



ORIGINAL RESEARCH ARTICLE

OPEN ACCESS

TO ASSESS THE STRESS OF CARE BURDEN AMONG CAREGIVERS OF SPECIAL CHILDREN IN SELECTED DISTRICTS OF PUNJAB WITH A VIEW TO DEVELOP INFORMATION BOOKLET

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ARTICLE INFO

Article History:

Received 23rd July, 2017

Received in revised form

04th August, 2017

Accepted 17th September, 2017

Published online 10th October, 2017

Keywords:

Stress of care burden,
Special children,
Zarit burden interview,
Information booklet.

ABSTRACT

Introduction: Caregivers of challenged encounter different problems at different stages feeling of burden in care giving leads to stress and it takes many forms, demands of daily care, emotional disturbances such as worries frustrations sadness, irritability and relationship problems between family members, in addition there is stigmatization, social embarrassment & financial implication. If the care givers come to know the proper coping strategies and relaxation techniques they can handle stress in more constructive way.

Aim of the Study: The aim of the study is to assess the stress of care burden among care givers of special children in selected districts of Punjab.

Material and Methods: A descriptive research design was used to conduct this research study. 100 care givers of special children in Ferozepur, Faridkot and Sri Muksar Sahib districts of Punjab were selected for this research study. Convenient Sampling Technique was used for data collection and Zarit Burden Interview was used to assess the stress of care burden. After data collection information booklet on stress management was provided to the care givers. Data was collected by interview schedule and analyzed by descriptive and inferential statistics by using SPSS 17.0 version.

Results: 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. There was significant association of stress of care burden with Total family monthly income, Type of family and Exposure to any health education or training of care givers as statistically analyzed by chi square test at 0.05 level of significance.

Conclusion: It was concluded that majority of care givers of special children had severe stress related to care burden. Information booklet on stress management would help them to relive the stress of care burden.

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Citation: Kaur Ramandeep, Tak Ghanshyam and Gupta Sanjay, K.. 2017. "To assess the stress of care burden among caregivers of special children in selected Districts of Punjab with a view to develop information booklet", *International Journal of Development Research*, 7, (10), 15965-15968.

INTRODUCTION

"The capacity to care is the thing that gives life its deepest meaning and significance"

Pablo Casals

Families are the foundation for a child's development, socialization, and formation of his/her values and beliefs.

Families can be a source of great happiness, as well as stress. Every parent dreams of giving birth to a normal child. A lot of preparation and planning is done for the arrival of the baby. But the birth of a physically or mentally challenged child is a transitional situation that triggers stress affecting all the family members. (Pelchat et al., 2007) Parents of children with disabilities cope with the same responsibilities and pressures

that other parents face; however, one reoccurring theme reported among these parents is the higher amounts of stress they experience and greater demands made by caring for a child with special needs. (World Health Organisation, 1976) The *World Health Organization* has defined disability as any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. Child with disability means a child who deviates from a normal child in mental or physical characteristics to such an extent that he requires special education and related services. (Latson, 1995)

United Nations agencies roughly estimated 10% of the world's population (600 million people) experience some form of disability in which 150 to 250 million are children. Disabilities affect significantly the children's independence. Thus, the family who has a disabled child is likely to be exposed to crisis situations, which lead to stress. (Wilker et al., 1981) One stressor for parents who have children with special needs is that they may continue to care for their child for extended periods of time, which can be physically and emotionally draining, society's negative attitude toward their child. (UNICEF, 2011) About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. (<http://www.censusindia.gov.in/>)

Disabled Population by Sex and Residence in India, 2011			
Residence	Persons	Males	Females
Total	26,810,557	14,986,202	11,824,355
Rural	18,631,921	10,408,168	8,223,753
Urban	8,178,636	4,578,034	3,600,602

Although India has a growing disability rights movement and one of the more progressive policy frameworks in the developing world, a lot more needs to be done in accomplishment and getting the basic right. We should teach disabled children's' parents how to become an effective supporter for their child. Informed, supportive families are better able to make good decisions for their child. (Educating Disabled Children, 2010) The *National Sample Survey (NSS)* categorized disabilities into loco motor (lame/crippled), visual, hearing, and mental disability.

Mental illness including retardation was seen among many people. (Facts and Statistics, ?) The parents of children with special needs definitely face more difficulties than parents of normal children, which in turn affect their emotional well being. The result of the study proves that children with delayed development manifest heightened behavior problems, which may negatively affect maternal well-being. (NSSO, ?) Living with a disabled child can have profound effects on the entire family, which in turn can affect the health and well-being of the child who is disabled. Much needs to be learned about how children's health affects their parents, siblings and other family members and how family characteristics and resources modify those associations. (Govt insensitive to disabled children's needs, 2012)

Objectives of the study

- To assess the stress of care burden among care givers.
- To find out the association of stress of care givers regarding care burden with their selected demographic variables.
- To develop information booklet regarding stress management of care givers.

MATERIALS AND METHODS

Research approach and design

A quantitative research approach and Descriptive Research Design was used for the present study.

Research setting

The present study was conducted at Free Homeopathy Medical Camp for the mentally retarded and physically disabled children, Ferozepur, Baba Farid Centre For Special Children, Faridkot and the Resource Centre of Government Senior Secondary School of village Bhangewala, district Sri Muktsar Sahib. The target population of the present study was the care givers of special children in Ferozepur, Faridkot and Sri Muktsar Sahib districts of Punjab.

Sample size and Sampling technique

Sample for this study comprised of 100 care givers of special children in selected Districts of Punjab, was selected through Convenient Sampling Technique. Care givers were selected for this study according to inclusion and exclusion criteria.

Development of tool

The tool for data collection will be consists of two parts:

Part I: Demographic variables: It includes selected demographical variables of study participants like Relationship of information provider with the child, Age, education, Occupation, Total family monthly income, Marital status, Type of family, Area of residence, Exposure to any health education/ training regarding home based care of special children, and Child is attending any special school or day care centre.

Part II: The Zarit Burden Interview was used to assess the stress of care burden among caregivers of special children. It is 5-point scale from 0-4.

Data collection procedure

Data collection was done from January 9, 2016 to January 27, 2016. Data was collected from 100 care givers by using interview schedule. The standardized Zarit Burden Interview scale was used to assess the stress of care burden which is the form of 5-point likert scale and it consist of 22 questions was administered to the study participants as research tool. The study participants were asked to answer all questions within 20 minutes. After collecting data information booklet on stress management was provided to the care givers.

RESULTS

Distribution of care givers according to relationship of information provider with the child revealed that the majority of the informer were fathers 47(47%), 44 (44%) were mothers, 8(8%) grandfathers and 1(1%) were grandmothers. Distribution of care givers according to age revealed that 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 and 12 % were above 50 years. Distribution of care givers according to educational standard depicts that the majority of care givers 47

(47%) were have primary education followed by 30(30%) have senior secondary, 16(16%) have middle level and 7(7%) were graduate or above. Distribution of care givers according to occupation revealed that the majority of care givers 55(55%) were unemployed, followed by 38(38%) were self-employed and 7(7%) were employed. In context with Total family monthly income most of the family 68(68%) were having monthly income less than or equal 10,000/-rupees, followed by 26(26%) having 10,001-20,000/- rupees, 5(5%) having 20,001-30,000 and only 1(1%) having above 30,000/-rupees. In relation to marital status of the care givers majority of the care givers 95(95%) were married, 2(2%) widow as well as 2(2%) were widowed and only 1(1%) were divorced. In accordance to type of family of the majority 70(70%) were living in Nuclear family followed by 30(30%) living in joint family and no one was living in extended family. In relation to Area of residence of the care givers 77(77%) were living in rural area and 18(18%) living in urban area and only 5(5%) were living in semi-urban area. In relation to the Exposure to any health education/ training regarding home based care of special children of care givers 87(87%) have no exposure and only 13(13%) have exposure to any health education or training. With regard to Children of care givers were attending any special school or day care centre includes 64(64%) children attending and 36(36%) were not attending any special school or day care centre.

Objective 1: To assess the stress of care burden among care givers

Mean and Standard Deviation of care burden among care givers.

Table 1.

N=100			
Minimum score	Maximum score	Mean	± SD
48	80	66.82	6.245

The table 1 describes the minimum score is 48, maximum score is 80, overall mean is 66.82, and \pm SD is 6.245.

Table 2. Frequency and percentage distribution of care burden level among care givers.

N=100		
Level of Burden	Frequency (n)	Percentage (%)
Little or no burden	-	-
Mild to moderate burden	-	-
Moderate to severe burden	14	14.00
Severe burden	86	86.00
Total	100	100.00

The table 2 describes the distribution of care burden level among care givers.

Objective 2: To find out the association of stress of care givers regarding care burden with their selected demographic variables

The chi square test was used to assess the association between the levels of stress of care burden among care givers with selected socio demographic variables. In this there is significant association of stress of care burden with Total family monthly income, Type of family and Exposure to any health education or training of care givers as statistically

analyzed by chi square value of 9.767, 5.711 and 7.426 respectively at $df=3,1$ and 1 respectively significant (S^*) at 0.05 the level of significance.

DISCUSSION

The findings are discussed in relation to the objectives-To assess the stress of care burden among care givers. The study results represents on table that on stress of care burden among care givers of special children was moderate to severe in 14% of care givers and severe in 86%. The above objective and findings are supported by study of Shyam et al. (2014) and major findings of the study revealed that mothers of children with both mental and physical disability and mothers of children with mental disability scored significantly higher level of parenting stress and family burden compared to mothers of children with physical disability, mothers of deaf and dumb children, and mothers of children without disability. -To find out the association of stress of care givers regarding care burden with their demographic variables. The study findings shows that there is significant association between stress of care givers regarding care burden with three demographic variables such as total family monthly income, type of family and for exposure to any health education or training of care givers at the $p<0.05$, and $p< 0.05$ level respectively. Upadhyaya et al. (2008) conducted a similar study and results revealed that mothers reported higher stress compared to fathers, the difference being significant at $P=0.001$ levels. Mothers report higher stress and in the area of financial stress, both fathers and mothers reported equal levels of stress. Higher levels of behaviour disorder were noticed in lower age of the mentally challenged parents, and lower income of the family are associated with higher stress.

Conclusion and future perspective

The above study was conducted on 100 care givers with the view to assess the stress of care burden among care givers of special children. Zarit Burden Interview was used to assess the stress of care burden and data was analyzed based upon objectives. 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. So it can be concluded that care givers have severe burden regarding care of special children. The study findings shows that there is significant association between stress of care givers regarding care burden with three demographic variables such as total family monthly income, type of family and for exposure to any health education or training of care givers at the $p<0.05$, and $p< 0.05$ level respectively.

Recommendations

On the basis of the findings of the study following recommendations have been made-

- An experimental study can be conducted with control group in order to see the effectiveness of structure teaching programme regarding various coping strategies or care of the special children.
- Comparative study can be conducted to compare the stress of care burden among families of normal and disable child.
- A study can be conducted to assess the quality of life, emotional intelligence, anxiety and depression in parents of disabled children.

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