Perceived Social Support And Satisfaction Levels Of Parents Of Children With Autism In Bangladesh.

Shipon Miah, Md. Monir Hossain, Imrul Kayesh

Shipon Miah, Consultant Speech And Language Therapist, Center For Speech Therapy And Autism Rehabilitation (C-STAR), Dhaka, Bangladesh

Md. Monir Hossain, Lecturer, Speech And Language Therapy Department, Bangladesh Health Professions Institute (BHPI), The Academic Institute Of Centre For The Rehabilitation Of The Paralysed (CRP), Savar, Dhaka-1343, Bangladesh.

Imrul Kayesh, Head Of Speech And Language Therapy Department, Center For Speech Therapy And Autism Rehabilitation (C-STAR), Dhaka, Bangladesh.

Abstract

Aim: To explore the relationship between perceived social support and the satisfaction levels of parents caring for children with autism within the Dhaka District of Bangladesh.

Materials and Methods: A descriptive cross-sectional study was conducted involving parents of children diagnosed with ASD aged 3 to 14 years. Participants were recruited from autism support groups and clinics in the Dhaka District. Data were collected through structured questionnaires that encompassed demographic information and assessed perceived social support and satisfaction levels. The questionnaires included questions about the number of children, education level, occupation, and family income, and utilized validated scales to measure perceived support from family, friends, and community. Statistical analyses were performed to investigate the associations between demographic variables and satisfaction levels.

Results: The maximum number participants, 25.6% (30) were in the age range 31-40 years. On average, most of the participants there are 97 (87%) female and 14 (13%) males from total 111 participants. The maximum 47.70% (53) participants completed their postgraduate degree (masters' level). Most of the participants are housewife 66.7% (74 participants). There were maximum number of 56. 8% (63) children in between (3-6) years. Most of the children (85) 76.6% were male and minimum children were (26) 23.4% female. Maximum 40.77% (45) participants sometimes had someone to provide social partnership support. Most of the participants 44.41% (49) were satisfied for having someone for social partnership support. Most of the participants 51.20% (57) were satisfied for having someone for information support. Maximum 39% (43) participants sometimes had someone to provide emotional support. Most of the participants 46.15% (51) were satisfied for having someone for emotional support. Maximum participants 40.05% (44) always had someone to provide maintenance support. most of the participants 53.65% (59) were satisfied for having someone for maintenance support. Most of the participants 48.85% (54) were satisfied with the social support they receive.

Conclusion: This study underscores the critical role of social support in enhancing the satisfaction levels of parents of children with autism in Bangladesh. The findings suggest that improving community and familial support can enhance the overall well-being of these families. Future research should consider larger samples and qualitative approaches to gain deeper insights into the experiences of parents, as well as to develop targeted intervention programs aimed at bolstering support for families affected by autism.

Keywords: Autism Spectrum Disorder, Parental Support, Satisfaction, Bangladesh, Social Support

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I. Introduction

This study explores the perceived social support of parents of children with autism and their satisfaction with that support. Bangladesh, a densely populated developing country, has a significant number of children with disabilities, with autism spectrum disorder (ASD) on the rise. According to a nationwide survey, at least 17 children per 10,000 in Bangladesh have ASD (Molla, 2018).

Autism is a complex developmental disorder characterized by challenges in social interaction, language development, psychological status, motor, and sensory abilities. Children with autism (CWA) exhibit behaviors such as repetitive body movements, lining up objects, and echolalia. They often struggle to form relationships and communicate effectively (Greenspan & Wieder, 2006). Additionally, behavioral issues like aggression, anxiety, mood changes, and speech difficulties make parenting particularly challenging (Luther,

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Canham, & Cureton, 2005). Such difficulties impact their learning and social functioning (Kamruzzaman et al., 2019).

Parents of CWA face unique caregiving challenges due to their children's repetitive and restricted behaviors. These children often struggle to express their needs, become distressed when routines are disrupted, and require constant caregiving, making it difficult for parents to manage their responsibilities (DePape & Lindsay, 2014). Parental involvement plays a critical role in the developmental outcomes of these children, as education and overall progress largely depend on the support and engagement of their caregivers (Sharabi & Marom-Golan, 2018).

The challenges parents of CWA experience extend beyond those of raising typically developing children. They seek information and support from fellow parents rather than professionals to cope with caregiving demands (Nelson, 2015). Parental stress intensifies due to their children's challenging behaviors, developmental delays, and limited access to resources, leading to frustration and emotional distress (Russa, Matthews, & Owen-DeSchryver, 2014). Research suggests that caring for a CWA is even more demanding than raising children with other lifelong or developmental disabilities (Luther et al., 2005).

Werner (2001), cited in Luther et al. (2005), identified three key insights from in-depth interviews with parents of CWA: (1) coping with challenging behaviors becomes their primary responsibility, (2) they feel they have lost their previous way of life, and (3) they perceive their lives as unpredictable and unstable. Given these difficulties, strong social support is crucial, as autism profoundly affects family dynamics. Parents struggle to balance work, leisure, and family responsibilities, making external support essential (Luther et al., 2005).

Social support is a powerful tool that mitigates psychological stress and enhances parental well-being. Effective social support has positive outcomes for both parents' mental health and the development of their CWA (Kuru & Piyal, 2018). One effective way for parents to connect with others facing similar challenges is through parent support groups, which provide insight, encouragement, and access to community resources (Marcus Autism Center, 2019).

Parents benefit from both formal and informal social support. Formal support comes from professionals such as doctors, social workers, and teachers, while informal support comes from family and friends. Both forms of support help parents navigate their responsibilities more effectively (Sharabi & Marom-Golan, 2018). Social support fosters a sense of relief and acceptance, leading to greater life satisfaction and emotional resilience (Habib, Asmat, & Naseem, 2016).

Ultimately, increasing social support for parents of CWA can enhance their involvement in caregiving and improve the overall well-being of both parents and children. The availability of physical, emotional, informational, and material support significantly contributes to parental coping mechanisms and life satisfaction (Lu et al., 2015).

II. Methodology:

The researcher employed a cross-sectional descriptive study design to explore the perceived social support and satisfaction level of parents of children with autism. This design was chosen as it provides a snapshot of a population at a single point in time without manipulating variables (Fraenkel & Wallen, 2000). The study was conducted in various special schools and therapy centers in Dhaka, focusing on parents of children with autism.

A purposive sampling method was used, which is a non-probability sampling technique where participants are selected based on specific characteristics relevant to the study (Hicks, 1999). This method was preferred as it is efficient, cost-effective, and allows for the easy selection of participants from different locations (Hicks, 2000). The sample size was determined based on statistical calculations, but due to practical constraints, the final sample included 111 parents.

Data were collected using a structured questionnaire, the "Revised Parental Social Support Scale (RPSSS)" by Sema Kaner. The questionnaire was translated into Bangla to ensure better comprehension. Most data were collected through face-to-face interviews, while some participants were given the questionnaire to complete at home. The researcher obtained permission from the Speech & Language Therapy department of Bangladesh Health Professions Institute (BHPI) and the relevant authorities of CRP and special needs schools. Participants were briefed about the study, assured of confidentiality, and informed that their personal information would not be disclosed.

A pilot study was conducted with four participants to test the clarity and feasibility of the questionnaire. The findings indicated that most parents received social support and were satisfied with it. Based on the pilot study, necessary modifications were made to improve the questionnaire's clarity and relevance.

Data analysis was performed using descriptive statistics, as they are commonly used to interpret survey data (Hicks, 2000). The Statistical Package for Social Sciences (SPSS) version 20 was employed to process and analyze the data. The results were presented using column and pie charts for better visualization.

Ethical approval was obtained from the Institutional Review Board (IRB) of BHPI (CRP/ BHPI/ IRB/12/2020/431). Participants provided written informed consent and were assured that participation was voluntary. They were informed about the study's objectives, and it was emphasized that there would be no physical or psychological harm, as the study was purely observational. Confidentiality was maintained by safeguarding personal data, which was shared only with the research supervisor. Participants were also given the right to withdraw from the study or refuse to answer any question at any stage.

The study followed a systematic and structured approach, ensuring rigor and credibility. The researcher maintained a neutral tone during the interviews, clarified any unclear questions, and created a comfortable environment for the participants. While most data were collected directly, a small portion was gathered through questionnaires sent home with participants' children. The study aimed to provide insights into the social support and satisfaction levels of parents caring for children with autism, addressing a crucial aspect of their well-being and caregiving experience.

III. Result

In this study, the investigator aimed to know the perceived social support and satisfaction level of parents of children with Autism. So, the investigator had collected 111 respondents and collected data from them. The data were analyzed by descriptive statistics and calculated as percentages and presented by using pie charts, columns and tables.

Gender of the Participants shown in the figure 01.

The chart shows that there are 97 (87%) female and 14 (13%) males from total 111 participants.

Age category of the participants shown in the figure 02.

The chart shows that most of the participant's age range in between 31-40, it is about 61.3% (68) participants. (24.3 %) participants' age in between 21-30. In between 41-50, there is 12.6% participants. In this category there was only 1.8% (2) participants in 51-60 range.

Gender of the children with autism shown in the figure 03.

The chart shows that most of the children (85) 76.6% were male and minimum children were (26) 23.4% female.

Age category of the children with autism shown in the figure 04.

The chart shows that there were maximum number of 56. 8% (63) children in between (3-6) years. In between (7-10) years there were 34.2% children and minimum 9% (10) children were in (11-14) year's age range.

Perceived emotional support of participants shown in the figure 05.

The chart shows that maximum 39% (43) participants sometimes had someone to provide emotional support and minimum 12.38% (14) participants had none for providing emotional support to them.14% (16) participants had rarely existed someone for providing emotional support. But 34.62% (38) participants always had someone for this support.

Satisfaction level of participants for emotional support shown in the figure 06.

The chart shows that most of the participants 46.15% (51) were satisfied for having someone for emotional support. Minimum 16.31% (18) participants were not satisfied for at all. Some participants 20.81% (23) were little satisfied. 16.65% (19) were very satisfied for having someone to provide emotional support. Overall satisfaction level of participants shown in the figure 07.

The chart shows that most of the participants 48.85% (54) were satisfied with the social support they receive. Minimum 13.92% (15) were no satisfied at all and 20.12% (22) participants were little satisfied. Some participants 17.18% (20) were very satisfied with the overall social support.

Association between gender of sample population and perceived social partnership support are shown in the Table 1.

In this study, among 111 participants, perceived social partnership support were found sometimes have highest in 40 participants who were female. Association between gender of sample population and perceived social partnership support examined by chi square test. The association was not significant (p>0.05).

Association between gender of sample population and satisfaction level from perceived social partnership support are shown in the Table 2.

In this study, among 111 participants, satisfaction level from social partnership support were found satisfied highest in 41 participants who were female. Association between gender of sample population and satisfaction level from perceived social partnership support examined by chi- square test. The association was not significant (p>0.05).

Association between gender of sample population and perceived emotional support are shown in the Table 3.

In this study, among 111 participants, perceived emotional support were found sometimes have highest in 37 participants who were female. Association between gender of sample population and perceived emotional support examined by chi square test. The association was not significant (p>0.05).

Association between gender of sample population and satisfaction level from perceived emotional support are shown in the Table 4.

In this study, among 111 participants, satisfaction level from perceived emotional support was found satisfied highest in 42 participants who were female. Association between gender of sample population and satisfaction level from perceived emotional support examined by chi square test. The association was not significant (p>0.05).

IV. Discussion

In this study data was collected from 111 parents of children with autism spectrum disorder to find out the "Perceived social support and satisfaction level of parents of children with autism" by using Revised Parental Social Support Scale- RPSSS by Sema KANER. From this study, among the 111 participants most of the parents 87% (97) were female and 13% (14) male. Most of the parents 61.3%, (68) were at the age in between 31-40 years. It means most of the parents were at middle aged. Previous study found that most of the parents were middle (35-44) aged (Meral & Cavkaytar, 2012). In the social partnership support subfield, findings show that maximum 40.77% parents sometimes had someone to provide social partnership support and most of them 44.41% were satisfied for having someone for this support. Subfield of information support, findings show that maximum parents 44.57% (49) sometime had someone for information support and most of them 51.20% were satisfied for having someone for this support. In the emotional support 39% parents sometimes and 35% parents always had someone to provide emotional support and average 46.15% were satisfied with the support. Maintaining a children with ASD always challenging for the parents. They need support for leading an easy life. In the maintenance support subfield, findings show that maximum parents 40.05% always had someone to get maintenance and maximum 53.65% of them were satisfied. From all of the subfield, most of the parents always had someone to receive the support in maintenance support field. On the other hand, there other subfield, parents sometimes had someone to provide these support. But in the satisfaction level from those support which they get, most of the parents from all subfield were satisfied. Overall perceived social support and satisfaction level of parents also been observed in this study. Investigator found that overall most 40% (44) of the parents of children with autism sometimes had someone to provide social support. Minimum parents 11.60% (13) had none for social support. Almost 34.50%

(38) parents always had someone to provide social support and 13.52% (16) parents had rarely exist someone to support them. The ratio means that they average time had someone to provide social support. Previous research also found that social support perception levels of families who have child with autism are above the average (Kuru & Piyal, 2018). After perceiving social support from someone of the society, it was found that most of the parents 48.85% (54) were satisfied with the support. Minimum parents were 13.92% (15) were no satisfied and almost 20.12% (22) parents were little satisfied. Some parents 17.18% (20) were very satisfied with the overall social support from the society. Previous study also found that the parents who have an adequate amount of perceived social support are satisfied with their life and those who perceived that they have no social support from any one is not satisfied with their life's life (Habib et al., 2016). Association between gender of sample population and perceived social partnership support examined by chi square test. The association was not significant (p>0.05).

In this study, among 111 participants, satisfaction level from social partnership support were found satisfied highest in 41 participants who were female.

Association between gender of sample population and satisfaction level from perceived social partnership support examined by chi- square test. The association was not significant (p>0.05).

In this study, among 111 participants, perceived emotional support o were found sometimes have highest in 37 participants who were female.

Association between gender of sample population and perceived emotional support examined by chi square test. The association was not significant (p>0.05).

In this study, among 111 participants, satisfaction level from perceived emotional support were found satisfied highest in 42 participants who were female.

Association between gender of sample population and satisfaction level from perceived emotional support examined by chi square test. The association was not significant (p>0.05).

V. Conclusion:

From this study, investigator observed that among the participants most of the parents were female, middle aged and higher educated. But most of them were housewife. Maximum parents had one child and their family was nuclear. From the results of four subfields of social support, investigator observed that most of the parents always had someone to receive the support in maintenance support field. On the other hand, other subfield, parents sometimes had someone to provide this support. But in the satisfaction level from those support which they get, most of the parents from all subfield were satisfied.

From overall perceived social support and satisfaction level of parents it was observed that overall, they average time had someone to provide social support. After perceiving social support from someone of the society, it was found that most of the parents were satisfied with the support. The frequent communication level indicates that the communication of the parents of children with autism spectrum disorder were quite good to their relatives, friend and neighbors. They could go out for visiting others home, for shopping. They almost every day communicate with their closest relatives and friends. The parents of children with autism did telephone conversation that face-to-face conversation every day with their closest friend, relatives and neighbors. Average parents had someone to provide social support and they are satisfied with that support.

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Conflicts of interests

All the authors declared that they do not have any conflicts of interest.

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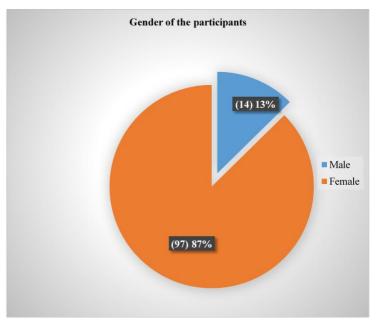


Figure-01: Gender of the participants

Figure-1 shows that there are 97 (87%) female and 14 (13%) males from total 111 participants. In this study the results are shown by using Column chart and Pie chart.

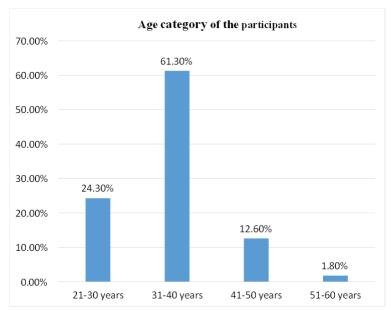


Figure-02: Age category of the participants

Figure- 2 shows that most of the participant's age range in between 31-40, it is about 61.3% (68) participants. (24.3 %) participants' age in between 21-30. In between 41-50, there is 12.6% participants. In this category there was only 1.8% (2) participants in 51-60 range.

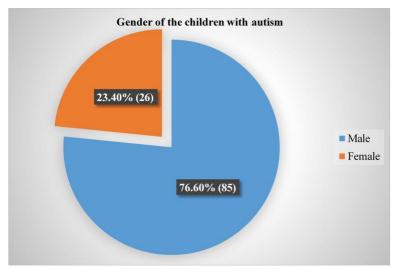


Figure No- 3 Gender of the children with autism

Figure-3 shows that most of the children (85) 76.6% were male and minimum children were (26) 23.4% female.

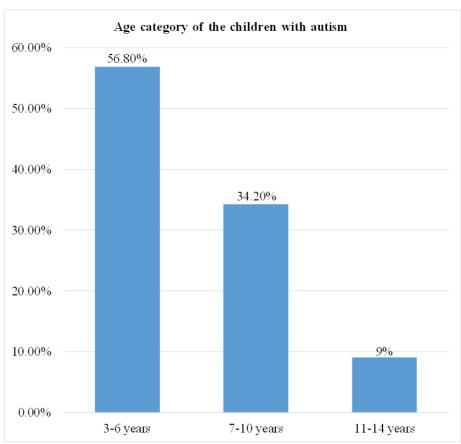


Figure No-04 Age category of the children with autism

Figure-4 shows that there were maximum number of 56. 8% (63) children in between (3-6) years. In between (7-10) years there were 34.2% children and minimum 9% (10) children were in (11-14) year's age range.

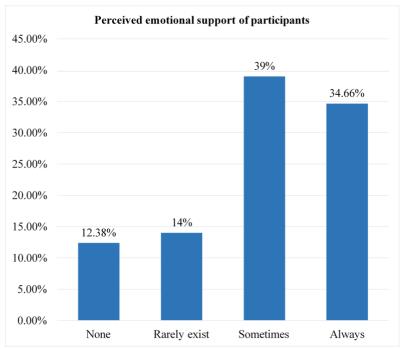


Figure No-5 Perceived emotional support of participants

Figure- 5 shows that maximum 39% (43) participants sometimes had someone to provide emotional support and minimum 12.38% (14) participants had none for providing emotional support to them.14% (16) participants had rarely exist someone for providing emotional support. But 34.62% (38) participants always had someone for this support.

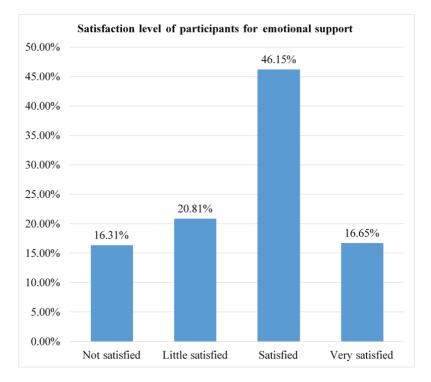


Figure No-6 Satisfaction level of participants for emotional support

Figure-6 shows that most of the participants 46.15% (51) were satisfied for having someone for emotional support. Minimum 16.31% (18) participants were not satisfied for at all. Some participants 20.81% (23) were little satisfied. 16.65% (19) were very satisfied for having someone to provide emotional support.

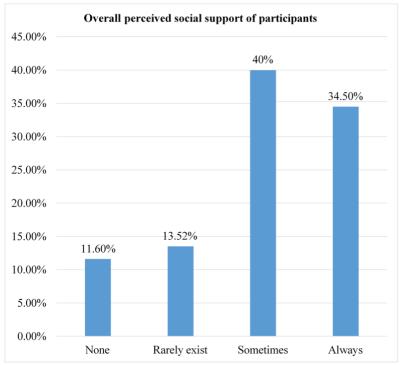


Figure No-7 Overall perceived social support of participants

Figure 7 shows that most of the participants 40% (44) of children with autism had someone to provide social support sometimes. Minimum participants 11.60% (13) had none for social support. Some participants 13.52% (16) had rarely exist someone to support them. About 34.50% (38) participants always had someone to provide social support.

Association between gender of sample population and perceived social partnership support

Gender vs perceived social partnership		Perceived social partnership support				Total
support		None	Rarely exist	Sometimes	Always	
	Male	1	3	5	5	14
Gender of the parents	Female	15	17	40	25	97
	Total	16	20	45	30	111

Table: 1 Association between gender of sample population and perceived social partnership support

In this study, among 111 participants, perceived social partnership support were found sometimes have highest in 40 participants who were female.

Association between gender of sample population and satisfaction level from perceived social partnership support

Gender vs satisfaction from social		Satisfaction level from social partnership support				
partnership		Not Satisfied	Little satisfied	Satisfied	Very satisfied	
support						
Gender of the	Male	1	3	9	1	14
parents	Female	19	21	41	16	97
Total		20	24	50	17	111

Table-2 Association between gender of sample population and satisfaction level from perceived social partnership support

In this study, among 111 participants, satisfaction level from social partnership support were found satisfied highest in 41 participants who were female.

Association between gender of sample population and perceived emotional support

Gender vs perceived social partnership		Perceived social partnership support				Total
	support	None	Rarely exist	Sometimes	Always	
	Male	1	1	6	6	14
Gender of the parents	Female	13	14	37	33	97
	Total	14	15	43	36	111

Table: 3 Association between gender of sample population and perceived emotional support

In this study, among 111 participants, perceived emotional support were found sometimes have highest in 37 participants who were female.

Association between gender of sample population and satisfaction level from perceived emotional support

Gender vs satisfaction from social		Satisfaction level from social partnership support				
partnership		Not Satisfied	Little satisfied	Satisfied	Very satisfied	
Support						
Gender of the	Male	1	3	9	1	14
parents	Female	17	21	42	17	97
Total		18	24	59	18	111

Table: 4 Association between gender of sample population and satisfaction level from perceived emotional support.

In this study, among 111 participants, satisfaction level from perceived emotional support were found satisfied highest in 42 participants who were female.

Association between gender of sample population and perceived social partnership support Chi-Square Tests

Chi Square Tests					
	Value	df	Asymp. Sig. (2-sided)		
Pearson Chi-Square	2.184a	3	.564		

Association between gender of sample population and perceived social partnership support examined by chi square test. The association was not significant (p>0.05).

Association between gender of sample population and satisfaction level from perceived social partnership support

Chi-Square Tests					
	Value	df	Asymp. Sig. (2-sided)		
Pearson Chi Square	5.066a	3	237		

Association between gender of sample population and satisfaction level from perceived social partnership support examined by chi- square test. The association was not significant (p>0.05).

Association between gender of sample population and perceived emotional support Chi-Square Tests

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	2.145 ^a	3	.585

Association between gender of sample population and perceived emotional support examined by chi square test. The association was not significant (p>0.05).

Association between gender of sample population and satisfaction level from perceived emotional support Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	
Pearson Chi-Square	5.076 ^a	3	.261	

Association between gender of sample population and satisfaction level from perceived emotional support examined by chi square test. The association was not significant (p>0.05).