



A study to assess quality of life and coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health centre of city in view to develop information booklet

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Abstract

Problem Statement

“A study to assess quality of life and coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health centre of city in view to develop information booklet.”

Background of The Study

A Day in the life of caretakers of a child with can include any number of challenges and stressors. Research has shown that several dimensions of the parents' quality of life affected years after a child diagnosed with ID. These included poor physical and psychological health, economic difficulties, lack of social and family support, and lack of time for self-care.

Materials and method

Quantitative research approach, descriptive study design used, non-probability convenient sampling technique used. A study conducted on caretakers of Intellectual disabilities children attending outpatient department of selected mental health care centre of city. The sample size was 100. By using the standardised questionnaire, quality of life and coping strategies among caretakers of Intellectual disabilities assessed.

Result

Majority 59% of caretakers of children with intellectual disabilities age group of 33-47 years and 32% of caretakers of children with intellectual disabilities were in the age group of 48 - 60 years of age. Mostly 61% of mother and 5% of the caretaker of children were cousins. Majority 44% of the caretakers of children were having primary education. 26% of the caretakers of children were having secondary education. Majority 54% of the caretaker were having own business and 38 % of the caretaker were doing daily wages work. Highest percentage 48% of the caretakers of were having 10001-20000 monthly income. 27% of the caretaker were having 20001-30000 monthly income. Majority 74% of the caretaker were having marriage out of family relations. Majority 48% of the caretaker were belonging to joint family and 27% of the caretaker were belongs to extended family. Mostly 39% of the caretaker were taking care of child since 6-10 years and 38 % of the caretaker were taking care of child more than 11 years. The mean quality of life among caretakers of children with intellectual disabilities was 79.68. It indicates that having good Quality of Life. The mean coping strategies score of caretakers of children with intellectual disabilities was 39.09. It indicates that caretakers of children with intellectual disabilities had good Coping strategies. There was no significant difference found in quality-of-Life score with selected demographic variables except Family monthly income. There was no significant difference found in coping strategies score with selected demographic variables except Educational Qualification and Family monthly income.

Keywords: Quality of life, coping strategies, caretakers, intellectual disabilities, children with special needs

Introduction

"Children are like buds in a garden and should be carefully and lovingly nurtured, as they are the future of the nation and the citizens of tomorrow."

Pt Jawaharlal Nehru

This beautiful quote emphasizes the importance of nurturing and educating children. Just as we tend to delicate buds in a garden, we must provide love, care, and guidance to our young ones. They hold the promise of our nation's future, and their growth and development shape the destiny of tomorrow. Let us cherish and invest in our children, for they are the seeds of progress and hope.

Intellectual disabilities are abnormality that has enormous social effects; it not only affects the people who suffer from it but also the family and society as a group. Intellectual disabilities are diminished cognitive ability that translates into a difference in the rate and efficiency with which the person acquires, remembers, and uses new knowledge

compared to the general population. In the last century, the persons with intellectual disabilities have experienced a radical change in all aspects of life: healthcare, employment, education, recreation, and living situation according to World Health Organization, 2000. It has been defined and renamed many times throughout history. Mental retardation, which was in use world over until late 20th century, has now been replaced with Intellectual disabilities in most countries. Diagnostic and Statistical Manual 5th Revision (DSM-V) has replaced it with Intellectual Disabilities. Causes of Intellectual Disabilities Approximately 70% of individuals with severe intellectual disabilities and 50% of individuals with mild intellectual disabilities have an organic or biological basis for their disorder (McLaren & Bryson, 1987).

“Quality of Life among Parents of Children with Intellectual Disabilities “Parents who have children with intellectual disabilities are often reported to have physical and psychological distress related to caring for their children,

thus affecting their quality of life. Parents or caretakers are definitely the heart of the family, who not only have to deal with the issues associated with child's disabilities but also have to maintain the household. Today, a number of studies have demonstrated that caretakers are more vulnerable to develop mental and physical problems as compared to non-caretakers.

Background of the Study

Anna M. Bujnowska (2021) ^[4] in this study previous findings indicated that parents of children with developmental disabilities face greater care giving demands and report higher levels of stress. This study explores the styles and strategies of coping with stress among parents of children with developmental disabilities compared to parents of children with typical development used by 167 parents of children with developmental disabilities and 103 parents of typical development children participated as a voluntary. The CISS and the COPE Inventory were used to assess the coping styles and strategies in rearing a child. The results from Multivariate Analysis indicated significant differences between parents of children with and without developmental disabilities in one of three coping styles and one of eight coping strategies. Parents of children with developmental disabilities less often used the avoidance-oriented style and emotional support strategy. The task-oriented style and strategies were the dominant approach in both groups of parents. In stressful situations connected with rearing a child, parents of children with developmental disabilities do not use as dominant strategies connected with seeking emotional support and religion, which occur in the parents of typical development children. Study finding concluded that the results suggest areas where coping may be different from in families of children without DD.

Need of the Study

Sapna Singh et al (June 2023) ^[6] Raising a child who is mentally Retarded requires emotional strength and flexibility. The child has special needs in addition to the regular needs of all children, and parents can find themselves overwhelmed by various medical, caregiving and educational responsibilities. Support from family, friends, the community or paid caretakers are critical to maintaining balance in the home. Parents of mentally challenged children commonly experience a gamut of emotions over the years. The aim of the study was to assess the coping strategies of parents of mentally retarded children. Coping Checklist by Kiran Rao, Subukrishna and Prabhu, Coping Check list, (1989) used to assess the coping. 250 parents of mentally retarded children selected through purposive sampling technique from different MR centers of selected urban area of North India. Majority of study subjects coping strategies score 99.6% was average and the least 0.4% was good but none of them had poor coping strategies score. Conclusion of the study suggests that there was need for support to parents who have severe MR children. Methodology Quantitative research approached, and descriptive research design adopted. 250 parents selected through purposive sampling technique. Standardized tool adopted to assess the coping strategies. Coping Checklist By. Kiran Rao, Subukrishna and Prabhu, Coping Check list, (1989) used to assess the coping among parents of MR children. This checklist provides some of the commonly used methods of handling stress and reducing

distress. In this checklist, there are seven types of coping strategies as shown Problem solving, Positive distraction, Negative distraction, acceptance/Redefinition, Religion /Faith, Denial/Blame & Social Support. Higher the scores indicate better coping mechanisms/strategies. Conclusion as Parents of mentally retarded children are less social due to stigma related to mentally retarded child. They are more caring towards their child due to more responsibilities. Some parents may have problems related to physical, mental & social. Based on the findings of the present study the conclusions drawn were the parents adopting varying degree of coping strategies. The majority of parents had average coping strategies scores and very few had low score. When level of mental retardation in children were compared with coping strategies score in parents, severe MR children's parents adopting coping more than Mild and Moderate MR children's parents.

Aim of the Study

To assess quality of life and coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city in view to develop information booklet.

Objectives

1. To assess Quality of life among caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city.
2. To assess the coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city.

Research Approach

Research approach was a systematic objective method of discovery with empirical evidence and rigorous control. The research approach spells out the basic strategies that the researcher adopts to develop information that was accurate and interpretable. The choice of research approach constitutes one major decisions, which must be made in conducting a research study has taken on research projects can greatly affect the outcome. In this study Quantitative Research, approach used.

Research Design

The research design spells out the strategies that the researcher adopts to develop information that is accurate, objective and interpretable. (Polit and Hungler, 1993) The selection of research design is the most important step as it provides the framework for the study. The research design helps the researcher in the selection of subjects, manipulation of independent variable, control, observation made and the statistical analysis used to interpret the data. Research design in this study was Descriptive Study Design.

Sampling Technique

The sampling technique used for the study is type of non-probability convenient sample technique. Non-probability convenient sampling was a technique in which the researcher selects samples based on the subjective judgement of the researcher rather than random selection. Non-probability convenient sampling method used in which samples selected from the population only because they are conveniently available to the researcher. In present study,

non-probability convenient sampling method used to select 100 Caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city in Maharashtra.

Description of the Data Collection Tool

The phenomenon in which researcher is interested must ultimately be translated into data that can be analyzed. The task of defining the researcher variable and selecting developing appropriate methods for collection methods the accuracy and robustness of the conclusions are always subject to challenge. The most important and crucial aspect of any research is data collection which provides answers to any questions under the study, Data collection relies on instruments. The present study aimed at assessing the quality of life and coping strategies among Caretakers of children with intellectual disabilities of selected attending outpatient department of selected mental health Centre.

Description of Tool

Section I: Demographic variables.

Section II: Standardized tool WHOQOL-BREF scale for assessing quality of life.⁵⁹ The WHOQOL-BREF contains 26 questions, in Likert response scale ranging from one to five. Of which, two items were the overall quality of life and general health facet, and the rest 24 were divided into four domains which includes physical health, psychological health, social health, and environmental health domains. The domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean scores of items within each domain used to calculate the domain score. The obtained raw score of each domain transformed manually to a 0-100 range score.

Section III: Standardized tool Coping Scale, Hamby, Grych & Banyard, 2013 for assessing Coping strategies.⁶⁰ this coping questionnaire assesses cognitive, emotional and behavioral methods of dealing with problems. It consists of 13 questions. Each answer category was assigned a value from 4 to 1.

Reliability of the Tool

Reliability of the tool is a major criterion for assessing the quality and accuracy. It is a degree of consistency with which it measures the attribute it is supposed to be measuring, after establishing the validity of the tool to use for the study, the final tool made and then the reliability of the tool done. Reliability has to do with the quality of measurement. In its everyday sense, reliability is the "consistency" or "repeatability" of measures. Reliability is a consistency of a set of measurements or measuring instrument. Reliability does not imply validity. Reliability is the extent to which the measurements of a test remain consistent over repeated tests of the same subject under identical conditions. The tool tested for reliability on 10 Caretakers of intellectual disability children of selected schools of city. Reliability analysis was done by using Cronbach's alpha selected Internal consistency was measured by using Cronbach's alpha method in SPSS software by using parallel form method. The reliability score for WHOQOL-BREF was 0.89 and reliability score for Coping Scale was 0.91, which shows that the tool is reliable.

Data Collection Process

A formal permission obtained from the concerned authorities. Caretakers of children with intellectual

disabilities attending outpatient department of selected mental health Centre who fit in the criteria. The investigator introduced self and informed the samples about the nature of the study to ensure better co-operation during the data collection. Objectives of the study discussed and written consent obtained for participating in study. Subjects assured about the confidentiality of the data. The duration of data collection from each sample was approximately 30 minutes. A semi structured questionnaire was used to obtain demographic data & Standardized tool WHOQOL- BREF scale was used to assess the quality of life and coping strategies were assessed by using standardized tool Coping Scale, Hamby, Grych & Banyard, 2013 among Caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre. The duration of data collection from each sample was approximately 30 minutes.

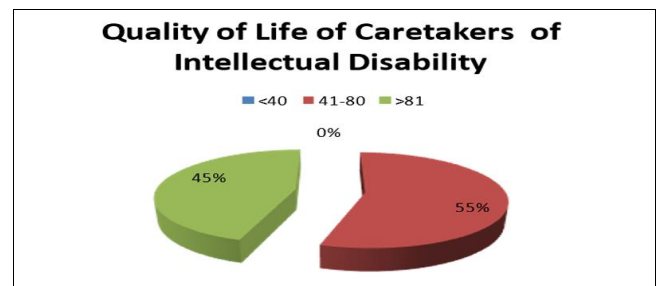
Result

Assessment of quality of life among caretakers of children with intellectual disabilities.

This section deals with the analysis of the data related to Quality of Life among caretakers of children with intellectual disabilities of children. The statistical values of means, mean score percentages and standard deviations are used to describe the scores.

Table 4.9: Assessment of Quality of life Among caretakers of children with intellectual disabilities. N=100

Quality of Life of Caretakers of Intellectual Disability		
QOL Score Group	Number of Caretakers	Percentage (%)
<40	0	0
41-80	55	55
>81	45	45
Total	100	100



Category	Maximum score	Mean	Standard deviation	Mean percentage
Quality of Life Score	100	79.63	10.99	61.25

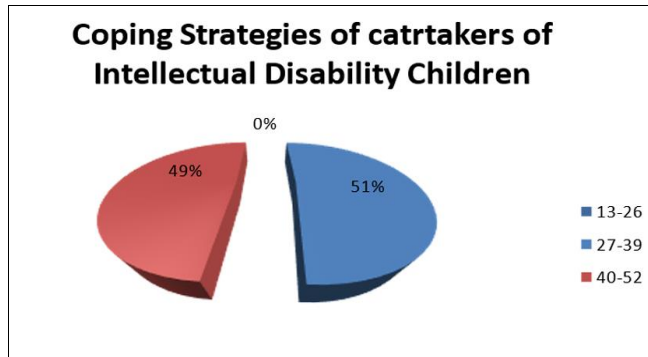
The above table 4.9 depicts that the mean quality of life among caretakers of children with intellectual disabilities was 79.68. It indicates that caretakers of children with intellectual disabilities were having good Quality of Life.

Assessment of coping strategies score of caretakers of children with intellectual disabilities.

This section deals with the analysis of the data related to Coping strategies of caretakers of children with intellectual disabilities. The statistical values of means, mean score percentages and standard deviations are used to describe the scores.

N=100

Coping Strategies Group	Score	Number of Caretakers	Percentage
13-26		0	0
27-39		51	51
40-52		49	49



Category	Maximum score	Mean	Standard deviation	Mean percentage
Coping strategies Score	49	39.09	5.49	75.17

The above table 4.10 depicts that the mean Coping strategies score of caretakers of children with intellectual disabilities was 39.09. It indicates that caretakers of children with intellectual disabilities had good Coping strategies.

Discussion

The finding of the study discussed with reference to the objectives of the study and with the findings of the other studies in this section.

The present study undertaken to assess the Quality of life and coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city.

The discussion based on Description of the caretakers of children with intellectual disabilities according to their demographic Variables.

Assessment of Quality of life among caretakers of children with intellectual disabilities.

Assessment of coping strategies among caretakers of children with intellectual disabilities.

Conclusion

The study carried out to assess Quality of life and coping strategies among caretakers of children with intellectual disabilities attending outpatient department of selected mental health Centre of city. 61% of the caretaker of children were mother. The mean quality of life among caretakers of children with intellectual disabilities was 79.68. The mean coping strategies score of caretakers of children with intellectual disabilities was 39.09. The QOL and coping strategies for most caretakers for the studied data set were good. However, more studies are required in establishing independent and reliable predictors of QOL of caretakers, so that effective methods and policies could be developed for betterment of the quality of life of caretakers.

Author conflict of interest: None

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