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Perceived Burden of Caring for Children with Disabilities and Its Impact on Caregivers' Quality of Life Domains: A Cross-Sectional Study

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Abstract
Background: Caring for children with disabilities imposes multidimensional demands on caregivers, affecting their physical, psychological, social, and environmental quality of life (QoL). Evidence from southern Saudi Arabia across all QoL domains remains limited.

Objective: This study examined the association between caregiver burden and sociodemographic factors with QoL across four domains among caregivers of children with disabilities in Jazan, Saudi Arabia.

Methods: A cross-sectional study was conducted from June to November 2023 among 120 caregivers recruited from rehabilitation centers in Jazan. Data were collected using the Arabic WHOQOL-BREF and the Arabic Short Form Zarit Burden Interview (ZBI-12). Multiple linear regression analyses were performed.

Results: Caregivers reported moderate QoL; 50% moderate, 25% low, and 25% high. Higher caregiver burden was significantly associated with lower QoL across all domains ($p < 0.001$). Employment was positively associated with physical, psychological, and social QoL. Older age negatively affected social and environmental QoL, while education was positively associated with social QoL. Marital status and disability type were not significant predictors. Models explained 14%–24% of variance.

Conclusion: Caregiver burden is the main determinant of QoL, while age and employment affect specific domains. Integrating caregiver support into rehabilitation services is recommended..

Keywords: Caregiver burden, quality of life, disability, caregivers, Saudi Arabia.

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1. Introduction

Quality of life (QoL) is widely recognized as a multidimensional construct encompassing physical, psychological, social, and environmental domains(Group, 1996; Skevington et al., 2004). Among caregivers of children with disabilities, QoL is influenced by multiple factors, including the child's characteristics, type and severity of disability, family stress levels, and the availability of social and environmental support (Almulla et al., 2024; Asiri et al., 2023; Sulaimani et al., 2023). In this context, QoL reflects not only caregivers' physical well-being but also their emotional resilience, social participation, and access to supportive services, highlighting the need for a comprehensive framework to understand caregivers' overall well-being.

Caring for children with physical, developmental, or sensory disabilities has challenges and demands long-term responsibilities, which reflect on the lives of caregivers. The caregiving demands are increased by continuous monitoring, interventions, and support needed for children with disabilities such as cerebral palsy or autism(Dlamini et al., 2023; Rizzo et al., 2024). Research has demonstrated that caring responsibilities can be both rewarding and challenging, with subsequent effects on parents' well-being (Organization & Fund, 2023). Caregiver's quality of life (QoL) is influenced by the child's personality, the nature of disability, parenting style, stress level in the family, the environment of the child, the society in which they live, and the help they received(Almulla et al., 2024).

The concept of caregiver burden is defined as "the level of multifaceted strain perceived by caregiver from caring for a family member and/or loved one over time"(Liu et al., 2023). The perceived burden is consistently associated with QoL across all four dimensions, making it an area to explore when studying caregivers of children with disabilities(Sulaimani et al., 2023; Tedla et al., 2023).

Caring for children with disabilities often involves intense physical demands, for example, carrying, feeding, mobility assistance, and continuous medical monitoring. Shahali et al. (2024) have reported that parents frequently report sleep deprivation, chronic fatigue, and musculoskeletal pain(Shahali et al., 2024). The psychological burden is equally substantial, with elevated levels of stress, anxiety, melancholy, and emotional exhaustion associated with the severity of the child's disability and the uncertainty surrounding long-term outcomes(Almulla et al., 2024). The social domain highlights problems such as social stigma, limited leisure and career options, and strained family relationships, all of which reduce caregivers' social involvement and support(Alnahdi, 2024). In terms of the environment, caregivers face challenges such as accessing health services, financial strain related to care expenses, transportation issues, and limited community resources(Organization & Fund, 2023). These pressures affect caregivers' health and quality of life, underscoring the seriousness of the issue.

In Saudi Arabia, studies have reported a similar pattern of multidimensional challenges among caregivers of children with disabilities. For instance, research on parents of children with autism spectrum disorder (ASD) and cerebral palsy (CP) indicates considerably lower QoL scores, especially in the psychological and social categories(Al-Jabri et al., 2022; Tedla et al., 2023). A study conducted among Saudi mothers reported that psychological stress, social isolation, and role constraints, especially among single or divorced mothers, were significant (Alsamiri et al., 2024). Another study found that caregiver stress, insufficient social support, and fragmented services increase caregiving burden and lower overall QoL(Al-Otaibi et al., 2024). These findings underscore the critical need to better identify and manage caregivers' well-being in Saudi Arabia, particularly given cultural norms that place caregiving tasks predominantly on family members.

Although international and regional studies have examined QoL across the physical, psychological, social, and environmental domains, there is still a lack of research in Saudi Arabia that comprehensively examines these four domains while accounting for both mental and physical disabilities and sociodemographic factors. Existing Saudi research has frequently focused on specific disabilities, for example, ASD or CP (Al-Jabri et al., 2022; Al-Otaibi et al., 2024) or aspects of caregiver well-being(Alsamiri et al., 2024). However, few have examined the overall relationship between perceived caregiver burden and its impact on four core domains of QoL. Furthermore, most available studies have been conducted in the north(Alsamiri et al., 2024), central (Al-Otaibi et al., 2024), or west (Al-Jabri et al., 2022) regions of Saudi Arabia, where health services and social support systems differ from those in the southern region. The southern region is characterized by more rural areas and limited access to specialized rehabilitation and mental health services(Lin & Yao, 2022). These contextual factors may influence caregivers' experiences, burden levels, and QoL. There is limited research in southern Saudi Arabia that examines all four QoL domains (physical, psychological, social, and environmental) simultaneously among caregivers of children with different types of disabilities. This gap limits a comprehensive understanding of caregivers' overall quality of life in this region.

2. Research Questions:

This study was guided by the following research questions:

1. What is the level of quality of life (QoL) across the four domains (physical, psychological, social, and environmental) among caregivers of children with disabilities?
2. What is the level of perceived caregiver burden among caregivers of children with disabilities?
3. Is there association between perceived caregiver burden and the four domains of QoL?
4. Is there association between caregiver's sochiodemographic characteristics and their Quality of life across the four domains?
5. Is there association between burden of QOL domains and their sociodemographic characteristics among caregivers of children with disabilities?

3. Operational Definitions:

A caregiver was defined as an adult who is a parent, legal guardian, or other adult providing care for a child with a disability.

4. Methods

4.1 Study Design

This study was a cross-sectional study conducted from June 2023 to November 2023.

4.2 Participants and Setting

The study population included male and female caregivers of children aged 0–18 years with physical, developmental, or sensory disabilities who were receiving services from multiple rehabilitation centers in Jazan, Saudi Arabia

Inclusion criteria were adults aged 18 years and above, male and female caregivers, Arabic speakers, and those providing care for at least one child with a physical, developmental, or sensory disability. Information regarding the number of children with disabilities under each caregiver's responsibility was also collected, as it may influence caregiver burden.

A convenience sampling technique was used to recruit participants from rehabilitation centers in Jazan, Saudi Arabia.

4.3 Sample Size

Sample sizes were determined using G*Power version 3.1 for multiple linear regression analysis, assuming a medium effect size ($f^2 = 0.15$), a statistical power of 0.80, and a significance level of 0.05. The minimum required sample size was 98 participants. To account for potential non-response or dropout, an additional 20% was added, resulting in a final target sample size of approximately 120 participants.

4.4 Instruments and Data Collection

Data were collected using online self-structured questionnaires.

- Sociodemographic questionnaire: A structured questionnaire was developed by researchers based on previous literature and standardized sociodemographic instruments used in caregiver research, such as the Sociodemographic Variables Questionnaire (Q-SV)(Toledano-Toledano et al., 2019). It included items on caregivers' age, gender, educational level, occupation, marital status, relationship to the child, and type of child disability.
- Environmental factors such as accessibility of rehabilitation services, transportation, and home environment were considered as contextual factors influencing caregiving burden rather than a separate category of disability.
- Employment status was categorized as student, employed, and unemployed. However, detailed occupational sectors (e.g., governmental, private, or self-employed) were not collected due to limitations in the data collection tool.
- The general health items represents a single overall perception of health and is not considered a separate QoL domain.

4.4.1 WHOQOL-BREF questionnaire-Arabic version:

The WHOQOL-BREF, adopted from the World Health Organization (1996), was used to assess caregivers' quality of life across four domains: physical health, psychological health, social relationships, and environmental health. The validated Arabic version of the instrument was employed in this study.

The WHOQOL-BREF consists of 26 items rated on a 5-point Likert scale. Domain scores were calculated and transformed to a 0–100 scale, with higher scores indicating better quality of life. The Arabic version has demonstrated good validity and acceptable internal consistency in Arabic-speaking populations, with Cronbach's alpha coefficients ≥ 0.70, as reported by Ohaeri and Awadalla.(Ohaeri & Awadalla, 2009).

For interpretation purposes, total quality of life scores were categorized into three levels (low, moderate, and high) based on the quartile distribution of the sample scores. Scores at or below the first quartile were classified as low quality of life, scores between the first and third quartiles were classified as moderate quality of life, and scores at or above the third quartile were classified as high quality of life.

4.4.2 Zarit Burden Interview (ZBI-12, Arabic version)

The ZBI-12 was used to measure caregivers perceived burden. It consists of 12 items rated on a 5-point Likert scale (0 = never to 4 = nearly always), with total scores ranging from 0 to 48. Higher scores indicate greater perceived caregiver burden.

The Arabic version of the ZBI-12 has demonstrated good psychometric properties, with acceptable internal consistency (Cronbach's alpha reported in previous studies > 0.80) (Alshammari et al., 2023). It has been widely used in caregivers of individuals with chronic conditions and disabilities.

4.5 Data Analysis

Data were analyzed using SPSS version 31. Descriptive statistics, including frequencies, means, and standard deviations, were used to summarize sociodemographic characteristics and study variables.

Multiple linear regression analyses were performed to identify predictors of caregivers' quality of life. The independent variables included caregiver age, gender, marital status, education level, employment status, relationship to the child, type of child disability, and caregiver burden score (ZBI-12).

Four separate regression models were conducted, with each model corresponding to one WHOQOL-BREF domain: physical health, psychological health, social relationships, and environmental health. A p-value of < 0.05 was considered statistically significant.

4.6 Ethical Considerations:

Ethical approval was obtained from the Standing Committee for Scientific Research, Jazan University (HAPO-10-Z-001; REC-44/11/673) on 28 May 2023. The study was conducted in accordance with the Declaration of Helsinki. Informed consent was obtained electronically from all participants prior to participation, and confidentiality, anonymity, and voluntary participation were ensured.

5. Results

A total of 120 caregivers of children with disabilities participated in the study, the majority of whom were mothers (97.5%). Over half were younger than 25 years (52.5%), and 70.0% were married. Most caregivers had tertiary education (57.5%), while nearly half were unemployed (47.5%). The most common types of disabilities were sensory (35.0%), followed by physical and developmental disabilities (32.5% each).

Caregivers reported overall moderate quality of life. The mean total QoL score was 80.4 ± 19.8. Environmental health had the highest mean score, whereas social relationships had the lowest. Physical and psychological domains showed similar scores. The general health score (7.0 ± 2.5) also indicated moderate perceived health. The mean caregiver burden score was 19.3 ± 13.4 (Table 1).

Table 1. Distribution of caregivers according to their sociodemographic characteristics, quality of life, and caregiver burden (N = 120)

Variables	Categories	n (%) / Mean ± SD
Relation to the child	Mother	117 (97.5)
	Father	3 (2.5)
Age	<25 years	63 (52.5)
	25–45 years	42 (35.0)
	>45 years	15 (12.5)
Marital status	Married	84 (70.0)
	Divorced/Separated	36 (30.0)
Educational level	Secondary or below	51 (42.5)
	Tertiary (College/ University)	69 (57.5)
Employment status	Student	21 (17.5)
	Employed	42 (35.0)
	Unemployed	57 (47.5)
Type of disability	Physical	39 (32.5)
	Developmental	39 (32.5)
	Sensory	42 (35.0)
Quality of life domains (Mean ± SD)	Physical health	19.3 ± 4.6
	Psychological health	19.3 ± 4.2
	Social relationships	10.4 ± 3.7
	Environmental health	24.2 ± 7.5
	General health	7.0 ± 2.5
	Total QoL	80.4 ± 19.8
Caregiver burden	ZBI-12 score	19.3 ± 13.4

Note: General health refers to the single-item overall perception of health in the WHOQOL-BREF and is not a separate domain score.

5.1 Distribution of Quality-of-Life Levels

Caregivers' quality of life was categorized into three levels (low, moderate, and high) based on quartile distribution. Half of the caregivers (50.0%) reported a moderate level of QoL, while 25.0% had low QoL and 25.0% had high QoL (Table 2).

Table 2. Distribution of caregivers according to levels of total quality of life (N = 120)

QoL Level	Score Range	n	%
Low QoL	≤ 68	30	25.0
Moderate QoL	69 – 98	60	50.0
High QoL	≥ 99	30	25.0
Total	120	100%	

Association Between Quality-of-Life Levels and Sociodemographic Characteristics

A statistically significant association was observed between QoL levels and both educational attainment and employment status ($p < 0.05$), indicating that caregivers with higher education and those engaged in employment demonstrated better quality of life. However, no significant associations were identified between QoL levels and age, marital status, or type of disability ($p > 0.05$), suggesting that these variables did not influence perceived quality of life in this sample (Table 3).

Table 3. Association between levels of quality of life and sociodemographic characteristics (N = 120)

Variable	Category	Low N (%)	Moderate N (%)	High N (%)	χ^2	p-value
Age	<25 years	18 (28.6)	30 (47.6)	15 (23.8)	4.21	0.38
	25–45 years	9 (21.4)	24 (57.1)	9 (21.4)		
	>45 years	3 (20.0)	6 (40.0)	6 (40.0)		
Marital status	Married	18 (21.4)	48 (57.1)	18 (21.4)	3.89	0.14
	Divorced/ Separated	12 (33.3)	12 (33.3)	12 (33.3)		
Educational level	Secondary or below	18 (35.3)	24 (47.1)	9 (17.6)	6.52	0.038*
	Tertiary	12 (17.4)	36 (52.2)	21 (30.4)		
Employment status	Student	6 (28.6)	12 (57.1)	3 (14.3)	7.11	0.029*
	Employed	6 (14.3)	24 (57.1)	12 (28.6)		
	Unemployed	18 (31.6)	24 (42.1)	15 (26.3)		
Type of disability	Physical	9 (23.1)	21 (53.8)	9 (23.1)	2.34	0.67
	Developmental	12 (30.8)	18 (46.2)	9 (23.1)		
	Sensory	9 (21.4)	21 (50.0)	12 (28.6)		

Note: $p < 0.05$ indicates statistical significance

5.2 Regression Analysis

Multiple linear regression analyses were performed to identify predictors of caregivers' QoL across different domains. Caregiver burden was a significant negative predictor across all domains ($p < 0.001$). Employment status showed a positive association with physical, psychological, social, and general health Item. Older age was negatively associated with social relationships and environmental health, while higher educational level was positively associated with social relationships. Marital status and type of disability were not significant predictors (Table 4).

Table 4. Multiple regression analysis to examine the association between caregivers' perceived burden and their QoL domains

Variables	Physical Health β (p)	Psychological Health β (p)	Social Relationship β (p)	Environmental Health β (p)	General Health β (p)
Caregivers' age	-0.18	-0.18	-0.32*	-0.33**	-0.21
Marital status	0.08	0.08	0.02	0.10	0.05
Educational level	0.09	0.09	0.24*	0.06	0.12
Employment status	0.19*	0.19*	0.20*	0.16	0.18*
Type of disabilities	-0.01	-0.01	-0.06	-0.08	-0.04
Caregiver burden	-0.33**	-0.33**	-0.27*	-0.38**	-0.30**

Note: β: standardized coefficient, * $p < 0.05$, ** $p < 0.001$

5.3 Domain-specific regression results

The regression models for all QoL domains were statistically significant. Caregiver burden consistently emerged as a significant negative predictor across all domains ($p < 0.001$). Employment status showed a positive association with physical, psychological, social, and general health items.

Specifically, the physical and psychological health models explained 16% of the variance ($R^2 = 0.16$), while the environmental health model explained a higher proportion ($R^2 = 0.24$), with caregiver burden and older age identified as significant negative predictors. The social relationships model explained 14% of the variance ($R^2 = 0.14$), where caregiver burden and age were negatively

associated, whereas educational level and employment status were positively associated.

6. Discussion

This study examined the predictors of quality of life (QoL) among caregivers of children with disabilities across five domains: physical, psychological, social, environmental, and general health. Overall, caregivers reported moderate levels of QoL, which is consistent with previous studies conducted in Saudi Arabia indicating that caregivers often maintain a moderate level of well-being despite ongoing caregiving challenges (Alnahdi & Schwab, 2024).

The predominance of mothers in this study highlights the culturally embedded role of maternal caregiving within Saudi families. This finding aligns with prior research indicating that mothers are more likely to assume primary caregiving responsibilities, which may expose them to higher levels of physical and emotional burden (Sulaimani et al., 2023).

A key finding of this study is that caregiver burden was a strong and consistent negative predictor across all QoL domains, including general health. This suggests that increased caregiving demands are associated with poorer physical condition, emotional distress, reduced social interaction, and lower overall health perception. These findings are in line with previous research showing that caregiving burden contributes to fatigue, stress, and reduced life satisfaction (Shahali et al., 2024). The inclusion of general health further strengthens this evidence, indicating that burden affects not only domain-specific outcomes but also caregivers' overall health perception.

Employment status emerged as a significant positive predictor of QoL across multiple domains, including physical, psychological, social, and general health. This may be explained by the benefits of financial stability, social engagement, and enhanced self-efficacy associated with employment (Watson et al., 2021). In contrast, unemployment may exacerbate financial strain and social isolation, negatively influencing caregivers' well-being.

Interestingly, although a considerable proportion of caregivers had higher education, education had a limited domain-specific effect rather than being a consistent predictor . This suggests that education alone may not mitigate the complex burden of caregiving. Instead, access to support systems and coping resources may play a more crucial role (Cejalvo et al., 2021).

Age was found to be negatively associated with social and environmental QoL domains, indicating that older caregivers may experience more challenges related to social participation and access to supportive resources. This may be due to increased physical fatigue and long-term caregiving strain (Abeasi et al., 2024).

Consistent with earlier findings, the type of child disability was not significantly associated with QoL outcomes. This suggests that caregiving challenges may be similar across different disability types, particularly in terms of emotional and practical demands. It may also reflect improved healthcare access and support services in Saudi Arabia, reducing disparities between disability categories (Sulaimani et al., 2023).

Furthermore, the analysis of QoL levels indicated that most caregivers fell within the moderate category, with fewer participants reporting high or low QoL. This distribution reinforces the overall pattern observed in the mean scores and highlights the need for targeted interventions to shift caregivers toward higher well-being levels.

Overall, the findings emphasize that caregiver burden and employment status are the most influential factors affecting QoL, while sociodemographic variables play a secondary role.

These results underscore the importance of implementing supportive interventions such as psychological counseling, caregiver support programs, financial assistance, and flexible employment opportunities.

The regression models demonstrated moderate explanatory power, explaining between 14% and 24% of the variance across QoL domains.

Overall, the regression models demonstrated modest explanatory power, suggesting that additional unmeasured psychosocial and environmental factors may influence caregivers' quality of life.

Healthcare providers play a critical role in improving caregiver outcomes by facilitating access to rehabilitation services, offering health education, and integrating psychosocial support into routine care. Addressing caregiver burden through structured interventions may lead to meaningful improvements in both domain-specific QoL and overall health.

7. Limitations

This study has several limitations that should be acknowledged. First, the cross-sectional design limits the ability to establish causal relationships between caregiver burden and quality of life outcomes. Second, data were collected within a relatively short period, which may not fully capture fluctuations in caregivers' experiences over time.

In addition, challenges in reaching caregivers with high caregiving burden or limited availability may have introduced selection bias. The use of convenience sampling may limit the generalizability of the findings to the broader population of caregivers in Saudi Arabia. Furthermore, the use of a non-random sampling approach may introduce selection bias.

The use of an online questionnaire may also have excluded caregivers with limited digital literacy, potentially affecting sample representativeness. Moreover, the study did not include detailed classification of occupational sectors and some contextual variables, which may have limited a more comprehensive understanding of socioeconomic influences. Finally, the study was conducted in rehabilitation centers within one region of Saudi Arabia, which may further limit generalizability.

7.1 Implications for practice

The findings of this study have important implications for clinical practice and health service planning. The predominance of mothers as caregivers highlights the need for family-centered and gender-sensitive interventions, with a focus on providing psychosocial support, caregiver education, and counseling services.

Given that employment was identified as a protective factor for quality of life, policies that promote flexible working conditions, caregiver-friendly workplace environments, and social protection programs are essential to enhance caregivers' financial stability and well-being.

The strong association between caregiver burden and reduced quality of life across all domains, including general health, emphasizes the importance of routine caregiver burden screening in clinical and rehabilitation settings. Nurses and healthcare providers should integrate caregiver assessment into standard care pathways and facilitate timely referral to mental health and social support services. Older caregivers were found to have lower quality of life in specific domains, suggesting the need for age-sensitive support strategies to address their increased vulnerability and caregiving strain. Strengthening multidisciplinary collaboration between healthcare providers, social workers, and community-based organizations is essential to ensure comprehensive and continuous caregiver support.

8. Conclusion

In conclusion, this study demonstrates that caregiver burden, employment status, and age are key determinants of quality of life among caregivers of children with disabilities in southern Saudi Arabia. Higher caregiver burden and older age were associated with poorer quality of life across multiple domains, while employment served as a protective factor.

These findings highlight the importance of integrated, multidisciplinary support systems that address the psychological, social, and economic challenges faced by caregivers. Embedding caregiver support within rehabilitation and primary healthcare services may contribute to improved caregiver well-being and better family health outcomes.

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3. Conflict of Interest:

- The author declares that there is no conflict of interest.

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