QUALITY OF LIFE OF THE PARENTS RAISING CHILDREN WITH AUTISM SPECTRUM DISORDER

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ABSTRACT

Background: *Autism Spectrum Disorder (ASD) is an emerging public health issue in globally. Parenting children with ASD is associated with impaired mental and physical health of the parents. The present study aimed to assess Quality of Life (QoL) of the parents raising children with ASD.*

Methods: *A cross sectional study was carried out from January to December 2016 among 190 parents of children with ASD. Data were collected by face-to-face interview with a semi-structured questionnaire. Medical Outcomes Study (MOS) 36-item was used to assess the QoL of the parents by eight subscales and two summaries Physical Component Summary (PCS) and Mental Component Summary (MCS). Parents personality traits and marital relationships were assessed with Five Factor Inventory (FFI) and Intimate Bond Measure (IBM) scales respectively. Both descriptive and inferential statistics were done.*

Results: *Among 190 participants 44.7% were mothers and 55.3%were fathers. Most (97.9%) of the parents were living together. The mean (±) age of the fathers and mothers was 41.99 ± 6.15 and 34.66 ± 6.01 years respectively.*

More than one third (38.1%) of the fathers and around one fourth (22.4%) of the mothers were post graduates. Mean QoL score of the fathers (91.10±10.57) was significantly higher (t=7.86, p<0.01) in comparison to that of the counterpart mothers (78.87±10.75). Mothers had significantly lower scores in the areas of role-physical (p<0.01), pain (p<0.01), physical function (p<0.01), social function (p<0.01), role-emotional (p<0.01), vitality (P<0.01) and mental health (p<0.01) except general-health (p>0.5) than counterpart fathers. Parents with Postgraduate and graduate level education revealed significantly higher score in all domains except HSC and SSC level education. A negative correlation was found between numbers of autistic children and QoL score (r=-0.153, p<0.05). QoL score of personality traits of the parents (r=-0.213, p<0.01).

Conclusion: *Parents suffer from both mental and physical stress for rearing their autistic children and mothers are worse victims. So, special measures should be taken to improve QoL of the parents raising autistic children specially mother.*

INTRODUCTION

Autistic Disorder is a neurological persistent developmental complaint that effects children's communication and social functioning. The disorder affects individuals from all ethnic groups and socioeconomic backgrounds and is considered the third most common growing disability following intellectual infirmity and cerebral palsy Centers for Disease Control and Prevention (CDC, 2010). Autism is the fastest growing serious progressive incapacity and since 2002 through 2006 its growth rate is around 57%. Almost 1% of the world's population or 70 million are affected by autism (WHO, 2013).

Autism Spectrum Disorder (ASD) is characterized by communicative problems, social deficits, and tedious behaviors, with evidence of intellectual dysfunction (APA, 2013). Developing disorder onset in infancy or childhood and characterized by impairment or delay in functions related to the central nervous system maturation. Principal symptoms include a variable mixture of impaired capacity for reciprocal socio-communicative interaction and a limited, stereotyped repetitive repertoire of interests and activities (WHO, 2013). ASD is a clinical disorder and it was very rare with almost 2-4 out of every 10,000 children being diagnosed. Usually ASD is diagnosed in children by the age of three where complications are documented in the areas of social contact, communication by language and typecast patterns of behavior (MacFarlane & Kanaya, 2009).

Autistic children mostly depend on their parents. Raising the children with ASD marks the Quality of Life (QoL) of the parents. The hypothesis of Quality of Life (QoL) represents one of the wide-ranging, multidimensional outcome measures based on the individual's subjective perception regarding several aspects of life experiences (WHO, 1996). Children with autistic disorder frequently show a pattern of composite behaviors that can significantly affect parents' and family's functioning. Parents of ASD children may find themselves burdened with a lifelong responsibility of caring for their children and reduced attention to their own health. Thus, those parents are considered to be at risk for a significant deterioration in several domains of their lives. Indeed, parents of children with ASD experience raised stress, impaired physical and social activity (Hartley *et al.,* 2010), impaired mental health and restricted family functioning.

Studying the quality of life of the parents with ASD children requires a holistic view for the factors that can possibly affect the parents' health and wellbeing. The Quality of Life (QoL) has been recently noted as one of the key health concerns for parents following a lifelong complex like such as raising a child with ASD (Yamada *et al.,* 2012). 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'' (WHO, 1996). The construct of QoL is believed to be an inclusive outcome measure incorporating an individual's physical health, psychological state, social relationships and relationship with salient features of the environment (WHO, 1996). In spite of increasing awareness, shaping, directing, delivering, and evaluating support services are need to use the construct of QoL.

Quality of life of parents of children with ASD is not well established, since only a few studies have comprised in this regard. Parenting a child with ASD can have a significant impact on the parents' life. Previous studies have uniformly found higher levels of parenting stress among parents of children with ASD compared to both parents of children with typical progress and parents of children with other developmental disabilities (Dabrowska & Pisula, 2010). Parenting stress can be defined as the negative strain related to the self, the child and the parent child interaction in the context of parenthood and high levels of parenting stress can contribute to a lower overall QoL for parents of children with ASD (Dardas *et al.,* 2014).

Parents of children with ASD experience a pile up of other stressors that are not necessarily related to ASD but can intensify its demands. Such stressors were found to be related to parental employment and

socioeconomic status, the lack of appropriate services and support systems and if present, the caring responsibilities toward other children. For example, parents with higher socioeconomic status have been found to report lower levels of stress and better QoL (Hatton & Emerson *et al.,* 2009). Another point worth mentioning is the differences between fathers and mothers in regard to their psychological reactions to the child's disability. While some researchers found that mothers have higher levels of stress and demoralization than fathers, with increased rates of physical health problems and poorer QoL (Yamada *et al.,* 2012). Others revealed that mothers and fathers experience similar levels of parenting stress and QoL (Dardas *et al* 2014). Apparently, more investigations are needed in this particular area of research.

Little data are available on QoL of the parents raising children with ASD as compared to other chronic disorders (APA, 2000). Quality of life of parents of children with ASD is not well established in Bangladesh. On the basis of this scenario, the study was designed to unveil the quality of life of the parents raising children with ASD in the context of Bangladesh.

METHODOLOGY

It was a cross sectional study conducted among 190 parents to assess the quality of life of the parents raising children with Autism Spectrum Disorder (ASD). The parents whose children were enrolled in two schools for autistic children of Dhaka city (1) Proyash, Institute of special education, Dhaka cantonment, Dhaka, Bangladesh. (2) Society for Assistance to Hearing Impaired Children (SAHIC), Mohakhali, Dhaka, Bangladesh. Convenience sampling technique with semi-structured questionnaire used for data collection. Data collection technique was face to face interview to the parents of children with ASD. Pre-testing of research instrument was done in a private autism school on 15 parents of children with ASD. It was done for modification, correction and finalization of questionnaire. Informed consent of the respondents was taken before the interview.

Inclusion criteria-
a. Parents who have the Children with ASD (2-17 years).
b. Parents of the children who were willing to participate in the study.

Exclusion criteria
a. Children were excluded from the study who have got previous interventions.
b. Parents who were severely ill.
c. Parents who were psychologically abnormal.

All collected data were checked and verified thoroughly to reduce the inconsistency. The data were coded, categorized, cleaned, and entered into computer. Analysis of data was done by the use of computer. Descriptive statistics included frequency distribution, percentage, mean, range, standard deviation etc. For inferential statistics non parametric test Chi-square test was done to find out association between different variables, Fisher 's Exact Test was done where more than 25% cells had count less than 5. To find out relation between different variables Pearson 's Correlation test was done, for comparison among the means t test was done and for comparison among the means more than two groups parametric test Analysis of Variance (ANOVA) was done. An analysis plan was developed keeping in view with the objective of the study.

RESULTS
Demographic characteristics of the parents

In respect of demographic characteristics, the study showed that out of 190 parents, majority i.e. 91(47.9%) were in the age group 31-40 years followed by 66 (3.7%) in 41-50 years, 25 (13.2%) in 20-30 years and 8 (4.2%) parents were in 50-60 years age group. The mean (±SD) age of the parents was 38.71 (±7.089) years with the range of 20-60 years. By sex, majority i.e. 105(55.3%) were male and 85(44.7%) were female.

Among all, most i.e. 186 (97.9%) of the respondents were married and the rest 4 (2.1%) were separated. It was found that, 150 (78.9%) parents had 1-2 children, 37 (19.5%) had 3-4 children and 3 (1.6%) had 5-6 children and the average number of children was 1.97 ± 0.91 with the range of 1-6, the highest percentage of single autistic children was 92.1, which is illustrated in the following

Table-1: Distribution of the parents by demographic characteristics (n=190)

Characteristics	Category	f (%)
Age of the parents (in year)	20-30	25 (13.2)
	31-40	91 (47.9)
	41-50	66 (34.7)
	51-60	08 (4.2)
	Mean ± SD: 38.71 ±7.089	Range: 20-60
Mean (±) age of fathers 41.99 ± 6.15, Mean (±) age of mothers 34.66 ± 6.01		
Sex of the respondents	Male	105 (55.3)
	Female	85 (44.7)
Marital status	Married	186 (97.9)
	Separated	04 (2.1)
Number of children	1-2	150 (78.9)
	3-4	37 (19.50
	5-6	03 (1.6)
	Mean ± SD: 1.97 ± 0.91	Range: 1-6
Number of autistic children	1	175 (92.1)
	2	15 (7.9)
	Mean ± SD: 1.08 ± .27	Range: 1-2
Educational status of the mother (n=85)	SSC	18 (21.2)
	HSC	18 (21.2)
	Graduate	30 (35.3)
	Postgraduate	19 (22.4)
Educational status of the father (n=105)	Primary	03 (2.9)
	SSC	09 (8.6)
	HSC	17 (16.2)
	Graduate	36 (34.3)
	Postgraduate	40 (38.1)

Table–2: Quality of life score (Domain specific) and sex of the parents (n=190)

Variables	Mean (±SD) Score		t	df	p-value
	Male (105)	Female (85)			
Physical Functioning	30.5 (±) 3.9	27.2 (±) 4.1	5.7	18	0.00
Role-Physical	6.5 (±) 1.2	5.5 (±) 1.5	5.4	18	0.00
Pain	6.2 (±) 1.4	5.1 (±) 1.6	5.2	18	0.00
General Health	12.4 (±) 2.2	12.8 (±) 1.5	-0.4	18	0.16
Mental Health	15.2 (±) 1.5	14.1 (±) 1.6	4.9	18	0.00
Role-Emotional	5.1 (±) 1.1	3.8 (±) 0.98	8.3	18	0.00
Social Functioning	5.7 (±) 1.2	4.3 (±) 1.5	6.9	18	0.00
Energy/Fatigue	11.7 (±) 1.5	10.9 (±) 1.5	3.9	18	0.00
Total Score	93.3 ± 14	83.6 ± 14.28			

By sex, the study revealed that the mean score of the male parents was higher (93.3 ± 14) in comparison to that of the counterpart female parents (83.6 ± 14.28) and this difference was statistically significant [t test=7.86, p<0.01], which is shown in following **Table-2**.

From different domain of QoL score women obtained worse and poor quality of life than men. The study found that all domain showed significant difference in role-physical (p<0.01), pain (p<0.01), physical function (p<0.01), social function (p<0.01), role-emotional (p<0.01), except general-health (p>0.5) which was not statistically significant.

Figure- 1. Distribution of the children by sex (n=190)
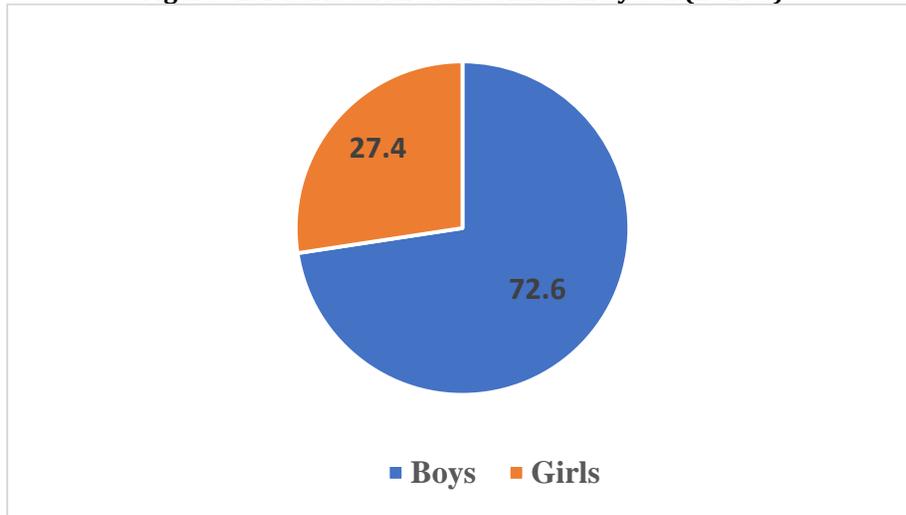
The study revealed that, among 190 children, two third i.e. 138 (72.6%) of them were boys and 52 (27.4%) were girls, as shown in **Figure-1**.

**Table-3: Distribution of the children by Demographic feature (n=190)**

Characteristics	Category	f (%)
Age of the child (In year)	2-5	59 (31.1)
	6-10	95 (50.0)
	11-15	36 (18.9)
	Mean ± SD: 7.47 ± 3.26	Range: 2-15
Birth order of the child	One	119 (62.6)
	Two	49 (25.8)
	Three	14 (7.4)
	Four	03 (1.6)
	Five	05 (2.6)

Out of all the children, half i.e. 95 (50.0%) of them were in 6-10 years age group followed by 59 (31.1%) in 2-5 years and 36 (18.9%) were in 11-15 years age group. The mean (±SD) age of the children was 7.47 (±3.26) years with the range of 2-15 years. Of all, most i.e. 119 (62.6%) of the child were the first issue of their parents followed by 49 (25.8%) were the second child, 14 (7.4%) were the third child, 3 (1.6%) were fourth and only 5 (2.6%) were fifth child respectively. Almost all children lived with their parents, follow **Table-3**.

**Figure-2: Correlation between age and QoL score**
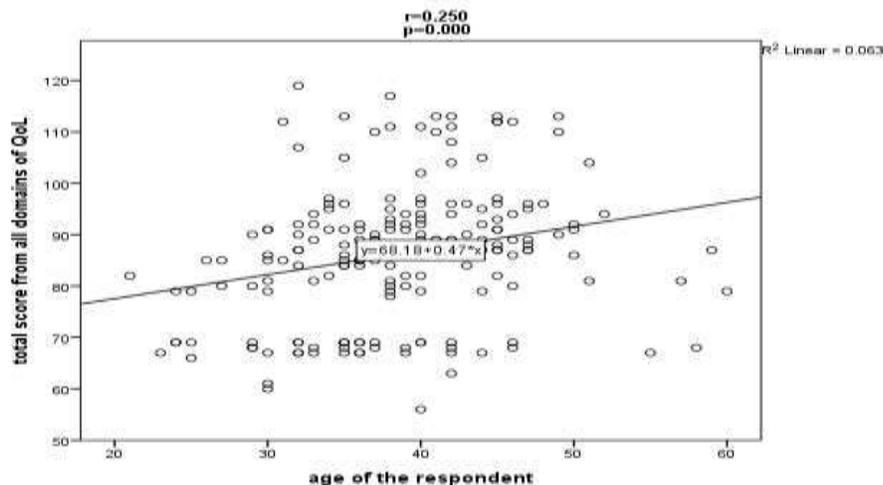
By age, the study revealed that, there were positive correlation between age of the parents and total quality of life. Therefore, parents with higher quality of life is related to more age [r=0.250, P<0.01], which is shown in **figure-2**.

Table-4: Correlation between QoL score and number of autistic children

Category	Mean ± SD	R	P value
Total score of QoL	86.31 ± 13.27	-0.153	0.003

The study showed that, negative correlation among number of autistic children and quality of life. Therefore, parents with more autistic children incurred lower quality of life score, which was statistically significant [r = -0.153, P<0.05], as illustrated in the following **Table-4**.

Figure-3: Personality trait and quality of life score of parents (correlation)
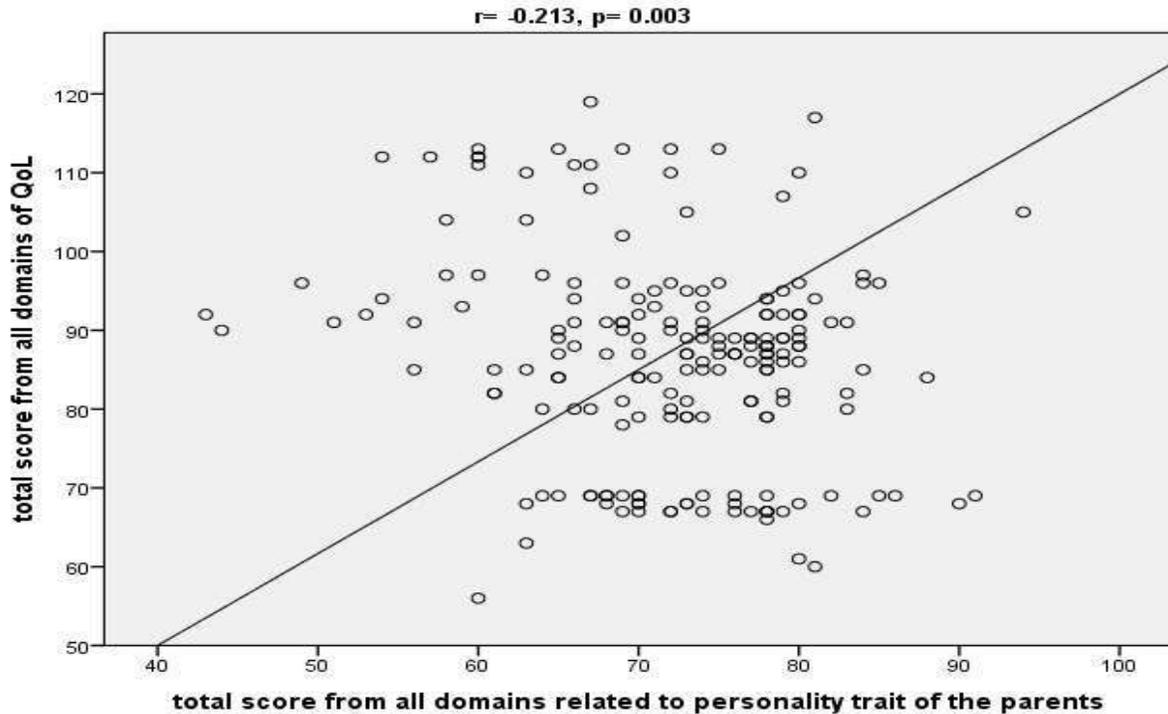
r= -0.213, p= 0.003

The study showed that, negative correlation between quality of life and personality trait of the parents. Therefore, a parent with higher quality of life is related to lower personality trait and it was statistically significant [r = -0.213, P<0.01], which is shown in the following **figure-3**.

Table-5: Association between sex of the parents and level of QoL
(n=190)

Parents	Level of QoL			Total	Significance
	Good f (%)	Average f (%)	Poor f (%)		
Father	10(9.5%)	87(82.9%)	8(7.6%)	105(100.0%)	χ2=31.69 df= 2 p<0.01
Mother	1(1.2%)	50(58.8%)	34(40.0%)	85(100.0%)	
Total	11(5.8%)	137(72.1)	42(22.1%)	190(100.0%)	

According to sex, out of 105 fathers 10(9.5%) incurred good quality of life, whereas out of 85 only 1(1.2%) mother incurred good quality of life. Most i.e. 87 (82.9%) of the father & 50 (58.8%) mother had average quality of life and a few 8 (7.6%) fathers had poor quality of life while 34(40.0%) mothers had poor

quality of life. This difference of quality of life by sex of the parents was statistically significant [χ^2=31.69, P=0.00], which is illustrated in the above **Table-5.**

Table-6: Association between level of QoL and education of parents (n=190)

Level of father education	Level of QoL				Significance
	Good f (%)	Average f (%)	Poor f (%)	Total f (%)	
Primary	0 (0.0)	3 (100)	0 (0.0)	3 (100)	Fisher's Exact =14.63 df= 8 P= 0.03
SSC	1 (11.1)	5 (55.6)	3 (33.3)	9 (100)	
HSC	0 (0.0)	14 (82.4)	3 (17.6)	17 (100)	
Graduate	4 (11.1)	30 (83.3)	2 (5.6)	36 (100)	
Postgraduate	5 (12.5)	35 (87.5)	0 (0.0)	40 (100)	
Total	10 (9.5)	87 (82.9)	8 (7.6)	105 (100)	
Level of mother Education					
SSC	0 (0.0)	12 (66.7)	6 (33.3)	18 (100)	Fisher's Exact = 4.52 df= 6 P=0.67
HSC	0 (0.0)	10 (55.6)	8 (44.4)	18 (100)	
Graduate	0 (0.0)	16 (53.3)	14 (46.7)	30 (100)	
Postgraduate	1 (5.3)	12 (63.2)	6 (31.6)	19 (100)	
Total	1 (1.2)	50 (58.8)	34 (40.0)	85 (100)	

According to the educational status of father, out of 105, 40 completed masters, among them maximum i.e. 35 (87.5%) incurred average QoL. Whereas, 12.5% completed Postgraduate level, 11.1 % Graduate and 11.1% secondary level incurred good QoL and 33.3% completed secondary level, 17.6% completed higher secondary level, only 5.6% with graduate level incurred poor QoL. This difference of QoL by educational status of father was statistically significant [Fisher's Exact =14.627, P<0.05]. It stated that, father with more educational qualification had good QoL which is illustrated in the above **Table-6**.

According to the educational status of the mother, 1 (1.2%) incurred good QoL and had postgraduate degree, whereas out of 19 completed master's majority 12 (63.2%) incurred average and 6 (31.6%) had poor QoL. However, this difference in QoL of the mother by education was not statistically significant [Fisher's Exact Test=4.522, P>0.05], which is shown in the above **Table-6.**

DISCUSSION

This cross-sectional study was conducted to assess quality of life of the parents raising children with autism spectrum disorder. The study findings were compared with the findings of other relevant studies in our country and abroad. Accordingly, logical arguments and explanations were forwarded for the discrepancies of the study findings with that of other studies.

Socio-demographic characteristics of the parents of children with ASD:

The study showed that out of 190 parents, majority (47.9%) were 31-40 years age group followed by only 3.7% in 41-50 years. The mean (±SD) age of the parents was 38.71 ± 7.08 years while the range of age was 20-60. A study conducted in Bangladesh revealed that 30.5% parents were in 19-30 years age, 59.0% in 31-40 age, and 10.5% in 41-50 age and the mean ± SD age was 33.6 ±5.7 years. This variation of the findings may be different study places between the present and previous study. Moreover, a significant segment of children was preschooler and younger in comparison to the children of the present study. From the gender perspective majority (55.3%) were male and 44.7% were female.

Among all, most of the respondents 97.9% were married and rest 2.1% were separated. The average family member was 1.30 ± 0.54 with the range 3-11. It was found that, 74.2% parents had family member within 6 persons, 21.6% had 6-8 family members and rest 4.2% had family members within 9-11 persons. Similar findings were revealed by another study conducted in Bangladesh which found that maximum (77.2%) respondents had 1-5 family members and rest (22.8%) had 6-10 family members.

According to educational qualification of mother, majority (35.3%) of the mother was graduate, 22.4% were post graduate, 21.2 % and 21.2 % had HSC & SSC level education respectively. A study conducted in Bangladesh (Khanom *et al,* 2015) revealed that among the cases 2% of the mother completed up to primary level education, 27.3% completed up to SSC, 30.3% completed HSC and 40.4% completed university education. Another study conducted in Dhaka, Bangladesh (Rahman, 2013) revealed that maximum mother (62.0%) were graduate. These little differences with the present study are due to time and place variation.

Regarding educational qualification of father, 38.1% fathers was postgraduate, 34.3% were graduate and 16.2% & 8.6% had HSC & SSC level of education respectively. Similar findings were found by another study was conducted in Bangladesh by Rahman, (2013) which found that maximum (37.8%) fathers were post-graduated and 33.5% were graduated.

Information related to children with autism spectrum disorder:

The study revealed that, among all the children, two third (72.6%) of them were boys and 27.4% were girls. A study was conducted in Bangladesh (Khanom *et al,* 2015) revealed that among case group male and female children were 74.70% and 25.30%. Another study conducted by Hasnain (2014) found majority of the children were males (78.0%). Similar findings were found by another study conducted in Dhaka by Rakib (2013) showed that the percentage of male autistic children is 60.0% more than female autistic children.

Out of all the children, half (50%) of them were in 6-10 years age group followed by 31.1% in 2-5 years and 18.9% were in 11-15 years age group. The mean (±SD) age of the children was 1.88 ± 0.7 years with the range of 2-15 years. A study conducted by (Amr *et el.* 2012) showed that the mean age of total sample was 5.2 ± 2 with a range from 3 to 13 years. This is almost similar with the present study.

Of all (62.6%) children were the first issues of their parents followed by 25.8% were the second child, 7.4% were the third child, 1.6% was fourth and only 2.6% were fifth child respectively. Almost all children lived with their parents. A similar descriptive cross-sectional study was conducted in Dhaka City, Bangladesh by Hasnain (2014) revealed that the birth-order of the child was important as 58% of children were first born and 33% were second born, whereas 7% and 2% were third and fourth born respectively. The result of this study is consistent with the present study.

By age, the study revealed that, QoL was positively associated with increased age. Elderly parents had higher QoL score [r=0.250, P<0.01]. A study in New York 2012 found younger parents had poor QoL (Zablotsky et al. 2012) but the study conducted by Cruz M*et. al.,* found diverse finding where QoL was poor in elderly parents (Croen *et.al.,* 2006). This difference might be due to variation of health facilities and financial support among the country.

The study revealed negative correlation between number of autistic children and quality of life. Therefore, parents with more autistic children incurred lower quality of life score, which was statistically significant [r = -0.153, P<0.05] as parents face extra burden for more children with ASD. Kaminsy & Dewey, 2002 conducted a study which supports our present study.

The study showed that, negative correlation between quality of life and personality trait of the parents. Therefore, a parent with higher quality of life is related to lower personality trait and it was statistically significant [r= -0.213, P<0.01]. Parents had anxiety, tension and more stress due to their children with ASD, so cumulatively increase stress and it is associated with low QoL score. Some researchers found that parents with higher level of stress had more physical health problems and poorer QoL (Dabrowska & Pisula, 2010).

By sex, 9.5% fathers and only 1.2% mothers had 'good' quality of life. Most (82.9%) of the fathers and 58.8% mothers had 'average' quality of life. On the other hand, 7.6% fathers and 40.0% mothers had 'poor' quality of life. This difference of quality of life by sex of the parents was significant ($\chi2=31.69$, P=0.00). Stress is higher among mothers than fathers, and mothers reported more anxiety or more depression. This difference may be due to mothers remain closer to child and suffers the real stress for their care and raring which makes their QoL poor. According to educational status father was statistically significant (Fisher's Exact =14.627, P<0.05) but mother was not positive association (Fisher's Exact Test=4.522, P>0.05).

By education, masters, most (87.5%) of the fathers had 'average' QoL while 12.5% postgraduate, 11.1 % graduates and 11.1% fathers having secondary level education had 'good' QoL. On the other hand, 33.3% fathers with SSC and 17.6% fathers with HSC level education had poor QoL. This difference of QoL by educational status of father was statistically significant [Fisher's Exact =14.627, P<0.05]. This difference of QoL can be explained by the facts that the fathers with higher educational qualification become more aware about themselves and their children.

According to the educational status of the mother, 1.2% postgraduate had 'good' QoL, whereas 63.2% masters had 'average' QoL and 31.6% had poor QoL. However, this difference in QoL of the mother by education was not statistically significant [Fisher's Exact Test=4.522, P>0.05].

CONCLUSION

Autism spectrum disorder is a burning issue and increasingly recognized as a major and growing public health problem in Bangladesh. Raising a child with Autistic Disorder can have significant impacts on the parents' QoL. The QoL of parents of children with ASD is contingent upon their demographic characteristics, personality trait and marital relationship. The study intended to assess QoL of the parents raising children with ASD. The study found that maximum parents of children with ASD were thirty to forty years age and lived in nuclear families. Since ASD is a growing public health problem in

Bangladesh, so countrywide proper early diagnostic facilities, cost effective treatment, special education, therapy facilities for autistic children and parental counseling programs, psychological and social support should be available to reduce economical, physical and mental stress of the parents. It ultimately improves overall QoL.

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