

QUALITY OF LIFE OF MOTHERS HAVING CHILDREN WITH AUTISTIC SPECTRUM DISORDERS AND LEARNING DISABILITIES

MOHD. FAIJULLAH KHAN¹, M. KHYOTHUNGLO HUMTSOE²

¹Department of Teacher Training and Non Formal Education, (IASE), Jamia Millia Islamia, New Delhi, INDIA.

Email: dlffaiz@gmail.com

²Cluster Innovation Centre, University of Delhi, Delhi, INDIA.

Email: glorykhyo@gmail.com

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ABSTRACT

The present study is aimed at ascertaining the quality of life experienced by mothers of children with Autistic Spectrum Disorders (ASD) and mothers of children with Specific Learning Disabilities (SLD). The sample consisted of 60 (30 mothers having children with ASD and 30 mothers of children with SLD). The WHOQOL-BREF questionnaire was used to assess the Quality of Life (QOL) of the 60 mothers of children with special needs. Following the administration, four domain scores were obtained. Analysis using t-test, independent measure was used to compare the two means. Significant differences were found between the two groups on all the four domains of the Quality of Life Scale. Thus, mothers of children having ASD had impaired Quality of Life as compared to mothers of children having SLD. These findings indicate that different effect as a consequence of different childhood conditions and also the need to provide adequate parental support when providing intervention to their children with disabilities.

Keywords: Quality of life, mothers, autistic spectrum disorders, specific learning disabilities.

1. INTRODUCTION

Parents play very important roles in children's psycho-social and academic development. Taking care of children with chronic disabilities like autism can affect a parent's mental health in more negative ways. Autistic Disorder is one of the most complex childhood developmental disorders that can devastatingly affect the children's intellectual, social, and linguistic abilities. Children who have such

Correspondence: Mohd. Faijullah Khan, Assistant Professor, Department of Teacher Training and Non Formal Education (IASE), Jamia Millia Islamia, New Delhi, INDIA, Tel: +91-9990343745, Email: dlffaiz@gmail.com.

significant impairments require access to a good health care facility and extensive caregiving from the parents. Such support however is not only required by the affected child but is also needed by the parents, as it has been found that parenting a child with Autistic Disorder can disturb the whole family's life and result in several economic, social, physical and psychological problems (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010). Therefore, it is important to consider the mental health of the parents in the interventions proposed for children with Autistic Disorder.

Specific Learning disability (SLD) is a general term that describes specific kinds of learning problems. A learning disability can cause a person to have trouble learning and using certain skills like reading, writing, listening, speaking, reasoning, and doing math. Such trouble affects schoolwork and can impede learning to read, write, or do math. It is a neurological disorder that affects the brain's ability to receive, process, store, and respond to information.

Quality of Life (QOL) is becoming a major health concern for parents who are forced to face many stressful situations while raising a child with disability. Quality of life can be defined as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1996). It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. The definition highlights the subjective aspect of quality of life, which is both negative as well as positive and is multidimensional. Thus, 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 (WHO, 1996).

Quality of life of parents with disabilities can be affected by the degree of disability, associated problems, amount of time spend on care-giving, presence of adequate social support etc. Thus, assessing Quality of Life of parents having children with disabilities is important as it can serve as a base for intervention for rehabilitation professionals, who work closely together with the child with special needs and his parents and in bringing efficient and effective treatment strategies, as well as an in-depth understanding of the needs of these parents. Such intervention may be aimed at improving the lifestyles of the parents in order to reduce the perceived stress. Interventions may also be aimed at actual targeting of any physical or psychological symptoms if the need arises.

Parents and other children in the family thus, undergo a variety of profound changes to adapt to the presence of a disabled member (Kumar, 2008). Mothers of children with both mental and physical disability and mothers of

children with mental disability experiences 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 (Shyam, Kavita, & Govil, 2014). Also, children with learning disabilities as compared to their siblings without learning disabilities perceived more warmth-affection in their mothers' attitude towards them (Vinayak & Sekhon, 2012).

A child with autistic disorder difficult characteristics has been seen to predict mothers' quality of life (Dardas & Ahmad, 2014). The effect on the families of children with developmental disabilities can be seen in the fact that they perceived high levels of stress related to pessimism, child characteristics, and parent and family problems (Wang, Michaels, & Day, 2011). Environmental barriers in the form of availability of resources, behavioral difficulties of the child, family functioning/impact, general health and child physical functioning has been seen to have negative and significant associations with physical quality of life (Law, Hanna, Anaby, Kertoy, King, & Xu, 2014).

Parents who have children with disabilities are often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life (QOL). Social relationships and environmental domains of QOL differed significantly in parents of children with disabilities such that parents who have children with more severe disabilities were found to have lower scores in physical, psychological, and environmental domains (Leung, 2003). Children with severe disabilities are more physically demanding of their parents, who might feel more stress when taking care of them. As a result parents' physical and psychological well-being might directly affect their children. This study thus, indicates the need for parental support when providing intervention to their children with disabilities. The aim of the study was to evaluate the Quality of Life between mothers of children with autistic spectrum disorders (ASD) and mothers of children with specific learning disabilities (SLD).

2. METHODS AND MATERIALS

2.1 Subjects

The sample comprised of 60 mothers (30 mothers having children with autistic spectrum disorders and 30 mothers of children with specific learning disability). Both the groups of mothers were assessed for their quality of life using the WHOQoL-BREF questionnaires. The children with ASD and SLD were those attending OPD at various neuro-psychiatric hospitals/clinics and special schools in National Capital Region of Delhi. Participants were mothers of children aged 6-15 years; mothers' age range was between 30 to 45 years; and children were diagnosed with SLD and Autistic Spectrum Disorders as per International

Classification for Diseases - Diagnostic Criteria for Research (ICD - 10). Mothers/family having any major psychiatric/medical illness that might contribute to stress, mothers Parents unwilling to participate and single mothers were excluded from the study. The sample thus comprised of two groups - Group 1 (mothers having children with ASD) and Group 2 (mothers having children with SLD).

2.2 Tool

To assess the quality of life, the WHOQoL-BREF was used. The WHOQoL-BREF is an abbreviated version of the WHOQoL-100, which is a self-administered questionnaire. It comprises of 26 items categorized into four broad dimensions - Physical Health, Psychological Well-being, Social Relationships and Environment Domain. The items are rated on a 5-point scale (WHO, 1998). The reported values for Cronbach alpha were 0.82 for physical health, 0.81 for psychological domain, 0.68 for social domain and 0.80 for environment domain. Domain scores are scaled in a positive direction.

2.3 Procedure

Participants were selected on the basis of the inclusion and exclusion criteria following which a written informed consent was obtained from the mothers. The WHOQoL BREF scale was administered on mothers of the two groups. Following the data collection, the mothers were debriefed about the findings. The data was thus collected following the above design and was interpreted using mean and standard deviation and compared through t-test, Independent measure.

2.4 Statistical Analyses

The data thus collected were statistically analyzed by using Statistical Package for Social Sciences (SPSS), version 16.0 software. Mean, standard deviation and independent *t*-test were computed to explore the presence or absence of any significant difference between the two groups on their QoL. The level of significance was set at 0.05 level.

3. RESULTS

Table 1: Mean and standard deviation of the two groups

Sl. No	Quality of Life Domains	Group 1		Group 2	
		Mean	SD	Mean	SD

1	Physical Health	49.20	8.80	61.17	11.09
2	Psychological	48.03	11.23	62.60	11.55
3	Social Relationships	56.70	12.29	66.07	10.96
4	Environment	48.50	8.20	59.83	9.57

Table 1 shows the mean and standard deviation of the two groups of mothers having children with autistic spectrum disorders and specific learning disabilities. On the physical health domain, the mean score of mothers having children with autistic spectrum disorders is 49.20, which is lower than the mean score of mothers having specific learning disabilities (61.17). On the psychological domain, the mean score of mothers having children with autistic spectrum disorders is 48.03 which is lower than the mean score of mothers having specific learning disabilities (62.60). On the social relationships domain, the mean score of mothers having children with autistic spectrum disorders is 56.70 which is lower than the mean score of mothers having specific learning disabilities (66.07). On the environment domain, the mean score of mothers having children with autistic spectrum disorders is 48.50 which is lower than the mean score of mothers having specific learning disabilities (59.83). Thus, on all the four domains, the mean scores contributed by mothers of children having ASD is lower than the mean score contributed by mothers having children with SLD.

Table 2: Summary of *t*-test, independent measure on the quality of life domains

Sl. No.	Quality of Life Domains	Test of Difference & Level of significance	
		<i>t</i>	Significance
1	Physical Health	4.62*	0.05
2	Psychological	4.95*	
3	Social Relationships	3.11*	
4	Environment	4.92*	

*Significant

Tab. $t_{0.05}(58) = 1.67$

Table 2 contains the summary of the Independent *t*-test that was calculated to see whether there was any difference in the two groups in the way they experience subjective well-being. It was found that there was significant difference between the two groups in all the four domains of quality of life. The independent *t*-test results indicated differences in all the domains which were significant at *p*.05 level.

4. DISCUSSION

Quality of life of mothers of children with special needs need was assessed with the intention of ascertaining whether different mothers' groups of children with special needs perceive the quality of daily life in similar way or differently. The four domains - physical, psychological, social and environment - were compared between the three parental groups as there has been very less literature on these three psycho-neurological disorders. The presence of child with psycho-neurological problems affects the specific aspects as well as the overall satisfaction of life. Having good health, feeling optimistic and being in control during stressful situations can have positive impact on the perceived quality of life. Thus, this attempt has been made to understand how the two groups differ or are similar in the way they perceive subjective well-being.

In the present study, it has been found that mothers of children with ASD showed significant impairment in the quality of life - physical health domain as compared to the mothers of children with SLD. The mean difference indicates presence of significant difference between the two groups in the way they perceive the quality of physical health being experienced by them. The mean scores suggest that mothers of children with specific learning disabilities seem to experience better quality in the physical domain as compared to the mothers of children with autistic spectrum disorder. Thus, it is very likely that mothers of children with autistic spectrum disorder experiences dissatisfaction with their capacity to work or in their performance of daily living activities. The responsibility of taking care of a dependent may also be taking its toll on the parents and as such they may experience some physical discomfort. This can be supported by a study on parents of children with special needs which showed significant difference from the parents of normal children on the Emotional Intelligence and quality of life of parents of children with special needs irrespective of the special needs category to which the child belongs. Also the condition of the child affects both the parents equally (Ravindranadan & Raju, 2008).

The mothers of children with specific learning disabilities may have better quality of life in the physical domain as they need not necessarily be physically present all the time to take care of the child. Since children with autistic disorders need to be supervised with most of their activities of daily living, their mothers are most likely experiencing poor quality of life in the physical domain. Parents of children with autism scored low on the physical domain as compared to the parents of non-affected children which might be because of stressful experiences with professionals, or dealing with difficult behaviors (Mugno, Ruta, Arrigo, & Mazzone, 2007).

Family environment affects the quality of life of mothers of children with ID. Regression analyses reveal that the physical domain of QoL was significantly predicted by active recreational orientation and independence (Malhotra, Khan, & Bhatia, 2013).

On the psychological domain, the mean scores indicate that mothers of children with specific learning disabilities are experiencing better psychological well-being as compared to the other groups. Mothers of children with autistic spectrum disorder are likely to be experiencing the least amount of subjective well-being in the psychological domain. Parents of children with disabilities face a number of challenges with respect to satisfaction with life, their emotional states, and their perception about the pleasantness of life. Thus, parents of children with disabilities who perceive these challenges in a negative way show poorer psychological well-being as compared to those faced by parents of children without any disability. Parents of children with autistic disorder who face difficulties in dealing with stressful situations tend to feel physical and psychological exhaustion (Hartley *et al.*, 2010).

The domain social relationship which assesses the individual's perception of the quality of life in the social relationships which includes facets like personal relationships, social support and sexual activity has also been found to be affected differently in the two groups. There was a significant difference in the social relationships domain between mothers of children with ASD and mothers of children with SLD. Parents of children with Autism have been found to use social diversion in a very limited way. The reason for parents of children with autism to use social diversion coping could be that the burden of raising a child with autism significantly limits parents' social activities. Mothers of children with Autism have been shown to have impairments in social relationships (Mugno *et al.*, 2007). The absence of a supportive network increases the need 'to provide protection' to the child diagnosed with Autism and also the perception of the difficulty of the child's behavior. If a parent perceives the availability of support, then he/she experiences satisfaction with family functioning. A positive feeling towards the child coupled with support from family, friends and community serves as important factors in determining parental stress (Armstrong, Birnie-Lefcovitch, & Ungar, 2005).

The environment domain assesses the individual's perception of the quality of life in the environment which includes facets like financial resources, health & social care, home environment, participation in & opportunities for recreation/leisure activities, physical environment etc. on this domain as well mothers of children with Specific Learning Disabilities have better quality of life as compared to mothers of children with ASD. The difficulties faced in carrying out activities of daily living of children with developmental disabilities result in requirements for long term care, far exceeding the usual needs of children as they

develop, or the expectations of their families as a parent. Thus, while taking care of children with disabilities is a normal part of being a parent, providing the high level of care required by a child with long term functional limitations can become stressful and may impact both physical and psychological health of caregivers. Research indicates that parents in the ASD and SLD group reported impairment in all the four domains of quality of life. Thus, parents of children with ASD and SLD seem to display a higher burden and impaired quality of life (Malhotra *et al.*, 2012). Families of children with autism reported a great deal of burden in child care which affects their participation in social activities and events and less involvement in community services. Most parents also report of either quitting their jobs or changing jobs to ensure better child care for their children with disabilities indicating financial burden. Such findings indicate the need for assess the relationship between parental distress and quality of life which some researchers have also proven that parental distress was a significant predictor for both parent's quality of life (Dardas & Ahmad, 2014).

5. CONCLUSIONS

Mothers of children with ASD seem to display impaired quality of life as compared to mothers of children with SLD. These findings need to be explored by professionals working in these areas so that adequate support can be provided to the mothers at the right time. Parent training and counseling should be provided to the mothers to make them look at the care giving process as apposite experience. The male parents should be encouraged to be more responsive in taking care of their child with developmental delay so that a friendly and optimistic home environment can be ensured. Lastly, proper knowledge and how to give proper care to children with developmental delays should be encouraged at the community level so that there is better acceptance of these children and the parents are felt supported at every possible ways.

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