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Original Paper

Psychological Burden of Chronic Kidney Disease Caregivers

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Introduction. Caregiver roles and responsibilities in chronic kidney disease (CKD) patients have pervasive effects on the physical, social, and emotional well-being of caregivers, yet these issues are often under-prioritized in medical management. This study assessed depression, anxiety, burden, and quality of life (QOL) in caregivers of CKD patients.

Methods. Caregiving burden, quality of life, depression, and anxiety were assessed using the Zarit Burden Interview (ZBI), SF-36 QOL questionnaire, Beck Anxiety Inventory, and Beck Depression Inventory, respectively, among caregivers of CKD patients on maintenance hemodialysis (HD), peritoneal dialysis (PD), and kidney transplantation (TX).

Results. The study groups consisted of 100, 105, and 62 caregivers among PD, HD, and TX patients, respectively. The mean scores of depression, anxiety, and burden in all caregivers were 13.44 (SD 11.57), 15.77 (SD 12.49), and 13.33 (SD 9.51), respectively. More than 40% of caregivers had depression, while 68.5% reported moderate to severe anxiety. Although anxiety, depression, and burden did not differ significantly across the three groups, the physical function scores of caregivers of PD patients were significantly better than those of the other groups ($P = .033$). Caregivers with higher depression, anxiety, and burden scores had significantly lower scores in both physical ($P < .001$, $P < .001$, $P = .022$) and psychological health (all $P < .001$) domains of QOL. Sex and education had a strong influence on depression, anxiety, burden, and QOL.

Conclusion. Caregivers of CKD patients, especially females with lower education, are at increased risk of psychological burden. Early screening for mental health issues in caregivers, along with supportive interventions, should be incorporated into treatment guidelines for CKD patients.

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INTRODUCTION

Chronic Kidney Disease (CKD) is characterized by a progressive loss of kidney function and classified into five stages by the KDOQI (Kidney Disease Outcomes Quality Initiative) guideline.[1] End-stage kidney disease (ESKD) is the final stage of kidney failure necessitating long-term dialysis or kidney transplantation for affected patients.[2] It represents a global health concern with substantial economic impact. Patients with ESKD are frequently lack the mental [3] and/or physical capacity to manage their treatment, making caregiver support essential.[4]

As the prevalence of ESKD increases, the burden on caregivers —both within families and across health systems —is increasing.[5]

Caregivers are involved in caring for patients and helping them during their time of illness. They experience a burden that intensifies with patients' functional or cognitive decline. Contributing factors include the caregiver–patient relationship, patient's psychological symptoms, caregiver sex, and adverse life events.[3,4] Caregiving for chronic illnesses involves managing medical, dietary, and psychosocial needs, and is associated with depression, anxiety, poorer physical health, impaired quality of life (QOL), social isolation, relationship strain, financial hardship, and even higher mortality among strained caregivers.[6-11] Burden is particularly high when managing home dialysis for adults or children,[12,13] yet caregivers' needs are often overlooked in CKD care.[14]

Caregiver burden (CB) reflects the perceived decline in emotional, physical, social, and financial well-being due to caregiving.[14] Reported predictors include female sex, anxiety, depression, poor health, longer caregiving hours, low socioeconomic status, and distance from dialysis centers, while social support and stronger family relationships may be protective.[15-17] Variability across studies suggests cultural factors may influence CB, warranting further research.[18-20]

Recent studies show that caregivers of CKD patients experience impaired QOL, like caregivers of other chronic diseases, though generally better than patients themselves. QOL did not significantly differ across dialysis modalities.[19,21] Factors influencing caregiver QOL include age, sex, social support, burden of care, comorbidities, coping strategies, marital relationship quality, and type of patient treatment.[20,22]

Understanding caregiver characteristics and their relationship to burden and QOL is critical for designing interventions that reduce adverse outcomes for patients and caregivers. This study aims to investigate the effects of depression, anxiety, and burden on caregivers' QOL in three CKD groups: kidney transplant recipients, hemodialysis, and peritoneal dialysis patients in Iran.

MATERIALS AND METHODS

Study participants

This cross-sectional study was performed in Shahid Modarres Educational Hospital, affiliated with Shahid Beheshti University (SBMU), Tehran, Iran. A total of 327 Iranian subjects were recruited from the hospital's dialysis center from March to October 2018, of which 267 caregivers (87 males and 180 females) completed the study. The study groups consisted of 100, 105, and 62 caregivers for (i) patients who underwent peritoneal dialysis, (ii) patients who underwent hemodialysis, and (iii) patients who underwent kidney transplant, respectively.

The inclusion criteria for caregivers across all three study groups were as follows: providing care for the patient for more than six months, serving as the primary caregiver, having no history of psychological disorder or medical disease for at least two months before starting the study, and an age range between 20 and 75 years old. All transplanted patients received organs from living unrelated donors.

Measures

Depression, anxiety, caregivers' burden, and quality of life were assessed using the Beck Depression Inventory-II (BDI-II), Beck Anxiety Inventory (BAI), Zarit Burden Interview (ZBI), and the 36-Item Short Form Health Survey (SF-36), respectively.

The BDI-II consists of 21 items scored 0–3, yielding a total score of 0 to 63. Cut-off points are: minimal (0–13), mild (14–19), moderate (20–28), and severe (29–63) depression.[23] The Persian version has shown high internal consistency (Cronbach's $\alpha = 0.87$) and good test–retest reliability ($r = 0.74$).[24]

The BAI is a 21-item scale with scores ranging from 0 to 63. Cut-off points are: minimal (0–7), mild (8–15), moderate (16–25), and severe (26–63) anxiety.[25] The Persian version demonstrates excellent reliability (Cronbach's $\alpha = 0.92$).[26]

The ZBI consists of 22 items, yielding a total score of 0 to 88. Severity is classified as little/no burden (0–20), mild-to-moderate (21–40), moderate-to-severe (41–60), and severe (61–88).[27,28] An Iranian validation reported acceptable reliability (Cronbach's $\alpha = 0.77$).[29]

SF-36 measures health-related quality of life across 8 domains, summarized into physical and mental component scores. Reliability coefficients typically exceed 0.80.[30] The Persian version has demonstrated good reliability (Cronbach's $\alpha = 0.87$)

and acceptable construct validity.[31]

RESULTS

A total of 327 caregivers of CKD patients participated in the study. The mean age of caregivers was 43.01 years, and most were female (66.8%) and married (74.9%). Over half possessed a high school diploma or higher. The patient cohort were predominantly consisted of males (65.7%), with treatment modalities comprising hemodialysis, peritoneal dialysis, and transplantation (Table 1).

The mean scores for caregivers were 13.44 (SD = 11.57) for depression, 15.77 (SD = 12.49) for anxiety, and 13.33 (SD = 9.51) for burden. In total, 41.9% of caregivers experienced depression, and 68.5% reported anxiety, with 42.5% exhibiting moderate to severe anxiety.

While anxiety, depression, and burden did not differ significantly across treatment groups, caregivers of peritoneal dialysis patients reported higher quality of life scores, and those of hemodialysis patients had lower scores, significantly so for the physical health component ($P = .033$) (Table 2). Higher depression, anxiety, and burden scores were strongly associated with lower physical and psychological quality of life (all $P < .05$).

Education and sex were significant predictors of caregiver outcomes: caregivers with at least a high school diploma had lower depression, anxiety, and burden and higher physical and psychological quality of life (all $P < .001$). Female caregivers had higher depression and lower psychological quality of life than males, with significantly lower scores in emotional well-being, energy, and emotional role, and higher pain scores. Married caregivers experienced a higher burden than single caregivers ($P = .009$).

Caregiver–patient relationship also influenced outcomes: parents and spouses reported the highest burden and depression, whereas siblings and children reported lower levels. Age impacted anxiety and physical health, as older caregivers reported higher anxiety and lower physical health scores. Income was not significantly associated with psychological outcomes($P > .05$), though higher income correlated with better physical quality of life ($P = .00$) (Table 3).

DISCUSSION

Increasing evidence indicates that caregiving responsibilities significantly impact caregivers' physical and mental health. Therefore, it is essential to identify primary caregivers who are at higher risk of physical and psychological issues and to

Table 1. Demographic characteristics of caregivers

Variable	Caregivers (n = 267)	Patients (n = 318)
Mean age (years, SD)	43.01 (14.42)	47.32 (19.57)
Gender, n (%)	Female: 178 (66.8) Male: 209 (65.7)	-----
Marital status, n (%)	Married: 200 (74.9)	-----
Education (≥ high school)	61.10%	-----
Relationship to patient	Spouse: 38%, Child: 39.9%, Parent: 15.6%	-----
Salary (USD/month)	< 1000 (USD): 69.1% 1000–2000 (USD):23.5% > 2000 (USD): 7.4%	-----
Treatment type (patients)		HD: 123, PD:122, TX: 73

HD: Hemodialysis; PD: Peritoneal dialysis; TX: Transplant.

Table 2. Depression, Anxiety, Burden and QOL among CKD caregivers regarding treatment modalities

	Groups			
Inventory	PD	HD	TX	*P*
Beck Depression	15.98	17.18069	18.6800	.554
Beck Anxiety	13.5345	17.481	15.5385	.200
Zerith Burden	15.1111	16.4156	16.7843	.664
QOL Physical	2.5671	2.1273	2.2466	.033
QOL Psychological	2.1552	1.9744	2.0030	.433

PD: Peritoneal dialysis; HD: Hemodialysis; TX: Transplant.

Table 3. Relationships between caregiver demographics, dialysis modality, and psychosocial outcomes in caregivers of CKD`s patients

Variable	Findings
Dialysis modality	No significant difference in depression, anxiety, burden; QoL is better in PD vs HD; significant for physical health (P = .033).
Depression/Anxiety/Burden vs QoL	Higher depression, anxiety, and burden significantly lower physical & psychological health components (all P < .001, except burden–physical P = .022).
Education	≥ High school diploma lower depression (11.05; P = .001), anxiety (13.19; P < .001), burden (11.48; P < .001), better total QoL, physical (2.24; P < .001), psychological (2.55; P < .001).
Gender	Females: higher depression (14.95; P = .002), lower psychological QoL (1.94; P = .008). Anxiety difference is nearly significant (P = .06). Lower emotional well-being, energy, emotional role; higher pain scores (all P < .001).
Marital status	Married caregivers: higher burden (14.00 vs 10.75; P = .009).
Relationship with patient	The highest burden is in parents (17.16), follow by spouses (14.47), children (10.00), and siblings (9.30). Depression: parents (15.46), spouses (15.23), children (11.67), siblings (6.60). Significant differences in burden (P < .001), depression (P = .025), and social function of QoL (lowest in spouses).
Age of caregiver	Older caregivers: lower physical health (1.74) and higher anxiety (22.47; P = .002, P < .001).

PD: Peritoneal dialysis; HD: Hemodialysis; TX: Transplant. QOL: Quality of life.

address their needs accordingly.[32]

This study demonstrated that caregivers experienced considerable levels of depression, anxiety, and burden, with more than half suffering from moderate to severe anxiety. Importantly, caregivers with higher levels of anxiety, depression, or burden reported poorer QOL (all $P < .001$). A 2018 systematic review showed that caregivers generally experience significant burden and poorer QOL, although depression rates were not consistently elevated.[33] However, studies using categorical outcomes reported depression rates between 34.7% and 55%, and less frequently used scales showed significant impairment in QOL.[33]

In this study, younger caregivers, those with lower educational degree, and females had higher levels of anxiety. Married caregivers, had lower educational degrees, or were the spouse or parent of the patient reported greater burden. Female sex and lower educational level were also risk factors for depression (all $P < .001$).

No significant differences were found in anxiety, burden, depression, or QOL among caregivers of patients undergoing different treatment modalities (all $P > .05$). This finding is consistent with the Paschou study, which showed that disease severity (dialysis-dependent versus non–dialysis-dependent) did not affect caregiver burden, depression, or QOL. Paschou reported moderate burden scores (mean = 27.26); depression levels ranging from none to mild (mean HAD score = 5.64), and no indication of stress disorder (mean GAD score = 1.90). In contrast, our caregivers had a lower mean burden score (13.44) but higher levels of anxiety and depression. Differences may be attributed to sample characteristics, as Paschou's study exclusively included spouses, with both patients (mean age 65–66 years) and caregivers (mean age 60–63 years) being around 20 years older than those in our cohort.[34] In some studies, caregivers of patients who had a renal transplant had less depression, anxiety, and burden in comparison with caregivers of patients on hemodialysis or PD.[35,36]

Gilbertson's review of 61 studies found that most caregivers were female spouses, most often caring for recipients of facility-based hemodialysis (72.3%) or peritoneal dialysis (20.6%). The QOL of caregivers was poorer than that of the general population but comparable to that of caregivers for patients with other chronic diseases, and often superior to the QOL of dialysis patients themselves. The QOL was comparable among dialysis modalities.[33] In our study, the physical health component of QOL was significantly lower in caregivers of hemodialysis patients compared with the other two groups, whereas Sajadi's review reported that caregivers of hemodialysis patients showed more impairment in mental rather than physical QOL.[37]

Our caregivers reported mild to moderate burden, consistent with findings from other studies showing that caregivers of patients with ESKD experience significant burden regardless of country.[38] Burden levels are influenced by a wide range of factors, including socio-demographic characteristics of caregivers and patients, disease-related and caregiving-related factors, environmental circumstances, and psychological aspects. Some factors appear relatively consistent across studies, while others remain inconclusive.[38] In our study, marital status, relationship with the patient, education, and patient age significantly affected caregiver burden. A systematic review reported that 27 of 38 studies explored age as a predictor of caregiver burden (CB).[38] Some studies found no relationship between caregivers' sex and burden, while others showed that female caregivers experienced greater burden.[38] In our study, female caregivers did not report more burden, but they did have higher levels of anxiety, depression, and poorer psychological health. In addition, they reported worse emotional well-being, emotional role functioning, energy, and significantly more pain than male caregivers. These differences may reflect the multiple roles and responsibilities of women caring for chronically ill patients, as well as their greater emotional involvement and less effective coping strategies along with a higher proportion of female caregivers than male caregivers in our study, which may limit the generalizability of gender comparisons. Future studies with more balanced gender distributions are needed to confirm these findings.

Some studies have found that spousal caregivers experience higher CB than caregivers with other types of relationships, while others reported high CB in parents.[38] Conversely, several studies suggested that relationship types do not predict CB.[38] In our study, spouses and parents had higher burden and poorer social functioning, which may be explained by cultural differences.

The times spent providing care (hours/day), the caregiving duration, duration and the severity of patients' disease and associated caregiving demands, and social supports are some important factors that we did not assess in this study.

CONCLUSION

This study highlights the significant psychological issues faced by caregivers of patients with chronic kidney disease, with high levels of anxiety, depression, and burden, particularly among younger, less educated, and female caregivers. Importantly, poorer mental health was closely linked with reduced quality of life. While treatment modality did not significantly affect caregiver outcomes, socio-demographic and relational factors played a major role. These findings underscore the need for early identification of at-risk caregivers and the provision of targeted psychosocial support to improve their well-being and sustain effective caregiving.

CONFLICT OF INTEREST

The authors of this manuscript have no conflicts of interest to disclose.

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