



## Quality of Life among Mothers of Children with Neurodevelopmental Disorders

Abhilash V. L.<sup>1</sup> and Jasseer J.<sup>2</sup>

<sup>1</sup>Research Scholar, Department of Psychology, University of Kerala, India; <sup>2</sup>Professor, Department of Psychology, University of Kerala, India. Corresponding Author: <[drjasseer@yahoo.co.in](mailto:drjasseer@yahoo.co.in)>

### KEYWORDS

Quality of life (QoL), Neurodevelopmental disorder (NDD), Intellectual Disability (ID), Specific Learning Disability (SLD), Attention Deficit Hyperactive Disorder (ADHD) and Autism Spectrum Disorder (ASD)

### ABSTRACT

*The present study is carried out to understand the quality of life (QoL) among mothers having children with different types of neurodevelopmental disorders (NDD). The participants were randomly chosen one consisted of 120 mothers, 30 each having children with intellectual disability (ID), specific learning disability (SLD), attention deficit hyperactive disorder (ADHD) and autism spectrum disorder (ASD). Data are collected using WHOQOL-BREF. The analysis of data using one-way ANOVA revealed that mothers having children with ID and ASD report significantly more impairment in four domains (general health, physical health, environmental health and overall health) of QoL than mothers having children with ADHD and SLD.*

### Introduction

Neurodevelopment is the link between genetic, brain, cognitive, emotional, and behavioural processes across the developmental lifespan. Persistent and significant disruption to this dynamic process through genetic and environmental risk could result in neurodevelopmental disorders and disability (Boivin, Kakooza, Warf, Davidson & Grigorenko, 2015). Intellectual disability (ID), autism spectrum disorder (ASD), specific learning disability (SLD), attention-deficit hyperactive disorder (ADHD), cerebral palsy and visual-hearing impairment are examples of neurodevelopmental disorder in children. They face difficulties with motor skills, learning, language and speech, behaviour, memory or other neurological functions. Some disabilities are lifelong, though the signs and symptoms of neurodevelopmental disorders often change or evolve as the child grows up (DSM V, 2013). The prevalence rate of a neurodevelopmental disorder among children aged 2-9 in India is nearly 12% (Arora, et al. 2018). This study is based on four types of neurodevelopmental disorders in children, viz., intellectual disability, specific learning disability, attention-deficit hyperactivity disorder and autism spectrum disorder.

Intellectual disability (ID) is characterized by deficits in general mental abilities such as reasoning, judgment, abstract thinking, planning, academic learning, problem-solving and learning from experiences. The global prevalence of intellectual disability is approximately 1%, and the prevalence rate varies by age. And around 6 per 1,000 is the prevalence of intellectual disability of severe type (DSM-V, 2013).

Specific learning disabilities (SLD) are a heterogeneous group of disorders manifested by significant difficulties in acquiring and using listening, speaking, reading, writing, reasoning, or mathematical abilities (NJCLD, 1998). The prevalence rate among school-age children across different cultures and languages is 5-15% (Karande & Kulkarni, 2009).

Attention deficit hyperactivity disorder (ADHD) is defined by impairing levels of inattention, disorganization and/or hyperactivity-impulsivity. Disorganization and inattention require the inability to stay on task, losing materials, or seeming not to listen at levels that are inconsistent with age or development. Hyperactivity-impulsivity involves over activity, inability to stay seated, fidgeting, inability to wait and intruding into other people's activities - symptoms that are excessive for age or developmental level (DSM-V, 2013).

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with a persistent deficit in social interaction and social communication across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviours used for social interaction and skills in developing, maintaining, and understanding relationships. Reported frequencies in recent years for autism spectrum disorder is 1% of the population for children and adults (DSM-V, 2013).

### **Parenting children with Neurodevelopmental disorders**

Parenting is the process by which mother and father support and promote a child's physical, social, intellectual and emotional development from infancy to adulthood. Parents find a lot of difficulties rearing their child if they have any NDD. They are more likely to experience distress and depression than parents of normal children. According to earlier studies, parents of disabled children feel a sense of helplessness, failure, and guilt (Dervishalaj, 2013). They have the risk of developing different psychological problems compared to parents of normally developing children (King, 1999). In every family, it is always the mother's responsibility more than father's to care for the child. If that child is having a psychological issue like NDD, it is a difficult task for the mother. The demands of every child with a neurodevelopmental disorder are different. It varies with the type of disorder and the child. Moreover, the mother is the one who is supposed to change according to that.

According to research, mothers of children with disabilities are more likely than mothers of children without disabilities to report being in bad health. (Barton, Lethbridge & Phipps, 2008). The long-term functional limitations of the child, along with the requirement of a high level of care, could create burdensomely and result in the mother's physical and psychological wellbeing. And finally, mothers' quality of life (QoL) is affected. A person's dynamic assessment of his life in connection to numerous areas related to his surrounding environment is referred to as quality of life (QoL) (World Health Organization, 1998). Gudmundsson, O' Laffur and Tomasson (2002) report that mothers of children with mental disorders experience a poor QoL, with a high prevalence of mental disorders themselves. Similar studies are conducted by Leung & Li-Tsang (2003) and Rotor (2006) on the QoL of parents with children with disabilities. Both studies conclude that raising, caring and parenting disabled children affected parental QoL.

This study compares the QoL of mothers of children with four different types of neurodevelopmental disorders in Kerala, India and the problems they face. The field of special education in Kerala could use this to understand the needs of these mothers.

### **Need and Significance of the study**

Stressors associated with parenting a child with a specific health need may be greater than those associated with raising normally developing children. (Baxter, Cummins, & Yiolitis, 2000). If a child

has serious disabilities, parents may need to spend most of their time caring for the child, which limits their ability to do other things, harms their social life, and lowers their QoL (Leung & Li-Tsang, 2003). Children with disabilities create special challenges for parents. Furthermore, evidence points to the possibility that parents' health results may be adversely affected by increased stress, which poses major health risks. (Hung, Wu, Chiang, Wu, & Yeh, 2010; Thurston, Paul, Loney, Ye, Wong, & Browne, 2011; Witt, Gottlieb, Hampton, & Litzelman, 2009). Disabilities in children cause not only financial burden but also lead to an incomplete state of wellbeing in physical health, psychological health and social health of the families.

In Kerala, India, neurodevelopmental disorder (NDD) is not uncommon. However, very few studies are only conducted on understanding the QoL of families having children with a neurodevelopmental disorder and the problems of these mothers. The current study attempts to investigate the quality of life of mothers having children with different types of neurodevelopmental disorders. The findings of this study would contribute to the scientific literature, which increases its significance. Further, the information revealed from this research work may also help clinicians plan and apply intervention strategies for these mothers to reestablish their quality of life.

### **Objective of the study**

To understand the quality of life of mothers having children with different types of neurodevelopmental disorders (ID, SLD, ADHD & ASD).

### **Hypothesis**

There is a significant difference among mothers having children with different types of neurodevelopmental disorders (ID, SLD, ADHD & ASD) on dimensions of quality of life.

### **Method**

#### *Participants*

A total of 120 mothers having children with four different types of neurodevelopmental disorders from Kerala, India – intellectual disability, specific learning disability, attention deficit hyperactivity disorder and autism spectrum disorder, which comprises 30 mothers each from all these categories.

#### *Variable*

#### *Quality of Life (QoL)*

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 (WHO, 1998). The sub-variables of quality of life are general health, physical health, psychological health, social relationships and environmental health.

#### *Measure*

Measure used in the present study includes,

#### *WHOQOL-BREF (1998) was used*

The WHOQOL-BREF is used to evaluate how people perceive themselves in relation to their culture, value systems, and individual objectives, standards, and challenges. It includes 26 items which measure

the following domains: general health, physical health, psychological health, social relationships and environmental. The psychometric properties of the test were well established.

### *Statistical Techniques*

The data were analyzed using One-way ANOVA and followed by Duncan Procedure. One-way ANOVA was used to find whether there is a significant difference among mothers having children with ID, SLD, ASD and ADHD in the dimensions of quality of life. Then Duncan test is carried out when one-way ANOVA indicates a significant difference among the groups to understand which group of mothers having children (ID, SLD, ADHD and ASD) differ from others in the dimensions of quality of life.

### *Procedure for data collection*

WHOQOL-BREF is given to mothers with a brief description of the purpose of the study, and they signed the consent form to participate in the study. The researchers assured the confidentiality of the data.

## **Result and Discussion**

In the present study, one-way ANOVA and post hoc Duncan procedure were used to identify the difference in mean score obtained by mothers having children with ID, SLD, ADHD and ASD in the five dimensions of QoL.

*Table 1 - Summary of ANOVA of QoL among mothers having children with different types of neurodevelopmental disorder (ID, SLD, ADHD & ASD)*

Variables	Groups	N	Mean	SD	F	Sig
G.H.	ID	30	6.93	1.507	3.493	.018
	SLD	30	7.57	1.165		
	ADHD	30	7.93	.907		
	ASD	30	7.43	1.194		
	TOTAL	120	7.47	1.250		
Phy. H	ID	30	24.37	3.882	5.970	.001
	SLD	30	27.80	3.508		
	ADHD	30	27.40	3.460		
	ASD	30	26.10	2.964		
	TOTAL	120	26.42	3.680		
Psy. H	ID	30	21.00	4.251	1.476	.225
	SLD	30	22.73	3.513		
	ADHD	30	22.73	3.562		
	ASD	30	21.73	3.850		
	TOTAL	120	22.05	3.828		
S.R.	ID	30	11.27	2.690	.504	.680
	SLD	30	11.97	1.938		
	ADHD	30	11.73	2.212		
	ASD	30	11.63	2.076		
	TOTAL	120	11.65	2.233		
E.H.	ID	30	25.03	5.690	5.226	.002
	SLD	30	29.00	5.795		
	ADHD	30	29.47	4.531		
	ASD	30	29.33	4.155		
	TOTAL	120	28.21	5.358		

From the table (1), it is evident that the four groups of mothers significantly differ among themselves in the dimensions of QoL such as general health ( $F=3.49$ ,  $p<.05$ ), physical health ( $F=5.97$ ,  $p<.01$ )

and environmental health ( $F=5.22$ ,  $p<.01$ ). No significant difference was found in the dimensions of psychological health ( $F=.22$ ,  $p>.05$ ) and social relationships ( $F=.50$ ,  $p>.05$ ). Duncan procedure was carried out to check which neurodevelopmental disorder is significantly differing from one another on QoL.

*Table: 2 - Multiple comparison of mean scores on the dimension general health obtained by different NDD groups*

NDD	N	Subset for alpha = 0.05	
		1	2
ID	30	6.93	
ASD	30	7.43	7.43
SLD	30	7.57	7.57
ADHD	30		7.93
Sig.		.057	.134

When considering general health, a significant difference was found between mothers having children with ID and ADHD. No such significant difference was obtained in the case of subgroups of ID, ASD and SLD. That is, mothers having children with ID, ASD & SLD observed a common general health pattern and also a consistent result was obtained among mothers of children with ASD, SLD and ADHD. As it can be observed from the table, the subgroup of ADHD had a mean score of 7.93 and ID had 6.93. That means mothers having children with ADHD have better general health than mothers having children with ID. This may be because it is comparatively easier to up bring a child with ADHD than ID. Once a mother knows what is going on in an ADHD child, it is possible to dramatically reduce the downside of ADHD and learn to handle the challenges in the child. However, a child with ID is more dependent on the mother than a child with ADHD.

*Table: 3 - Multiple comparison of mean scores on the dimension physical health obtained by different NDD groups*

NDD	N	Subset for alpha = 0.05	
		1	2
ID	30	24.37	
ASD	30	26.10	26.10
ADHD	30		27.40
SLD	30		27.80
Sig.		.055	.075

It can be seen from the table that there was no significant difference between the subgroups ID and ASD in physical health. Also, no significant difference was found among subgroups of SLD, ADHD and ASD. But there was a significant difference between subgroups of mothers having children with ID and ADHD. Similarly, mothers of children with ID and SLD also differ significantly. Mean values for the physical health of subgroups of ID, ADHD and SLD are 24.37, 27.40 and 27.80, respectively. So, mothers of children with SLD have greater physical health than the other two subgroups of NDD. This result supports the finding that mothers of children with developmental disabilities, such as ID and ASD have higher rates of physical health issues and, ultimately, their wellbeing (Eisenhower et al., 2005). This can be because children with SLD are good at some things but poor at others, and they feel anxious about what they can and cannot do. Proper interventions and resources help in empowering those children. This reflects in mothers as they can concentrate on their own activities of daily living, and they feel energetic. A similar trend was found by Craig, Operto, Giacomo & Margari (2016) as parents of children with ASD and ADHD reported higher parenting stress than parents of children with SLD.

Table: 4 - Multiple comparison of mean scores on the dimension environmental health obtained by different NDD groups

NDD	N	Subset for alpha = 0.05	
		1	2
ID	30	25.03	
SLD	30		29.00
ASD	30		29.33
ADHD	30		29.47
Sig.		1.000	.741

In the case of environmental health, the table showed that there was no significant difference among mothers of children having SLD, ASD and ADHD. However, a significant difference exists between mothers of children with ID with all other NDD. It can be observed from the table that the mean score of ID, SLD, ASD and ADHD are 25.03, 29.00, 29.33 & 29.47, respectively. Therefore, mothers of children with ADHD have comparatively higher environmental health than other subgroups. This could be because children with ADHD are energetic, spontaneous, hyper-focused, creative and inventive. This promotes home environment, provides opportunities for mothers to acquire new information and skills as well as participation in and opportunities for recreation and leisure activities. These findings from the study confirms that mothers of children with developmental disorders, such ID and ASD, are more likely to experience mental health issues. (Bailey et al., 2007; Singer, 2006; Abhilash & Jasseer, 2019). Two previous studies also showed that parents of children with autism (Mugno, Ruta, D'Arrigo & Mazzone, 2007) and mental retardation (Malhotra, Khan & Bhatia, 2012), particularly mothers, experience more stress than parents of typically developing children.

## Conclusion

The findings of the study revealed a significant difference among mothers having children with neurodevelopmental disorders in the dimensions of QoL such as general health, physical health and environmental health. Mothers having children with ID report the lowest level of QoL, followed by mothers having children with ASD. Comparatively it is mothers of SLD and ADHD children have a better QoL.

This indicates that mothers of ID and ASD children undergo many challenges in meeting their child's long-term personal needs and demands. Support in the form of reassurance and encouragement at every stage of the process, from diagnosis to treatment, shall also help reduce the family's anxiety and stress and thus improve the QoL. These results signify the importance of broader intervention policies involving the families and to develop intervention programmes such as coping skills training, positive thinking and stress management for the families of children with the neurodevelopmental disorder to reduce their stress and to enhance their quality of life. Also, this shall assist in identifying the effectiveness of services available in Kerala, India and guidelines for managing stress-related issues in the family.

## References

- Abhilash, V. L., & Jasseer, J. (2019). *Quality of life in relation to burnout among mothers of children with neurodevelopmental disorders* [Unpublished master's thesis]. University of Kerala.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.
- Arora, N. K., Nair, M. K., Gulati, S., Deshmukh, V., Mohapatra, A., Mishra, D., & Vajaratkar, V. (2018). "Neurodevelopmental disorders in children aged 2–9 years: Population-based burden estimates across five regions in India". *PLOS Medicine*, *15*(7), e1002615. doi:10.1371/journal.pmed.1002615
- Bailey, D. B., Golden, R. N., Roberts, J., & Ford, A. (2007). "Maternal depression and developmental disability: Research critique". *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 321-329. doi:10.1002/mrdd.20172
- Baxter, C., Cummins, R. A., & Yiolitis, L. (2000). "Parental stress attributed to family members with and without disability: A longitudinal study". *Journal of Intellectual & Developmental Disability*, *25*(2), 105-118. <doi.org/10.1080/13269780050033526>
- Boivin, M. J., Kakooza, A. M., Warf, B. C., Davidson, L. L., & Grigorenko, E. L. (2015). "Reducing neurodevelopmental disorders and disability through research and interventions". *Nature*, *527*(7578), S155-S160. <doi.org/10.1038/nature16029>
- Burton, P., Lethbridge, L., & Phipps, S. (2008). "Children with disabilities and chronic conditions and longer-term parental health". *The Journal of Socio-Economics*, *37*(3), 1168-1186. <doi:10.1016/j.socec.2007.01.032>
- Craig, F., Operto, F. F., De Giacomo, A., Margari, L., Frolli, A., Conson, M., Ivagnes, S., Monaco, M., & Margari, F. (2016). "Parenting stress among parents of children with neurodevelopmental disorders". *Psychiatry Research*, *242*, 121-129. <doi.org/10.1016/j.psychres.2016.05.016>
- Dervishalaj, E. (2013). "Parental Stress in Families of Children with Disabilities: A Literature Review". *Journal of Educational and Social Research*. <doi:10.5901/jesr.2013.v3n7p579>
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). "Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being". *Journal of Intellectual Disability Research*, *49*(9), 657-671. <doi:10.1111/j.1365-2788.2005.00699.x>
- Guðmundsson, Ó. Ó., & Tómasson, K. (2002). "Quality of life and mental health of parents of children with mental health problems". *Nordic Journal of Psychiatry*, *56*(6), 413-417. <doi.org/10.1080/08039480260389325>
- Hung, J. W., Wu, Y. H., Chiang, Y. C., Wu, W. C., & Yeh, C. H. (2010). "Mental health of parents having children with physical disabilities". *Chang Gung medical journal*, *33*(1), 82–91.
- Karande, S., & Kulkarni, S. (2009). "Quality of life of parents of children with newly diagnosed specific learning disability". *Journal of Postgraduate Medicine*, *55*(2), 97. doi:10.4103/0022-3859.52839
- King, G. (1999). "Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome". *Journal of Pediatric Psychology*, *24*(1), 41-53. doi:10.1093/jpepsy/24.1.41
- Malhotra, S., Khan, W., & Bhatia, M. S. (2012). "Quality of life of parents having children with developmental disabilities". *Delhi Psychiatry Journal*, *15* (1).
- Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). "Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder". *Health and Quality of Life Outcomes*, *5*(1). <doi.org/10.1186/1477-7525-5-22>
- Operationalizing the NJCLD "Definition of Learning Disabilities for Ongoing Assessment in Schools. (1998). *Learning Disability Quarterly*, *21*(3), 186-193. <doi:10.2307/1511080>
- Rotor, Mia (2006). "Quality of Life of Filipino Caregivers of Children with Cerebral Palsy". *Philippine Journal of Occupational Therapy*. 1(2).
- Singer, G. H. (2006). "Meta-Analysis of Comparative Studies of Depression in Mothers of Children With and Without Developmental Disabilities". *American Journal on Mental Retardation*, *111*(3), 155. <doi:10.1352/0895-8017(2006)111[155:mocsod]2.0.co;2>
- THE WHOQOL GROUP. (1998). "Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment". *Psychological Medicine*, *28*(3), 551-558. <doi:10.1017/s0033291798006667>
- Thurston, S., Paul, L., Loney, P., Ye, C., Wong, M., & Browne, G. (2011). "Associations and costs of parental symptoms of psychiatric distress in a multi-diagnosis group of children with special needs". *Journal of Intellectual Disability Research*, *55*(3), 263-280. <doi.org/10.1111/j.1365-2788.2010.01356.x>
- WHOQOL-BREF. (2010). *Handbook of Disease Burdens and Quality of Life Measures*, 4353-4353. <doi:10.1007/978-0-387-78665-0\_6927>
- Witt, W. P., Gottlieb, C. A., Hampton, J., & Litzelman, K. (2009). "The impact of childhood activity limitations on parental

health, mental health, and workdays lost in the United States”. *Academic Pediatrics*, 9(4), 263-269. <[doi.org/10.1016/j.acap.2009.02.008](https://doi.org/10.1016/j.acap.2009.02.008)>

Yuen Shan Leung, C., & Wai Ping Li-Tsang, C. (2003). “Quality of life of parents who have children with disabilities”. *Hong Kong Journal of Occupational Therapy*, 13(1), 19-24. <[doi.org/10.1016/s1569-1861\(09\)70019-1](https://doi.org/10.1016/s1569-1861(09)70019-1)>