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Original Article

Pattern of sociodemographic characteristics in relation with caregivers' burden of intellectually disabled children

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Background: : Caregivers of any chronic, life-long, debilitating condition experience severe burden. There are various sociodemographic variables of caregivers associated with Intellectual Disability (ID) as it is a life-long disability and has a major impact, not only on the lives of the children who suffer but also affects several aspects of caregiver's life negatively including poor physical and emotional state. These suggest that stress occurs in a broader context than simply the provision of care for a child with an intellectual disability.

Objectives: The aim of this study was to find out the sociodemographic profiles of the caregivers and see the relation with the level of burden experienced by them.

Methods: A descriptive, cross-sectional study was conducted among the caregivers of intellectually disabled children attending the child psychiatry clinic in the outpatient department and admitted as inpatients in the National Institute of Mental Health (NIMH), Dhaka. A pre-designed structured questionnaire to identify the sociodemographic characteristics was prepared after doing literature review and with the help of expert opinion was applied on the caregivers of 66 intellectually disabled children whose diagnoses were already confirmed by a psychiatrist using the Diagnostic and Statistical Manual-5 (DSM-5). The Bangla version of the Zarit Burden Interview (ZBI-B) scale was applied to measure the level of burden by the caregivers of the intellectually disabled children T-test, one-way ANOVA, Pearson correlation test were done to compare the relation of caregivers' burden with different sociodemographic variables of the caregivers. Data analysis was done by Statistical Package for Social Sciences (SPSS) version 24.0.

Results: A total of 66 respondents were interviewed for the study (N=66). The results for the gender of the caregiver, nuclear and joint family type were clinically significant ($p \leq 0.05$). However, residence, history of mental disorder of the caregivers, and respite care did not show any clinical significance ($p > 0.05$). It was also revealed that burden of the caregiver increased with age which was clinically significant ($p \leq 0.05$), but it was found that an increase in family income, an increase in the number of family members, and more time spent by the caregivers caring for the intellectually disabled did not clinically increase the burden ($p > 0.05$).

Conclusions: Caring for those who are intellectually disabled is often itself stressful as caregiving affects several aspects of caregiver's life negatively including poor physical and emotional state. It has now been demonstrated in this study that caregivers are always family members, mostly mothers of children. Various intervention measures should not only be directed towards handicapped people, but also towards their family who also suffer to a great extent. Only then there will be a change of viewpoint about the care of such children.

Declaration of interest: None

Keywords: Caregiver burden; intellectually disabled children; sociodemographic variables.

Introduction

The term "Caregiver" as used in Nesmith Library policies[1] is defined as a person who meets one of the following criteria:

a. family member or helper who regularly looks after a child or a sick, elderly, or disabled person.
b. has significant responsibility for managing the behavior and or well-being of the individual diagnosed.
c. is designated as such by the child's parent or legal guardian.

There is no published study solely on caregivers' burden on intellectually disabled children in Bangladesh. The caregivers are usually the mother of the child, elderly family members, or the unemployed members of the family. A study in India found that mothers of children with intellectual disability displayed lower physical health, impairment in social relationships, psychological state and poorer perception of their environment.[2] The possible reasons for this could be that most mothers were home-makers and comparatively spent a lot more time with the children without additional help and also restricted to home with no time or provision for leisure activity.[3] Mothers, elderly or unemployed family members do not normally plan to be caregivers but find the need unavoidable, they do not receive any preparation for the role and as they once get engaged to it, they then find it to be very demanding.[4] The caregiver may find lack of control of what happens in their own lives which eventually takes a toll on their health. Mbuaga et al (2011)[5] studied the prevalence of depression among 114 family caregivers of children with intellectual disability in a rural setting in Kenya. 79% of the caregivers were at risk of having clinical depression, where severe were 31.6%, moderate 21%, mild 26% and caregivers suffering from minimal depression were 21.1%. Factors that have been shown to contribute to poor health outcomes of the caregivers include child's behavior, temperament, level of communication ability, severity of the disability, low self-esteem of the caregiver and poor social support.[5] Moreover, the characteristics of the caregiver (e.g. age, marital status, coping ability), the shared history between the caregiver and the child, economic factors (e.g. socioeconomic status, ability to access formal care, employment) and cultural context also influence the outcome of the care giving situation.[6] Factors that reduce psychological distress include a positive belief and non-critical family network. Other coping factors include stress management strategies, family functioning and support from the spouse.[7] The objective of this study was to find out the sociodemographic profiles of the caregivers and see their relationship with the level of burden experienced by them.

Methods

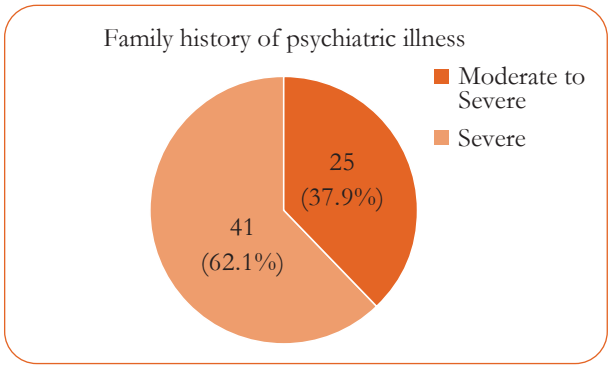
A descriptive, cross-sectional study was conducted among the caregivers of intellectually disabled children attending the child psychiatry clinic in the outpatient department and admitted as inpatients in the National Institute of Mental Health (NIMH), Dhaka. A total of 66 caregivers were selected purposefully and informed written consent was taken from each respondent. A pre-designed structured questionnaire to identify the sociodemographic characteristics was prepared after doing literature review and with the help of expert opinion. This questionnaire was prepared to determine the sociodemographic characteristics of the respondents, including age, sex, residence, marital status, family type, family income, provision of respite care, etc. A pre-testing was done among 5% of the sample size. According to the findings of pre-testing, the questionnaire was finalized after necessary modifications. It was applied on the caregivers of the intellectually disabled children whose diagnoses were already confirmed by a psychiatrist using the Diagnostic and Statistical Manual-5 (DSM-5). The Bangla version of the Zarit Burden Interview (ZBI-B) scale was applied to measure the level of burden by the caregivers of the intellectually disabled children. T-test and one-way ANOVA were done to compare the relation of caregivers' burden with different sociodemographic variables of the caregivers. The Pearson correlation test was applied to see the correlation between age of the caregiver, family monthly income, number of family members and time spent on caregiving with the burden of the caregivers of the ID children. Data analysis was done by Statistical Package for Social Sciences (SPSS) version 24.0.

Results

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. None of the respondents experienced mild to moderate, little or no burden. (Figure 1)

Comparison of mean ZBI Score results showed that the t-value obtained for the independent variables, gender of the caregiver and family type were clinically significant ($p \leq 0.05$) whereas residence, history of mental disorder of the

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



caregivers and respite care did not show any clinical significance (p>0.05). (Table1)

Table 1: Comparison of mean ZBI Score of independent variables of two levels (N=66)

Independent variable	Mean±SD ZBI Score	T	p value
Caregivers' gender			
Male	62.1 ± 5.1	2.0	.047
Female	66.4 ± 9.9		
Family type			
Nuclear	68.2 ± 9.2	-2.7	.008
Joint	62 ± 8.6		
Residence			
Urban	66.1 ± 10.1	0.5	.562
Rural	64.7 ± 7.5		
History of mental disorder			
Yes	66 ± 8.5	0.09	.925
No	65.7 ± 9.6		
Provision of respite care			.
Yes	71.3 ± 5.9	2.2	055
No	65.2 ± 9.6		

***p value was calculated by independent samples t-test*

The mean ZBI Score of the male caregivers was less than the female indicating severe burden in both males and females (ZBI Score > 60=severe burden). The difference was clinically significant (t=2.0, p=.047), stating that the burden experienced by the female caregivers was more than the males in this study.

The mean ZBI Score of the caregivers living in a nuclear family was more than the caregivers living in a joint family. This shows that caregivers living in a joint family experienced severe level of burden but less than those living in a nuclear family, and this was clinically significant (p=.008)

The mean ZBI Score of the urban residents was more than the rural residents, which was severe in both categories, but since the t-value was not found to be clinically significant (t=0.5, p=.562), the residence had no impact on the level of burden.

Similarly, the mean ZBI score of the caregivers who also had a history of mental disorder was more than the caregivers with no history of mental disorder which was also severe in both categories but not clinically significant in this study (t=0.09, p=.925).

The caregivers who received respite care had a mean ZBI Score which was more than those who did not receive any indicating severe level of burden experienced in both categories, whether respite care was provided to them or not. However, the difference in their burden was not found to be clinically significant in this study (t=2.2, p=.055).

The mean ZBI Score in every category of independent variable was more than 60, indicating severe burden experienced by the caregiver irrespective of their gender, type of family, residence, history of mental disorder of the caregiver or whether respite care was provided to them.

Table 2: Comparison of mean ZBI Score independent variables of three or more levels (N=66)

Independent variable	Mean±SD ZBI score	F	df	p value
Educational status				
Illiterate	67.4 ± .5	1.51	5	.199
Primary	67.2 ± 8.4			
Secondary	58.4 ± 6			
SSC	67.3 ± 13.9			
HSC	68 ± 12.7			
Graduate and higher	66.3 ± 9.4			
Occupation				
Unemployed	65.1 ± 11.1	0.4	2	.671
Service	65.7 ± 7			
Self-employed	68.5 ± 4.8			

Independent variable	Mean±SD ZBI score	F	df	p value
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Illiterate	67.4 ± .5	1.51	5	.199
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Graduate and higher	66.3 ± 9.4			
Occupation				
Unemployed	65.1 ± 11.1	0.4	2	.671
Service	65.7 ± 7			
Self-employed	68.5 ± 4.8			
Relationship with the patient				
Mother	66.8 ± 9.9	2.04	2	.138
Father	62.1 ± 5.1			
Sibling	57 ± .00			
Marital status				
Single	57 ± .00	1.96	2	.149
Married	65.4 ± 9.8			
Others	70.8 ± 2.6			
Age group				
21-30	62.6 ± 8.7	.58	3	.629
31-40	66.4 ± 9.0			
41-50	66.2 ± 11.4			
51-60	68 ± .00			
Income group				
0-15K	67.2 ± 10.2	1.41	2	.251
15-30K	64.5 ± 6.8			
>30K	62.0 ± 9.1			
Total	**65.7 ± 9.4**			

**p value was calculated by one-way ANOVA*

Table 2 showed the comparison between variables at three or more levels.

The mean ZBI Score at all levels of educational status was more than 60, except those who completed up to secondary education had moderate to severe burden. But these results were not clinically significant (F=1.51, p=.199).

The occupation of the caregivers, whether unemployed, service holders or self-employed had mean ZBI Score of more than 60 which was also not clinically significant (F=0.4, p=.671).

Fathers and mothers as caregivers experienced severe burdens, however siblings experienced moderate to severe burdens, but the results were not found to be clinically significant (F=2.04, p=.138).

ANOVA test showed that single caregivers had moderate to severe burden but married and caregivers with other marital status (widowed, divorced, etc.) experienced severe burden. These findings, however, were not clinically significant (F=1.96, p=.149).

The mean ZBI Score for all age groups, between 21 to 60 experienced severe burden but the result was not clinically significant (F=0.58, p=.629).

The severity of the burden did not vary with the family income of the caregivers, as the mean ZBI Score among all income groups was more than 60, which again, was not found to be clinically significant (F=1.41, p=.251).

Pearson correlation test was applied to see the correlation between age of the caregiver, family monthly income, number of family members and time spent on caregiving with the burden of the caregivers of the intellectually disabled children. (Table 3)

Table 3: Pearson correlation test of age, income, number of family members, time spent on caregiving with ZBI score (N=66)

Variable	Caregiver burden	
	r value	p value
Age of the caregiver	.273	.026
Monthly income	.222	.073
Number of family members	.194	.118
Time spent on caregiving (hours/day)	.183	.142

∑*r= Pearson correlation coefficient*

The burden of the caregiver increased with age or the older caregivers experienced more burden than the younger ones, which was found to be clinically significant (r=.273, p=.026).

It was found that with an increase in family income, the burden of the caregiver decreased but this finding was not clinically significant (r=-.222, p=.073) and that with an increase in the number of family members, the burden decreased, which was also not found to be clinically significant (r=-.194, p=.118).

When the time spent by the caregivers caring for the intellectually disabled child was more, the burden was also more. However, the results were not found to be significant (r=.183, p=.142).

Discussion

Intellectual Developmental Disorder (IDD) imposes psychological, social and financial distress among the caregivers. Out of 66 respondents interviewed for the study, 50% of the respondents were in the age group of 31-40 years, close to the findings of other studies.[2, 5, 8, 9]

This study indicates that older caregivers feel greater burden than younger ones as well as the severity of the burden felt by the caregivers increase with age. Physical health deterioration of the caregivers with age is a major reason for this.[8]

A great majority of the respondents (83.3%) were females in the current study who were mostly mothers of the children (80.3%), others were grandmothers and elder sisters. The remaining 16.7% were males, mostly fathers. Almost every study on caregivers of ID children showed that females, especially mothers, were the primary caregivers. Mothers of children with intellectual disability displayed poor physical health and psychological state, impairment in social relationships and poorer perception of their environment.[10] An African study showed 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[11] 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.[12]

The mean time spent by the caregiver in the current study was found to be 9.5 hours per day ± 3.3 SD, where the minimum time spent was 4 hours and maximum 18 hours per day. As more time is spent on the disabled children, mothers are restricted to home with no time or provision for leisure activity.[13]

40 (60.6%) of the respondents in this study belonged to nuclear family and 26 (39.4%) to joint family type. The finding was close to a similar study by Sethi, et al.[13] The average number of family members was 5.5 ± 2.4 SD, with a minimum of 3 and maximum of 10 family members. Caregivers in both categories experienced severe level of burden but caregivers living in a joint family experienced less burden than those living in a nuclear family. A reason for this may be that a larger number of family members divided the task load and care-giving hours spent by the primary caregiver every day. The caregiver found time for rest and recreation, their level of stress is reduced to an extent and hence, the burden. Family caregivers who provide care to other family members also need supervision or assistance in illness or disability.[7]

Among the respondents in the current study, 40 (60.6%) had a monthly family income of around 15,000 BDT, 16 (24.2%) earned between 16,000- 30,000 BDT and 10 respondents (15.2%) earned more than 30,000 BDT. This showed that the majority of the respondents belonged to lower socioeconomic class. In another similar study in India,[14] found that most of the families, 67%, belonged to the poorer section with total family income less than Rs. 5000/month. Around 30% of the families had a reasonably good income in the range of 5000-15000/month. These findings as well as the current findings were similar to other studies in India,[2,15,16] Kenya,[5] Qatar[17] and Australia[18]. The majority of the respondents were poor, and they do not have other sources of income other than their monthly income to take care of their special children with special needs. It is a known fact that income is the ultimate need of all families to fulfill their basic needs as well as special needs. Studies showed that respondents had borrowed money to meet the household expenses and treatments. They used to borrow money from their neighbors, relatives, and mortgage their jewels and some got money from the money lenders for their urgent needs.[8]

A study in India found that great majority (85%) of the respondents received the stipend of Rs. 1000/- given by the government to the children as well as care takers, got the equipment, and access to day care centers for their children with special needs.[8] Only 6 (9.1%) of the respondents admitted having 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.[5]

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.[8] Studies also show that level of burden increase when there is more than one disabled child in the family[19] and also presence of physical disabilities, other co-morbidities

along with intellectual disability, further increase the burden[20]. This association was reported by many studies [21,22] 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.

Conclusion

Caring for those who are intellectually disabled is often itself stressful as caregiving affects several aspects of caregiver's life negatively including poor physical and emotional state. It has now been demonstrated in this study that caregivers are always family members, mostly mothers of the children, who are usually homemakers and spend a large amount of time solely caring for the intellectually disabled. Financial problems, difficulty enjoying leisure activities due to lack of additional help and poor family support, older age and various degree of distress while trying to understand the behaviors of the children are all associated with and increase the burden on the caregivers. The negative consequences of burden on caregivers harm their care-giving effectiveness, whereas experiencing subjective gains and satisfaction may enhance their care-giving ability. Various activities including education about the child's condition, encouragement, improving the mental health of the mothers of disabled children, focusing on poverty reduction, enhancing the resilience of mothers in the face of adversity, and improving the social, emotional and behavioral development of disabled children, counselling services, treatment if required are needed. Regular screening of mothers, community-based approaches to help in reach people who are not even aware of hospital settings for the intellectually disabled children will help to reduce stigma among the people in the community. Educational activities for parents on parenting a disabled child, the availability of services, and how to utilize them should start from the time the mentally disabled child is born. Welfare programs have been started for the mentally handicapped individuals by the government and voluntary organizations, but families of these handicapped children are ignored. Intervention should not only be directed towards handicapped people, but also towards their family who also suffer to a great extent. Only then there will be a change of viewpoint about the care of such children.

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