

## Caregivers' burden of children with intellectual disability

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**Background:** Intellectual Disability (ID) is a life-long disability which has a major impact on the lives of the children who suffer and their caregivers. Caring for those who are intellectually disabled is often itself stressful as care-giving affects several aspects of caregiver's life negatively including poor physical and emotional state. Caregivers experience depression, burden, lack of social support and coping resources than non-caregivers. However, little attention is given to the health of the caregivers or families of these children.

**Objectives:** To find out the level of burden experienced by the caregivers and study their sociodemographic profiles.

**Methods:** A descriptive, cross-sectional study was conducted among the caregivers of intellectually disabled children attending the child guidance clinic in the outpatient department of National Institute of Mental Health (NIMH), Sher-e-Bangla Nagar, Dhaka. The Bangla version of the Zarit Burden Interview (ZBI-B) scale was applied to measure the level of burden experienced by the caregivers of the intellectually disabled children whose diagnoses were already confirmed by a psychiatrist using the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5). A semi-structured questionnaire was used to find out the sociodemographic variables. Data analysis was done by Statistical Package for Social Sciences (SPSS) version 24.0. Ethical clearance was taken from the authority of NIMH, Dhaka.

**Results:** The level of burden measured using the ZBI-B scale among the 66 caregivers of the intellectually disabled children, found that 41 (62.1%) of the respondents experienced severe burden and 25 (37.9%) experienced moderate to severe burden. Among them, 50% were in the age group of 31-40 years, 83.3% were females who were mostly mothers of the children (80.3%), 16.7% of the respondents were fathers and 3% were siblings of the intellectually disabled. The respondents attending the outpatient department of NIMH were mostly from urban residence (72.2%) and more than half of them were unemployed or housewives (59.1%). It was also found that with increasing age, level of burden increased and caregivers living in joint families experienced comparatively, less burden. Only 6 (9.1%) of the respondents admitted to have respite care provision, while the remaining 60 (90.9%) respondents did not have any respite care.

**Conclusions:** All caregivers experience burden taking care of intellectually disabled children. Therefore, education about the child's condition, encouragement, family support, counselling services, regular screening of mothers should also be included in the protocol for management of ID. Community based approaches will help in reaching people who are not even aware of hospital settings for the intellectually disabled children.

**Declaration of interest:** None

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**Keywords:** Caregiver burden; intellectually disabled children; tertiary care hospital.

## Introduction

Intellectual Developmental Disorder (IDD) or Intellectual Disability (ID), according to the World Health Organization (WHO) has overall prevalence of 1-3% in the global scenario.<sup>1</sup> In Bangladesh, Rabbani et al (2009) reported that the prevalence of intellectual disability is 3.8% in the young children age group of 5 to 17 years.<sup>2</sup> In November 2013, an act for the protection of the persons with neurodevelopmental disorder was enacted in Bangladesh.<sup>3</sup> However, as much attention and laws that have been passed for the rights and better future of the intellectually disabled children, very little attention is given on their caregivers. Caregiver burden is defined as “a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring”.<sup>4</sup> Burden of care has two components, namely subjective and objective burden.<sup>5</sup> Objective burden includes measurable effects such as financial and occupational burden, loss of social and leisure activities, household disruptions, restrictions on relationships within and outside the family, etc. Subjective burden is mainly the psychological sufferings of the caregivers themselves and is experienced by them as embarrassment, shame and guilt, sometimes even hatred, uncertainty, depression, etc. Stress occurs in a broader context than simply providing care for a child with an intellectual disability. Caring for those who are intellectually disabled is often itself stressful as care-giving affects several aspects of the caregiver’s life negatively including poor physical and emotional state. Caregivers experience depression, burden, lack of social support and coping resources than non-caregivers. Hence, we can assume that negative consequences of burden among the caregivers can affect the effectiveness of their care-giving whereas positive gains and satisfaction may enhance their care-giving ability.<sup>6</sup>

In Bangladesh, there have been only a few systematic interventions to raise awareness about children with disabilities at the community level. Several children with their caregivers visit the Child Guidance Clinic of NIMH every week from various areas of the country. While attending these children, the researcher started to grow an active interest in the caregivers who clearly appeared mentally, emotionally and physically distressed. The objective of the study was to find out the level of burden experienced by the caregivers and study their sociodemographic profiles.

## Methods

A descriptive, cross-sectional study was conducted in NIMH, Dhaka. It is a 400-bed tertiary level hospital as well as a psychiatric research institute having both inpatient and outpatient departments with a Child Guidance Clinic. The study was carried out for 12 months from April 2020 to March 2021. The sample size to be interviewed was estimated to be 66 for this study. Convenient sampling technique was used to enroll participants and written informed consent was taken from all those who gave consent to participate in the study. Caregivers who got paid or did not live with the children were excluded from the study. Also, caregivers with severe mental disorder were excluded. Both male and female intellectually disabled children in the age group 7-17 years were included but those with co-morbid behavioral disturbances, mental disorders or any other physical illnesses were excluded from the study. Following enrollment, a semi-structured questionnaire containing sociodemographic and other variables was used. The Bangla version of the Zarit Burden Interview (ZBI-B)<sup>7</sup> scale was applied to measure the level of burden experienced by the caregivers of the intellectually disabled children whose diagnoses were already confirmed by a psychiatrist using DSM-5. The Zarit Burden Interview is a popular caregiver self-report measure used by many agencies, originated as a 29-item questionnaire. The revised version contains 22 items. 21 of the items are supposed to measure several aspects of burden, whereas item 22 is a global measure of burden and is not usually included in factor analyses.<sup>8</sup> Each item is a statement in which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never), 1 (Rarely), 2 (Sometimes), 3 (Quite Frequently), 4 (Nearly Always). The sum total of the score may range from (0 - 21) indicating little or no burden, (21 - 40) mild to moderate burden, (41 - 60) moderate to severe burden and (61 - 88) refers to severe burden. Data were analyzed with Statistical Package for Social Sciences (SPSS) Windows version 24.0. All ethical issues were considered and ethical clearance was taken from the authority of NIMH, Dhaka.

## Results

A total of 66 respondents were interviewed for the study (N=66). Among them, 50% of the respondents were in the age group of 31-40 years and 83.3% were females. The respondents attending the outpatient department of NIMH were mostly from urban residence (72.2%) and more than half of them were unemployed or housewives (59.1%). Table 1 shows the sociodemographic characteristics of the caregivers.

**Table 1: Sociodemographic characteristics of caregivers (N=66)**

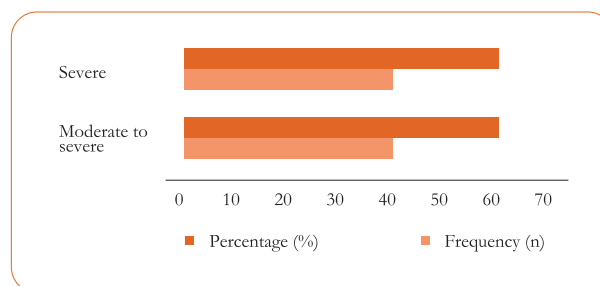
Variable	Frequency (n)	Percentage (%)
<b>Age Group (year)</b>		
21-30	13	19.7
31-40	33	50
41-50	17	25.8
51-60	3	4.5
<b>Gender</b>		
Male	11	16.7
Female	55	83.3
<b>Marital Status</b>		
Single	2	3
Married	57	86.4
Others	7	10.6
<b>Family type</b>		
Nuclear	40	60.6
Joint	26	39.4
<b>Residence</b>		
Urban	48	72.7
Rural	18	27.3
<b>Educational Status</b>		
No formal education	7	10.6
Primary	15	22.7
Secondary	10	15.2
SSC	13	19.7
HSC	4	6.1
Graduate and higher	17	25.8
<b>Occupation</b>		
Unemployed	39	59.1
Service	19	28.8
Self-employed	8	12.1

Among the respondents, 53 (80.3%) of them were mothers of the children. 11 (16.7%) of the respondents were fathers and 2 (3%) were siblings of the intellectually disabled. Only 6 (9.1%) of the respondents admitted to have respite care provision, while the remaining 60 (90.9%) respondents did not have any respite care. (Table 2)

**Table 2: Relationship with the child, living with the child and respite care provision status of caregivers (N=66)**

Variable	Frequency (n)	Percentage (%)
<b>Relation with the patient</b>		
Mother	53	80.3
Father	11	16.7
Sibling	2	3
<b>Respite care</b>		
Yes	6	9.1
No	60	90.9

The level of burden measured using the Zarit Burden Interview (ZBI) scale among the 66 caregivers of the intellectually disabled children found that 41 (62.1%) of the respondents experienced severe burden and 25 (37.9%) experienced moderate to severe burden. (Figure 1)

**Figure 1: Severity of burden among caregivers (N=66)**

## Discussion

Among the 66 respondents interviewed, 50% of the respondents were in the age group of 31-40 years. Of the remaining half, 17 (25.8%) of them belonged to 41-50-year age group, 13 (19.7%) belonged to 21-30-year age group and only 3 (4.5%) of the respondents were in 51-60-year age group. These findings were close to the findings similar studies done in Tamil,<sup>9</sup> Kerala,<sup>10</sup> Kenya.<sup>11</sup>

A great majority of the respondents (83.3%) were females who were mostly mothers of the children (80.3%), 16.7% were fathers and the remaining 3% were siblings. These findings were similar to Maheswari's study where great majority of the respondents (88%) were females and the remaining were male and especially fathers.<sup>9</sup> Almost every study on caregivers of ID children showed that females,

especially mothers were the primary caregivers. Studies also show that mothers of children with intellectual disability displayed poor physical health and psychological state, impairment in social relationships and poorer perception of the environment, and the level of burden increased as the severity of ID increased.<sup>12</sup> In the African context, it is more acceptable for the woman to take up the role of the caregiver as the women are responsible for the emotional care of the children which may result in low self-esteem and loss of self and eventually be associated with maternal depression due to subjective care-giving burden among them.<sup>13</sup>

In this study, 17 (25.8%) of them completed graduation or postgraduation, 15 (22.7%) completed primary education, 10 (15.2%) secondary, 13 (19.7%) completed SSC exam, 4 (6.1%) completed up to HSC and 7 (10.6%) of them had no formal education. In an Indian study, majority of the respondents were found to be educated up to secondary level<sup>9</sup> as well as in another study conducted by Kaur and Arora.<sup>14</sup> These findings were not consistent with the current study.

Among the respondents, 39 (59.1%) were unemployed and most of them were homemakers. 9 (28.8%) were service-holders and the remaining 8 (12.1%) were self-employed. The findings were similar to many other studies<sup>5,9,11,15</sup> where majority of the caregivers, up to 80% were unemployed or home-makers.

Only 6 (9.1%) of the respondents admitted to have respite care provision, while the remaining 60 (90.9%) respondents did not have any respite care in the current study. The burden related to financial costs is further aggravated by insufficient public resources at the community level, such as lack of schools for the intellectually disabled and proper health facilities to meet their health needs.<sup>11</sup>

The level of burden was measured in this study using the Zarit Burden Interview (ZBI) scale among the 66 caregivers of the intellectually disabled children. It was found in the current study that 41 (62.1%) of the respondents experienced severe burden and 25 (37.9%) experienced moderate to severe burden. A comparison study was carried out by Singh et al.<sup>6</sup> where family burden of intellectually disabled children was compared with that of normal children. The burden was much higher among the study group similar to this study. Another study showed that 20.0% of the caregivers experienced no burden, 32.2% of them had mild burden, while 41.7% of

them had moderate burden and 6.1 % of the caregivers had severe burden.<sup>9</sup> These findings were quite different from the current study. Darsana et al.<sup>10</sup> found in his study that 70% of the caregivers experienced moderate burden and 28% severe burden which was similar to the findings in this study.

Burden is experienced on various aspects such as poor financial support, lack of accessibility, poor usage of appliances, lack of knowledge and understanding about intellectual disability, lack of support from family, poor skill in disability management, physical health deterioration of caregivers, etc., all play a major role in causing burden.<sup>9</sup> Studies also show that level of burden increase when there is more than one disabled child in the family<sup>16</sup> and also presence of physical disabilities, other co-morbidities along with intellectual disability further increase the burden.<sup>17</sup> A study by Manuel et al. found that 30% of the mothers suffered from depression.<sup>18</sup> This association was reported by many studies<sup>19,20</sup> which can be attributed to the degree of child dependency on the mother in daily activities of life, such as toileting, bathing, feeding, clothing and mobility, which increase the burden of caring.

Caring for those who are intellectually disabled is often itself stressful as care-giving affects several aspects of caregiver's life negatively including poor physical and emotional state.<sup>21,22</sup> The negative consequences of burden on caregivers harm their care-giving effectiveness, whereas experiencing subjective gains and satisfaction may enhance their care-giving ability. In a study by Taanila et al,<sup>23</sup> found that parents who received information and advice on caring for their disabled children, reported positive feelings towards caring for them. Education about the child's condition, encouragement is therefore a way to go approach for reducing burden. Community based approaches will help in reaching people who are not even aware of hospital settings for the intellectually disabled children. This will also help to reduce stigma among the people in the community and also reduce the social burden caregivers suffer from because for most of the caregivers, their social and family life both have been disturbed by the so-called illness of their child.<sup>10</sup> Widespread implementation of effective early intervention and child development programs<sup>24</sup> and parenting training programs<sup>25</sup> will help to break the cycle and shape health and well-being of the children as well as their caregivers.<sup>26</sup> Welfare programs should not only be directed towards handicapped person, but also towards the family who also suffers to a great extent.<sup>14</sup> Only then there will be change of viewpoint about care of such children.



## Conclusions

All caregivers experience burden taking care of intellectually disabled children. Therefore, education about the child's condition, encouragement, family support, counselling services, regular screening of mothers should also be included in the protocol for management of ID. Community based approaches will help in reaching people who are not even aware of hospital settings for the intellectually disabled children.

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