

STUDY ON QUALITY OF LIFE, OF MOTHERS OF CHILDREN SUFFERING WITH AUTISM.

Dr. Aditi Kulkarni¹, Aishwarya. A. Marde², Prajakta .A. Kulpe³

¹(School of Occupational Therapy, D.Y. Patil Deemed to be University, India)

²(School of Occupational Therapy, D.Y. Patil Deemed to be University, India)

³(School of Occupational Therapy, D.Y. Patil Deemed to be University, India)

ABSTRACT:Quality of life is the general well-being of individuals and societies, outlining negative and positive features of life. It observes life satisfaction including everything from physical health, family, education, employment, wealth, safety, and security to freedom, religious beliefs, and the environment. Autism Spectrum Disorder is a developmental disorder that affects communication and behavior. Its symptoms generally appear in the first two years of life. Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience. People with ASD have difficulty with social communication and interaction, restricted interests, and repetitive behaviors. The current study aimed to Carry out the survey on the quality of life of mothers of autistic kids, to help them improve their quality of life. According to the results, the most affected domain is the physical domain. The study concludes that most of the difficulties were due to lower socioeconomic class, limited finance lack of awareness about the disease, and available health care facilities.

Keywords- Quality of Life, Mothers, Children, Autism

1. Introduction

Quality of life is a term for the quality of the various domains in life. It is a subjective multidimensional concept that defines a standard level for emotional, physical, material, and social well-being. It serves as a reference against which an individual or society can measure these different domains of one's own life. The extent to which one's own life coincides with this desired standard level, put differently, the degree to which these domains give satisfaction and as such contribute to one's subjective well-being, is called life satisfaction. Quality of life is the general well-being of individuals and societies, outlining negative and positive features of life. It observes life satisfaction including everything from physical health, family, education, employment, wealth, safety, and security to freedom, religious beliefs, and the environment.¹

Medically it is measured by using a quality-of-life scale. Quality of life measures has become a vital and often required part of health outcomes appraisal. For populations with chronic disease, measurement of QOL provides a meaningful way to determine the impact of health care when cure is not possible.

Autism Spectrum Disorder(ASD)²: Autism Spectrum Disorder is a developmental disorder that affects communication and behaviour. Its symptoms generally appear in the first two years of life. Autism is known as a “spectrum” disorder because there is wide variation in the type and severity of symptoms people experience. People with ASD have difficulty with social communication and interaction, restricted interests, and repetitive behaviours.

Causes Of ASD:

- Pregnancy at older age.
- Having certain genetic conditions – people with conditions such as down syndrome, fragile X syndrome and Rett syndrome are more likely than others to have ASD.
- Very low birth weight.

Treatments and therapies : Treatments for ASD should begin as soon as possible after diagnosis. Doctor may use medication to treat some symptoms that are common with ASD such as irritability, aggression, repetitive behavior, hyperactivity, attention problems, anxiety and depression. People with ASD may be referred to an occupational therapist, speech therapist and doctors who specialize in providing behavior, psychological, educational, or skill building interventions.

2. Aims and objectives

1. Carry out the survey on the quality of life of mothers of autistic kids , to help them improve their quality of life.
2. To identify the domains of life which contribute to a reduction in quality of life.
3. To identify the root cause of the same.
4. To take the necessary corrective measures to make their life joyful

3. Review of literature

3.1. Quality of life among parents of children with autistic disorder.⁵ By Dardas LA, et al. Res Dev Disabil . 2014. Conclusion: The environmental health was relatively poor. The QOL of parents was contingent upon their stress, coping, demographics, and to some extent their cultural context. Experiences impacting the quality of life of mothers of children with autism and intellectual disability. By :Fairthorne ,Jennifer Christine orcid .org(2014)⁶

Result : Identified three multidimensional themes as essential to the experiences of living with child with autism and intellectual disability and impacting on the mothers QOL. These were:

1. Living with the traits of the child's disability.
2. Adapting to a new lifestyle.
3. Surviving challenges and savoring rewards.
4. Studies on QOL in general population⁴.

By : Sherrill Evans and Peter Huxley (2009)

Conclusion: large proportions of the population are satisfied with their lives in general terms and in domain specific terms, ratings of life quality are frequently highest in family and lowest in finance.

3.2. The quality of life of caregivers of children with special needs.³

By : Flom- meland, C, Mohr (2005)

Conclusion : It was clear that caregivers of children with special needs experience a great amount of stress. The caregivers in the study demonstrated an overall decrease in their quality of life .

4. Methodology

Study location:

This study was conducted in private clinic named KULHARIS SPECIALITY CENTRE, Navi Mumbai.

Study population :

Mothers of the 20 autistic children between 2-18 years of age attending the centre with voluntary willingness to participate in the study were enrolled.

Confidentiality was promised to enhance accuracy of the scores.

Study design:

This was a questionnaire-based study.

Inclusion criteria: The mothers of ASD kids who are visiting the centre regularly since 3 months were identified as eligible subjects.

Exclusion criteria: The mothers of ASD kids who have joined the centre recently and come for therapy irregularly were excluded from the survey. The mothers having kids with other disabilities in addition to ASD were also excluded.

Sampling and data collection:

The permission for the study was priorly obtained from the head of the centre. Mothers were explained about the study procedure. The interviews were held in separate rooms in the center. The semi-structured questionnaire consisted of two parts:

1. The personal information profile along with demographic details of parents and affected children.
2. The WHO Quality Of Life questionnaire-short version⁸, that was used to assess the quality of life. It was ensured that the caregivers understood the questions and sufficient time was given for them to answer.

Scoring : WHO QOL questionnaire short version consists of 26 questions divided into four domains:

- A. Physical health
General health assessment, pain, and discomfort, dependence on medication and medical aids, energy, and fatigue, sleep and rest, ability to work and perform ADL, mobility.
- B. Psychological health
Body image, positive and negative feelings, self-esteem, personal belief, spirituality, religion, thinking, learning, memory, and concentration.
- C. Social relationships
Personal relationships, received social support, sexual activity. Items 19, 20, and 21 of the questionnaire represent social dimensions.
- D. Environment relationships
Freedom, safety, environment, physical environment, transport, finances, information, accessibility of health and social care, leisure time. Items 8, 9, 13, 14, 22, 23 and 24 of the questionnaire reflect satisfaction with one's environment.

Each question was assigned an appropriate number of points from 1 to 5, and the patient had to choose from the following possible answers: 1 point-very dissatisfied, 2 points-dissatisfied, 3 points-neither satisfied nor dissatisfied, 4 points-satisfied, 5 points very satisfied. Domain scores were scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain was used to calculate the domain score. The

The interpretation was done as per the specification in the WHO-QOL-BRIEF questionnaire. The scale also included items

(Questions) that were analyzed separately: Question 1: pertaining to the individual overall perception of quality of life; Question 2: pertaining to the individual overall perception of own health.

The possible raw scale score ranges for each domain are as follows: Physical health=28, Psychological =24, Social relationship=12, and environment =32. Scoring exercise and test dataset for the WHOQOLBRIEF INSTRUMENT.

The purpose of this scoring exercise is to help WHOQOL- brief users to evaluate results from each step in the process of calculating the domain summary scores of the instrument. After all necessary items have been recoded, a raw score is calculated for each domain. Both facets and domains are scored through a simple algebraic summation of each item in that scale. As stated earlier, each question contributed equally to the domain score.

5. Results

This study assessed the quality of life of parents of children with ASD. On x axis there are domains, and on y axis there is percent of health . The mean average of each domain was taken and then according to percentage was calculated.

The results were as follows:

	Affected QOL	Good QOL
DOMAIN 1	55.53%	44.47%
DOMAIN 2	57.52%	42.48%
DOMAIN 3	62.49%	37.51%
DOMAIN 4	57.30%	42.70%

According to the results, the most affected domain is physical domain .

6. Discussion

Mothers who have children with autism are often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life. This study explored the QOL among parents who have children suffering from autism spectrum disorder. A child with ASD suffers from several problems such as speech , eye contact, communication, limitations in self care functions such as feeding, dressing, bathing and also suffers from irritability and sensory problems. Taking care of such a challenging child is full time job with great demands ,and it exerts a great stress on a mother. Unfortunately ,this happens without prior preparations, and the caregivers find themselves suddenly in this demanding situation. This not only causes increased economic burden on the family and time spent on taking care of the affected child but also has impact on physical , psychological and social aspects of the QOL of the mother. The QOL of the mother should be studied thoroughly to improve the care of the affected children and overall health status of the mother. Thus the study was planned to understand and determine the extent of the problem and improve the QOL of mothers.

7. Conclusion

Most of the parents reported overall quality of life as neither good nor bad may be because they would have learned to cope with the situation. The major affected domain was physical followed by psychological domain. Majority of parents were satisfied with their own social relationships. Most of the difficulties were due to lower socioeconomic class, limited finance lack of awareness about the disease and available health care facilities.

8. Scope in Future

Fathers of the children as well as grandparents or any other caregivers should also be interviewed

Counseling of the parents and other concerned members of the family should be done.

Prioritizing techniques should be taught.

Proper home program should be explained to the mothers. Regular occupational therapy for the child should be encouraged.

The mothers should be re-interviewed after a span of time to ensure a higher score on the scale after proper treatment and counseling .

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