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Keya Samanta
Staff Nurse, Ghatal SSH, Ghatal, Paschim Medinipur, West Bengal, India

Binapani De
Ph.D. Scholar, MGU, Bhopal, Madhya Pradesh and Reader, Govt. College of Nursing, DMGMCH, Purulia, West Bengal, India

Corresponding Author:
Keya Samanta
Staff Nurse, Ghatal SSH, Ghatal, Paschim Medinipur, West Bengal, India

Burden and adopted coping strategies among caregivers of mentally challenged children in selected special school at Bankura, West Bengal

Keya Samanta and Binapani De

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Abstract
Background: Parents or caregivers of mentally challenged children experience a high level of burden from different aspects of their lives. Taking care of a mentally challenged child is more stressful than taking care of a normal child.
Aims: The aims of this study are to assess the burden, adopted coping strategies of the caregivers of mentally challenged children and find out the relationship between the caregiver's burdens and adopted coping strategies.
Materials and Methods: 106 caregivers of mentally challenged children were selected by purposive sampling from a selected special school at Bankura, West Bengal. Standardized Zarit Burden Interview (ZBI) schedule was used to assess burden and standardized brief COPE scale was used to identify adopted coping strategies.
Results: The study result revealed that 30.18% of caregivers had severe burden, 58.49% had moderate to severe burden, 9.45% had mild burden and 1.88% had no burden and they experienced highest burden in finances. Majority (76.41%) of caregivers adopted moderate coping strategies. Burden was negatively correlated with adopted coping strategies at 0.05 level of significance.
Conclusion: As mentally challenged children is increasing day by day which increases the caregiver's burden, so prior assessment will help to prevent and manage disabilities and to adopt effective coping mechanism to reduce the caregiver's burden.

Keywords: Burden, adopted coping strategies, mentally challenged children

Introduction
The term "mentally challenged" or "mental retardation" (MR) refers to a disorder that manifests during the developmental stage and is characterized by significantly below-average general intellectual function, an IQ of 70 or lower, and an impairment in adaptive behaviour [1].
Because the difficulties of the children affect family members' lives as well, the birth and care of mentally challenged children are frequently traumatic situations for family members. Having a child that is intellectually impaired in the family comes with a lot of issues. The issues are primarily connected to societal stigma and mockery. The child could become socially and familiarly isolated as a result of this. The child might be forbidden from coming out in front of the family, and occasionally, the family may have forgotten about them at homealone when going out [2].
There is no doubt that mental retardation is a lifelong disability which has severe impact on the lives of the children and their families. So, the caregivers of mentally challenged children will also be at risk for different kinds of family life as well as physical, psychological, and social problems also [3].
Mothers are more active in their child's care and bear most of the burden related to it.They frequently give themselves little time to adjust because the disabled child still needs regular care. Mothers typically struggle with child care, eating, bathing, dressing, and finding time to care for their children. When mothers see that their child is retarded, they frequently experience a loss of self-esteem [4].
Many families must have started dealing with long-term doubts about their children's present and future functioning as they saw their children grow. Due to the child's specific needs, such as equipment, medical attention, or a need for special education, the financial load has

also increased. It will be challenging for both parents to work outside the home in this circumstance, and income will decrease [5].

Caring for a child with mental retardation frequently places a mild, moderate, or severe burden on various areas of the caregivers. They occasionally choose not to share their feelings with others. The caregivers use a variety of coping mechanisms to handle this demanding circumstance. They can choose to behave in a positive or negative manner, depending on the stage of life.

After reviewing literature and current scenario of mentally challenged children, the researcher wants to assess the burden and identify the adopted coping strategies by the caregivers. The researcher also think that it will give emphasis on caregiver's psychology and any kind of treatment requirement for caregivers having mentally challenged children, because if they are fit physically and psychologically, the children will receive more attention and care and quality of life of caregivers as well as the children will improve.

Materials and Methods

Study Design and sample size: This study was a descriptive survey and participants were obtained from a selected special school at Bankura, West Bengal. 106 caregivers of mentally challenged children were selected by purposive sampling technique with 95% confidence interval.

Selection criteria

Participants included either male or female caregivers who are responsible to give care to mentally challenged children, age of the mentally challenged children will be between 4-12 years and caregivers who can speak in Bengali. Caregivers who are not willing to participate were excluded from the study.

Ethical consideration

The ethical clearance was obtained from Institutional Ethics Committee, BSMC, Bankura. The written informed consent was obtained from the caregivers before conducting the interview. Confidentiality and anonymity was maintained throughout the study.

Data collection

Final data collection period was from 12.01.2023 to 11.02.2023. After getting permission from all concerned authorities data collection procedure was done from 106 samples who met the inclusion criteria in special school BIKASH at Bankura, West Bengal.

At first the investigator interviewed the caregivers of mentally challenged children by using semi-structured interview schedule to collect the demographic data. After that the investigator again interviewed the caregivers by using Zarit Burden Interview (ZBI) schedule to assess the level of burden. Then the investigator interviewed the caregivers by using Brief COPE Scale to identify the coping strategies adopted by them. Time for interviewing was 30 mins for each respondent.

Data collection tools and technique

There are three validated and reliable tools are used to collect the data. Semi structured interview schedule was developed to collect demographic data. It consists of 13 items which includes Age, sex, educational status, occupational status, marital status, type of family, socioeconomic status (According to modified B.G. Prasad scale January, 2022), residence, number of children, number of having mentally challenged children, relationship with the mentally challenged children, duration of staying with the mentally challenged children, caregivers' addiction.

Standardized Zarit Burden Interview schedule **(**22 questions) is used to assess the level of burden experienced by the principal caregivers. A higher score suggests greater caregiver burden (Range of score 0 to 88). The score range between 0 - 20 indicates mild or no burden, in mild to moderate burden score range is 21-40, in moderate to severe burden score range is 41-80 and score range 61 - 88 indicates severe burden.

Standardized Brief COPE Scale (Containing 28 items) were used for measuring coping and regulating cognition in order to get relief from stress or burden. The score range below <Median-1SD indicates poor coping, Median-1SD to Median+1SD indicates moderate coping and range of score >Median+1SD) suggests good coping. All data were collected by using interviewing technique.

Statistical analysis

Data have been organized in statistical way so that the summarized result will be visualized scientifically. Both descriptive and inferential statistics had been used to classify, tabulate and analyse data. The collected data were analysed by computing frequency percentage. Pearson's correlation and coefficient formula was used to find out the relationship between burden and adopted coping of the caregiver. Chi-square test was also used to determine the association of selected demographic variables with burden and adopted coping of the caregiver.

Results

Maximum of caregivers (39.62%) were in the age group of 19-30 years. most of caregivers (89.63%) were female. Majority of caregivers (71.69%) were lived in urban area. maximum of caregivers (35.84%) had primary education. majority of the caregivers (72.65%) were home maker. Most of the caregivers (91.51%) were married. majority of caregivers (50%) belonged to nuclear family. Data also revealed that socioeconomic status of maximum caregivers (34.90%) were from lower middle class and lower class. majority of caregivers (56.61%) had two children and most of the caregivers (93.40%) had only one mentally challenged child. majority of caregivers (79.24%) were mother of mentally challenged children. Data also showed that majority of caregivers (56.61%) stayed with mentally challenged children for 8-12 years. Maximum caregiver (16.04%) had addiction.

Findings related to level of burden of caregivers of mentally challenged children

Table 1: Distribution of respondents according to level of burden n =106

Variables	Range of score	Frequency (f)	Percentage (%)
Little or no burden	0-20	2	1.88
Mild to moderate burden	21-40	10	9.45
Moderate to severe burden	41-60	62	58.49
Severe burden	61-88	32	30.18

Minimum score=0, Maximum score=88

Data presented in Table 1 depicted that majority of caregivers (58.49%) were having moderate to severe burden followed by (30.18%) were having severe burden.

Table 2: Domain wise Mean and Mean Percentage of level of burden of caregivers of mentally challenged children n=106

Domains	Range of score	Mean	Mean Percentage (%)
Burden in relationships	0-24	16	67
Emotional well being	0-28	16	57.1
Social and family life	0-16	7.92	49.5
Finances	0-4	2.78	69.5
Loss of control over one's life	0-16	10.7	66.9

Data presented in Table 2 interpreted that among five domains of burden, caregivers experienced highest burden in finances, mean percentage of which was (69.5%) and lowest burden in social and family life, mean percentage was (49.5%).

Findings related to adopted coping strategiesof caregivers of mentally challenged children

Table 3: Distribution of caregivers of mentally challenged children in terms of adopted coping strategies n =106

Variables	Range of score	Frequency (f)	Percentage (%)
Adopted coping strategies			
Poor coping	<Median-1SD (<50.4)	12	11.33
Moderate coping	Median-1SD to Median+1SD (50.4- 64)	81	76.41
Good coping	>Median+1SD (>64)	13	12.26

Minimum score=28, Maximum score=112

Data presented in Table 3 revealed that majority of caregivers (76.41%) were adopted moderate coping strategies and (11.33%) were adopted poor coping strategies.

Table 4: Domain wise Mean and Mean Percentage of adopted coping strategies of caregivers of mentally challenged children n=106

Domains	Mean	Mean Percentage (%)
Self-distraction	5.41	67.62
Active coping	4.1	51.25
Denial	2.28	28.5
Substance use	2.08	26
Emotional support	4.36	54.5
Use of information support	4.40	55
Behavioral disengagement	2.7	33.8
Venting	3.91	48.8
Positive reframing	2.44	30.5
Planning	3.2	40
Humor	2.04	25.5
Acceptance	6.95	86.67
Religion	6.71	83.87
Self-blaming	4.14	51.75

Minimum score=2, Maximum score=8

Data presented in Table 4 depicted that caregiver used humor (mean percentage 25.5) as adopted coping strategies minimum times whereas, acceptance (mean percentage 86.67) used maximum time as adopted coping strategies.

Findings related to relationship between burden and adopted coping strategies of caregivers of mentally challenged children

H_{01}: There is no significant relationship between burden and adopted coping strategies among caregivers at 0.05 level of significance.

Table 5: Relationship between burden and adopted coping strategies among caregivers of mentally challenged children n=106

Variables	Mean	SD	Correlation coefficient (r)
Level of burden	52.5	11.7	-0.14
Adopted coping strategies	57.2	6.8	

df (104) =.087 at 0.05 level of significance, P value (0.087>0.05)

Data presented in Table 5 showed that there is significant statistical correlation between burden and adopted coping strategies among caregivers of mentally challenged children at 0.05 level of significance (r= -0.14, p>0.05, df=104) as evident from calculated 'r' value. So, null hypothesis was rejected. This leads to conclusion that burden of caregivers of mentally challenged children was negatively correlated with their adopted coping strategies at 0.05 level of significance. It means when level of burden increases then coping strategies decreases.

Findings related to association between burden of caregivers with selected demographic variables

There was significant statistical association between burden of caregivers of mentally challenged children and their socioeconomic status (χ^2=4.26, p=0.03 at df=1), number of children (χ^2=4.10, p=0.04 at df=1),their addiction (χ^2=5.96, p=0.01 at df=1) at 0.05 level.

There was no significant association between burden of caregivers and their age, sex and educational status, occupational status, marital status and type of family, residence, number of mentally challenged children, relationship with mentally challenged children and duration of staying with mentally challenged children.

Findings related to association between adopted coping strategies of caregivers of mentally challenged children with selected demographic variables

There was significant statistical association between adopted coping strategies of caregivers of mentally challenged children and their occupational status (χ^2=4.03, p=0.04 at df=1), addiction (χ^2=4.19, p=0.04 at df=1) at 0.05 level.

There was no significant association between adopted coping strategies of caregivers of mentally challenged children and their age, sex and educational status, marital status and type of family, socioeconomic status and residence, number of children and number of mentally challenged children, relationship with mentally challenged children and duration of staying with mentally challenged children.

Discussion

A discussion was made in relation to major variables of the study.

Discussion related to demographic characteristics of caregivers of mentally challenged children

The present study was supported by the study of Kavitha P, Sivapriya S (2021) conducted in India, to assess the burden

level in caregivers of mentally challenged children. Here the researcher identified that 7% of caregivers were in 25-30 years, majority 87% were parents, 43% were undergraduate, 37% lived in urban area, 40% belonged to lower middle class and 3% belonged to lower class [7].

In the present study the researcher identified that maximum of caregivers (39.62%) was in the age group of 19-30 years, majority of caregivers (71.69%) were lived in urban area, maximum of caregivers (35.84%) had primary education, maximum caregivers (34.90%) was from lower middle class and lower class, majority of caregivers (79.24%) were mother of mentally challenged children.

The present study was supported by the study (2017) of Kaur R, Tak G, Gupta S, K to assess the stress of care burden among caregivers of special children in selected Districts of Punjab with a review to develop information booklet. The researcher identified that the majority of the informer were fathers 47(47%), 44 (44%) were mothers, the 32(32%) of the care givers were in the age group of 30- 40 and 32(32%) were in the age group of 41-50 years, majority of care givers (47%) were have primary education, the majority of care givers 55(55%) were unemployed, most of the family 68(68%) were having monthly income less than or equal 10,000/-rupees, majority of the care givers 95(95%) were married, the majority 70(70%) were living in nuclear family, 77(77%) of caregivers were living in rural area and 18(18%) living in urban area [8].

The present study was supported by the study (2016) of P Abirami conducted in S.R.M. General Hospital, Tamil Nadu, India to assess the burden on caregivers of children with selected disabilities. The researcher found that majority of the care givers, 48 (48%), were 26-35years old, and 70 (70%) of them were female. Considering the educational qualification, 30 (30%) were non- literate, 53 (53%) were unemployed; 81 (81%) care givers were residing in urban. Considering the marital status, 64 (64%) care givers were married; regarding relationship with the child, 48 (48%) were mothers and regarding type of family, 69 (69%) were nuclear family [9].

Discussion related to burden of caregivers of mentally challenged children

The present study was supported by the study (2017) of Kaur R, Tak G, Gupta S, K to assess the stress of care burden among caregivers of special children in selected Districts of Punjab with a review to develop information booklet. The findings of the study revealed that out of 100 care givers, 86 (86%) had Severe burden and 14 (14%) had Moderate to severe burden [8].

The present study was supported by the study of P Abirami (2016) conducted in S.R.M. General Hospital, Tamil Nadu, India to assess the burden on caregivers of children with selected disabilities. The analysis depicted that 89 (89%) caregivers were having moderate level of burden and 11 (11%) were having severe level of burden [9].

In the present study researcher found that majority of caregivers (58.49%) were having moderate to severe burden followed by (30.18%) were having severe burden. C aregivers experienced highest burden in finances, mean percentage of which was (69.5%).

The present study was supported by the study of Shanthi C, Sireesha S (2015) at Hyderabad to assess the caregiver burden and psychiatric morbidity in primary caregivers of mentally retarded subjects. This study showed that 51.46% of caregivers expressed mild burden, 29.88% moderate burden and 18.26% severe burden [6].

Discussion related to coping strategies of caregivers of mentally challenged children

The present study was supported by the study of Din N, Teli BA, Majid A (2022) on perceived stress and coping strategies among mothers of Intellectual Disabled children. The majority of mothers were willing to utilize acceptance, religion, and positive reframing coping mechanisms, and study results showed that mothers who had children with intellectual disabilities behave less disengaged and used substances less frequently [10].

The study on stress and coping among mothers of mentally challenged children in selected special schools, proposed by John J and Gandhimathi M (2020), provided support for the present study. Study result showed that about 33.3% of mothers are adequately adapted with stress, 46.7% have moderately adapted and 20% mothers are having very poor adaptation [11].

In the present study researcher revealed that majority of caregivers (76.41%) were adopted moderate coping strategies. Caregiver used humor (mean percentage 25.5%) as adopted coping strategies minimum times whereas, acceptance (mean percentage 86.67%) used maximum time as adopted coping strategies. Mean score of adopted coping strategies was 57.2, Standard Deviation was 6.8.

This study was supported by the study of Kaur K and Kumar Y (2020) to assess the attitude, stress and coping strategies of parents caring for mentally challenged children in selected special school of Ambala, Haryana. The study result showed that 35.7% of parents were using accepting responsibility as ways of coping while caring for mentally challenged children [12].

Discussion related to association between burden of caregivers with selected demographic variables

The present study was supported by the study of P Abirami (2016) conducted in S.R.M. General Hospital, Tamilnadu, India to assess the burden on caregivers of children with selected disabilities. Here, the researcher found that there was significant association between the care givers burden and their demographic variables of sex, education, occupation, income, and relationship with the child [9].

In the present study the researcher revealed that there was significant statistical association between burden of caregivers of mentally challenged children and their socioeconomic status at 0.05 level of significance.

Discussion related to association between adopted coping strategies of caregivers of mentally challenged children with selected demographic variables

In the present study the researcher identified that there was significant statistical association between adopted coping strategies of caregivers of mentally challenged children and their occupational status and their addiction at 0.05 level significance.

This study was supported by the study of Kaur K and Kumar Y (2020) to assess the attitude, stress and coping strategies of parents caring for mentally challenged children in selected special school of Ambala, Haryana. The study result depicted that coping strategies and time spends with children (17.672) & employments of parents (8.704) were statistically significant at 0.05% level of significance [12].

Limitation of the study is that the study findings will not be generalized beyond the present study sample. Because randomization was not possible to select the study sample which was in the previous plan.

Conclusion

The aim of the study was to assess the level of burden among caregivers of mentally challenged children and also the coping strategies adopted by them. The study is concluded from the study findings that majority (58.49%) of caregivers were having moderate to severe burden and (30.18%) were having severe burden and when burden increased then coping strategies adopted by the caregivers are decreases. So, educational intervention can be implemented to improve the coping among caregivers and to reduce the burden.

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Conflict of Interest

Not available.

Financial Support

Not available.

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