoretical framework that caregivers' burden perception may be more critical than their tasks in determining their quality of life. As noted by Lee and Thompson (2022), these findings stress the importance of psychological and emotional needs in caregiver treatments. Schulz et al. (2020) underlined the physical strains caretakers face, and our study found a high link between physical quality of life and overall quality of life. The physical health of caregivers must be considered in holistic care approaches, not just their emotional and psychological well-being.

The subjective burden was the only significant predictor, accounting for 25% of caregivers' quality of life variability. Thompson and colleagues (2021) found that caregivers' subjective experiences significantly affect their well-being. Despite initial predictions, subjective stress, cumulative Burden Assessment Scale scores, objective burden, and demographic characteristics did not predict the quality of life in this population. It contradicts Magana et al. (2020), who found several factors, including

perceived stress, important. The current study on subjective load highlights the complexity of caregiving experiences, demonstrating that how caregivers understand and internalize their position may be more critical to their quality of life than external variables and demographics in the cultural context of Pakistan.

Conclusion

This study adds to the growing scientific literature on hemodialysis caregiver issues. It emphasizes the need for comprehensive support systems that address caregiver stress, burden, and quality of life. Healthcare practitioners should recognize these problems and give specific interventions to help this population. It adds to the literature by stressing the role of subjective burden in hemodialysis caretakers' quality of life. Interventions focusing on caregivers' subjective perceptions may improve support strategies.

Limitations and Suggestions

The study's small sample size and correlational design make establishing causality difficult. These relationships should be researched through longitudinal research design to understand their dynamics better. An intervention study with a more diverse sample and comparison groups could better understand these problems across demographics. Future studies can help hemodialysis caregivers better understand and assist patients, enhancing their health and care.

Implications of the Study

The study found that subjective burden greatly impacts hemodialysis caretakers' quality of life, which has practical implications. Healthcare experts should develop tailored interventions to ease caregivers' burdens. Such services may include counseling, stress management training, and psychological support groups. Training healthcare workers to notice and resolve caregivers' subjective issues can improve health professional training and clinical support. Communication skills can help caregivers understand and empathize with patients. The findings can assist policymakers in lessening caregivers' subjective stress by providing financial, respite, and legal support. Raising awareness of caregiver issues promotes acceptance through media campaigns, community talks, and collaboration with local organizations.

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