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Original Article

Caregiver Burden in Chronic Diseases: Role of Perceived Social Support and Duration of Care in Arthritis and Diabetes

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ABSTRACT

Objective: To assess the relationship between caregiver burden and perceived social support, and caregiver burden and caregiving duration of arthritis and diabetes, and to analyze gender differences.

Study Design: Cross-sectional study

Place and Duration of Study: Fatima Memorial Hospital, Combined Military Hospital Lahore, Pakistan, from Feb to Mar 2024

Methodology: The study comprised 388 caregivers of individuals with arthritis and diabetes. The data were distributed into four equal groups (n=97, 25% each): male caregivers of diabetes patients, female caregivers of diabetes patients, male caregivers of arthritis patients, and female caregivers of arthritis patients. Voluntary consenting caregivers partook in filling out the ZBI-22 and MSPSS questionnaires measuring caregiving burden.

Results: Out of 388 caregivers of arthritis and diabetes patients, a small negative correlation between caregiving burden and perceived social support ($r=0.27$, $p<0.05$), while caregiving duration had no significant effect on caregiving burden ($r=0.03$, $p>0.05$). The caregiving burden was higher for arthritis caregivers (Mean±SD 30.74 ±14.831) and female caregivers(Mean±SD= 29.20 ±14.91), while perceived social support was higher for diabetes (Mean±SD= 62.09±14.482) and female caregivers (Mean±SD= 61.92±14.42). Caregiving duration was higher for diabetes (Mean±SD= 4.48±1.87) and male caregivers (Mean±SD= 4.37 ± 1.88).

Conclusion: The study, conducted in Lahore, Pakistan, emphasizes the importance of disease-specific factors in caregiving, finding that greater perceived social support reduces caregiving burden, while caregiving duration has little effect. Caregivers of arthritis and female caregivers reported a higher burden than caregivers of diabetes and male caregivers. The study calls for comprehensive support systems and policies to assist caregivers.

Keywords: Arthritis, Caregiver Burden, Caregiving Duration, Diabetes, Perceived Social Support, Caregivers

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INTRODUCTION

For caregivers of chronic illnesses such as arthritis and diabetes, the availability of strong perceived social support is vital for mitigating stress and burden. The study aims to highlight the need for ongoing, long-term support interventions tailored to the specific needs of chronic disease caregivers. Measuring how social support and caregiving time affect burden among family caregivers of diabetes and arthritis patients is crucial and context-dependent. Their multifaceted role often leads to burnout and reduced social activities.[1] This stressful role causes negative health outcomes,[2] including physiological, psychological, and behavioral effects, which are influenced by caregiver age and gender.[3] The American Psychological Association defines caregiver burden as the stress and psychological symptoms experienced by family caregivers caring for individuals with physical or mental disabilities.[4] Unpaid family caregivers bear physical, emotional, financial, and social stress, significantly contributing to this burden.[3]

Arthritis and diabetes are exponentially increasing, indicating a growing need for informal caregivers. The World Health Organization concluded that out of 528 million people with osteoarthritis, 18 million people had rheumatoid arthritis in 2019. Akhter et al., reviewed that an increase of even 0.1% in arthritis prevalence rates in Pakistan and India could affect millions.[5] The International Diabetes Federation reported 463 million diabetes mellitus patients globally in 2019, with 32,964,500 individuals in Pakistan affected by diabetes in 2021, indicating a prevalence rate of 26.7%. Diabetes itself is not chronic, but it leads to complications that require complex caretaking.[6] Gender role shifts in recent years have garnered academic attention due to the complex interplay of factors, including caregiving duration and perceived social support.[7] Perceived social support,

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encompassing emotional, instrumental, and informational help from social networks, is critical in reducing caregiver strain for both genders.[8] Prolonged caregiving increases burden, with its impact and the effectiveness of social support differing by gender. Understanding caregiving dynamics is crucial for creating targeted interventions to support informal caregivers of chronic arthritis and diabetes patients.

In Pakistan, a notable research gap persists regarding caregiving burden in arthritis and diabetes, especially those focused on quantitative correlational studies examining the interplay between social support and caregiving duration. Additionally, this research seeks to uncover gender-based disparities among caregivers, further enriching the medical discourse.

METHODOLOGY

The study followed a correlational, cross-sectional research design. The research was approved by the Board of Studies and Ethics Review Committee (PSYC499-23-013). This was followed by approval from the Institutional Review Board (IRB-542/01-2024). Consent and IRB approval were obtained from relevant departments of Fatima Memorial Hospital (FMH-06/03/2024-IRB-1365) and Combined Military Hospital Lahore (511/2024). The study duration was from Feb to Mar 2024, and data were collected through a convenience sampling strategy. G power formula was used to calculate the sample size of caregivers of arthritis and diabetes for data collection in Lahore. In a study from Pakistan, the prevalence of psychological effects as a result of caregiving burden was 47.8%.[9]

Inclusion Criteria: Caregivers of any gender, aged 18 to 45 years, of patients with arthritis and diabetes were included in the study.

Exclusion Criteria: Caregivers of patients with terminal illnesses were not included due to ethical considerations. Family members or caregivers of patients who could self-manage their ailment were not included.

The caregivers were classified based on the time duration they devoted to the care of the patients (at least three hours daily) and gender. The data was collected by reaching out within the researcher's own extended family and friends circle, OPD of the rheumatology department of a medical center, and was also collected from the in-patient ward (soldiers and officers), gynecological in-patient ward, OPDs of the rheumatology department, and rehabilitation department of a tertiary care hospital. At the time of z data collection, participants were informed about the aims of the study, right to denial of participation, protection of data, and anonymity of participant and the consent of the participants was obtained.

Two scales were used to measure caregiving burden and perceived social support. Caregiving duration was based on the number of years of provided care and number of hours devoted to care daily.

The 22-item scale assesses the perceived impact of care provision to patients on the physical and emotional health, social activities, and financial situation of the informal family caregiver, which provides a holistic picture of the overall burden being. The scale measures five aspects of the caregivers' burden using five subscales, which are burden in the relationship, emotional well-being, social and family life, finances, and loss of control over one's life. The responses are measured on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always). A summation of the scores on the assessment should be between 0 and 88, where a score of 0 -21 indicates no to mild burden, 21-40 indicates mild to moderate burden, 41-60 moderate to severe burden, and 61 and above indicates severe burden.[10]

The Multidimensional Scale of Perceived Social Support (MSPSS) is rated on a 7-point Likert-type response format. The responses range from 1 (very strongly disagree) to 7 (very strongly agree). It aims to measure the perceived social support from social relationships of the caregiver during long-term and chronic medical illness of patient. The items are distributed into subscales based on the type of social support, i.e., items 1,2,5, and 10 measure social support from significant others, items 3,4,8, and 11 from family, and 6,7,9, and 12 from friends. Scores from each subscale are individually added and then divided by 4 for mean scores. For total scores, all [12] items are summed and divided by 12 to obtain a collective score.[11]

The time duration of caregiving was examined by drawing a timeline between the first time the caregiver started to look after the patient to current date. This data was collected in months and years. It was also explored approximately how many hours these caregivers dedicate to caregiving in a given day.

Data analysis was done using Statistical Package for Social Sciences (SPSS) version 25. To understand the relationship between the subscales of

Multidimensional Scale of Perceived Social Support and caregiver burden and caregiver duration and caregiver burden, Pearson's correlation coefficient was applied. Standard multiple regression analysis was used to determine the slope between the independent variables "social support" and "caregiver duration" and dependent variable "caregiver burden". Furthermore, independent samples t-test was conducted to determine the differences in caregiving burden between male and female caregivers of arthritis and diabetes.

RESULTS

Three hundred and eighty-eight caregivers of arthritis and diabetes, with a mean age of 29.65 years, were taking care of patients of arthritis and diabetes with a mean age of 57.38 years. The data was distributed into equal groups of caregivers of diabetes patients and caregivers of arthritis patients.

Descriptive statistics were used to calculate the distribution of gender in the sample. The sample was uniform with (n= 194, 48.3%) groups in two ways, dependent on caregiver's gender (male and female) and patient's disease (arthritis and diabetes). The data were distributed into equal groups (n=97, 25%) of male caregivers of diabetes patients, female caregivers of diabetes patients, male caregivers of arthritis patients, and female caregivers of arthritis patients.

The time devoted by the caregivers daily was around 8.90 hours. Among the three hundred and eighty-eight caregivers 43.8% (n= 176) of the caregivers had provided care for more than 5 years, 9% (n= 36) for less than 5 years, 8.7% (n= 35) for less than 4 years, 11,9% (n= 48) for less than 3 years, 12.7% (n= 51) for less than 2 years and 10.4% (n= 42) for less than a year.

Table-II: Regression Coefficients of Perceived Social Support and Caregiving Duration on Caregiving Burden (n=388)

	Caregivers of Diabetic Patients	**Caregivers of Arthritis Patients**	t(386)	*p*-Value	Cohen's d
Variables	Mean± SD	Mean± SD			
Caregiving Burden	26.43 ± 13.77	30.74 ± 14.83	2.97	0.09	0.301
Perceived Social Support	62.09 ± 14.48	61.11 ± 14.34	0.66	< 0.001	0.067
Caregiving Duration	4.48 ± 1.87	4.15 ± 1.93	1.72	0.51	0.173

The Zarit Caregiver Burden Interview (ZBI-22) measured the burden across five subscales which are burden in the relationship, emotional well-being, social and family life, finances and loss of control over one's life. The scale exhibited good reliability with Cronbach's alpha value of .884. Similarly, the Multidimensional Scale of Perceived Social Support (MSPSS) measured the social support of caregivers across three subscales. These included social support from significant other, family and friends. The scale exhibited excellent internal consistency with a Cronbach's alpha value of 0.898. The mean score for caregiver burden, as measured by the Zarit Burden Interview (ZBI), was Mean±SD = 28.57±14.45, while perceived social support, assessed using the Multidimensional Scale of Perceived Social Support (MSPSS), had a mean of Mean±SD = 61.60±14.40. Table-I indicates the relationship between caregiving burden and perceived social support, and caregiving burden and caregiving duration measured in months and years was evaluated. There was a small, significant negative correlation between caregiving burden and perceived social support (r=0.27, $p<0.05$); however, there was no significant correlation between caregiving burden and caregiving duration (r=0.03, $p>0.05$).

Table-I: Correlations between Caregiving Burden and Perceived Social Support and Caregiving Burden and Caregiving Duration (n=388)

Variables	**Mean ± SD**	**Caregiving Burden (r-value)**	**Perceived Social Support (r-value)**
Caregiving Burden	28.57 ± 14.45	-	
Perceived Social Support	61.60 ± 14.40	0.27	-
Caregiving Duration	4.32 ± 1.90	0.03	0.06

Table-II shows the impact of perceived social support and caregiving duration on the caregiving burden in the patients of diabetes and arthritis. The R2 value of 0.08 revealed that the predictor variables explained 8% variance in the outcome variable with F(2, 385) =15.659, $p<0.001$. The findings revealed that perceived social support negatively predicted caregiving burden ($\beta = 0.27$, $p<0.001$), whereas caregiving duration had a non-significant effect on caregiving burden ($\beta =0 .05$, $p> 0.05$). Table-III revealed that the caregiving burden was higher among the caregivers of arthritis than in caregivers of diabetes. The perceived social support was higher among the caregivers of diabetes than in caregivers of arthritis. Caregiving duration was higher among the caregivers of diabetes than in caregivers of arthritis. Table-IV revealed that the caregiving burden was higher among the female caregivers than in male caregivers. The perceived social support was higher among female caregivers than in male caregivers. However, caregiving duration was higher among male caregivers than among female caregivers.

Table -III: Mean Comparison of Caregivers of Diabetes and Arthritis on Caregiving Burden, Perceived Social Support, and Caregiving Duration

Variables	B	SE	t value	p-value	95%CI
Constant	46.94	3.59	13.08	< 0.001	39.88-53.99
Perceived Social Support	0.27	0.05	5.57	< 0.001	0.37-0.18
Caregiving Duration	0.34	0.37	0.92	0.360	1.07-0.39

Note. CI = Confidence Interval

Table-IV: Gender Differences in Caregiving Burden, Perceived Social Support, and Caregiving Duration

	Male Caregivers	Female Caregivers	t(386)	*p value*	Cohen's d
Variables	Mean± SD	Mean± SD			
Caregiving Burden	27.94 ± 13.990	29.20 ± 14.90	0.86	0.39	0.087
Perceived Social Support	61.28 ± 14.420	61.92 ± 14.41	0.44	0.66	0.024
Caregiving Duration	4.37 ± 1.884	4.26 ± 1.93	0.56	0.58	0.057

DISCUSSION

The research highlights the correlation between caregiving burden, perceived social support, and caregiving duration. A negative correlation was found between caregiving burden and perceived social support, indicating that greater support corresponds to a lower burden. In Pakistan's collectivistic culture, where familism is prominent, perceived social support is higher, leading to reduced caregiving burden.[12] Caregivers share their burden with family and friends, boosting self-appraisal as reflected by higher scores on the Multidimensional Scale of Perceived Social Support (MSPSS).

This conclusion aligns with study of Falzarano *et al.*, stress-buffering theory, which suggests that social support alleviates the negative impact of stress. Social support provides carers with emotional comfort, practical help, and a sense of community, reducing their perceived burden.[13] In Pakistan, caregivers often rely on extended family for daily tasks, emotional support, and respite care, which helps distribute caregiving responsibilities and lowers stress. This support also reduces caregiving hours, as multiple caregivers share the load. Research by Xu *et al.*, indicated that social support buffers against caregiving stress, offering emotional reassurance, practical aid, and community[14]. This support reduces isolation and perceived burden, which improves care outcomes for recipient, as shown in a study by Hajek *et al.*[15]. Lower burden scores suggest that strong social support mitigates caregiver stress. Practical assistance with tasks like medication management, providing financial aid, or transportation and emotional support reduces depression, loneliness, and exhaustion. Both forms of support were associated with lower burden scores as advocated by Li *et al.*[16]

There was no significant correlation between caregiving burden and duration. While research by Gerain *et al.*, suggested that long-term caregiving can increase stress and burnout,[17] others have found no significant relationship, or even a decrease in burden over time as carers adapt and develop coping mechanisms, as delineated by Untas *et al.*[18] Hence, longer caregiving duration doesn't always increase burden. Burden is highest initially during diagnosis, as caregivers adjust to patient care, but decreases over time as patient management becomes routine. Chronic illnesses like arthritis and diabetes often stabilize, and factors like disease severity, caregiver health, and resources may affect this relationship as determined by Marinho *et al.*[19]

The regression analysis revealed that perceived social support and caregiving duration significantly influenced caregiving burden among diabetic and arthritis carers. While caregiving duration had minimal impact, contrary to social support, which notably reduced burden as shown by Costa *et al.*[20] These factors meaningfully contribute to understanding caregiving burden, though they explain only part of the variability in the sample. Perceived social support significantly predicted caregiving burden with a negative beta coefficient, indicating that higher social support is linked to lower burden among carers of diabetic and arthritis patients. This underscores the importance of social support networks in alleviating caregiving stress.[21] Such support reduces mental and physical stress by providing practical help and emotional encouragement. The collectivistic culture facilitates dividing caregiving duties, reducing burden and hours spent caregiving. It was found in a study by Galloway *et al.*, that diseases can become routine over time, making them more manageable and not necessarily increasing burden with duration relevant to the arthritis and diabetes context here. Caregivers may also develop coping skills and resilience, leading to steady or decreased perceptions of load.[22]

The beta coefficient suggests that the time spent caring for diabetes and arthritis patients has little effect on caregivers' perceived burden. While caregiving duration may affect aspects like caregiver well-being and life quality, it shows minimal direct impact on caregiving burden. Caregivers of these manageable, non-terminal diseases generally report low burden levels, with arthritis caregivers experiencing slightly higher burdens, possibly due to shorter caregiving durations and greater physical disability.[23]

Additionally, no significant differences in caregiving burden were found between male and female caregivers, though females reported a higher burden due to multiple role strains. This indicates the need for targeted support for female caregivers in Pakistan. Interestingly, female caregivers reported slightly higher social support, while males had longer caregiving durations, highlighting a trend of more equal caregiving responsibilities between genders.[24]

The study highlights the increasing psychological impact of caregiving in arthritis patients in Pakistan, particularly due to inadequate social support for caregivers. Mental health institutions should address the burden of informal caregiving. It's crucial to implement culturally appropriate strategies, including support groups, counseling, and respite care. Additionally, sharing caregiving responsibilities can help reduce the burden on primary caregivers, with male family members encouraged to assist alongside females, thereby alleviating gender disparities in caregiving roles.

LIMITATION OF STUDY

The study was quantitative and cross-sectional, examining perceived social support and caregiving duration while excluding factors like disease intensity and socioeconomic status. Future research should utilize mixed-methods and longitudinal designs to explore caregiving burden and evaluate support programs' effectiveness. Culturally sensitive interventions and inclusion of marginalized groups are vital for understanding diverse caregiving experiences.

CONCLUSION

The research highlights the importance of disease-specific factors in caregiving, noting that challenges differ by patient and caregiver conditions. Conducted in Lahore, Pakistan, it found that increased social support reduces caregiving burden, while duration has minimal impact. The study calls for interventions to address psychological effects and emphasizes the need for comprehensive support systems and policies for caregivers at local and national levels.

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Authors' Contribution

Following authors have made substantial contributions to the manuscript as under:

MU & MF: Data acquisition, data analysis, critical review, approval of the final version to be published.

SM: Study design, data interpretation, drafting the manuscript, critical review, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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