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Family Burden of Caregivers of Cognitively Impaired Children Attending Selected Special Centres in Malappuram District

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Abstract

The present study was conducted to assess the family burden of caregivers of cognitively impaired children attending selected special centers in Malappuram district.

Objectives: Assess the level of family burden of caregivers of cognitively impaired children; Find out association between family burden of caregivers of cognitively impaired children with demographic variables.

Methodology: Quantitative approach was used for the study and descriptive design was selected. Data were collected from 100 caregivers of cognitively impaired children attending selected special centres in Malappuram district. The sample consisted of 100 caregivers of cognitively impaired children and selected by using proportionate stratified sampling technique. A socio demographic proforma to collect the socio demographic data and Zarit burden interview to assess the level of family burden of caregivers of cognitively impaired children were the tools used for the study. The caregivers who were meeting the inclusion and the exclusion criteria were selected from the two special centres as the participants for the study. The selected participants were explained about the purposes of the study and were administered with demographic proforma to record their responses. Zarit burden interview was then done for each participant and after the interview with each individual the participants were asked to record their responses by their own. The data collection was done for 1 week.

Results: The study results revealed that out of the total caregivers, 64% of the caregivers of cognitively impaired children experience mild to moderate burden, 23% felt little or no burden, 11% felt moderate to severe burden and 2 % felt severe burden. The study revealed that there is no significant association between the family burden of caregivers and the demographic variables.

Conclusion: The study concluded that caregivers of cognitively impaired children experience different levels of family burden and there is no significant association between family burden of caregivers of cognitively impaired children and demographic variables. **Keywords:** Family burden; special centre; cognitively impaired children.

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Introduction

Background of the study

Health is a state of physical, mental, social and spiritual wellbeing and not merely absence of disease or infirmity. The emotional wellbeing of children is just as important as their physical health. Good mental health allows children and young people to develop the resilience to cope with whatever life throws at them and grow into well-rounded, healthy adults.

It is said that 450 million people suffer from a mental or behavioral disorder per year (WHO 2003). Cognitive impairment is defined as having either a psychiatric disorder, an organic impairment or a developmental disorder that affects cognitive or emotional functions to the extent that capacity for judgment and reasoning is significantly diminished.

The fact that in addition to the core symptoms, cognitively impaired children and adolescents often display a number of co-morbid behavioral problems.

The term family burden, was mentioned first by Grad and Sainsbury. Parents of such children experience stress related to the child's characteristics, particularly behavioural

problems, inadequate support, parental conflict associated with caring for their child with disability, lack of financial and social support, and alteration in family's lifestyle and leisure activities due to care giving responsibilities.

Need and significance of the study

- As per the world disability report 2011, about 15% of the population in the world has disability and among them 2 to 4 % is suffering from severe disabilities. An Anganwadi based survey conducted in partnership with Indian Association of Pediatrics in 2016, found out that 2.5% -3.6% of children had disabilities and among these 69.3%. constituted by cognitive disabilities and remaining by the speech, gross motor, hearing and vision disabilities. Mothers face more stress as compared to fathers because mothers bear disproportionate share of responsibilities in raising their disabled child. Similarly a study examining Asian mothers and Malay Muslim mothers with intellectually disabled children found that Asian mothers seek support beyond the family whereas Malaya mothers mainly rely on support from within the family for taking care of their children The rise in number of special schools for cognitively impaired in India also necessitated the need to undertake study on this area. There are 3000 special schools at present for the disabled children in India. Among these, 1000 special centres are for mentally challenged and remaining constitutes other disabilities. In addition to this, government of India has introduced several national schemes such as DISHA, VIKAAS etc recently for the welfare of the cognitively impaired children which also gives an indication for the rise in the number of cognitively impaired children in India. Its strong impact on the family makes it of extreme importance to investigate methods to assess level of family burden experienced by caregivers of such children and to find measures to reduce the severity of the burden.

Statement of the problem

A study to assess the family burden of caregivers of cognitively impaired children attending selected special centres in Malappuram district.

Objectives of the study:

- Assess the level of family burden of caregivers of cognitively impaired children.
- Find out association between family burden of caregivers of cognitively impaired children with selected demographic variables.

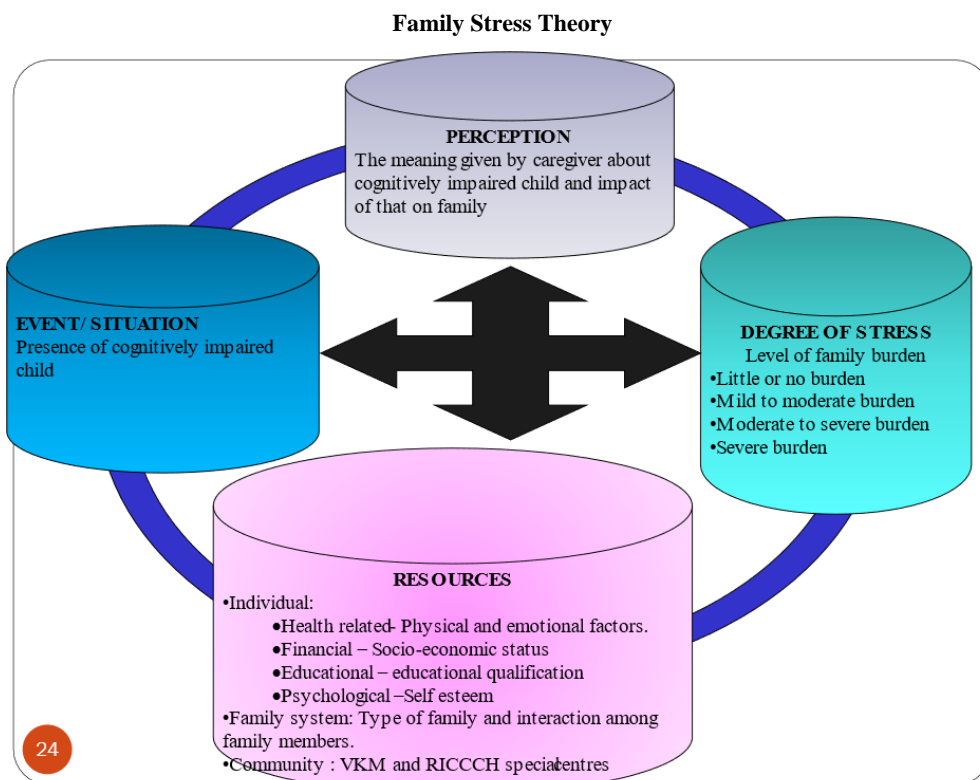
Operational definitions

- Assess:** This refers to measurement of the level of family burden of caregivers of cognitively impaired children by using Zarit burden interview.
- Family burden:** This refers to presence of problems and difficulties faced by caregivers of cognitively impaired children which are likely to affect the family functioning.
- Special centres:** This refers to institutions where cognitively impaired children are studying.
- Care giver:** Mothers who take care of cognitively impaired child.
- Cognitively impaired children:** This refers to children studying in special centres who are diagnosed with cognitive impairments such as autism, mental retardation, cerebral palsy.

Hypothesis

- H1. There is a significant association between the family burden of the care givers of cognitively impaired children with the selected demographic variables.

Conceptual framework



Methodology

Quantitative approach was used. The research design adopted for the study was non experimental descriptive survey design. The research variable of the study was family burden of caregivers of cognitively impaired children. The demographic variables included in the study were age, educational qualification, occupation, religion, place of residence, type of family, socio- economic status, number of children, presence of members with disability in the home, age of the child and sex of the child. The tools used for the data collection in this study are divided into two sections.

Section A: Socio demographic proforma It comprises of 11 items. The tool was developed to assess the demographic factors. It includes age, educational qualification, occupation, religion, type of family, place of residence, socio economic status, number of children, presence of members with disability in the family, age of the child and sex of the child. **Section B: Zarit Burden Interview** It is a standardized tool developed by Steven. H. Zarit in 1980 to assess the level of burden experienced by primary caregivers of older persons with senile dementia and disabled persons. Even though it has been developed to use in caregivers of adults it has been used in research with family caregivers of children with intellectual and behavioural problems. It consists of 22 negatively phrased questions/ statements each with a 5-point likert response scale. (0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always)

The key to determine type of family burden is: 0 to 20 = little or no burden 21 to 40 = mild or moderate burden 41 to 60 = moderate to severe burden 61 to 88 = severe burden

Data collection process

Formal permission from director of special centres was obtained. The data collection was carried out for a period of 1 week. The investigator selected the samples by using convenient sampling technique from those who were included in the inclusion criteria. Initially investigator obtained consent from the participants and assured that the data will be kept confidential. The purpose of the study was explained to the participants before conducting the study. A total of 100 samples were selected from the both centres. Initially socio demographic proforma was administered to the samples and demographic data was collected through self-reporting. Then the family burden of the caregivers was assessed by conducting interview with each caregiver using Zarit burden interview and then by collecting responses for the items in the Zarit burden interview through self-reporting

Ethical considerations

The initial permission for carrying out the study was obtained from institutional ethical committee. Permission obtained from concerned authority of selected special centres and individual consent from the participants of the study. Confidentiality was maintained. No ethical issues were aroused during the course of the study

Results

Section A: Distribution of demographic characteristics of cognitively impaired children and their caregivers.

Section A The characteristics of the study population were as follows: • Regarding the age, 73% of the subjects

belonged to age group of 26 and 40 years, 24% are less than 25 years and 3% are above 40 years. • With respect to type of family, 46% belongs to joint family and 54% belongs to nuclear family. • In case of educational qualification, 54% are having secondary education, 27% are having primary education and 19% are having degree and above. • With regard to occupation, 88% of the subjects are unemployed and 12% are employed. • Regarding religion, 68% are Muslims, 30% and 2% are Hindus and Christians respectively. • With respect to socioeconomic status, 43% possess blue ratio card, 28% possess pink ration card, 14% and 15% possess yellow card and white card respectively. • In case of number of children 66% are having 2 children, 18% are having 1 child, 13% are having 3 children and 3% are having more than 3 children. • With regard to place of residence, 74% belongs to rural region and 26 % belongs to urban region. • Regarding presence of members with disability in family, 95% mothers are not having disabled children other than cognitively impaired children and only 5% are having disabled child other than cognitively impaired children. • In case of gender of cognitively impaired child, majority 54% are male and 46% are female children. • Regarding age of child, 38% are having 3 to 6 years of child, 31% are between 6 to 12 years of age, 20% are between 1 to 3 years of age, 11 % are between 12 to 18 years of age

Section B: Assessment of family burden of caregivers of cognitively impaired children. Majority, 64% caregivers of cognitively impaired children feel mild to moderate burden, 23% feel little/ no burden, 11% feel moderate to severe burden and 2% feel severe burden

Section C: Association between family burden of caregivers of cognitively impaired children. The study revealed that there is no significant association between family burden of caregivers of cognitively impaired children and selected demographic variables like age, educational qualification, occupation, religion, place of residence, type of family, socio economic status, number of children, presence of members with disability in the family, age of child, and gender of child.

Conclusion

The study assessed burden of caregivers of cognitively impaired children attending selected special centres in Malappuram district. The researcher found out that among the 100 caregivers 64% of caregivers had mild to moderate family burden, 23% had little / no burden, 11% had moderate to severe burden and 2% had severe burden. There is no significant association between family burden of cognitively impaired children with demographic variables age, Gender, Education, Occupation, Type of family, Socio economic status, place of residence, number of children, Presence of members with disability in the family, age of the child and sex of the child. From the present study, it can be concluded that majority of the caregivers of cognitively impaired children experience family burden and the level of family burden vary for different caregivers.

References

1. Madhuchandra MK, Srimathi NL. Psychological health and Psychological Illness among college students. IJIFR Research.2017;4(7): 6609-16.

2. Shyam R, Kavita, Govil D. Stress and Family Burden in Mothers of Children with Disabilities. *IJIMS*, 2014;1 (4):152-159.
3. Oruche MU. Research With Cognitively Impaired Participants. *J Nurs Law*. 2009 [cited 2011 Aug 1]; 13(3). Available from: 73227162. PMID: PMC3148014. PMID: 21814457
4. Sen E, Yurtsever E. Difficulties Experienced by Families with Disabled Children. *JSPN*.2007;12(4): 238- 252
5. Maheswari K. Burden of the caregivers of mentally retarded children. *IOSRJHSS*.2014;19(7):06-08.
6. Reddy MS. Depression: The Disorder and the Burden. *Indian J Psychol Med*.2010;32(1):1–2. Available from: MCID: PMC3137804.PMID: 21799550. doi:10.4103/0253-7176.705 10;https://www.ncbi.nlm.nih.gov/pmc/articles/pmc3137804
7. Education for children with disabilities. Available from: <http://vikaspedia.in/educationm/parents-corner/guidelines-for-parents-of-children-with-disabilities/education-for-children-with-special-needs>
8. Latson R. Preventing Parent Burn Out: Model for Teaching Effective Coping Strategies. Available at: http://www.ldonline.org/article/Preventing_Parent_Bur_Out%3A_Model_for_Teaching_Effective_Coping_Strategies.
9. Nehra KD, Sharma N, Kumar R, et.al. Study of burden in parents of children with mental retardation. *SIMH*. March 2014;8(2).13-20.
10. Disabled persons in India. A statistical profile.2016. Available at: http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016.pdf.
11. Nair MK, Princly P, Leena ML, et al. Early detection of developmental delay /disability among children below 3 years in Kerala. A cross sectional Survey. *Indian J Pediatr*. [cited on:Oct 2014].
12. Asagi ER. Parents of Intellectually Disabled children: A Study Of Their Psychosocial Issues.2018; [cited on: August 2018].3(8):58-66. Available online at :ISSN 2456-4931; <http://ijissh.org/wp-content/uploads/2018/08/8.pdf>
13. Pelchat D, Ricard N, Bouchard JM, Perreault M, et al. Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child Care Health Dev* 1999;25:377–97.
14. Masood A, Arshad R, Mazchir S. Families of children with cerebral palsy: Family functioning domains. *Int J Sch Cog Psychol* [cited Mar 26 2015];2:119. Available online at: doi: 10.4172/1234-3425.1000119.
15. Meyers M, Lukemeyers A, The cost of caring: childhood disability and poor families *Social Service Review*.1998;72(2): 209-223.
16. Shanthi C, Sireesha S, Kuna S. A Crosssectional study of caregiver burden and psychiatric morbidity in primary caregiver of mentally retarded subjects Attending Tertiary Care Hospital (IMH) and Rehabilitation Centre (SWE EKAR). *Sch. J. App.Med.Sci*. [cited on 2015];3(3C):1199-1205. Available on: <https://pdfs.semanticscholar.org>
17. Boztope H, Cinar S, Kilic C. Predictors of caregiver burden in mothers of children with leukemia and cerebral palsy. *J Psychosoc Oncol*.2019;37(1):69-78. doi:10.1080/107347332.2018.Epub2019Nov13.
18. Oliveira LA, Oliveira A, Meideiros LG, Santos RB. Burden of caregivers of children and adolescents with Down Syndrome. *Rio de Janeiro*. 2017;22(11). Available on: 3625-3632 DOI: 10.1590/1413-812320172211.31102016.