

## Quality of Life of Caregivers of Children with Autism Spectrum Disorder

Chinmay Desai<sup>1\*</sup>, Dr. Mukesh Prajapati<sup>2</sup>

### ABSTRACT

Children with special needs (CWSN) experience disabilities in various areas. The birth of a child with special needs causes stress in the family, most especially among parents, consequently affecting parental quality of life (QOL). This paper describes the QOL of parents of Ahmedabad CWSN and examines the determinants of parental QOL using a mixed-methods design. The ADHD and ASD children's parents were taken into account in the sample selection. The participants are parents of Ahmedabad CWSN (n = 100) and were asked to answer the Quality-of-Life Questionnaire developed by S. Sharma and N. Nasreen. Clinical Interviews were also conducted among a sub-sample of the parents who answered the questionnaire earlier. Results indicate a gender-wise quality of life as parents of Ahmedabad children with special needs express and exhibit negative stresses that affect their lives.

**Keywords:** *Quality of Life, parents, children with special needs, AUTISM, Attention Hyperactive Disorder*

Quality of life (QOL) means a good life. Living a good life is the same as living a quality life. Quality of life is the degree to which a person's life experience satisfies their wants and needs (both physical and psychological). The term 'quality of life' overlaps but is not synonymous with several terms, including 'well-being', 'social indicators' and 'lifestyle' (Andrews, 1980), among others. Many researchers in this field have adopted the phrase "Level of Well-Being," which seems to express the concept of quality of life most succinctly. However, the definition referred to in this report is somewhat broader and is suggested by Rice (1984, p. 157). Quality of life is also about the suitability of an individual's life with expectations, how satisfied the individual is with his life, and an understanding of individual elements that are not yet in accordance with expectations and need to be changed. Quality of Life has been defined in literature as a person's dynamic appraisal of his lifestyle with regards to numerous domain names because it pertains to his environment (World Health Organization, 1997). Health-care specialists normally agree on four QOL dimensions: physical, psychological, social, and spiritual (Hilderley, 2001).

<sup>1</sup>Research Scholar

<sup>2</sup>Assistance Professor, S.V. Arts College

\*Corresponding Author

Received: January 12, 2024; Revision Received: January 29, 2024; Accepted: February 03, 2024

## Quality of Life of Caregivers of Children with Autism Spectrum Disorder

Attention deficit/hyperactivity disorder (ADHD) is a childhood-onset neurodevelopmental disorder characterized by developmentally inappropriate levels of inattention, hyperactivity, and/or impulsivity, along with pervasive and significant functional impairment (American Psychiatric Association [APA]). In DSM-5, diagnostic criteria include at least six designated symptoms of inattention and/or hyperactivity/impulsivity (lowered to five in adolescents over age 17 years) appearing before age 12 years, with symptoms present for at least six months, occurring in more than one setting, and of a degree that is impairing functioning or normal development (APA, 2013). Three presentations of ADHD can be identified based on symptomatology: 1) predominantly inattentive, 2) predominately hyperactive-impulsive, and 3) combined presentation. An individual's symptoms, and, consequently, presentation, may change over time.

Autism spectrum disorder is a condition related to brain development that impacts how a person perceives and socializes with others, causing problems in social interaction and communication. The term "autism" is derived from the Greek word "autos", which means "self". In the 1940s, Leo Kanner, a doctor at Johns Hopkins University, began using the term to describe children whose behavior was socially and emotionally withdrawn. Autism Spectrum Disorder (ASD), sometimes referred to as "autism", is "a chronic disorder whose symptoms include failure to develop normal social relations with other people, impaired development of communicative ability, lack of imaginative ability, and repetitive, stereotyped movements" (Carlson, 2007, p. 594).

Parenting children with special needs may have an adverse effect on their general well-being (Cummings, Bayley, & Rie, 1966; DeMyer, 1979). Boyd (2002) states that if support is not sought, the development of depression and anxiety is postulated for mothers. Mothers of children with autism (CWA) and children with behavior disorders are at risk of experiencing dysphoria, which seems to be linked to the stresses brought on by parenting a child with special needs (Dumas, 1991).

### *Quality of Life (QOL) of Parents of CWSN*

Quality of Life has been described in literature as a person's dynamic appraisal of his life in relation to various domains as they relate to his environment (World Health Organization, 1997). A person's QOL is not a single phenomenon but rather an interplay between and among several dimensions. Health-care professionals generally agree on four QOL dimensions: physical, psychological, social, and spiritual (Hilderley, 2001). The impetus for research concerning the quality of life of individuals with disabilities has been seen for the past twenty years (Hughes & Hwang, 1996; Schalock, 1997, 2000), but not until recently has there been more focus on its effect on parental QOL.

### *Objectives*

- To study the gender differences in terms of Quality of Life among caregivers of children with autism.
- To study the religion differences in terms of Quality of Life among caregivers of children with autism.

### *Hypotheses*

- There will be no significant difference in Quality of Life among Male and Female caregivers of children with autism.

## Quality of Life of Caregivers of Children with Autism Spectrum Disorder

- There will be no significant difference in Quality of Life among Hindu and Muslim caregivers of children with autism.

### Materials

In the present investigation, the tool was Quality of Life, developed by Sarika Sharma and Dr. Nakhat Nasreen.

### Procedure

In the present study, the researcher investigated the level of quality of life among Autism patients' caregivers. A sample of 120 subjects was selected through the random sampling method. The whole data was obtained using the Quality-of-Life Scale (QOLS) constructed by Sarika Sharma and Dr. Nakhat Nasreen. The whole procedure of filling out the inventory was explained to the subjects very clearly. Also, the instructions given on the inventory were clearly explained to the subjects. The scores were assigned for different responses according to the items. The scores were arranged in tabular form before ANOVA was applied.

### Variables

- **Independent Variable:**  
Gender: Male and Female
- **Dependent Variable:**  
Quality of Life

## RESULT AND DISCUSSION

*Table No.1 shows that Quality of Life among caregivers of children with autism:*

Source of variance	df	Sum of Square	Mean sum of square	F	Table Value (0.05)	Level of significant
SSA	1	208.03	208.03	0.3	3.92	NS
SSB	1	3286.53	3286.53	4.74	3.92	S (.05)
SSAB	1	282.14	282.14	0.41	3.92	NS
SS Error	116	80469	693.7			
SST	119	84245.7				

*\*S=Significant or 0.01, 0.05 Level of Significant*

**SSA = Gener (A<sub>1</sub> = Male, A<sub>2</sub> = Female)**

**SSB = Religion (B<sub>1</sub> = Hindu, B<sub>2</sub> = Muslim)**

*Table No. 1* shows the difference between male and female caregivers of ASD children. The findings of the above table indicate that there is no gender difference in Quality of life. Thus, there is a no significant difference between male and female who care givers of ASD children. The null hypothesis is accepted. Table shows the difference between hindu and muslim caregivers of ASD children. The finding shows that there is significant difference between hindu and muslim caregivers. Thus, there is significant difference between hindu and muslim caregivers of ASD children. It means hypothesis is rejected. Parents of children with autism spectrum disorder seem to display a higher burden and a significant impairment in their quality of life. These findings must be taken into account in policymaking to provide better and more specific supports and interventions for this group of diseases. More attention should be given to parents' (and, in particular, mothers') needs. Social support and different coping strategies should be developed to respond positively to individual changing needs and buffer parents from the stress of having a child with a disability. New research should be

## Quality of Life of Caregivers of Children with Autism Spectrum Disorder

conducted to measure the effectiveness of these strategies. In addition, effective and sustainable psychosocial programs are needed to provide the necessary support for the special needs of the children and their families.

### *Suggestions for Further Research*

- A study on the Stigma level of disability among males and females can be further undertaken.
- Level of family stress of the ASD children in relation to their socioeconomic status, locality can be studied.
- Attitude of parents towards Autistic children can be studied.

## REFERENCES

- American Psychiatric Association. (2016), Diagnostic and Statistical Manual of Mental Disorders (4th ed.) Washington, DC: American Psychiatric Association.
- C. R. Kothari, 'Research Methodology', Ilektra Kotzampopoulou(2015),' Quality of life in families having children with disabilities: The parents' perspective', UNIVERSITY OF OSLO.
- Migerode, F., Maes, B., Buysse, A., & Brondeel, R. (2012). Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience Journal of Developmental and Physical Disabilities, 487-503. doi:10.1007/s10882-012-9285-1
- N.Nasreen & S.Sharma(2014), 'Manual for Quality of Life – SSNN', National Psychological Corporation',AGRA.
- R Panday, N Fatima (2016), Quality of Life among Parents of Mentally Challenged Children, International Journal of Indian Psychology, Volume 3, Issue 3, No. 11, DIP: 18.01.205/20160303, ISBN: 978-1-365-21307-6
- Sirgy, J. M. (2012). The psychology of quality of life: Hedonic well-being, life satisfaction and eudaimonia (2nd ed., Vol. 50). London: Springer.

### *Acknowledgment*

The author(s) appreciates all those who participated in the study and helped to facilitate the research process.

### *Conflict of Interest*

The author(s) declared no conflict of interest.

**How to cite this article:** Desai, C. & Prajapati, M. (2024). Quality of Life of Caregivers of Children with Autism Spectrum Disorder. *International Journal of Indian Psychology*, 12(1), 425-428. DIP:18.01.040.20241201, DOI:10.25215/1201.040