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Quality of Life of Parents of Children with Autism Spectrum Disorder in Biratnagar

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ABSTRACT

Background: The developmental disorders in children, including Autism Spectrum Disorder (ASD), are disorders of early brain development. ASD causes impairments in communication and social interaction, which seriously hinder the daily functioning of children and severely impede their educational and social attainments. Parenting a child with ASD requires long-term care. This challenge affects parents' psychological well-being, including financial constraints, lack of social support, deficiencies of health services, and labeling with autism, ultimately affecting quality of life. The objective of the study was to find out the quality of life of parents of children with ASD.

Method: A cross-sectional research design was used; 50 parents were sampled. Data were collected through an interview technique by using the WHOQOL-BREF scale and analyzed in descriptive and inferential statistics using SPSS version 16.0.

Result: Most (92%) of the respondents reported that their quality of life is satisfactory i.e., neither good nor bad and only 6% had good quality of life. Among the four domains of quality of life, physical and psychological domains are associated with the occupation of the parents (p=0.022 and p=0.010 respectively). Overall quality of life is also associated with the occupation of the parents (p=0.021)

Conclusion: The majority of the parents of children with autism spectrum disorder reported their quality of life quite satisfactory i.e., neither good nor bad. Among the four domains of quality of life i.e., Physical, Psychological, Social, and Environmental, physical and psychological domains are associated with the occupation of the parents. Parents need psychological support from the family, friends and other related professional. They also need social acceptance and support and must get to enjoy friendly environment.

Keywords: Autism spectrum disorder, Children, Quality of life, Quality of life of parents

INTRODUCTION

Autism is a persistent lifelong neurodevelopmental disability that develops before the age of 3 years.[1] The developmental disorders, including autism spectrum disorder (ASDs), are disorders of early brain development. The exact cause of ASDs is unknown; some other specific risk factors such as prenatal and perinatal factors, including high maternal and paternal age specific gene mutations, and environmental factors, have been identified. Which major risk factors contribute to the increment in the prevalence of ASD is still unclear.[2]

Neurodevelopmental communication, social interaction impairments, and unusual ways of perceiving and processing information can seriously hinder the daily functioning of people with ASDs and severely impede their educational and social attainments. With different levels of support, some individuals with ASDs and other developmental disorders can lead to independent and productive lives as they have varying degrees of abilities and others who are severely affected require life-long care and support.[2]

Autism is a global phenomenon. An estimated 1–2% of children worldwide lie on the autism spectrum disorder, with approximately 52 million

autistic individuals across the globe.[3] The reported prevalence of ASD in South Asia ranged from 0.09% in India to 1.07% in Sri Lanka that indicates up to one in 93 children have ASD in this region. Alarmingly high prevalence (3%) was reported in Dhaka city.[4] The prevalence of ASD was estimated to be as high as three in every 1000 persons in Nepal.[5] It is reported that ASD occurs in all races, ethnicity, and socioeconomic groups.

Children with autism are extremely different from others. The core features, associated symptoms, and behavior problems of autism have a significant negative impact on families and parental well-being.[6] Because of the unusual behavior of autistic children, parents/caregivers have to face difficulties while teaching them to communicate/interact or teaching them basic life skills, making them aware then from danger or preparing them for their future adulthood.[7]

Manifestations of ASD range from mild-to-severe, and this causes families to face numerous challenges. The families inevitably have a lot of difficulties raising ASD children. The course of the problem is more stressful for the family which requires alterations in family life and daily routine. Many studies showed that parents of children with ASD reported more stress than parents of children diagnosed with other disabilities and children who are developing normally. Financial limitations; inadequate social support; shortages of health services; and tagging with autism are the common challenges that are confronted by parents that affect their psychological well-being. The number of visits made to the health service centers; the obligation to prescribe treatment; the requirement of special education, and the arrangement of coordinated family services lead to increment in financial burden to the family of child with ASD. And also parents' employment decisions are affected as not taking a job; giving up a job; or changing employment to accommodate their child's needs.[8]

Having a child with a disability as a parent, high levels of stress, poor mental health, and decreased physical performance in both parents (Baker, Brightman, 2008). They have impairment in their physical activity and social relationships overall perception of their quality of life is poorer.[9]

METHODOLOGY

A quantitative, cross-sectional analytical research design was used to identify the quality of life of parents of children with autism spectrum disorder in Biratnagar. Parents of children who were clinically diagnosed with autism spectrum disorder at Biratnagar Metropolitan City, Koshi Province, Nepal. According to the Biratnagar Metropolitan office, there were around 50-54 cases registered in the Department of Disabilities of the metropolitan office in FY 2080/81. A total 50 samples were taken from the institutions registered in the office of Biratnagar Metropolitan City which provides service to children with autism spectrum disorder

Data was collected after approval from the Institutional Review Committee (IRC) of the Nepal Health Research Council (NHRC). Permission was taken from each institution, participants were explained the objectives of the study, and informed written consent was taken before the collection of data. The interview technique was adopted for data collection. The data collection tool was divided into three parts. The first part consisted of questions related to socio-demographic characteristics of parents, the second part was to collect information regarding characteristics of children i.e., age, sex, mode of delivery, birth order, age of diagnosis, and severity of the problem during diagnosis. The third part, the WHOQOL-BREF scale was used to gather information on the quality of life of parents.

The WHOQOL-BREF is a 26-item instrument consisting of four domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environmental health (8 items).[10] Each individual item of the WHOQOL-BREF is scored from 1 to 5 on a response scale, which is specified as a five-point Likert scale. Respondents responded the questions in a five-point Likert scale ranging from very satisfied to very dissatisfied and there was a neutral point in the middle of the scale. It took around 20-25 minutes to complete the interview schedule. The score cutoff was ≤60.66 for poor quality of life, from 66.67-95.33 for satisfactory and a score between 95.34-130 was good quality of life[11,12]. WHOQOL-BREF scale is a valid and reliable established tool that had good internal consistency as Cronbach's alpha coefficient for the overall scale was 0.91.[13]

The WHOQOL-BREF is widely used by health professionals in the assessment and evaluation of treatment efficacy. Many studies in Nepal have used WHOQOL BREF and it has been translated in Nepali version.[14] The results were presented in descriptive form as frequency, percentage, mean and standard deviation. For inferential statistics, a normality test of the total score of quality of life was done. Data were found to be normally distributed (Shapiro-wilk p=0.528). So, t-test and one-way ANOVA test was done to identify the quality of life.

RESULTS

The majority (82%) of the participants were mothers. The mean and standard deviation of the age of the participants were 34.2±5.817. More than half (52%) of respondents were from the Brahmin/Chhetri ethnic group followed by Janajati and Madhesi ethnic group which accounts equally i.e 22%. In the religious aspects, the majority (92%) of respondents follow the Hindu religion. An almost equal percentage (46-46%) of respondents achieved higher secondary level and higher education level respectively. Almost half (50%) of respondents were home makers, followed by 13% service holder. Less were involved in business and agriculture.

The overall mean and standard deviation of the age of children was 5.76±2.678. The majority (76%) of the autistic children were male, the majority (60%) were first born, 60% were born with cesarean section, almost half (52%) were diagnosed with autism before the age of 3, followed by 38% at the age of 3 to 5 years of age and rest were after the age of 5 years. Regarding severity of the problem, 48%, 42%, 10% of children were diagnosed with mild, moderate, and severe problem respectively.

Table 1: Level of Quality of Life of Respondents **n=50**

Level of QOL	Frequency (f)	Percentage (%)	Mean	SD
Poor	**1**	**2**		
Satisfactory	**46**	**92**	**81.56**	**91.19**
Good	**3**	**6**		

Table 1 shows the level of qualities of life of respondents. This presents that most (92%) of the respondents responded their quality of life is satisfactory and only 6% had good quality of life.

Table 2: Distribution of Different Domain of Quality of Life **n=50**

Domains	Mean ±SD	Minimum	Maximum
Physical Domain	25.06±3.787	16	31
Psychological Domain	19.82±2.833	11	26
Social Domain	11.58±24.90	9	15
Environmental Domain	24.9±3.382	19	32

Table 2 delineates the distribution of different domain of quality of life and their mean score and standard deviation of the score.

Table 3: Association Between QOL and Characteristics of Parents and Children* **n=50**

Parent's Characteristics	f	Mean	SD	p-value
Relation to Child				
Father	9	80.11	13.977	0.607
Mother	41	81.88	7.988	
Age (in Years)				
Less than 36	30	80.57	7.951	0.355
36 and More	20	83.05	10.836	
Types of Family				
Nuclear	27	82.96	9.192	0.246
Joint	23	79.91	9.110	
Education				
Up to Higher Secondary	27	79.70	9.194	0.123
Higher Education	23	83.74	8.889	
Child Sex				
Male	38	82.21	9.154	0.379
Female	12	79.50	9.395	
Child Birth Order				
First	30	82.27	9.944	0.511
Second	20	80.50	8.056	
Types of Delivery				
Normal	20	78.40	7.451	.052
Operation	29	83.62	9.908	

*= t-test

Table 3 presents the association between quality of life and different socio-demographic characteristics of parents and quality of life of parents with children. However, there is no association between quality of life and socio-demographic characteristics of parents as well as children.

Table 4: Association Between QOL and Characteristics Parents and Children, **n=50**

Characteristics	p-value#
Ethnicity	0.284
Parent's Occupation	0.021
Child's Age	0.510
Child's Age at Diagnosis	0.237
Severity of the Problem	0.366

#=One Way ANOVA

Table 4 shows the relationship between quality of life and different characteristics of parents and children. There was a significant association between the quality of life of parents with their occupation and other parental and children characteristics were not significantly associated with quality of life.

Table 5: Association Between Domains of QOL and Characteristics Parents and Children[#] n=50

Characteristics	Physical	Psychological	Social	Environmental
Ethnicity	.254	.563	.286	.305
Parent's Occupation	.022	.010	.513	.152
Child's Age	.369	.387	.250	.684
Child's Age at Diagnosis	.283	.032	.282	.904
Severity of the Problem .	490	.528	.878	.223

#=One Way ANOVA

Table 5 shows the relationship between domains of quality of life and different characteristics of parents and children. There was a significant association between the physical and psychological domain with the occupation of parents. Other parental and children characteristics were not significantly associated with all four domains.

DISCUSSION

This study assessed the Quality of Life of Parents of Children with Autism. This study found that the majority (82%) of the respondents were mothers and one-third (32%) were from 25-30 years age category. Mostly (92%) followed Hindu religion and almost half (54%) of the respondents live in a nuclear family. Almost half (50%) were homemakers and this is because either parent had to leave their job or business to take care of the autistic child. Among children with autism spectrum disorder, it was found that the boys girl ratio was approximately 3:1, and this could be because autism spectrum disorder is more seen in boys than girls with the ratio of 4:1.[15,16]

The mean age (in years) at diagnosis of autism is 3.19 ±2.7. This finding is compatible with the result of the systematic review and meta-analysis that the mean age at diagnosis is 43.18 months.[17] But contrary to the result of this study, the study done in the Czech Republic showed that the mean age of diagnosis is 5.8 ± 2.2 years.[18] This study result showed that the percentage of mild to moderately affected children is almost equal i.e., 48% and 42% respectively. Only 10% of children were severely affected. [mild, moderate & severe are labeled as Level 1, level 2 and Level 3.[19]

This study showed that the majority (92%) of the respondents had satisfactory quality of life and only 6% and 2% had good and poor quality of life respectively. This result might be due the interview has taken place in special schools and enrolling in such type of school, parents' life has been a bit easy and arouses hope in their life. In contrast to this result, a study done in Pakistan showed that more than fifty percent (58.3%) of respondents had a poor quality of life(12), Similarly, the result of the study done in South Africa also showed that parents of children with ASD had lower mean QOL scores representing a poor quality of life.[20]

Similarly, regarding the association of quality of life with different characteristics, this study showed that there was an association between quality of life and occupation (p=0.021) however, other characteristics were not significantly associated with the characteristics of parents as well as children. This might be because most of the parents now working as a home maker were used to do job or business before the diagnosis of autism of their children. After diagnosis, they left their job or business to take care of their children. This study result is supported by study done in India that there were no significant

characteristics that affected quality of life of autistic child parents.[21]

The physical domain contains physical health, sleep, disturbances by pain and coping with everyday life and impairments in socio-adaptive functioning in children with disabilities along with increased dependency on parents is time-consuming and impairs daily physical activities. The present study found that the parent's occupation is associated with the physical domain (p=0.022). The reason might be because of leaving a job or business to take care of curtailed income and at the same time extra expenses required for a child. The domain of psychological well-being is associated with negative feelings of mood, sadness, anxiety, and dissatisfaction with oneself. This domain is also associated with parental occupation (p=0.010).

The domain 'social relationship', which especially contains questions about satisfaction with personal relationships and with support by friends. This study found no significant association between social domain and other parental and child characteristics. Most of the time parents, especially the mother considered herself responsible for the child's condition and this guiltiness might arouse problem in personal relationship between spouses. Along with this problem, in our context, society often avoid to be in contact with family who has autistic child. On the other hand, parents also avoid to participate in social functions because of embarrassment or they do not want other people get to know about child's disability. These both situations cause parents to consider that there is no support from society thus having lower perceived social quality life.

The 'environment domain' includes questions about physical safety and security, home environment, health and social care, opportunities for leisure activities, adequacy of expenditure etc. Because of the autistic child, parents often experience a hectic daily schedule, feelings of anxiety, low mood, constant worry about the safety and security of their child, which may lead to low quality of life in the environment domain, though there is no association with parents' and children's characteristics.

CONCLUSION

Developing countries like our country, Nepal, where there is little knowledge about autism and also is the subject of embarrassment to be exposed as parents of autistic children causes heavy impact on the quality of life of the family especially parents. This study was conducted to find out the quality of life of parents of children with ASD.

This study showed that the majority of the parents of children with autism spectrum disorder reported their quality of life as quite satisfactory, i.e., neither good nor bad. Among the four domains of quality of life, i.e., Physical, Psychological, Social, and Environmental, the Physical and Psychological domains are associated with the occupation of the parents. Parents need psychological support from the family, friends and other related professionals. They also need social acceptance and support, and must get to enjoy a friendly environment.

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Conflict of Interest

No any conflict of interest

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