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RESEARCH ARTICLE

BURDEN PERCEIVED BY THE PARENTS WITH DIFFERENTLY ABLED CHILDREN.

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Abstract

Introduction: The assessment of burden perceived by the parents with differently abled children will provide a further basis of helping parent's adaptation. This study was undertaken to assess the burden perceived by the parents with differently abled children at selected special schools of Idukki District, Kerala.

Method: The present study was an exploratory study of 60 parents whose children are differently abled and students of selected special schools of Idukki. Data were collected by using structured burden scale which is prepared by the researcher. Scale were 3point with 20 statement. Domains were finance, social, emotional, personal and physical. Maximum score were 60. Reliability of tool done by using split half method. Sample were selected as per the criteria with non-probability purposive sampling technique.

Results: Results of this study showed 55% of the parents with differently abled children were having severe burden. Only 13 % were having mild burden. The parents were having burden in all five domains. There is no association with demographic variables and perceived

Conclusion: In the present study majority of parents were having severe burden. Familiarity with coping strategies and the method to use them could balance the social, emotional finance, personal and physical consequences of parents who have differently abled children.

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Introduction:-

Childhood is the period where every individual learns the basic of almost everything. Human beings have a keen sense to adapt to their surroundings and this is what child development encompasses. This period is not the same for everyone but certain milestones have been formulated which can be used to measure the progress of the child's development. When the child reaches these milestones in the prescribed time he is considered as a normal child. The normal childhood seems to be one in which parents do not emphasize the important qualities of the life to their children. Child development refers to the biological, psychological, and emotional changes that occur in human beings between birth and end of adolescence then through adulthood as the individual progresses from dependency to increasing autonomy.

Current research findings have indicated that of differently abled child is commonly experienced as having a devastating effect on parent's lives. Parents are definitely the heart of the family; who is not only has to deal with the issues associated with child's disability but also had to maintain the household. To date, a number of studies

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have demonstrated that parents are more vulnerable to develop mental and physical problems as compare to non-care givers.

Recent studies of caregiving have focused on the term, burden. The term, family burden, was mentioned first by Grad and Sainsbury. They defined it as the negative expenditures created by the intellectually disabled children for their families.

Maladaptive and challenging behaviors of differently abled children may be strong source of stress for parents. Children require constant supervision for their own safety, and their sibling's safety as well. The World Health Organization (WHO) estimates that globally over 450 million people suffer from mental disorders. Currently, mental and behavioral disorders account for 12% of the global burden of disease. This is likely to increase to 15% by 2020. The major proportions of mental disorders come from low- and middle-income countries. The problem is further complicated by a lack of adequate trained manpower and a low priority of mental health in health policy. Reviews shows that there are lot of problems faced by the parents of children with disability. There is lack of knowledge in the parents about the care and how to overcome the problem. Interestingly there are some parents who are happily looking after their children with difficulties. Reviews and personal experience of the investigators helped to think about the present topic so that some strategies can develop on the basis of findings so as to improve the quality of life of the child and parent

Materials and Methods:-

From July to August 2019, 60 parents (Either mother or Father) having differently abled children attending the special schools of Idukki, Kerala participated in the present study. The study population was determined using available simple random sampling method. The inclusion criteria was parents who is staying with differently abled children and willing to participate in the study.

Data were recorded in a questionnaire divided in to two parts. The first part covered the demographic information including number of children, income of family, age of the child and gender. The second part consisted of the structured burden scale with 20 items. The maximum score was 40. Domains were finance, social, emotional, personal and physical. The scoring of the tool was based on the 3 point likert scale, strongly agree, agree, and disagree. The scale was translated in to local language for better understanding by the parents.

Results:-

Section 1:

The frequency and percentage of demographic variables are presented in table 1

Table 1:-Description of samples (Parents with differently abled children) according to demographic characteristics by frequency and percentage (N=60)

Demographic variable	Frequency	%
Number of children		
one	17	28%
Two	28	47%
Three or more	15	25%
Income		
Less than 5000/ month	14	23%
5000-15000 / month	31	52%
15000 or more /month	15	25%
Age of the child		
4-7 years	14	23%
7-12 years	21	35%
12 -16 years	25	42%
Gender of the child		
Male	34	57%
Female	26	43%

The demographic information of parents presented in Table 1 shows that most of the parents are having two children (47%) ,52% of the parents are having monthly income of Rs 5000-15000.The revealed that 42 % of the are having differently abled children between 12-16 years, and 57 % are male children

Section II

Table 02:-Perceived burden of parents with differently abled children (N=60)

Perceived burden	Frequency	%
Mild	08	13%
Moderate	19	32%
Severe	33	55%

Data from the table 2 indicates that 55 % of the parents with differently abled children are having severe burden.

Table 03:-Mean of domains of perceived burden (N=60)

Domains of perceived burden	Mean	SD
Physical	4.9	0.51
Personal	5.6	0.67
Social	4.8	0.56
Financial	5.33	0.75
Emotional	5.8	1.3

The result as demonstrated in Table 3 showed that parents are experiencing emotional burden more as mean value is 5.8 with SD of 1.3

The association between perceived burden and demographic variable was done using analysis of variance. The summary of the result of ANOVA are tabulated below

Table 04:-The association between perceived burden and demographic variable assessment (N=60)

Demographic variable	F	p-value
Number of children	0.3	0.84
Income	0.4	0.53
Age of the children	0.2	0.76
Gender of the child	0.4	0.87

The result of the study showed that there is no association with perceived burden and demographic variables as the p value is more than 0.05

Discussion:-

Present study was conducted to assess the burden perceived by parents with differently abled children. Structured burden scale contained five domain i.e. Financial, Social Personal Physical, Emotional. Result of the present study showed that 55 % of the parents with differently abled children were having severe burden. The parents were having burden in all the domains, but more burden was seen in emotional domain as the mean value is 5.8 with SD of 1.3. There is no association with perceived burden and selected demographic variables.

Hendrik R (2008) conducted a study to assess the effect of mentally retarded children on their parents. Result revealed that parents were having severe social and emotional problems. Parents use different coping strategies to overcome the situation. This study was consistent with the study findings of Hoffman C D (2013), in which the results revealed that the parents were having physically or mentally retarded children experiencing severe stress.

Conclusion:-

The findings have important implications for parents, researchers and health care professionals. The parents with differently abled children are experiencing burden. The adequate use of strategies would help the parents to cope with child's condition more efficiently. Parents should be encouraged more to learn and use about various coping strategies. Necessary facilities should also be provided for implementation of these strategies.

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