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Original Research Article

Caregiver Burden of Rheumatoid Arthritis Patients with Self-Care Deficit at KRL Hospital Islamabad

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Abstract: Background: **Objective:** To assess the caregiver burden of rheumatoid arthritis patients with self-care deficit. **Study Design**: Cross-sectional study. **Place and Duration of Study**: Department of Psychiatry, KRL Hospital Islamabad, from 1st January 2025 to 30th June 2025. **Methods:** A total of 62 caregivers of patients with RA (functional class III–IV) were recruited using non-probability consecutive sampling. Caregiver burden was assessed using the Caregiver Burden Inventory (CBI), which measures multidimensional strain across time, developmental, emotional, social, and physical domains. Sociodemographic, caregiving, and disease-related data were collected through structured questionnaires and interviews. Data were analyzed using SPSS version 25. Chi-square tests were applied to determine associations between burden levels and independent variables, with $p \leq 0.05$ considered statistically significant. **Results:** The mean age of caregivers was 41.6 ± 13.7 years, with the majority being male (62.9%) and married (79%). Nearly half were spouses (48.4%), while 51.6% were other family members. Most patients had a disease duration of ≤15 years (62.9%), and most caregivers had been providing care for ≤5 years (69.4%). The mean CBI score was 13.7 ± 13.9. Overall, 67.7% of caregivers experienced mild to moderate burden, while 32.3% reported severe burden. Severe burden was more common among those with longer caregiving duration (33.3%) and longer disease history (30.4%), though these associations were not statistically significant ($p > 0.05$). **Conclusion:** Caregiving for RA patients imposes a considerable burden, with one-third of caregivers reporting severe strain. Routine assessment of caregiver well-being and targeted interventions such as counseling, social support, and respite services are essential to mitigate this burden and improve holistic patient care.

Keywords: Caregiver burden, Rheumatoid arthritis, Chronic illness, Cross-sectional study, Pakistan

INTRODUCTION

Rheumatoid arthritis (RA) is a widespread autoimmune disease, which is characterized by chronic inflammation that is mainly localized in the joints. RA may cause joint deformities and severe functional impairment in its advanced stages and a self-care deficit is a common outcome. It is more common in women and is common between the ages of 30-60 years. Raising productivity and quality of life in Pakistan is significant as the population is mainly composed of the young population. This is a heavy load especially to women who often have to shoulder two responsibilities in the management of the home and childcare.(1) (2)

The chronic nature of RA necessitates long-term care, which can place a substantial physical and emotional strain on caregivers.(3) The burden of caregiving can result in chronic stress and exhaustion, as well as deterioration of psychosocial health, which can consequently have a negative impact on the quality of care. The physical and mental well-being of the caregivers is vital in providing sustainable patient care and hence it is vital to determine which of the issues causes the maximum distress to the caregiver and what the cause is. This knowledge can be used to

develop measures to decrease caregiver stress and improve the quality of life of patients and caregivers.(4, 5)

The term caregiver burden has been identified since the 1960s and it is considered to be the cumulative physical, emotional, social and financial burden on people who are involved in the care of chronically ill patients (6).Caregiver burden can be either subjective (stress, frustration, or helplessness) or objective (time demands, financial burden or physical burden). Studies show that those who take care of patients having deficits in self-care have other burdens as they are obliged to help them with activities of daily living (ADLs) like bathing, feeding, and mobility. This workload tends to cause emotional fatigue, loneliness and loss of coping ability..(7)

There have been several studies in caregivers of patients with RA. Yu Ding et al. found average Caregiver Burden Inventory (CBI) scores of 8-40 among caregivers of Chinese RA patients with self-care deficits, indicating a high burden. But there is a lack of data from Pakistan, where cultural pressures, lack of health care and family demographics may affect caregiver burden.(8, 9)

It is important to study the burden of caregivers of RA patients with self-care deficit. This will not only improve our knowledge of the burden of care but also help enhance patient care and inform health care policies. Reducing caregiver burden will not only help improve the quality of life for both the caregiver and rheumatism arthritis patient, but also improve health outcomes. The current study sought to determine the caregiver burden of rheumatoid arthritis patients with self-care deficit.

METHODOLOGY

Study Design

This study was conducted as a cross-sectional survey.

Study Location

This study is conducted in the Department of Psychiatry, KRL Hospital Islamabad, over a period of six months from 1st January 2025 to 30th June 2025. Following approval of the research synopsis and ethical clearance from the institutional review board of KRL Hospital Islamabad. Participants were recruited using non-probability consecutive sampling.

Sample size

The sample size was calculated using OpenEpi software, with a mean Caregiver Burden Inventory (CBI) score of 44.0±14.9, assuming a 95% confidence level and a margin of error of 1.0, which yielded a required sample of 62 participants.(10)

Inclusion criteria

- Caregivers were included in the study if they were responsible for providing constant and daily care to patients diagnosed with rheumatoid arthritis (RA) in functional class III and IV, confirmed by a rheumatologist, for at least three months prior to enrollment.
- Caregivers between 18 and 60 years of age of both genders were considered eligible.

Exclusion Criteria

Caregivers with cognitive impairment that could interfere with accurate reporting or those with severe comorbidities such as advanced cardiovascular disease, end-stage illnesses, or severe psychiatric disorders were excluded.

Potential participants were identified through two main approaches: screening patients during hospital visits in both outpatient and inpatient departments, and reviewing medical records to trace previously diagnosed RA patients with functional deficits. Potential caregivers were identified and informed of the aims, methods, risks and benefits of the study. Signed informed consent was received from the patients and caregivers, confirming voluntary consent and confidentiality.

A caregiver was defined as a person who had been providing physical, emotional or practical assistance to a patient with rheumatoid arthritis (RA) for at least three months. Caregivers might include relatives, friends, or paid professionals who provided support for the patients' needs. Caregiver burden was defined as the level of physical, emotional, social or psychological difficulty felt by caregivers, and it was assessed using the Caregiver Burden Inventory (CBI). (11)

The CBI is a well-established measure made up of 24 items with 5-point Likert scale responses ranging from 0 (never) to 4 (nearly always). The instrument assesses subjective caregiver burden in five areas: (1) time-dependence burden, which measures the extent to which the caregiver feels constrained in his/her own time; (2) developmental burden, which indicates interference of caregiving with the caregiver's personal and emotional development; (3) emotional burden, which measures the caregiver's feelings of guilt, frustration or resentment associated with the care provided; (4) social burden, which measures the extent to which the caregiver's social life is negatively impacted by the care provided; and (5) physical burden, which measures the physical strain and fatigue associated with caregiving. A higher score on the CBI represents a higher level of caregiver burden (scores range from 0 to 96).

A structured questionnaire, developed by the researchers, was used to gather data. The Caregiver Burden Inventory (CBI) was used to measure caregiver burden in terms of time-dependence, developmental, physical, social, and emotional burden. Interviews were also conducted with caregivers to gain in-depth insights into their caregiving burden, coping mechanisms, and support needs. We also obtained information on patients' diagnosis, severity of disease, treatment history and level of self-care deficit from the medical records to supplement the caregiver's data.

Data were tabulated and analysed using the Statistical Package for Social Sciences (SPSS) version 26. Continuous data, including age, duration of disease, duration of caregiving and Caregiver Burden Inventory (CBI) scores were expressed as mean ± standard deviation (SD). Categorical variables, such as sex, education, occupation, marital status, relationship with the patient, duration of disease (0-5 years, 6-10 years, 11-15 years, and over 15 years), duration of caregiving (0-5 years, 6-10 years, 11-15 years, and over 15 years), and levels of burden, were expressed in frequencies and percentages. Caregiver burden (primary outcome variable) was defined as mild-moderate burden (CBI score ≤25) and severe burden (CBI score >25). The Chi-square test was used to assess the relationship between caregiver burden and other independent variables (relationship with patient, duration of disease, and duration of caregiving). A p-value of ≤0.05 was considered statistically significant.

RESULTS

The majority were males (62.9%) while females accounted for 37.1%. In terms of education, 43.5% had low educational attainment (up to matric), 32.3% had completed intermediate or graduation, while 24.2% had higher degrees. Regarding occupation, 32.3% were unemployed or household workers, 35.5% were engaged in skilled or unskilled jobs, and 32.3% were professionals. Most participants were married (79.0%), whereas only 21.0% were unmarried. (Table 1)

Table1: Sociodemographic Characteristics of Caregivers (n = 62)

Variable	Categories	n (%)
Gender	Male	39 (62.9%)
	Female	23 (37.1%)
Education	Low (Primary, Under/Up to Matric, Middle)	27 (43.5%)
	Middle (Intermediate, Graduate)	20 (32.3%)
	High (Masters, M.Phil/PhD, Professional degrees)	15 (24.2%)
Occupation	Unemployed/Household (Housewife, Household, Student, Retired)	20 (32.3%)
	Skilled/Unskilled Jobs (Farmer, Driver, Labour, Mechanic, Shopkeeper, etc.)	22 (35.5%)
	Professional (Teacher, Banker, Govt/Private Officers, Engineers, Lecturers, etc.)	20 (32.3%)
Marital Status	Married	49 (79.0%)
	Unmarried	13 (21.0%)

The mean age of caregivers was 41.61 ± 13.68 years. The mean duration of disease was 118.52 ± 98.38 months, while the mean caregiving duration was 60.44 ± 74.14 months. The mean outcome (CBI score) recorded among participants was 13.66 ± 13.87. (Table 2)

Table 2: Descriptive Statistics of Study Variables (n = 62)

Variable	Mean ± SD
Age (years)	41.61 ± 13.68
Duration of Disease (months)	118.52 ± 98.38
Duration of Care (months)	60.44 ± 74.14
Outcome (CBI Score)	13.66 ± 13.87

Nearly half of the caregivers were spouses (48.4%), whereas 51.6% were other family members such as sons, daughters, daughters-in-law, or nieces. A majority reported that the duration of disease was short to moderate (<15 years) (62.9%), while 37.1% reported longer durations (≥15 years). Similarly, caregiving duration was short to moderate (<5 years) among 69.4% of participants and long (>5 years) among 30.6%. Regarding outcome burden, 67.7% of caregivers reported mild to moderate burden, while 32.3% experienced severe burden. (Table 3)

Table 3: Caregiving Characteristics of Participants (n = 62)

Variable	Categories	n (%)
Relationship with Patient	Spouse (Husband/Wife)	30 (48.4%)
	Others (Son, Daughter, Daughter-in-law, Niece)	32 (51.6%)
Duration of Disease	Short–Moderate (<15 years)	39 (62.9%)
	Long (≥15 years)	23 (37.1%)
Duration of Care	Short–Moderate (<5 years)	43 (69.4%)
	Long (≥5 years)	19 (30.6%)
Outcome (CBI Score)	Mild–Moderate burden (0–25)	42 (67.7%)
	Severe burden (>25)	20 (32.3%)

Caregivers who were spouses reported a slightly lower rate of severe burden (25.9%) compared to other relatives (28.6%), though this association was not statistically significant (p = 0.116). Similarly, severe burden was somewhat more frequent among those with longer disease duration (30.4%) compared to short–moderate duration (25.6%), but the association did not reach significance (p = 0.343). Duration of care also showed a non-significant trend, with 33.3% of long-term caregivers experiencing severe burden compared to 25.0% of those with short–moderate care duration (p = 0.189). (Table 4)

Table 4: Association of Outcome with Caregiver and Disease Characteristics (n = 62)

Variable	Categories	Mild–Moderate Burden (0–25)	Severe Burden (>25)	p-value
Relationship with Patient	Spouse	20 (74.1%)	7 (25.9%)	0.116
	Others	25 (71.4%)	10 (28.6%)	
Duration of Disease	Short–Moderate (≤15 years)	29 (74.4%)	10 (25.6%)	0.343
	Long (>15 years)	16 (69.6%)	7 (30.4%)	
Duration of Care	Short–Moderate (≤5 years)	33 (75.0%)	11 (25.0%)	0.189
	Long (>5 years)	12 (66.7%)	6 (33.3%)	

DISCUSSION

In this study involving 62 caregivers, the majority were spouses (48.4%), while the remaining were children or other relatives (51.6%).(12) More than half of the patients had a disease duration of ≤15 years (62.9%), and most caregivers had been providing care for ≤5 years (69.4%). Analysis of caregiver burden using the Caregiver Burden Inventory (CBI) revealed that 67.7% experienced mild to moderate burden, while 32.3% reported severe burden.(13) These findings indicate that although many caregivers are able to cope at a moderate level, a substantial proportion still faces a severe degree of strain, particularly among those involved in longer caregiving durations and chronic disease conditions.(14)

The overall prevalence of severe burden in our sample (≈32%) is broadly consistent with other recent reports showing substantial—but variable—levels of burden among caregivers to persons with chronic musculoskeletal disease.(15) Several recent studies and reviews indicate that most caregivers experience at least some burden and a sizable minority experience moderate to severe burden.(16) For example, a 2023 national study of informal caregivers to adults with musculoskeletal conditions reported elevated psychological and time-related burden among caregivers, consistent with our finding that a substantial minority (≈32%) experience severe burden.(17)

Education and targeted caregiver training have repeatedly been shown to modify caregiver strain.(18) Intervention studies and program evaluations published in 2020–2021 reported that family-caregiver education and home-care nursing programs reduced subjective burden and improved coping or patient outcomes, suggesting that the moderate majority in our study might be amenable to similar interventions to lower burden levels.(19) These intervention studies align with our implication that identifying high-burden caregivers could guide support programs.(20)

Comparisons with RA-specific caregiver studies are limited but informative.(21) Studies from China and other settings have shown comparable burden levels and similar correlates (patient functional limitations, ADL dependence, longer disease duration, and caregiver health).(12) While many RA studies reported that caregiver burden tracks with patient disability and ADL dependence, our analysis did not find significant associations for duration of disease or caregiving after collapsing categories — possibly because our sample was selected for patients already in advanced functional classes (III–IV).(22) This restriction in patient severity may reduce between-group variability and thus mask associations other studies detected when samples included a wider spectrum of disease.(23, 24)

A number of recent papers have emphasized caregiver physical health and mental distress as important concomitants of burden.(25) National surveillance data from 2022–2023 documented increased rates of mental distress and depression among caregivers compared with no caregivers, reinforcing the clinical importance of even "moderate" burden levels such as those we observed in most participants. These findings support routine screening of caregivers for mental health needs in RA clinics.(26, 27)

Several cross-discipline systematic reviews and qualitative studies highlighted that caregiver burden is multidimensional—time, emotional, social, and physical strains, and that family structures, cultural norms, and access to services strongly influence burden.(28) That complexity may explain why simple bivariate tests (relationship, disease duration, care duration) in our study did not reach significance; broader multivariable models or qualitative data often reveal mediators (e.g., financial strain, social support, caregiver comorbidity) that modify the observed associations.(29) In other words, our non-significant p-values do not imply the absence of clinically important differences, just that they were not

detectable with the sample size and categorization used.(30, 31)

Comparing effect sizes is difficult because different studies used different instruments (Zarit Burden Interview, CBI, BSFC, FBIS) and different cutoffs for "severe" burden.(32) For example, some recent RA caregiver studies and conference reports used the CBI or other multidimensional measures and found that carers of patients with greater activity limitation reported higher burden—consistent qualitatively with our descriptive pattern where carers of more dependent patients tended toward higher CBI scores even if the association did not reach statistical significance here.(33) This measurement heterogeneity underscores the need for standardized caregiver assessment in RA research.(30, 34)

A few recent cohort and cross-sectional reported also emphasized occupational impact (absenteeism, presenteeism) and economic costs for caregivers of chronic disease patients, which resonates with our sample where a mix of paid professionals and household caregivers report burden.(35) Policymakers and hospital administrators should therefore consider caregiver-support programs that address financial and work-related consequences as well as psychosocial support.(3, 36)

Strengths of our study include use of a validated, multidimensional burden measure (CBI) and focus on caregivers of patients with advanced functional impairment (ACR functional class III–IV), a group that is underrepresented in some community samples.(37)Limitations include a single-center design, modest sample size that reduced power for stratified analyses, and collapsing of continuous duration variables into broad categories that may obscure dose–response relations. Also, as noted, heterogeneity in instruments across the literature complicates direct numeric comparisons.(38)

Our findings confirm that caregiver burden is common among caregivers of patients with advanced RA, most reported mild–moderate burden, and about one-third had severe burden.(39) These findings are qualitatively consistent with recent studies demonstrating significant caregiver burden in RA and other musculoskeletal diseases, and support routine screening of caregivers, education and intervention strategies to address the psychosocial impact and policy changes that address financial and work related issues.(40) Future studies should include larger, multicenter cohorts, standardised measures of caregiver burden and multivariable analyses to identify independent predictors and mediators (social, caregiver health, economic) that can be addressed in interventions.(41)

The results have important clinical implications. Our study shows that many caregivers report moderate to severe burden, particularly those caring for over five years or those caring for patients with long-term illness.(42) This highlights the need for psychological support, caregiver support groups and respite care. Health-care providers should take into account the needs of the caregiver as part of patient care, and screen for caregiver burden in the clinical encounter. Stress reduction, coping and educational interventions about the illness process can help ease caregiver burden. And policies should focus on financial supports, caregiving services, and workplace accommodations for informal caregivers.(43)

CONCLUSION

To sum up, this research highlights that caring for chronically ill patients is a significant burden for family members; more than two-thirds of caregivers report a mild to moderate burden and almost one-third report a severe burden. The results are consistent with recent international evidence of caregiving as an important but neglected public health issue. This study highlights the invisible struggles of caregivers and calls for the design of specific interventions to not only improve the quality of life of caregivers but also of patients. Larger, multi-site, longitudinal studies are needed to better understand the factors influencing caregiver burden, and to assess the impact of interventions. In summary, caregiver health must be prioritised to maintain the quality of care and to improve the overall care of chronic illnesses.

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