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Quality of life among the mothers of mentally challenged children at special schools

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Abstract

Birth of the special child is a major shock for the parents and has distressing effects on social, family, psychological, emotional, economical and interpersonal relationship of the parents. Many factors can influence the quality of life of the parents with mentally challenged children in family.

Objectives: (1) The present study is aimed to assess the quality of life among the mothers of mentally challenged children in selected special schools at Ernakulam, Kerala; (2) To determine the association between quality of life and selected demographical variables like age, education, occupation, type of family, area of living, number of children's affected with disability, severity of disability.

Methods: 30 mothers of mentally challenged children who presented to the Navajeevan special school at Ernakulam from June to July 2019 were enrolled after getting informed consent and study approval. Demographic data of children and mothers in the study group by convenient sampling were entered into a proforma and the mothers were administered with WHO-QOL BREF Questionnaire to assess the Quality of life.

Results: The study results were found that mothers had low to moderate Quality of life in all the domains, i.e., physical health, psychological health, social relationship, environmental health. Higher mean score was observed in the social relationship domain. When the educational status of the parent is higher, mothers reported a low Quality of life score, though no such difference was seen with the educational status, occupation of mothers or other variables.

Conclusion: These findings must be taken into account in providing better and more specific supports and interventions for mothers to improve Quality of life. Social support and different coping strategies should be developed to respond positively to individual changing needs of mothers from the stress of having a child with disabilities.

Keywords: Mothers of mentally challenged children, quality of life

Introduction

Human Being is endowed with numerous abilities, mental, intellectual, and social temperamental, motivational, and attitudinal. But still some person is found deficient in some of the abilities. Sociological, biological and various environmental factors are responsible for the deficiency of the children. They suffer even from prenatal stage as a result of which they are born with several disabilities in mental and even in physical aspects. Though these deficiencies are not expected in the society, but it is the reality that these deficient children exist and they cannot be thrown out of the society. The society has the responsibility to take care of the specific deficiencies from which they suffer, and should render maximum effort to consider them sympathetically and provide them the service so that they can utilize their capacity to the maximum and be a part of the mainstream society.

Mental retardation is a worldwide problem and in India it is a shocking and alarming fact that approximately 2.5 to 3% of the total populations are mentally retarded. Mental retardation is not only a biological, educational or psychological problem but it is a multi-dimensional problem of a mixture of psycho-social, biological and educational factors. According to the Diagnostic and Statistical Manual of the American Psychiatric Association "persons with Mental Retardation (MR) have significantly below-average intellectual functioning with an IQ of 70 or below". Mental retardation, according to the 10th edition of the American Association on Mental Retardation (AAMR), is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. Many factors can influence the quality of life of the parents with mentally challenged children in family.

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Parents are in family who deal with the issues associated with child's disability and also maintain the household so it is very important for parents to take some time to care for themselves as individuals and getting enough sleep, eating regular meals, taking a short walk, and doing the things that they really enjoy. Parents having a child with mentally challenged experience a variety of stressors and stress reactions related to the child's disability and known to get impacted in many ways because of having a special child. These include feeling sad, depression at various stages of life and experiencing other emotional reactions

Birth of the special child is a major shock for the parents and has distressing effects on social, family, psychological, emotional, economical and interpersonal relationship of the parents. It affects parenting skills, parenting attitude, which in turn effects the psychological, social, emotional and personality development of the child.

It has been estimated that about 10% of children experience developmental disabilities requiring access to the health care system and extensive caregiving, often throughout childhood and into the adult years. Mental Retardation and autism are two such developmental disorders. This term indicates a general deficit in cognitive function that emerges during childhood.

Quality of Life (QoL) as a concept has been increasingly accepted as an important outcome measure in patients and caregivers of chronic illnesses. Quality of Life includes the conditions of life resulting from the combination of the effect of complete range of the factors such as those determining health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression. The concept is further understood as an individual's perception of their position in life in context of the culture and value systems in relation to their goals, expectations, standards and concerns. The presence of a child with developmental disability in the family calls for a lot of adjustment on the parents and other family members. Although, the unmet needs of parents of children with disabilities are universally linked to stress, there could be some cultural differences in the way this stress impacts parents and their quality of life. In India, patients with mental illness and mental retardation (MR) are cared by their families. In caregiving, problems such as disturbance of routine, family leisure, family health, and emotional stress can have a negative impact on quality of life (QOL). The care provided for MR is mainly home based and alternate support systems such as day-care centers, weekend care, and special schools are meager, the impact of care on caregivers can be enormous. The problems associated with rearing of such children can be multifold, and problems such as disturbance of routine, family leisure, family health, work absenteeism, and physical and emotional stress not only result in increased economic costs, but also have a negative impact on the QOL of caregiver. Parents with children having intellectual disability experience more stress compared to their counterpart who have children with no intellectual disability. Disabilities of children may burden their family members, especially their parents, who are their long-term caregivers. Mother act as the primary caregiver within the family. Intellectual disability or mental retardation as it persists throughout lifetime. It contributes to 1.2% of the mental illness in Kerala. Intellectual disability is the most prevalent childhood psychiatric disorder. Among them, majority of

the cases (85%) belong to mild mental retardation.

Care that is given to a normal child itself is taxing for the parents many a times and to provide a higher level of life long care to a child suffering from long-term functional limitations may be strenuous for the parents and thereby may be affecting their QOL. Becoming the parent of a child who has some disability in itself can be a time of great stress and change.

The birth of a disabled child can influence the relationships of all the family members. It also requires a reassessment of the family functioning. Majority of family's cope with the situation relatively well and are able to continue their life normally.

Research in India has indicated that receiving maximum social-emotional support from the spouse, family members, relatives, and friends are facilitators for effective coping. The physical support from within and outside the family is one of the greatest facilitators in coping

Stress is a factor which seriously affects the QOL of parents. This systematic review is intended to bring out pooled evidence on QOL of parents with children having an intellectual disability, which in the rehabilitation of the affected child.

Government entrusts various supporting schemes for these children and parents, but this does not have an impact on stress and QOL of parents. This review will aid in identifying the domains of QOL which are affected negatively by their children's disability. By considering the findings of this review, suggestions to modify supporting schemes can be put forward.

It was found from initial review that no systematic reviews were conducted specific to this area and this project aims to study the aspect of QOL of mothers with intellectually disabled children.

Thus, it is important that the QOL is needed to be adequately researched and studied in the caregivers of children with MR. This will ensure the sensitivity while dealing comprehensively with not only children suffering from MR, but also the sufferings of caregivers especially mothers.

Aim and Objectives

The present study is aimed to assess the quality of life among the mothers of mentally challenged children in selected special schools at Ernakulam, Kerala; (2) to determine the association between quality of life and selected demographical variables like age, education, occupation, type of family, area of living, number of children affected with disability, severity of disability

Methods

30 mothers of mentally children who presented to the Navajeevan special school at Ernakulam from June to July 2019 were enrolled after getting informed consent and study approval. Demographic data of children and mothers in the study group by convenient sampling were entered into a proforma and the mothers were administered with WHO-QOL BREF Questionnaire to assess the Quality of life.

Results

Demographic aspects

Regarding age of mothers, highest percentage 21(70%) in the group between 30-41 years, 7 (23.3%) belongs the age group of 20 to 31 years and only 2 (6.7%) were at the age

above 41 years. With regards to the religion 18(60%) of mothers belongs to Hindus and 8 (26.6%) were Christians and minimum subjects 4(3.3%) were Muslims.

While seeing the education of mother, majority of them i.e.) 17 (56.7%) completed their Higher secondary level of education and 11(36.7%) completed their Degree and above level of education and least number of samples 2(6.7%) finished their high school level of education. With regard to the education of father, 15(50%) have completed their secondary level of education and 9(30%) have completed their primary level of education.

Only very few members 6(20%) completed their High school. While portraying the occupation of mother, majority 13(43.3%) were House wife and 12(40%) of them doing private job and only few 3(10%) were Government employees and very least 2(6.7) were factory workers. With regard to the occupation of father, majority 16(53.3%) were Private employees and 4(13.3%) were Government employees and 2 (7.9%) were factory workers and only 1 (3.3%) were Agricultures.

Regarding family income about 11(36.7) were have income of Rs20, 000/- 30,000/- and 9(30%) were have above Rs30, 000/- income /month and 7 (23.3%) were have Rs10, 000/- 20,000/- and only very numbers 3(10.0%) were having Rs5000/- -10,000/- income /month. Regarding area of living 15((50%) belongs to the rural background and other half numbers 15(50%) belongs to Urban community.

About 21(70%) have 2 children and 8 (26%) have one child and only one parent have three children. Regarding birth order 19(63.3%) had one child and 10 (33.3%) had two children and only one parent 1 (3.3%) had three children.

About 29 (96.7%) had disability in one child in the family and 1 (3.3%) had 2 children in the family. Regarding level of retardation 13(43.3%) had severe retardation and 12 (40.0%) had moderate retardation and least numbers 5 (16.7%) had mild retardation.

In this study, researcher found that mothers had low to moderate Quality of life in all the domains where majority (63.3%) of mothers' experiences low QOL and around 36.7% experiences moderate QOL (Table.1). Moreover, QOL comprised of physical health, psychological health, social relationship, environmental health.

However, higher mean score 23.24 (SD=16.5) was observed in the social relationship domain and the least found with psychological health with mean value 11.5 (SD=4.2) (Table.2).

The study revealed that there was no association between quality of life and various demographic variables such as education of the father, education of the mother, occupation of the father, occupation of the mother, type of family, Area of living, Number of children's and level of retardation ($p>0.05$).

On the other hand, education and occupation of mother shows significant association with quality of life ($p<0.05$) (Table.3).

Table 1: Quality of life of mothers

Quality of life	Frequency (f)	Percent (%)
Low	19	63.3
Moderate	11	36.7
Total	30	100.0

Table 2: Mean and SD of domains in quality of life N=30

Domains in QOL	Mean	SD
Physical health	16.5	7.3
Psychological health	11.5	4.2
Social relationships	23.24	16.5
Environmental health	22.46	8.02

Table 3: Association between quality of life and demographic variables N=30

Variable	Chi-square	Df	Significance
Education of father	1.340	2	0.512
Education of mother	30.0***	2	0.000
Occupation of father	3.394	4	0.494
Occupation of mother	10.153*	3	0.017
Type of family	0.718	1	0.397
Area of living	1.292	1	0.256
No of children	3.471	2	0.176
Level of retardation	0.348	2	0.840

* $p<0.05$, ** $p<0.01$, *** $p<0.001$

Discussion and Conclusion

Mental retardation (MR) is one of the most prevalent developmental disabilities. Family is the main source of support for the persons with disabilities in any society. Multiple factors seem to be responsible for poor QOL of mothers of mentally retarded children. When the educational status of the parents is higher, mothers reported a low Quality of life score, though no such difference was seen with the educational status or occupation of mothers. These finding must be taken into account in providing better and more specific supports and interventions for mothers to improving Quality of life. Social support and different coping strategies should be developed to respond positively to individual changing needs of mothers from the stress of having a child with disabilities

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