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A STUDY TO ASSESS THE BURDEN OF CARE AND COPING STRATEGIES AMONG MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES IN A SELECTED SPECIAL CHILDREN'S SCHOOL OF BHOPAL

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ABSTRACT

OBJECTIVES:

1. To assess the burden of care among Mothers of children with developmental disabilities in a selected special children's school of Bhopal.

2. To assess the coping strategies among Mothers of children with developmental disabilities in a selected special children's school of Bhopal.

3. To find an association between burden of care and coping among Mothers of children with developmental disabilities with their demographic variables

4. To find correlation between burden of care and coping strategies among Mothers of children with developmental disabilities.

HYPOTHESES

H1. There will be significant association between burden of care among Mothers of children with developmental disabilities and their demographic variables.

H2. There will be significant association between coping strategies among Mothers of children withdevelopmental disabilities and their demographic variables

H3. There will be significant correlation between burden of care and coping strategies among Mothers ofchildren with developmental disabilities.

SETTING: The study was conducted Swavlamban School of Bhopal (M.P.).

Sample size: The sample size was 60 Mothers of children with developmental disabilities

Sampling technique: The convenient sampling technique was used.

Method of data collection procedure: Data were collected from Mothers of children with

Developmental disabilities to assess the burden of care and coping by using Burden scale for family care and coping strategies inventory. The collected data were tabulated and analyzed by descriptive and inferential statistics.

Results: Results of the study were interpreted in terms of objectives and hypothesis of the study.

The finding of the study shows that majority of the Mothers (30%) had severe burden of care, 40% had moderate burden of care and 10% had non to mild burden of care. Majority of the Mothers (55%) had inadequate coping, (38.3%) had moderate coping and (6.7%) had adequate coping.

There was a significant correlation between burden of care and coping of the mothers of children with multiple developmental disabilities. Hence H3 is accepted.

KEYWORDS:

Disabilities, Infection, Children, Smoking, Drinking, Social Environment, Family Members, Gender, Mentally Challenged, Education, Stress, Feelings, Impairments.

INTRODUCTION

BACKGROUND OF THE STUDY

Developmental disabilities comprise a group of psychiatric conditions originating in childhood that involve serious impairment in different areas.

According to the individuals with disabilities education act (IDEA), developmental disabilities refer to the "association of impairments such as intellectual disability, blindness, intellectual disability-orthopedic impairment, etc.

Developmental disabilities include limitations in function resulting from disorders of the developing nervous system. Children with disabilities are often affected in multiple domains of function because of the nature and extent of brain impairment or increased susceptibility to other causes of disability.

Developmental disability is a term applied to a group of chronic disorders caused by physical and mental impairments that occur before age twenty-two and typically last for a lifetime. These disorders affect a person's ability to learn, speak effectively, take care of themselves, hold a job, and live independently.

Developmental disabilities begin before a baby is born, but some can happen after birth because of injury, infection, or other factors. Most developmental disabilities are thought to be caused by a complex mix of factors. These factors include genetics, parental health, and behaviors such as smoking and drinking during pregnancy.

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

Multiple developmental disabled children for their families. Family members' especially the mother roles and responsibilities start to change. These changes may be seen in mothers' roles, private living spaces, social environments, expectations, plans, and careers. Factors such as social, economic, and educational status, profession, marital adjustment and cultures of the parents, lack of social support, difficulties in communication, the severity of the disability, children's age, distortions of family routines, the level of need for medical aid and financial burden caused by the child conditions affect the mother stress level.

NEED OF THE STUDY:

Developmental disabilities in children are a diverse group of severe chronic conditions that are due to mental or physical impairments. A large proportion of developmental disabilities have origin in inherited or sporadically occurring genetic or chromosomal

aberrations or the combined effects of genetic traits and environmental exposures. Some factors include injury to the brains, spinal cord and nerve cells injury or an infection to the neuron system, nutritional deficiencies, and other exogenous insults or exposures during critical periods of neurodevelopment.

The worldwide incident rate of developmental disabilities in children ranges is 5 to 16% per year in children.

In India, as per census 2011, out of the 1210 million populations, 26.8 million persons are disabled, which is 2.21% of the total population. A large number of individuals are directly or indirectly affected while caring for an individual with some form of disability. Parenting is a highly stressful job, and becoming a parent of a child with a disability is one of the most stressful life events that can occur. When a child is born with developmental disabilities, a mother felt helpless and felt uncertain about the fate of her child. Raising a disabled child is a challenge for the Mother. It requires intensive physical engagement as well as coping with emotional reactions to the child's condition.

The care given to a child with a disability often at times is overwhelming for the parents, which leads to a burden on the parents. Parents and families concerned with continuous effort in day-to-day activity related to the child with disability normally show fatigue and changes in behavior.

Parents bear the load and many times they prefer not to talk about it, which can lead to anxiety. depression, irritability, and feeling of tiredness, sleep deprivation, trouble concentrating, and health issues.

Research tells us that parents of disabled children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (Jones & Passes, 2004). Thus, increased parental stress that leads to poor parental health and well-being, can negatively affect the health and well-being of the child.

Current researchers have reported that caring for a child with intellectual disabilities can be physically and mentally exhausting due t the demand of caring for the child around the clock.

Though many of the researchers have reported that caring for a child with developmental disabilities can be a stressful experience (Grant& Whittel, 2000; Lloyd & Hastings, 2008), it is not that every family will buckle under the stress of caregiving. Rather some may see it as an opportunity for extraordinary psychological growth. (Sharma & Mishra, 2016). But it cannot be ascertained that the coping resources necessary for the adjustment are available to all. The facilitating factors and inhibiting factors of positive coping appear to include a set of socio-cultural factors, parental characteristics, and a child's characteristics.

Developmental disabilities in children impact the entire family because of the demands for change and increased use of family at risk for poor coping, communication, disturbance in social and family roles and recreational activities. Different coping strategies are adopted by different individuals, as mothers' coping strategies may differ from the father's. Every parent has a unique way of dealing with the situation. Some have a positive way of dealing and some negative, and it differs in every stage of life

Determining the family burden of the mother of developmentally disabled children is important for providing professional support to mothers who suffer from the burden and for identifying coping behaviors. The families of disabled children will feel that they are not alone and will be able to receive professional support for the issues that burden them. Hence researcher felt that doing so will make it possible to teach Mothers according to their abilities and ensure that using positive coping strategies will lead lives without causing stress and burden for their families and society.

METHODOLOGY:

Methodology of research organizes all the components of study in a way i.e. most likely to valid answer to the problem that has been posted. Research methodology deals with a decision about the methods to be used to address the research question and careful planning for the actual collection and analysis of data.

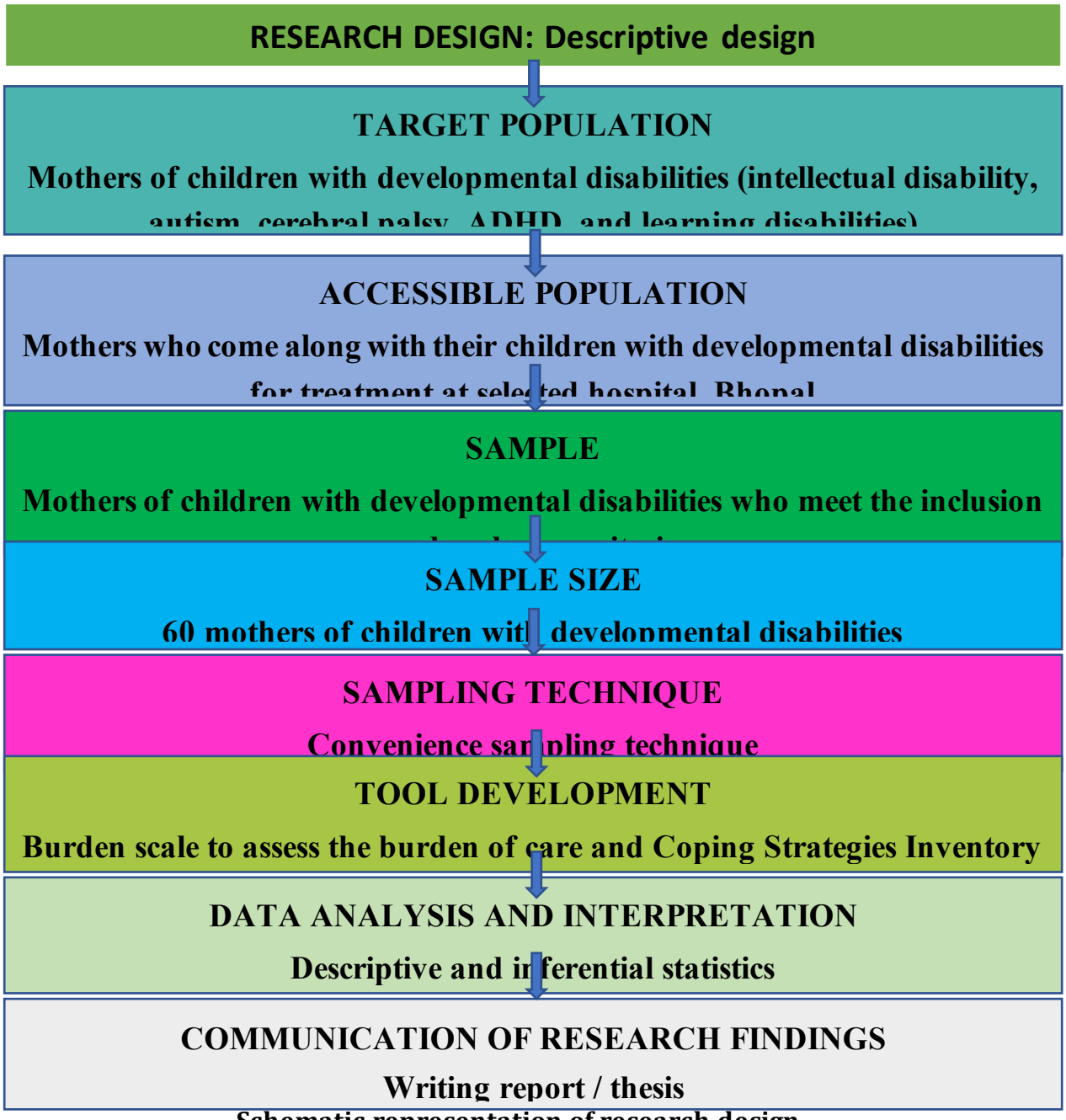
This study is to assess the burden of care and coping among mothers of children with developmental disabilities in selected special children's schools of Bhopal.

RESEARCH APPROACH AND DESIGN

A research approach tells the researcher from whom the data is to be collected, how to collect it and how to analyze the data. It also suggests a possible conclusion and helps the research in answering a specialist question most accurately and efficiently. In this study, the researcher used a quantitive approach.

A researcher's overall plan for obtaining an answer to the research question is referred to as research design.

In this study research design used was descriptive research design.



Schematic representation of research design.

RESEARCH SETTING

According to Polit and Hungler (1999), the setting is a specific place where data collection occurs.

The physical location where the data collections take place

The study setting

The study was conducted from the following special children's school of Bhopal.

1. Swavlamban school of Bhopal (M.P.)

2. Nav Jyoti Special care School Jabalpur (M.P.)

Ethical and legal considerations

- Written permission was obtained to conduct the study from the head of Special children's school of Bhopal.
- Consent was be taken from the mothers of developmental disabilities who will be at the time of data collection.
- The procedure and purposes of the study were explained in detail to the mothers of developmental disabilities
- The intervention would not cause any harm to the sample or the working environment of the special children's school.
- Confidentiality was maintained by assigning code to each sample.

Results:

Results of the study were interpreted in terms of objectives and hypothesis of the study.

The finding of the study shows that majority of the Mothers (30%) had severe burden of care, 40% had moderate burden of care and 10% had non to mild burden of care. Majority of the Mothers (55%) had inadequate coping, (38.3%) had moderate coping and (6.7%) had adequate coping.

There was a significant correlation between burden of care and coping of the mothers of children with multiple developmental disabilities. Hence H3 is accepted.

DISCUSSION:

The aim of the study is to assess the burden of care and coping strategies among mothers of children with disabilities and to find out the correlation between burdens of care coping among Mothers of children with developmental disabilities.

Objectives

The objectives of the study were:

The first objective was to assess the burden of care among Mothers of children with developmental disabilities in a selected special children's school of Bhopal.

The major finding of this study reveals that 30(50%) of Mothers had a severe burden of care, 24(40%) had a moderate burden of care and 6(10%) had mild burden care. The mean score was 46.3 with a Standard Deviation of 12.47

The second objective was to assess the coping strategies among Mothers of children with developmental disabilities in a selected special children's school of Bhopal.

The present study revealed that 7(11.7%) Mother of children with developmental disabilities had adequate copings, 25(41.7%) Mothers of children with developmental disabilities had moderate coping and 28(46.7%) Mother of children with developmental disabilities had inadequate coping.

The third objective was to find an association between the burden of care and coping strategies among mothers of children with developmental disabilities with their demographic variables.

There was a significant association between family income per month, occupation of mother, number of children affected, and diagnosis of Mothers of children with developmental disabilities and burden of care.

Association between coping strategies among Mothers of children with developmental disabilities with demographic variables

There was a significant association between family income, support system, number of children affected, and diagnosis of Mothers of children with developmental disabilities and coping stratetgies of Mothers.

The fourth objective was to find a correlation between the burden of care and coping strategies among mothers of children with developmental disabilities.

The study revealed a significant correlation between the burden of care and coping among mothers of children with multiple developmental disabilities ($r=-0.9$, $p<0.001$). Hence H3 is accepted. The result revealed that as the burden of care increases, mothers' coping ability decreases.

CONCLUSION

The study findings provide that statistical evidence that clearly indicates that burden of care and coping strategies are negatively correlated to each other.

IMPLICATION OF THE STUDY

Nursing Practice:

The nurses can play an important role in imparting preventive health care and also deal in providing comprehensive care to the individual and family. Health education conducted by the nursing personnel in the community and health care setting helps in imparting knowledge regarding developmental disabilities. Staff Nurses can also educate the Mothers and family members who visit the outpatient department or inpatient department and also do screening programs regarding childhood developmental disabilities. The education can help the Mothers of children with developmental disabilities how to care using effective coping techniques.

NURSING RESEARCH:-

Nursing research is research that provides evidence used to support nursing practices and improve the quality of nursing care. The Nurses should research to understand the burden of care faced by the Mothers and family members of children with developmental disabilities.

Nursing Administration:

Nurse administrators are responsible to identify the nature of the problem and organize programs related to health promotion for the target people. The study assists the nursing administrative authorities to initiate and carry out health education programs in health care settings. Nurse administrators should take the initiative in imparting education and providing counselling to the Mothers and their family members in taking

care of children with developmental disabilities and coping with the situation using effective coping techniques.

RECOMMENDATION

The following recommendations are made for future research.

➤ A similar study can be conducted on a larger sample with demographic characteristics.

➤ A similar study can be conducted in different settings.

➤ A comparative study can be done to assess the burden of care and coping strategies among Mothers and Fathers of children with developmental disabilities

➤ A study can be done to determine the knowledge of Mothers regarding developmental disabilities.

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