ORIGINAL ARTICLE



INTERNATIONAL JOURNAL OF RESEARCH IN PHARMACEUTICAL SCIENCES

Published by JK Welfare & Pharmascope Foundation

Journal Home Page: <u>https://ijrps.com</u>

A study to assess the quality of life among parents of autism spectrum disorder patients

Mary Minolin T^{*}, Jojimol J, Jemima M, Kowsalya K

Department of Child Health Nursing, Saveetha College of Nursing, SIMATS, Chennai, Tamil Nadu, India

Article History:	ABSTRACT
Received on: 15.04.2019 Revised on: 04.07.2019 Accepted on: 08.07.2019 <i>Keywords:</i>	Children with autism are more at risk for developing many due to expressive communication difficulties. Research continues to show that stress is related to parenting practices and parent effectiveness within the family system, the parents, the child, and their interaction are three possible sources of parental stress which disturbs the quality of life. The study aims is to assess the demo-
Autism Spectrum	graphic variable on quality of life among parent of autism child and to assess
Disorder,	the knowledge on quality of life among parents of autism child. A quantitative
Quality of Life,	research approach was adopted with convenient sampling technique to select
Parent	40 parents who attend the child development hospital. Data was collected by using standardized questionnaire . The data was organized and analyzed in term of descriptive statistics. The data collection tabulated and analyzed by using mean and standard deviation. Majority of the sample has a fair quality of life, some of the samples has a good quality of life, and a minority of the sample has a poor quality of life. The study results suggest that parents of autism children's need more guidance to improve their quality of life.

*Corresponding Author
Name: Mary Minolin T
Phone:
Email: minolinbabu@gmail.com

ISSN: 0975-7538

DOI: https://doi.org/10.26452/ijrps.v10i4.1606

Production and Hosted by

IJRPS | https://ijrps.com

 $\ensuremath{\textcircled{O}}$ 2019 | All rights reserved.

INTRODUCTION

Autism Spectrum Disorder is a Neuro formative issue described by two areas according to indicative and measurable manual. Autism Spectrum Disorder has a pervasiveness of around 1%. Flow research recommends the contribution of complex communication among hereditary and natural variables. Co grim conditions are basic in Autism Spectrum Disorder happening in the same number of as 70% and 26-38% of people with Autism Spectrum Disorder likewise have scholarly handicap a decline from past paces of 70% due to expanded consciousness of advanced Autism Spectrum Disorder (W.H.O, 2003).

Maladaptive practices, for example, animosity, selfdamage and dangerous conduct, have a commonness of 82-93.7% in youngsters with Autism Spectrum Disorder. Kids with chemical imbalance are more in danger for creating youngsters and other formatively postponed kids perhaps because of expressive correspondence troubles (W.H.O, 2003). Encouraging issue, for example, trouble in strong take-up and sustenance limitations, may happen because of tactile preparing distinction for instance not ready to endure certain consistency of nourishment, for example, sticky things or because of correspondence troubles, latrine preparing might challenge because of a general formative deferral or because of tyke's tangible issues or focal point of consideration somewhere else. As guardians of a kid with a chemical imbalance, guardians take on duties related with conclusion, wellbeing, and conduct and

helping their kid in regular life (WHO, 2008).

(Allik *et al.*, 2006), he learned about the personal satisfaction among the guardians of chemical imbalance youngsters were the customers came to PDD recovery focuses at Sweden. As per his examination, the discoveries are moms of chemical imbalance kids have less fortunate physical wellbeing than father (Allik *et al.*, 2006).

Mugno *et al.* (2007), he did the exploration about the personal satisfaction among the guardians of chemical imbalance youngsters were the customers came to tyke nervous system science and mental focus at Italy. According to his examination, the discoveries are guardians of youngsters with chemical imbalance have less fortunate personal satisfaction than the guardians of other children (Mugno *et al.*, 2007).

Montalbano and Roccella (2009), they did the examination about the personal satisfaction among the guardians of mental imbalance youngsters were the customers came to chemical imbalance social orders and schools at Italy. As per their examination, the discoveries are parental, and personal family satisfaction is influenced in mental imbalance children. The family's job is crucial in the arrangement of the youngster's character, speaking to the main social encompassing; The family assumes a significant job in building up the child's capacities and abilities, and maybe the nearness of a crippled tyke in the family may speak to a change point in lives of the whole family, it perceives the life and needs for adapting to new conditions. Globally, a chemical imbalance is assessed to influence 24.8 million individuals starting at 2015 (Montalbano and Roccella, 2009; Larsson et al., 2005).

Halawa and Muhammad (2010) accommodated that personal satisfaction generally got more consideration both in principle and practice due to varying perspectives among scientist about this concept (Halawa and Muhammad, 2010) demonstrated that the degree of personal satisfaction among the groups of youngsters with mental imbalance range issue was medium. Mental imbalance Spectrum issue is one such formative condition whose frequency is expanding quickly over the globe. This condition was first portrayed by Leo Kanners in 1943 and later contemplated by numerous scientists. It is one of the most serious formative inabilities which show up in the initial three years of life. It includes hindrances in social association and verbal and nonverbal correspondence. A few people with chemical imbalance have constrained interests, abnormal dozing or eating practices or a propensity to get things done to hurt them, for

example, slamming their heads or gnawing their hands. In the individual, Autism Spectrum Disorder influences relational abilities, social collaboration and conduct; while in the family, it influences connections with the youngster, among guardians and between the family and the network. Studies have revealed that guardians of youngsters with different formative handicaps experience elevated pressure, overburden and minimization in the public arena feeling of self fault, tiredness or exhaustion (Ezzati *et al.*, 2005).

Child-rearing youngsters with Autism range issue is more upsetting than child-rearing ordinarily creating kids or kids with other formative inabilities. , guardians demonstrated that they avoided partaking in exercises outside the home in light of the fact that their consideration was always on their tyke with the mental imbalance and in light of the fact that they felt that others didn't comprehend their youngster's conduct issues. Along these lines, Quality of Life of the groups of kids with Autism range issue is impacted by its shifting degrees of social problems (Tischler *et al.*, 2004).

The family is the essential power adding to the advancement of kids and youth. This commitment might be sure, unbiased, or negative in nature. Early connection and secure connection between a mother and infant bring about the prosperity and advancement of the tyke. These early parentyoungster collaborations are related with social and subjective improvement, scholastic execution, school participation, conduct, and social abilities. This relationship is especially significant for youngsters/youth with disabilities (Simonoff et al., 2008). Individual qualities of each individual from the family can either reinforce or confine the whole nuclear family. At the point when a tyke has an incapacity, individual form's the family may react in an unexpected way, contingent upon the qualities of the kid (e.g., the sort and the seriousness of the inability, the beginning age of the handicap) just as the attributes of the family (e.g., family size, number of guardians present in the home, birth request. Another trademark that effect a family are a capacity of the person to issue understand, physical and psychological wellness, correspondence, and inspiration level. The conduct collections of youngsters/youth with ASD (e.g., trouble with verbal and nonverbal correspondence, social conduct) may affect the family framework (both prompt and more distant family) kids/youth with a mental imbalance on their families (Munir, 2016). They found either a negative impact or no distinction on the conjugal subframework.

In any case, when couples have a decent relationship, managing a kid's handicap may fortify and enhance the relationship. Parents of youngsters with a mental imbalance, for the most part, report a larger amount of worry than guardians of a run of the mill kids. With respect to the kin subsystem, the outcomes are uncertain. Personal satisfaction is characterized as an impression of a person's fulfilment with home and network living, business, and wellbeing working. While it is an emotional build, it depends on the recognition held by an individual concerning different parts of life encounters, including individual qualities, target life conditions, and an impression of huge others (Yusuf *et al.*, 2004).

In the course of recent decades, family qualities have changed. There has been an expansion in family units with a solitary parent, youngsters living in destitution, and moms working outside the home (Fairthorne *et al.*, 2015). Research keeps on demonstrating that pressure is identified with childrearing practices and parent viability inside the family framework, the guardians, the youngster, and their cooperation are three potential wellsprings of parental pressure

The investigation points is to survey the statistic variable on personal satisfaction among parent of mental imbalance kid, to evaluate the information on personal satisfaction among guardians of chemical imbalance kid and to evaluate the relationship between statistic variable with the degree of learning on personal satisfaction among guardians of mental imbalance children's. So the analyst has endeavored to assess the personal satisfaction of the guardians with Autism Disorder patients. Autism Spectrum Disorder is a Neuro developmental disorder characterized by two domains as per diagnostic and statistical manual.

MATERIALS AND METHODS

Quantitative approach with descriptive research design was used to assess the quality of life of the parents with Autism Disorder patients at child development hospital with convenient sampling technique to select 40 parents who attend the child development hospital. Data was collected by using standardized questionnaire. The study investigators explained to the parents about objectives consent was obtained to participate in the study. The investigators then provided instructions for filling the questionnaire. During the filling of questionnaires, the investigators helped the individuals throughout and helped to simplify the meaning of each question, clarifying doubts and checking for completeness of filling up the questionnaire. The

data were analyzed using descriptive statistics. The project has been approved by the ethical committee of the institution.

Table 1: Frequency and percentage distribution on Quality of life among parents of autism children's

Quality of life	Frequency	Percentage
Poor quality of life	16	40%
Fair quality of life	19	47.5%
Good quality of life	5	12.5%
Total	40	40%

RESULTS AND DISCUSSION

Responses were collected from 40 parents of age between 25 to 45 years. Majority of the sample were between the age group 37.5% (31-35 years). 40%(16) were graduates well-educated 45%(18) were having their own business 20%, 55% (22) belong to middle class, 45%(18) obtained there Allik *et al.* (2006) source of information from T.V, 37.5%(15) reside in rural area and 60%(24) live in a nuclear family.



Figure 1: Quality of life among parents of autism children's

The present study showed that majority of a parent has a fair quality of life19 (19%), 16(16%) of parents has a poor quality of life, 5(5%) of parents has a good quality of life among parents of autism spectrum disorder children's (Table 1 &Figure 1).

The present study showed the mean deviation of Quality of Life among Parents of Autism spectrum disorder was 53.4, and the standard deviation is 19.20.

The present investigation results delineates that samples were between the age bunch of 37.5% (31-35 years). 40%(16) were graduates accomplished 45%(18) were having their very own business 20%, 55% (22) have a place with working-class, 45%(18) acquired there wellspring of data

from T.V ,37.5%(15) dwell in rustic territory and 60%(24) live in a family unit. The present examination demonstrated that greater part of a parent has reasonable nature of life19 (19%), 16(16%) of guardians has a low quality of life, 5(5%) of guardians has great personal satisfaction among guardians of mental imbalance range issue children's.

The present examination is bolstered by Eapen (2016) investigation includes 30 guardians of chemical imbalance range issue children's. He evaluated the feeling of anxiety among guardians of chemical imbalance kids. A consequence of his investigation found that 90% parent of chemical imbalance youngsters, in the long run, went to the burdensome stage because of serious pressure (Eapen, 2016).

Fairthorne *et al.* (2015) investigation includes 25 guardians of mental imbalance range issue children's. He additionally evaluated personal satisfaction among guardians of chemical imbalance kids. A consequence of his investigation found that giving more help like mental, physical Table 1 and otherworldly. It will expand the personal satisfaction of ASD youngster's guardians (Fairthorne *et al.*, 2015).

CONCLUSION

The study reveals that majority of the sample had a fair quality of life, so study results suggest that parents of autism children's need more guidance to improve their quality of life.

REFERENCES

- Allik, H., Larsson, J. O., Smedje, H. 2006. Healthrelated quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. Health and Quality of Life Outcomes. 4(1):1.
- Eapen, V. 2016. Parental Quality of Life in Autism Spectrum Disorder: Current Status and Future Directions. *Acta Psychopathologica*, (01):2–2.
- Ezzati, M., Hoorn, S. V., Lawes, C. M. M., Leach, R., James, W. P. T., Lopez, A. D., Murray, C. J. L. 2005. Rethinking the "Diseases of Affluence" Paradigm: Global Patterns of Nutritional Risks in Relation to Economic Development. *PLoS Medicine*, 2(5).
- Fairthorne, J., Jacoby, P., Bourke, J., Klerk, N. D., Leonard, H. 2015. Onset of maternal psychiatric disorders after the birth of a child with intellectual disability: A retrospective cohort study. *Journal of Psychiatric Research*, 61:223–230.
- Halawa, A., Muhammad 2010. Quality of life, the concept and dimensions. A paper submitted to the

Seventh Scientific Conference of Faculty of Education. Quality of life as an investment for Educational and Psychological Sciences. pages 13–14.

- Larsson, H. J., Eaton, W. W., Madsen, K. M., Vestergaard, M., Olesen, A. V., Agerbo, E., Mortensen, P. B. 2005. Risk factors for autism: perinatal factors, parental psychiatric history, and socioeconomic status. *American journal of epidemiology*, 161(10):916–925.
- Montalbano, R., Roccella, M. 2009. The quality of life of children with pervasive developmental disorders. *Minerva Pediatric*, 61:361–370.
- 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).
- Munir, K. M. 2016. The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder. *Current opinion in psychiatry*, 29:95–102.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., Baird, G. 2008. Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(8):921–930.
- Tischler, V., Karim, K., Rustall, S., Gregory, P., Vostanis, P. 2004. A family support service for homeless children and parents: users' perspectives and characteristics. Health and Social Care in the Community. 12:327–335.
- W.H.O 2003. World Health Organization (WHO)/International Society of ASD statement on management of Autism spectrum disorder. volume 21, pages 1983–1992.
- WHO 2008. AIMS report on mental health system in oman. A report of the assessment of the mental health system in Oman using the World Health Organization - Assessment Instrument for Mental Health Systems. Muscat, Oman. WHO-AIMS.
- Yusuf, S., Hawken, S., Ounpuu, S., Dans, T., Avezum, A., Lanas, F., Lisheng, L. 2004. Investigators IS. Effect of potentially modifiable risk factors associated with myocardial infarction in 52 countries (the INTERHEART study): case-control study. *Lancet*, 364(9438):937–952.