

Caregiving for Intellectual Disability: A Burden Analysis of the Primary Family Caregivers

Sandesh Sawant ^{1*}, Nitu Basnet ², Dikendra Sanjyal ³, Subhechya Basnet ⁴, Ruchi Mittal ⁵, Manisha Chapagai ⁶

1. Associate Professor, Department of Psychiatry, National Medical College, Birgunj, Nepal.

2. Junior Resident, Department of Psychiatry, National Medical College, Birgunj, Nepal.

3. Junior Resident, Department of Psychiatry, National Medical College, Birgunj, Nepal

4. Junior Resident, Department of Psychiatry, National Medical College, Birgunj, Nepal

5. Junior Resident, Department of Psychiatry, National Medical College, Birgunj, Nepal

6. Associate Professor, Department of Psychiatry & Mental health, Maharajganj Medical Campus, TUTH, Ktm, Nepal.

Abstract

Background

Caregiving for individuals with intellectual disability (ID) often places a significant burden on primary family caregivers, as it requires lifelong care and support. This demanding role can lead to physical, emotional, and financial strains, collectively referred to as "caregiver burden."

Objectives

This study was conducted to identify who serves as a primary caregiver in the family, the caregiver burden experienced by caregivers of intellectually disabled people, and other associated factors.

Methods & Materials

A cross-sectional quantitative study was conducted, using purposive sampling. A sample of 50 primary caregivers was included in this study. The data collection tools used were the Burden Scale for Family Caregivers (BSFC-s) and the Vineland Social Maturity Scale (VSMS). The translated Nepali version of the BSFC-s was used after the validation process. The Vineland Social Maturity Scale was used in its original form, as it is typically administered by clinicians through interviews with informants.

Results

The data indicate that 92% of primary caregivers are mothers, with 60% having no formal education bearing the majority of caregiving responsibilities. The majority (74%) experienced severe to very severe burden, while 24% reported moderate burden. Only 2% experienced mild to no burden. The analysis revealed a significant positive correlation between caregiver burden and patient IQ ($r = 0.419$, $p = 0.002$). Caregivers with secondary support report significantly lower burden levels compared to those without support ($M = 2.58-3.00$, $p = .003$).

Conclusion

In the Nepalese population studied, primary caregivers, mostly mothers, faced severe burden, which was significantly linked to patient IQ and eased by secondary support. The study highlights the urgent need for support systems in Nepal to reduce caregiver burden among those caring for individuals with intellectual disabilities, informing by forming policies and healthcare interventions.

Keywords

Primary caregiver, burden, intellectual disability

*Corresponding Author

Sandesh Sawant

Associate Professor, Department of Psychiatry, National Medical College, Birgunj, Nepal.

Email: saudsandu1234@gmail.com

INTRODUCTION

Intellectual disability (ID) is a lifelong condition requiring varying levels of care and support. It often burdens primary caregivers, typically family members.^{1,2} Caregiving for individuals with an intellectual disability is a demanding task, as caregivers frequently experience physical, emotion-

al, financial, and social strains, collectively referred to as "caregiver burden".³ Burden can have serious effects on caregivers' well-being, increasing their risk of depression, and anxiety, and lowering life satisfaction.⁴

The burden experienced by caregivers is multifaceted, influenced by factors such as the severity of the intellectual disability, co-occurring mental or behavioral challenges, the availability of social support, and caregivers' coping strategies.^{5,6} Studies show that the severity of the disability, functional impairment, and the presence of psychiatric or behavioral problems are significant contributors to caregiver burden.^{7,8} Also, sociodemographic factors like the

caregiver's age, gender, and socioeconomic status also impact the perceived burden.^{9,10}

Cultural and societal norms further shape the caregiver burden experience. In many societies, caregiving for individuals with ID is seen primarily as a female responsibility, leading to significant gender disparities in caregiver burden.¹¹ Studies suggest that mothers may experience higher levels of burden compared to fathers.^{12,13} The availability and quality of social support systems, both formal such as respite care, and support groups and informal like family and friends, play a crucial role in reducing caregiver burden.^{14,15} Despite growing global research on caregiver burden, there is limited understanding of family caregiving patterns and role-specific burden levels within Nepal's cultural context.

Hence, this study aims 1. To determine who serves as the main caregiver within families 2. Assess the level of burden experienced by those caring for individuals with intellectual disabilities 3. Explore various factors that may influence or be connected to this caregiving experience

METHODS

This cross-sectional quantitative study was conducted at the National Medical College in Birgunj, Nepal, from November 1, 2023, to April 30, 2024, following ethical approval (Ref. F-NMC/675/080-081). The study focused on primary caregivers of individuals with intellectual disabilities, specifically those who provide daily care. A purposive sampling method was employed. Since the prevalence of intellectual disability was 1%,¹⁶ the likelihood of having primary caregivers in the outpatient department (OPD) was considered proportional. Therefore, a 1% prevalence rate was used to estimate the caregiver population for the study. The calculated sample size was 15, with a 95% confidence level and a 5% margin of error. Although the minimum 15 sample size was required, 50 participants were enrolled to ensure the study's validity, reliability, and depth of analysis, ensuring more comprehensive and generalisable findings.

Primary caregivers who accompanied patients for intelligence assessments at the outpatient psychiatry department were assessed at the clinical psychology unit. Upon confirming below-average intelligence in the patients, the caregivers were informed about the study, and those who provided consent were included as participants.

The study variables included the intellectual disability, caregiver's age, gender and relation, education level, employment status, and caregiver burden level.

Data collection tools included the Vineland Social Maturity Scale (VSMS),¹⁷ which has also been used for the assessment of intelligence,¹⁸ and the Burden Scale for Family Caregivers (BSFC-s), which measured the subjective burden of caregivers. The BSFC-s is a validated 10-item scale with high internal consistency (Cronbach's alpha = 0.92).¹⁹ The Vineland Social Maturity Scale was used in its original form, as it is typically administered by clinicians through interviews with informants. The BSFC-s questionnaire was translated into Nepali and validated through forward-backwards translation, expert review, and pilot testing to ensure linguistic and conceptual equivalence and interviewer-assisted administration was used due to the participants' limited literacy.

RESULTS

Table 1: Socio-demographic profiles of the participants (n = 50)

| Characteristics | | Frequency | Percent |
|-------------------|------------------|-----------|---------|
| Address | Parsa (Nepal) | 16 | 32 |
| | Bara (Nepal) | 34 | 68 |
| Age | 20-29 | 10 | 20 |
| | 30-39 | 15 | 30 |
| | 40-49 | 13 | 26 |
| | 50-59 | 10 | 20 |
| | 60 & above | 2 | 4 |
| Primary caregiver | Mother | 46 | 92 |
| | Father | 3 | 6 |
| | Brother | 1 | 2 |
| Occupation | Homemaker | 43 | 86.0 |
| | Working on wages | 3 | 6 |
| | Farmer | 4 | 8 |
| Total | | | |

Table 1: Socio-demographic profiles of the participants (n = 50)

Table 1 presents the socio-demographic profile of the participants. Out of 50 caregivers, the majority (68%) were from Bara, while 32% were from Parsa. Most caregivers were aged 30–39 (30%) and 40–49 (26%), followed by those aged 20–29 (20%) and 50–59 (20%). Only 4% were aged 60 and above. The majority of primary caregivers were mothers (92%), with fathers (6%) and brothers (2%). The occupational status of the caregivers shows that 86% are homemakers, while 6% are skilled workers, and 8% are non-skilled workers.

Table 2.

| Caregiving for Intellectual Disability (ID) | Severity level of ID | Frequency | Percent |
|---|----------------------|-----------|---------|
| | Mild | 2 | 4 |
| | Moderate | 21 | 42 |
| | Severe | 21 | 42 |
| | Profound | 6 | 12 |
| Total | | 50 | 100 |

Table 2 presents the severity levels of intellectual disabilities supported by primary caregivers. The majority of caregivers provided care to individuals with Moderate and Severe Intellectual Disabilities, each comprising 42% of cases, while Profound Intellectual Disability accounted for 12%, and Mild Intellectual Disability was observed in only 4% of cases.

Table 3.

| Caregiver Burden | Severity level | Frequency | Percent |
|------------------|-------------------------------|-----------|---------|
| | 0-4 (none to mild) | 1 | 2 |
| | 5-14 (Moderate) | 12 | 24 |
| | 15-30 (Severe to very Severe) | 37 | 74 |
| Total | | 50 | 100 |

Table 3 presents the caregiver burden experienced by the participants. Among all the participants 74% of caregivers experienced severe to very severe burden, 24% reported moderate burden, and only 2% reported mild to no burden.

Table 4.

| t-test (comparing means) | Characteristics | Frequency | p-value |
|--------------------------|---------------------------------|----------------|---------|
| | Secondary caregiver Present | 33 (Mean=2.58) | .003 |
| | Secondary caregiver not Present | 17 (Mean=3.00) | |

Table 4 presents t-test findings comparing caregivers with and without secondary support. It shows that those participants who had secondary caregivers to support reported lower burden levels, with a mean score of 2.58 compared to 3.00 when compared with the participants who had no secondary support. The difference in burden levels was found to be statistically significant ($p = .003$).

Table 5

| Pearson Correlation | Correlation | p-value |
|------------------------------------|-------------|---------|
| Intellectual disability and Burden | .419** | .002 |

Table 5 show a correlation between Intellectual disability and Burden experienced by the caregiver. The analysis revealed a significant positive correlation between the patient's IQ and the burden experienced by the caregiver ($r = 0.419$, $p = .002$).

DISCUSSION

This study provides crucial insights into the experiences of primary caregivers of individuals with intellectual disabilities (ID), highlighting the significant burden they face and the factors influencing this burden. The predominance of female caregivers, particularly mothers (92%), indicates caregiving predominantly falls on mothers. The findings from this study aligns with previous research indicating that caregiving responsibilities for individuals with ID often fall disproportionately on women.¹¹ This gender disparity in caregiving roles reflects broader societal norms and expectations, which can exacerbate the burden experienced by female caregivers.¹²

The high proportion of homemakers (86%) among caregivers further underscores the intersection of gender roles and caregiving responsibilities, potentially limiting opportunities for personal development and social engagement outside the home.⁹ The large proportion of homemakers reflects the influence of traditional gender roles, where women, particularly those not employed outside the home, are responsible for caregiving duties. This also suggests that caregiving responsibilities add to the already substantial household responsibilities of homemakers, increasing their overall burden.

The severity of caregiver burden observed in this study, with 74% of caregivers reporting severe to very severe burden, is particularly concerning. This high level of burden is consistent with findings from other studies that have highlighted the significant challenges faced by caregivers of individuals with ID.²⁰ The positive correlation between the severity of intellectual disability and caregiver burden ($r = 0.419$, $p = .002$) supports previous research indicating that caregivers of individuals with more severe disabilities experience higher levels of stress and burden.^{7,8} This finding highlights the immense challenges faced by the majority of caregivers, especially those dealing with individuals who require intensive support.

The significant difference in burden levels between caregivers with and without secondary support ($p = .003$) underscores the crucial role of support systems in mitigating

caregiver burden. This finding aligns with research emphasizing the importance of both formal and informal support networks in reducing stress and improving well-being among caregivers.^{14,15}

The moderate to profound ID (96%) among care recipients in this study indicates a significant level of care needs, which likely contributes to the high burden levels reported by caregivers. This finding emphasizes the need for targeted interventions and support services tailored to the specific challenges faced by caregivers of individuals with more severe intellectual disabilities.^{5,6}

The findings show there is a clear need for comprehensive support systems, including both formal and informal support networks, to alleviate caregiver burden. Developing and expanding educational programs for children with intellectual disabilities can promote their independence and help reduce caregiver burden.²¹ Enhancing social support systems is essential to addressing caregivers' emotional needs.²² Developing and testing effective interventions can further alleviate caregiver strain.²³ Additionally, improving adult services and addressing caregiver dissatisfaction during the transition to adulthood may help reduce stress and prevent feelings of helplessness.²⁴

While this study provides useful findings, it has certain limitations. The cross-sectional design limits understanding of changes in caregiver burden over time, and the sample size may affect generalizability. This study does not assess caregivers' mental health and solely assesses caregiver burden, which may contribute to their perceived burden. Future research should explore changes in burden and evaluate support programs to improve services for caregivers of individuals with intellectual disabilities in Nepal.

CONCLUSION

This study highlights the significant burden faced by caregivers of individuals with intellectual disabilities, especially mothers. Despite support from secondary caregivers, primary caregivers still experience high levels of strain. Strengthening support systems is essential to reducing caregiver stress and improving overall well-being.

FUNDING SOURCE

Self

ACKNOWLEDGEMENT

None

CONFLICT OF INTEREST

None

References

1. Maes B, Broekman TG, Došen A, Nauts J. Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*. 2003 Sep;47(6):447-55.
2. De Schipper JC, Schuengel C. Attachment behaviour towards support staff in young people with intellectual disabilities: associations with challenging behaviour. *Journal of Intellectual Disability Research*. 2010 Jul;54(7):584-96.
3. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. *International journal of nursing sciences*. 2020 Oct 10;7(4):438-45.
4. Unsar S, Erol O, Ozdemir O. Caregiving burden, depression, and anxiety in family caregivers of patients with cancer. *European Journal of Oncology Nursing*. 2021 Feb 1;50:101882.
5. Datta SS, Russell PS, Gopalakrishna SC. Burden among the caregivers of children with intellectual disability: associations and risk factors. *Journal of Learning disabilities*. 2002 Dec;6(4):337-50.
6. Al-Krenawi A, Graham JR, Al Gharaibeh F. The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society*. 2011 Mar 1;26(2):139-50.
7. Irazábal M, Marsà F, García M, Gutiérrez-Recacha P, Martorell A, Salvador-Carulla L, Ochoa S. Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder. *Research in developmental disabilities*. 2012 May 1;33(3):796-803.
8. Dawson F, Shanahan S, Fitzsimons E, O'Malley G, Mac Giollaibhui N, Bramham J. The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. *Journal of Intellectual Disability Research*. 2016 Jun;60(6):553-63.
9. McManus BM, Carle A, Acevedo-Garcia D, Ganz M, Hauser-Cram P, McCormick M. Modeling the social determinants of caregiver burden among families of children with developmental disabilities. *American journal on intellectual and developmental disabilities*. 2011 May 1;116(3):246-60.
10. Chou YC, Fu LY, Lin LC, Lee YC. Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *International psychogeriatrics*. 2011 May;23(4):562-72.
11. Rathee S, Kumar P, Singh AR. Burden and quality of life among caregivers of children with intellectual impairment: Across the gender. *Journal of Disability Studies*. 2019 Dec 12;5(2):33-6.
12. Lauderdale-Littin S, Blacher J. Young adults with severe intellectual disability: Culture, parent, and sibling impact. *Journal of Intellectual & Developmental Disability*. 2017 Jul 3;42(3):230-9.
13. Boström PK, Broberg M. Openness and avoidance—a longitudinal study of fathers of children with intellectual disability. *Journal of Intellectual Disability Research*. 2014 Sep;58(9):810-21.
14. Sahu S, Sahu KK, Tanwar S. Perceived Stress, Social Support, Family Burden and Stigma among Caregivers of Persons with Intellectual Disability. *Journal of Disability Studies*. 2019 Jun 28;5(1):31-6.
15. Sit HF, Huang L, Chang K, Chau WI, Hall BJ. Caregiving burden among informal caregivers of people with disability. *British journal of health psychology*. 2020 Sep;25(3):790-813.
16. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. Text revision. 2000.
17. Doll EA. The measurement of social competence: A manual for the Vineland Social Maturity Scale. *Journal of Consulting Psychology*. 1954 Feb 28;18(1):74.
18. Roopesh BN. Advanced Scoring and Interpretation of Vineland Social Maturity Scale: Procedure to obtain 'Impairment Adjusted Social Quotient'. *Indian Journal of Mental Health*. 2022;9(1).
19. Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC geriatrics*. 2014 Dec;14:1-9.
20. Bhatia MS, Bhatia S, Gautam P, Saha R, Kaur J. Burden assessment, psychiatric morbidity, and their correlates in caregivers of patients with intellectual disability. *East Asian Archives of Psychiatry*. 2015 Dec 1;25(4):159-63.
21. Dolatabadi E, Bagheri M. The Effectiveness of Education for Children with Intellectual Disabilities on reducing the burden of parental care. *Tolooebehdasht*. 2024 Feb 10;22(6):1-4.
22. Santos T, Steinway C, Mastrogianis A, Chen J, Woodward J, Riddle I, Spicer B, Berens J, Davis T, Cornacchia M, Wright C. Caregiver support, burden, and long-term planning among caregivers of individuals with intellectual and developmental disabilities: A cross-sectional study. *Journal of Applied Research in Intellectual Disabilities*. 2023 Nov;36(6):1229-40.
23. Ptomey LT, Barton K, Swinford E, Bodde A, George A, Gorczyca AM, Niedens CM, Sprague SC, Yeager A, Helsel B, Teri L. Preliminary translation of 'Reducing Disability in Alzheimer's Disease' among individuals with intellectual disabilities and caregiver dyads. *Journal of Applied Research in Intellectual Disabilities*. 2024 May;37(3):e13239.
24. Kanthasamy S, Miskon N, Barlas J, Marsh NV. Family Caregiver Adaptation during the Transition to Adulthood of Individuals with Intellectual Disabilities: A Scoping Review. *InHealthcare* 2024 Jan 3 (Vol. 12, No. 1, p. 116). MDPI.