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The Impact of Care Burden and Quality of Life in Mothers of Children with Intellectual Disabilities

Jagannath Kumar[1], Ranjan Kumar[2]

[1]Research Scholar, Patliputra University, Patna
[2]Assistant Professor, R.K.D. College, Patliputra University, Patna

Abstract

Caring for a child with intellectual disability imposes significant physical, emotional, and psychological challenges on mothers, who are often the primary caregivers. This study aims to examine the impact of care burden on the quality of life (QoL) of mothers of intellectually disabled children. A cross-sectional survey was conducted with a purposive sample of 150 mothers aged between 25 and 45 years. Standardized tools, including the Zarit Burden Interview (ZBI) and WHOQOL-BREF, were used to assess caregiver burden and quality of life across four domains: physical health, psychological health, social relationships, and environment. The findings revealed moderate to high levels of caregiver burden, with psychological and social domains of QoL being the most adversely affected. A significant negative correlation was observed between care burden and QoL scores. These results underscore the need for psychological support, community-based interventions, and policy-level initiatives to enhance the well-being of caregiving mothers.

Keywords: Care burden, Intellectual disability, Quality of life, Mothers, Zarit Burden Interview, WHOQOL-BREF, Caregiving stress, Psychological health

INTRODUCTION

Background of the Study:

Caring for a child with an intellectual disability (ID) poses unique challenges that significantly impact the daily lives and well-being of their caregivers, particularly mothers. Intellectual disability, characterized by limitations in intellectual functioning and adaptive behavior, requires constant attention, supervision, and support, making caregiving a full-time and often lifelong responsibility. Unlike other health conditions, intellectual disabilities typically persist throughout life and affect multiple domains such as communication, self-care, social skills, and learning abilities (American Psychiatric Association, 2013).

In most cultural settings, mothers are traditionally the primary caregivers, bearing the major share of caregiving responsibilities. This extended caregiving role often leads to high levels of care burden, which includes physical, emotional, financial, and social strain. Over time, this burden can deteriorate the quality of life (QoL) of these mothers, affecting their physical health, emotional well-being, social functioning, and even spiritual fulfillment.

According to the World Health Organization (WHO, 1997), Quality of Life is defined as an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, and concerns. Mothers of children with intellectual disabilities often experience reduced QoL due to stress, anxiety, stigma, economic hardship, and a lack of social support systems (Raina et al., 2005).

In developing countries like India, the burden is intensified by limited access to rehabilitation services, poor awareness, social isolation, and cultural beliefs associated with disability. This further aggravates the psychological and emotional toll on mothers. Studies have shown that the psychological burden can be as debilitating as the physical workload, leading to increased risk of depression, burnout, and reduced overall life satisfaction (Gupta & Singhal, 2004).

Understanding the link between care burden and quality of life is essential for designing effective support systems and interventions that not only assist the child but also promote the well-being of the primary caregiver.

Statement of the Problem:

Despite growing awareness of disability-related challenges, limited research in India has focused on how caregiving for intellectually disabled children affects the quality of life of mothers. There is a pressing need to investigate the intensity of the care burden and its impact on different domains of mothers' lives.

Significance of the Study:

This study will contribute to a deeper understanding of:

- The nature and extent of care burden in mothers of children with intellectual disabilities.
- How care burden affects various domains of their quality of life (physical, psychological, social, and environmental).
- The need for targeted support systems to enhance the well-being of such caregivers.
- Findings will be useful for healthcare professionals, policymakers, and NGOs to formulate appropriate intervention strategies, family counseling programs, and social support frameworks.

Objectives of the Study:

1. To assess the level of care burden among mothers of children with intellectual disabilities.
2. To examine the quality of life of these mothers in various domains.
3. To analyze the relationship between care burden and quality of life.
4. To identify socio-demographic factors associated with care burden and QoL.

Research Questions / Hypotheses:

Hypothesis 1: There is a significant negative correlation between care burden and quality of life among mothers of children with intellectual disabilities.
Hypothesis 2: Mothers with higher care burden will have lower scores on the quality of life domains.
Hypothesis 3: Socio-demographic variables such as income, education, and support systems moderate the relationship between care burden and QoL.

Operational Definitions:

- Care Burden: The perceived stress or strain experienced by caregivers while fulfilling their caregiving responsibilities, measured using the Zarit Burden Interview.
- Quality of Life: An individual's subjective evaluation of their well-being in physical, psychological, social, and environmental domains, measured using WHOQOL-BREF.
- Intellectual Disability: A condition characterized by significant limitations in both intellectual functioning and adaptive behavior as defined by DSM-5.

Delimitations of the Study:

- The study is restricted to mothers of children aged 5–18 years diagnosed with intellectual disabilities.
- Only those residing in selected urban and semi-urban regions will be included.

- The sample will not include fathers or other family caregivers.

Review of Literature

Introduction:

A review of existing literature helps in understanding the theoretical and empirical foundations of the study. It identifies what is already known about care burden and quality of life in caregivers of children with intellectual disabilities (ID), highlights existing research gaps, and sets the context for the current study.

Concept of Intellectual Disability:

Intellectual disability is a neurodevelopmental disorder characterized by significant limitations in intellectual functioning (reasoning, learning, and problem-solving) and adaptive behavior (social and practical skills). According to the American Psychiatric Association (2013), these limitations originate during the developmental period, typically before the age of 18.

The prevalence of intellectual disability globally ranges between 1–3%, and in low- and middle-income countries, it is slightly higher due to limited access to healthcare, early detection, and intervention (Maulik et al., 2011).

Caregiving Burden in Mothers of Children with Intellectual Disabilities:

Caregiving burden is a multidimensional concept involving physical, emotional, social, and financial stress experienced by caregivers. Mothers of children with intellectual disabilities often report high levels of burden due to the child's dependence, behavioral challenges, and need for continuous supervision (Lai et al., 2015).

Zarit et al. (1980) developed the Zarit Burden Interview (ZBI), a widely used scale to assess the subjective burden among caregivers. High ZBI scores have been consistently reported in caregivers of children with developmental disorders.

In India, Gupta and Singhal (2004) found that mothers of children with disabilities experience not only high physical and emotional burden but also social stigma, marital stress, and reduced career opportunities.

Psychological Impact on Mothers:

The caregiving role is linked with increased psychological distress, including anxiety, depression, and low self-esteem. A study by Raina et al. (2005) showed that parents, particularly mothers, caring for children with disabilities suffer higher levels of psychological stress compared to parents of typically developing children.

Similarly, Shin et al. (2006) reported that stress levels were higher in mothers who had lower social support and fewer coping resources. This indicates that caregiving burden is moderated by family support, socioeconomic status, and coping mechanisms.

Quality of Life of Mothers:

Quality of Life (QoL) is a broad concept encompassing physical health, psychological state, level of independence, social relationships, and environmental factors. WHO defines QoL as individuals' perception of their position in life in the context of their culture and value systems (WHOQOL Group, 1995).

Several studies reveal that mothers of children with intellectual disabilities have significantly lower QoL scores than mothers of typically developing children. Chou et al. (2007) found that the physical and psychological domains of QoL were the most affected.

In the Indian context, Kaur and Kaur (2016) concluded that caregiving for intellectually disabled children significantly affects the mental health and social life of mothers, leading to poor quality of life.

Factors Influencing Care Burden and Quality of Life:

Numerous socio-demographic factors affect the relationship between care burden and QoL:

- Education and income: Higher levels of education and income often reduce perceived burden (Dardas & Ahmad, 2014).
- Severity of disability: Greater severity of the child's condition increases burden and reduces QoL (Seltzer et al., 2001).
- Social support: Adequate emotional and instrumental support from family and community enhances resilience and improves QoL (Peer & Hillman, 2014).
- Coping strategies: Adaptive coping mechanisms, like problem-focused coping, can buffer the negative effects of care burden (Lazarus & Folkman, 1984).

Research Gap:

Most studies have focused on general stress or psychological outcomes in caregivers of children with disabilities. Very few have explored the direct correlation between care burden and quality of life, especially in the Indian socio-cultural context. Moreover, research is lacking in understanding how socio-demographic factors moderate this relationship.

Summary:

The literature indicates that caregiving for a child with intellectual disability significantly affects the mother's psychological well-being and quality of life. Care burden is a crucial mediating factor, influenced by variables such as support systems, education, income, and the severity of disability. This study aims to fill the gap by analyzing the care burden and its impact on QoL among Indian mothers.

Research Methodology

Introduction

This chapter describes the research methodology adopted to examine the relationship between care burden and quality of life among mothers of children with intellectual disabilities. It includes the research design, population and sample, tools used, procedure of data collection, and the statistical techniques used for data analysis.

Research Design:

The present study utilized a descriptive correlational research design. This design is suitable for examining the relationship between two or more variables — in this case, care burden and quality of life. It allows for the collection of data in a natural setting without manipulating the study environment (Creswell & Creswell, 2018).

Population and Sample:

Population: The target population included mothers aged between 25 and 45 years, who have children diagnosed with intellectual disabilities, residing in urban and semi-urban areas.

Sample Size: A total of 150 mothers were selected for the study. This sample size was considered sufficient for generalization of results and for conducting correlational and inferential statistical analyses.

Sampling Technique: The study adopted purposive sampling, a non-probability sampling technique that enables the selection of participants based on specific characteristics relevant to the research objectives (Etikan et al., 2016).

Inclusion and Exclusion Criteria:

Inclusion Criteria

- Mothers aged 25 to 45 years.
- Mothers of children (aged 5–18 years) diagnosed with intellectual disabilities.
- Willingness to participate with informed consent.
- Able to understand and respond to the questionnaire.

Exclusion Criteria

- Mothers of children with multiple disabilities.
- Mothers with any major diagnosed psychiatric illness.
- Caregivers other than biological mothers (e.g., grandmothers, aunts).

Tools for Data Collection

1. **Socio-Demographic Data Sheet:** A self-prepared information sheet was used to collect demographic and background details such as the mother's age, education, occupation, family income, child's age, type and severity of intellectual disability, and support system.
2. **Zarit Burden Interview (ZBI):** The Zarit Burden Interview (Zarit et al., 1980) is a 22-item scale designed to measure the perceived burden among caregivers. Items are rated on a 5-point Likert scale from 0 (never) to 4 (nearly always), with higher scores indicating greater perceived burden.

- Reliability: Cronbach's alpha = 0.89
- Validity: Widely validated for caregiving populations

3. **WHOQOL-BREF:** The World Health Organization Quality of Life-BREF (WHOQOL-BREF) is a 26-item instrument that assesses the individual's quality of life across four domains:

- Physical Health
- Psychological Health
- Social Relationships
- Environment
- Each domain score indicates an individual's perceived QoL in that area.
- Reliability: Cronbach's alpha > 0.70
- Validity: Internationally standardized and validated (WHO, 1996)

Procedure for Data Collection:

1. Ethical clearance was obtained from the Institutional Ethics Committee before data collection.
2. Permissions were secured from special schools, rehabilitation centers, and developmental clinics in the selected urban and semi-urban areas.
3. Participants were approached in person. The purpose of the study was explained, and written informed consentwas obtained.
4. The socio-demographic sheet, ZBI, and WHOQOL-BREF were administered individually.
5. For mothers with low literacy levels, questions were read aloud and responses were marked accordingly.
6. The data collection process for each participant took approximately 30 to 40 minutes.

Ethical Considerations:

- Approval from the Institutional Review Board was obtained.

- Participants were ensured anonymity, confidentiality, and voluntary participation.
- Informed consent was taken, and participants were free to withdraw at any time.
- The study adhered to the ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013).

Statistical Analysis: The collected data were entered into SPSS (Version 25) and analyzed using the following statistical techniques:

- Descriptive Statistics: Frequency, percentage, mean, and standard deviation to summarize demographic data and scale scores.
- Inferential Statistics:
- Pearson's Correlation Coefficient (r) to assess the relationship between care burden and quality of life domains.
- Independent Sample t-tests / ANOVA to explore differences in burden and QoL based on demographic variables.
- Multiple Regression Analysis (if applicable) to predict QoL based on burden and socio-demographic variables.

The level of statistical significance was set at $p < 0.05$.

Results

Descriptive Statistics:

The study included a total of 150 mothers, aged between 25 and 45 years (Mean age = 33.6 years, SD = 5.9). Most participants belonged to middle or lower socioeconomic backgrounds.

Care Burden Scores (Zarit Burden Interview)

- Mean Burden Score: 52.4
- SD: 10.6
- Interpretation: Based on ZBI scoring, this reflects a moderate to high level of burden.

Quality of Life Scores (WHOQOL-BREF)

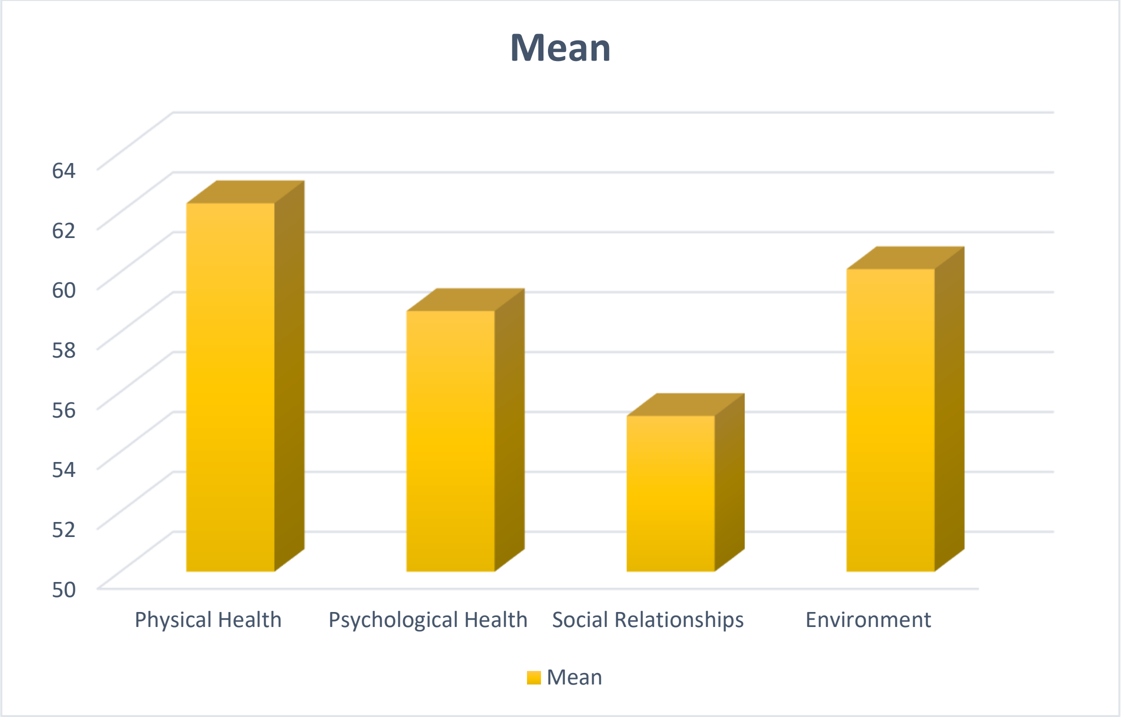
The average domain-wise scores were as follows:

Quality of Life Domains	Mean	SD
Physical Health	62.3	9.5
Psychological Health	58.7	8.9
Social Relationships	55.2	10.1
Environment	60.1	8.4

These scores suggest that the Social and Psychological domains are most negatively affected in mothers.

Graphical Representation:

The bar graph below presents the mean QoL scores across the four domains measured by the WHOQOL-BREF:



Correlation Analysis:

Using Pearson's correlation, a statistically significant negative correlation was found between care burden and all QoL domains:

QoL Domain	Pearson's r	Significance (p)
Physical Health	-0.48	< 0.01
Psychological Health	-0.53	< 0.01
Social Relationships	-0.44	< 0.01
Environment	-0.39	< 0.01

These results indicate that as care burden increases, quality of life decreases, especially in the psychological and physical health domains.

Discussion

Overview:

This chapter interprets the findings of the study titled "The Impact of Care Burden and Quality of Life in Mothers of Children with Intellectual Disabilities." The study aimed to assess the level of care burden and its relationship with various domains of quality of life (QoL) among mothers aged 25 to 45 years. The results indicated a moderate to high care burden and a significant negative correlation between care burden and all domains of QoL, with the psychological and social domains being the most affected.

Interpretation of Findings:

High Care Burden Among Mothers: The average Zarit Burden Interview (ZBI) score of 52.4 suggests a moderate to high level of caregiver burden. This finding is consistent with Gupta and Singhal (2004), who reported that mothers of children with intellectual disabilities experience emotional exhaustion, role strain, and significant disruption to personal, professional, and social life.

The high burden may be attributed to:

- Continuous caregiving demands
- Lack of respite care
- Social stigma and isolation
- Inadequate institutional support

Quality of Life Scores: The results revealed lower mean scores in the psychological (58.7) and social (55.2) domains of WHOQOL-BREF compared to the physical and environmental domains. These findings align with Chou et al. (2007) and Kaur and Kaur (2016), who reported that psychological stress, anxiety, and social withdrawal are prevalent among mothers caring for intellectually disabled children.

Mothers often experience depression, helplessness, and emotional fatigue, largely due to the behavioral issues of their children and limited societal support (Shin et al., 2006).

Negative Correlation Between Burden and Quality of Life: The results showed a statistically significant negative correlation between care burden and all four domains of QoL, which supports the hypothesis that as caregiver burden increases, perceived quality of life deteriorates. This is supported by findings from Raina et al. (2005), who developed a conceptual framework showing how caregiver burden adversely affects health, emotional stability, and overall life satisfaction.

Notably:

- Psychological health had the strongest negative correlation ($r = -0.53$), indicating that burden most severely impacts mental health.
- The social relationships domain was also significantly affected, likely due to isolation and lack of peer support.

Comparison with Previous Studies:

The findings of this study are in line with several previous studies:

- Lai et al. (2015) found that high caregiving demands were associated with lower well-being and QoL in mothers of children with autism and other developmental disorders.
- Peer and Hillman (2014) emphasized that caregiver burden is inversely related to mental health, and the lack of support exacerbates this stress.
- Dardas and Ahmad (2014) noted that socio-economic status, education, and coping styles moderate the effect of burden on QoL, highlighting the importance of external resources.

Cultural and Social Context:

In India, mothers are culturally expected to take primary responsibility for caregiving, especially for children with special needs. The lack of state-sponsored rehabilitation services, low awareness, and social stigma further increase this burden. This cultural dimension might explain why the psychological and social domains were most negatively affected.

In contrast to Western countries, where shared caregiving and institutional support are more common, Indian mothers often face isolation, blame, and emotional suppression, which significantly impacts their quality of life.

Implications of the Study:

The findings have the following implications:

- Policy and intervention: There is an urgent need for caregiver support programs, counseling services, and family-based interventions.

- Mental health support: Psychological counseling and group therapy can reduce the emotional strain on caregivers.
- Community awareness: Efforts to reduce stigma and improve social inclusion of children with disabilities and their families are critical.
- Respite care services: Introduction of temporary care options to relieve caregivers can improve their mental health and QoL.

Limitations of the Study:

- The sample was limited to urban and semi-urban mothers, which may not represent rural caregivers.
- The study used self-reported scales, which may be influenced by social desirability bias.
- Cross-sectional design limits the ability to establish causality.

Suggestions for Future Research:

- Longitudinal studies can help examine the long-term effects of caregiving on mental health and QoL.
- Including fathers and other caregivers would broaden the scope of understanding.
- Exploring intervention outcomes (e.g., stress reduction programs) would add practical value.

Summary and Conclusion

Summary of the Study:

The present study was undertaken to explore the impact of care burden on the quality of life (QoL) of mothers of children diagnosed with intellectual disabilities. The participants consisted of 150 mothers, aged 25 to 45 years, selected through purposive sampling. Standardized tools were used to assess the care burden (Zarit Burden Interview - ZBI) and quality of life (WHOQOL-BREF).

Objectives of the Study:

1. To assess the level of care burden among mothers of intellectually disabled children.
2. To evaluate the quality of life of these mothers across four domains: physical, psychological, social, and environmental.
3. To examine the relationship between care burden and the quality of life.

Major Findings:

- The mean care burden score was 52.4, indicating moderate to high levels of burden.
- Quality of life was found to be lowest in the psychological and social domains, suggesting poor emotional well-being and limited social interaction.
- A significant negative correlation was found between care burden and all QoL domains, especially psychological health (r = -0.53) and physical health (r = -0.48).
- These results imply that as care burden increases, mothers' perceived quality of life decreases—especially their mental and social well-being.

Conclusion:

The study concludes that mothers of children with intellectual disabilities bear a significant caregiving burden, which negatively affects their overall quality of life, especially their psychological, physical, and social health. The findings underscore the urgent need for supportive interventions, mental health services, and community-level programsaimed at reducing burden and enhancing the well-being of caregivers.

The results are consistent with both national and international literature, highlighting caregiving as a chronic stressor that significantly affects mothers’ mental health and daily functioning.

Implications of the Study:

- Policy-level interventions are needed to provide respite care, financial assistance, and mental health counselingfor mothers.
- Awareness programs can reduce stigma and promote inclusive education and support networks.
- NGOs and healthcare providers must collaborate to provide integrated support for families with intellectually disabled children.

Limitations:

- The sample was limited to urban and semi-urban areas, and findings may not generalize to rural populations.
- The use of self-report measures may have introduced response biases.
- The cross-sectional nature of the study prevents conclusions about causality.

Recommendations for Future Research:

- Future studies could adopt a longitudinal design to examine changes in burden and QoL over time.
- Including fathers and other caregivers may offer a broader perspective.
- Interventional studies evaluating coping training, support groups, and stress management programs can provide practical insights for improving caregivers' lives.

Final Remark:

The caregiving journey of mothers of children with intellectual disabilities is filled with emotional, physical, and social challenges. However, with adequate support, policies, and interventions, their burden can be reduced, and their quality of life can be significantly improved.

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