

ORIGINAL ARTICLE

MALTREATMENT IN AUTISM SPECTRUM DISORDER CHILDREN FROM PARENT'S PERSPECTIVE: A SINGLE-CENTERED CROSS-SECTIONAL STUDY AT DHAKA, BANGLADESH

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ABSTRACT

Children with disabilities are at an increased risk of experiencing child maltreatment (CM). We aimed to estimate the prevalence of different forms of CM among children with autism spectrum disorder (ASD) in Dhaka, Bangladesh. We interviewed 45 randomly selected mothers of ASD children who attended a tertiary care hospital in Dhaka, Bangladesh, to treat their children. Data regarding CM was collected using a standard screening tool recommended by the International Society for the Prevention of Child Abuse and Neglect (ISPCAN). We asked mothers to report about their child-rearing practices to identify CM, including physical, psychological, and sexual abuse, and neglect, along with their non-violent disciplinary practices. The children's age range was 3 to 9 years, and approximately 82 percent were boys. All children were found to have experiences of physical and psychological abuse throughout their childhood. Seventy-three percent of children experienced neglect during the past year while 82 percent during their childhood. The reported prevalence of sexual abuse was 4.4 percent in the past year and 8.9 percent during their childhood. However, all parents followed non-violent disciplinary practices, and the prevalence of maltreatment did not differ between boys and girls. Higher instances of CM in Bangladesh, especially among ASD children, raise concern for its adverse social consequences and calls for appropriate mitigation practices as proclaimed by the United Nations Child Rights Charter.

Keywords: Autism spectrum disorder, Child maltreatment, Prevalence, ICAST-P, Bangladesh.

INTRODUCTION

Child maltreatment (CM) by their parents is an increasing social malady across the world¹. When a child is incapacitated with physical or emotional disorders, their ability to communicate and respond freely to social demands substantially diminishes, and they easily fall prey to maltreatment².

Studies revealed that children with disabilities are at an increased risk of experiencing CM. Fisher et al. stated that children with autism spectrum disorder (ASD) are 2.5 times more likely than those not referred to the child protection facilities in the USA due to abuse, while Sullivan and Knutson revealed that disabled children are four times more likely to be sexually abused than a child without disabilities^{3,4}. In a caregivers' reported study by Mandell et al., approximately 20 percent of children with ASD are physically abused, and 17 percent are sexually abused in the USA⁵.

Studies from Bangladesh revealed almost all rural children aged 11-17 years, irrespective of their physical and mental conditions, faced at least one form of physical abuse (PA) or psychological abuse (PsyA) in the past year^{6,7}. Although studies revealed that CM is highly prevalent in Bangladesh, there is no study regarding the prevalence of CM among children with ASD^{6,8}. So, we aimed to determine the prevalence of CM in a selected group of Bangladeshi children with ASD.

METHODS

This cross-sectional study was conducted at the Institute of Paediatric Neuro-disorder & Autism (IPNA) of Bangabandhu Sheikh Mujib Medical University (BSMMU), a tertiary care hospital in Dhaka. IPNA is the largest national institution of Bangladesh in providing programs for early identification and intervention, as well as ensuring a secure atmosphere for autistic children. Since this centre provides health care and other support services to a large number of

disabled children, choosing it as our research site makes it convenient to enrol ASD children in this study.

Mothers of ASD children who attended the out-patient department of IPNA to treat their children were selected as the study population. Children with ASD were diagnosed and evaluated by experts in IPNA using the criteria of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)⁹.

The formula z^2pq/d^2 was used to determine the sample size¹⁰. A total of 45 mothers of registered ASD child were selected, and the sample size was determined considering the prevalence of CM 85 percent regardless of their mental and physical condition from a previous study, q is $1 - p$, allowable error 10 percent (d) and 95 percent confidence interval⁸. The sample was collected from the IPNA's out-patient clinic. Every day, a substantial number of ASD children are enrolled at these facilities for routine medical care. The list of registered children served as our sampling frame. From this list, we invited mothers of each alternate registered child to participate in our study. In case the selected participant was not available or refused to take part in the study, the next mother of the child on the list was interviewed.

Data collection tool

The International Society for the Prevention of Child Abuse and Neglect (ISPCAN) Child Abuse Screening Tool - Parent (ICAST-P) version was used in this study. ISPCAN developed this tool with the collaboration of UNICEF, the UN Secretary General's study on violence against children, the office of the High Commissioner of Human Rights, and the World Health Organization to collect data on specific parental or caregiver's behaviours that are considered as CM¹¹.

ICAST-P is an appropriate tool for the systematic data collection on certain abusive practices of parents or caregivers directed toward an indexed child in order to assess the incidence and prevalence. Using ICAST-P, parents and/or caregivers can be asked about their behaviour in the context of child-rearing. This tool has 15 questions on background and demographic information, 17 on PA, 14 on PsyA, 5 on neglect, 2 on sexual abuse, and 6 on non-violent disciplinary practices¹¹. PA was categorized as severe and moderate. Choking, kicking, beating up repeatedly, burning or scalding, and giving drug or alcohol were considered as severe, while slapping, spanking, shaking, keeping knelt or stand, hitting, pinching, twisting ear, pulling hair, knuckling, and pouring chili in the mouth were considered as moderate forms of PA¹².

ICAST-P is a valid and reliable tool, as revealed in different studies. The internal consistency of all subscales of ICAST-P was previously assessed, and

Cronbach's alpha found was in a very good range (0.62-0.78)¹².

A back-to-back translated Bengali version of ICAST-P was made culturally valid in previous community-based research of the first author, according to ISPCAN guidelines (author's unpublished manuscript).

All questions related to different disciplinary actions, negligence treatment, and sexual abuse consist of multiple-choice answers: "once a week or more often (≥ 50 times)", "several times a month (13-50 times)", "about once a month (6-12 times)", "several times a year (3-5 times)", "once or twice a year (1-2 time/s)", "not in the past year, but it has happened before", "never in my life" and "no answer". Participants were also asked to respond to any other caregiver's behaviour towards the indexed child. Both caregivers' abusive behaviours and reported sexual abuse towards the indexed child were considered for analysis.

Among general characteristics, indexed child's age (2-5, 6-9, 10-13-, and 14-17-years age groups), and sex; parents' age, educational level (i.e., up to the primary, secondary, higher secondary, and graduate and above), mother's occupation (housewife, government job, non-government job), father's occupation (service, business, and others) and number of caregivers (>2 and ≤ 2 , the median was used to determine the cutoff point.) were recorded. These questions followed the original ICAST-P questionnaire.

Data collection procedure

Mothers of the children were interviewed face to face in an isolated room at IPNA. Pretesting of the questions was done on similar participants at the Department of Neonatology, BSMMU. Necessary modifications of the data collection tool were made based on the recommendations that came from pretesting. In case of ambiguity in understanding the language of any question, detailed clarification was given.

STATISTICAL ANALYSIS

Descriptive analysis was done on socio-demographic variables like age, gender, education, occupation and the frequency of different forms of abuse. Categorical variables were presented in frequency and percentage, and continuous variables were expressed in mean and standard deviation (SD). A Chi-square test was performed to compare numerical data of two or more independent groups. The past year (PY) and lifetime (LT) prevalence of different forms of parenting practices were calculated using descriptive statistics. The principal component analysis (PCA) was used to build a Household Wealth Index from household properties. This approach was derived from the World Bank method for calculating a household wealth index,

commonly used in resource-poor countries. PCA factor 1 was used for analyses because it explained the most variance. The values of this factor were then used to categorize participants into three groups: lower, middle, and upper, corresponding to the participant's socioeconomic status.¹³

Different types of CM and positive parenting practices occurring in the PY were counted as 1 if "once a week or more often" or "several times a month" or "about once a month" or "several times a year" or "once or twice a year" was checked. The LT exposure was counted as 1 if any of the above responses or "not in the past year but it happened before" was checked. PY and LT frequency were estimated as the proportion of children who have experienced CM and non-violent disciplinary practices during their PY and LT, respectively. The PY prevalence rate was calculated by dichotomizing all forms of CM and non-violent disciplinary practices based on any vs. no exposure in the past year. For LT prevalence, different forms of CM and non-violent disciplinary practices were dichotomized based on any vs. no exposure in the past year or ever. Prevalence is shown in percentage with a 95 percent confidence interval (CI).

Data were analysed using the Statistical Package for Social Sciences, SPSS (version 22).

Ethical consideration

We obtained ethical permission from the Institutional Review Board of BSMMU (2018/12088). Informed written consent was taken from each participant before the interview. All participants were informed about the aim and objectives of the study, the procedure of study, benefit and risk of participation, right to refuse to participate or withdraw from the study, confidential handling of data, and principal investigator's identity. They were also informed that some of the questions about their children might cause distraction, and they might not answer those questions. After every interview, participants were asked about how they felt. Participants were also requested to talk with any person whom they trust if any mental upset occurred.

RESULT

Demographic information

Table 1 shows the demographic characteristics of the parents and their children. The average age of mothers was 32 years, with a range of 21-50. Almost half of them were university graduates. Every nine in ten mothers were housewives, and almost 55 percent of fathers were service holders. Most children were male, with a median

age of 7 and the age range was between 3 to 9 years.

Prevalence of parental disciplinary practices

Table 2 shows the disciplinary practices of parents like PA and PsyA, negligent treatment, sexual abuse and non-violent disciplinary practices to their children. Almost all parents reported that they practiced non-violent disciplinary measures. All children of enrolled mothers experienced moderate physical and psychological aggression both in the PY and LT. The PY and LT prevalence of parental neglectful behaviour were 73 percent and 82 percent, respectively. Sexual abuse was reported less in comparison to physical and psychological abuse. Only two mothers reported that their children had been sexually abused in the PY, while this rate was 9 percent during their LT. However, there were no significant differences between male and female children regarding different types of CM and non-violent disciplinary practices during the PY and LT, respectively.

Parent responses regarding psychological abuse, physical abuse, neglect and positive parenting.

Table 3 shows parental non-violent disciplinary practices towards their children. All parents said they explained their children for any wrong-doing and advised them to stop doing anything unacceptable. Almost half of the parents used time out, and three-quarters of parents took privileges away from their children as a means of disciplinary practices.

The PY and LT prevalence of different forms of CM are given in Table 4. The most common forms of both the PY and LT physical disciplinary actions were slapping on the back of the head (88.9%), spanking (86.7%) and shaking (64.2%). None of the children experienced forceful drug and alcohol intake, but one child experienced forceful feeding of chili pepper in the mouth as punishment. Shouting (97.8%), threatening to hurt or kill (95.6%), and forbidding to going out of home (84.4%) were the most common forms of PsyA to the children, while withholding food and locking out of the house were the least common forms. Prevalent forms of neglect for the PY and LT were unmet medical needs (46.7% vs. 51.1%) and inadequate supervision after getting hurt (33.3% vs. 48.9%), whereas the least prevalent form was inappropriate clothing (8.9% vs. 13.3%) (Table 4).

Table 1 Socio-demographic characteristics of parents and their children (n=45)

Socio-demographic variable	Frequency (%)
Parents' characteristics	
Age of mother (year): Mean $\pm$ SD	32 $\pm$ 6.5
Age of the father (year): Mean $\pm$ SD	39 $\pm$ 7.6
Mother's education level	
Primary	1 (2.2)
Secondary	12 (26.7)
Higher-secondary	10 (22.2)
Graduate and above	22 (48.9)
Father's education level	
Primary	2 (4.4)
Secondary	7 (15.6)
Higher-secondary	10 (22.2)
Graduate and above	26 (57.8)
Mother's occupation	
Housewife	40 (88.9)
Govt. Job	2 (4.4)
Non-govt. Job	3 (6.7)
Father's occupation	
Service holder	25 (55.6)
Business	17 (37.8)
Others	3 (6.6)
Socio-economic status	
Lower	17 (37.8)
Middle	16 (35.6)
Upper	12 (26.7)
Total caregiver	
>2	4 (8.9)
$\leq$ 2	41 (91.1)
Child characteristics	
Child sex	
Male	37 (82.2)
Female	8 (17.8)
Child age	
2-5 years	20 (44.4)
6-9 years	15 (33.48)
10-13 years	8 (17.8)
14-17 years	2 (4.4)

Table 2 Child maltreatment prevalence among children with ASD (n=45)

Types of maltreatment	PY prevalence		LT prevalence	
	Frequency (%)	95% CI	Frequency (%)	95% CI
Non-violent disciplining	45 (100.0)	92.0-100.0	45 (100.0)	92.0-100.0
Moderate physical abuse	45 (100.0)	92.0-100.0	45 (100.0)	92.0-100.0
Severe physical abuse	22 (48.9)	33.7-64.2	24 (53.3)	37.9-68.3
Psychological abuse	45 (100.0)	92.0-100.0	45 (100.0)	92.0-100.0
Neglect	33 (73.3)	58.1-85.4	37 (82.2)	67.9-92.0
Sexual abuse	2 (4.4)	0.5-15.1	4 (8.9)	2.5-21.2

Table 3 Frequency distribution of different types of non-violent disciplinary practices (n45)

Non-violent disciplinary practices	Frequency (%)	
	Past year	Lifetime
Explained	45 (100.0)	45 (100.0)
Told to stop something	45 (100.0)	45 (100.0)
Gave award	44 (97.8)	44 (97.8)
Gave something to stop or change behaviour	44 (97.8)	44 (97.8)
Took away privileges	31 (68.9)	31 (68.9)
Time out	20 (44.4)	22 (48.9)

Table 4 Frequency distribution of different types of CM (n=45)

	Frequency (%)	
	Past year	Lifetime
Physical abuse		
Moderate		
Slapped back of the head	40 (88.9)	40 (88.9)
Spanked	39 (86.7)	39 (86.7)
Shook the child	29 (64.4)	29 (64.4)
Painful kneel or stand	24 (53.3)	24 (53.3)
Hit elsewhere with object	23 (51.1)	24 (53.3)
Pinched	22 (48.9)	22 (48.9)
Hit on buttock with object	17 (37.8)	17 (37.8)
Twisted ear	12 (26.7)	13 (28.9)
Pulled hair	11 (24.4)	11 (24.4)
Knuckled back of the head	3 (6.7)	3 (6.7)
Put chili, pepper in the mouth	1 (2.2)	1 (2.2)
Locked or tied to restrict movement	16 (35.6)	19 (42.2)
Severe		
Choked	15 (33.3)	16 (35.6)
Kicked	8 (17.8)	8 (17.8)
Beat up repeatedly	7 (15.6)	10 (22.2)
Burned or scalded	1 (2.2)	1 (2.2)
Gave drugs or alcohol	-	-
Psychological abuse		
Shouted	44 (97.8)	44 (97.8)
Threatened to hurt or kill	43 (95.6)	43 (95.6)
Forbade from going out	38 (84.4)	38 (84.4)
Refused to speak	34 (75.6)	34 (75.6)
Wished for death or for never being born	30 (66.7)	30 (66.7)
Threatened to abandon	29 (64.4)	29 (64.4)
Blamed for misfortune	27 (60.0)	27 (60.0)
Insulted	21 (46.7)	21 (46.7)
Cursed	20 (44.4)	22 (48.9)
Public humiliation	18 (40.0)	18 (40.0)
Threatened to invoke harmful people, ghost	17 (37.8)	18 (40.0)
Locked out of the house	11 (24.4)	13 (28.9)
Withheld food	3 (6.7)	4 (8.9)
Neglect		
Unmet medical needs	21 (46.7)	23 (51.1)
Inadequate supervision after getting hurt	15 (33.3)	22 (48.9)
Did not provide a safe place to live	11 (24.4)	15 (33.3)
Inadequate food or liquid	8 (17.8)	9 (20.0)
Inappropriate clothing	4 (8.9)	6 (13.3)

DISCUSSION

This study used ICAST-P to examine CM behaviours in parents who attended IPNA to treat their ASD child. The striking finding was that all ASD children experienced both PA and PsyA, whereas neglect was reported comparatively less than PA and PsyA, and sexual abuse was reported only in a few cases. All parents used non-violent disciplining measures for upbringing their children.

All children of the present study were physically abused, and 50 percent were severely abused physically in the PY. In a study from China, Duan et al. also stated that 88 percent of the parents physically abused their ASD children while 86 percent of parents mildly abused their children physically, and 36 percent abused severely during the past three months¹⁴.

Empirical studies revealed that children with disabilities are at an increased risk for maltreatment. Sullivan and Knutson found a 9 percent prevalence rate of maltreatment for non-disabled children and 31 percent for disabled (mostly mental and developmental) children of Nebraska, USA⁴. Similarly, Hoover and Kaufman stated that children with ASD are 3 to 4 times more likely to be maltreated in the USA than normally developed children¹⁵.

ASD children have behavioural problems, including fear, anger, anxiety, frustration, hyperactivity and emotional dysregulation. In addition, ASD children have a higher prevalence of aggressive behaviour than non-ASD children¹⁶. These behavioural challenges can often cause caregivers more distress, which leads them to take aggressive disciplinary actions^{4,5}. Different ecological models explained that children with ASD are at elevated risk of CM. It is due to a complex interaction of individual factors like social difficulties, communication deficits, and difficult behaviours; parental factors like family stress, and environmental factors like cultural attitudes¹⁷. Studies revealed that parental abusive behaviours toward their children are related mainly to their stressful personal experiences¹⁷. Having a child with disabilities have a negative impact on the parent's mental state, causing immense emotional, physical, and economic stress, which subsequently makes them abusive towards their children^{4,5}.

However, in some previous studies, higher rates of child PA (95%), PsyA (97%) and neglect (70%) were reported among normally developed

children in Bangladesh [6, 7]. So, the prevalence of different types of maltreatment reported in the present study is not exceptionally high than previous studies' findings in children without disabilities. In consistent with this explanation, some population-level studies failed to find that children with ASD are at elevated risk for maltreatment compared to population controls¹⁸. After a violent war, Bangladesh got its independence from Pakistan in 1971, in which some three million people were killed and 0.2 million women raped¹⁹. Since its independence, Bangladesh has witnessed repeated political violence, frequent natural disasters, and famine. It also has a high prevalence of poverty, intimate partner violence and domestic violence with an uneven record of human rights²⁰. According to Belsky's ecological model, these macro-level societal and cultural factors of Bangladesh might have an association with CM²¹. Besides, failure to implement the Convention on the Rights of the Child in the legislature of Bangladesh is one of the major macro-level factors that seem to be responsible for the high prevalence of CM²². Thus, the reflection of the present finding reveals that lone child characteristics such as ASD do not solely make a child prone to become a victim, rather different macro-level factors within a larger social arena simultaneously contribute CM.

The prevalence of sexual abuse has been found to be less reported in the present study. This might not be the actual representation of the social scenario of Bangladesh. The persistent culture of shame and stigma in disclosing sexual abuse in Bangladesh makes it report less²³. Ferdous et al. studied on 216 children with disabilities in Bangladesh and reported that half of the children were victims of sexual abuse²⁴. In addition, Sullivan and Knutson found that disabled children are three times more likely to be sexually abused in comparison with normally developed children⁴. Murphy pointed out that parents are also often unable to provide information to their ASD children regarding human sexuality or preventive strategies to protect themselves from sexual abuse²⁵. On the other hand, Bangladesh being a Muslim-dominated conservative society; providing sex education to children within the family level is a matter of embarrassment for adults and considered taboo²⁶. However, Algood et al. opined that parent come only to educate their ASD children about sexuality when a child becomes a victim of sexual abuse¹⁷. Within a conservative societal context, parental avoiding attitude to teach their disabled children about sexuality

seem to make children vulnerable to sexual abuse.

Despite the high prevalence of various forms of aggressive measures, all parents in the present study also used nonviolent disciplinary methods to upbringing their ASD children. According to Sofuoglu et al., roughly 90 percent of Turkish parents have a positive attitude toward their normally developing children²⁷, despite the fact that little is known about children with ASD. Parents of children with ASD experience high stress, which causes them to focus on the negative aspects of their child's behaviour and, in some situations, to use less positive parenting methods, resulting in maltreatment²⁸. In a recent national study in Bangladesh, Haque et al. investigated challenging situations of caregivers linked to life events of their children with neurodevelopmental disorders, revealing that female caregivers were more stressed²⁹. Empirical studies have found a connection between stressful life events for parents and child maltreatment³⁰. The stressful daily lives of the interviewed mothers of the present study could be the cause of their harsh disciplinary measures against their children.

Despite this, all interviewed mothers mentioned that they were providing positive parenting to their autistic children. All parents in this study were recruited from IPNA, where regular parenting programs teach parents how to deal with their children's aggressive behaviour. This may be the central tenet of the study's documented 100 percent positive parenting history. On the other hand, this positive parenting finding may not be seen in other ASD children whose parents have not undergone parenting training.

The use of the ICAST-P instrument, which has been internationally validated, is a strength of this research. This study has some limitations also. The result presented in this study may not be generalized for the whole of Bangladesh as this study was conducted in a single centre. Failure to compare the findings of ASD children with that of normally developed children was another limitation.

CONCLUSION

Children with ASD in Bangladesh experience a high burden of maltreatment. The most common forms of physical abuse included slapping on the back of the head, spanking, and shaking; psychological

abuse included screaming, threatening to injure or kill, and forbidding children from leaving the house; and unmet medical needs and inadequate supervision after being hurt were the most commonly recorded neglectful incidents.

The reported 100 percent positive discipline practices may be a result of the institutional parenting program.

According to the United Nations Convention on the Rights of the Child (UNCRC), the government should take effective measures to ensure child rights and safety. To better understand the relationship of CM with ASD, future research should examine how socio-cultural and economic factors influence maltreatment towards ASD children. The social and health consequences of maltreatment on ASD children need to be evaluated.

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