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ORIGINAL ARTICLE

Determinants of Health-Related Quality of Life in Mothers of Children With Autism Spectrum Disorder in Bangladesh

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Abstract

Background/Aim: Autism spectrum disorder (ASD) has a significant impact on the quality of life of children with this disorder as well as their mothers. ASD prevalence in Bangladesh has been estimated to be 0.15-0.8 %, but the health-related quality of life (HRQoL) of mothers having children with ASD has not been studied. This study aimed to estimate the HRQoL of these mothers and the main determinants that affect it.

Methods: This study adopted a cross-sectional design using the SF-scale among 160 mothers who were selected through two stage sampling technique (stratified random and purposive sampling) attending at 16 service centres for persons with disabilities from January to June 2023.

Results: The mean age of the participants was 32.78 years and they were mostly married (95 %), were Muslims (84.4 %) and only had primary education (29.4 %). The average monthly family income was 17,781 Bangladeshi Taka (BDT). The total HRQoL was significantly low (37.70 ± 18.27). The physical component score (40.32 ± 21.36) and the mental component score (35.08 ± 15.17) revealed that there were severe deficits. The findings also suggest that the maternal age, less education, less income, family structure, children age and child-behaviour issues were all significant predictors of poorer HRQoL ($p < 0.05$).

Conclusions: This paper thus concludes that the HRQoL of the mothers of children with ASD in Bangladesh is critically impaired, due to the effect of socio-economic, family and child related factors.

Key words: Autism spectrum disorder; Caregivers; Health-related quality of life; Mothers; SF-36.

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Introduction

Autism spectrum disorder (ASD) is a complicated neurological development condition with impaired interaction and communication with others, accompanied by limited interests and habitual actions.[1] The total prevalence of ASD across the world has increased exponentially and according to the latest estimates, ASD currently impacts about 1 in 54 children.[2] In South Asia, where epidemiological evidence is limited, a prevalence of 1:93 children has been described, independent studies in India and Sri Lanka reported prevalence of 0.09 to 1.07.[3] This trend

has been reflected in Bangladesh. National data show a prevalence ranged from 0.15–0.8 % and a significant difference between urban (Dhaka, 3 % across) and rural regions (0.15 %-0.8 % across) on beneficial relations to the importance of awareness and diagnosis capacity.[3] Even with this increased awareness, there is no nationwide study and substantial backing to provide services to the families that are affected in Bangladesh.

The main burden of caring in these families falls upon mothers, who experience continuous stress which greatly affects their health-related quality of life (HRQoL).[4] By definition, HRQoL is the multidimensional concept that includes physical and psychological well-being of an individual in the long run stated by the Centres for Disease Control and Prevention.[5] In the case of mothers with ASD children, the without ceasing pressure of parenting, exacerbated by access to finances and social exclusion create an abysmal drop in HRQoL.[4] Studies that are done on those mothers all indicate that they face overwhelming incidences of depression, worry and physical health degradation and in many cases this decline in state is not necessarily acknowledged by these mothers themselves.[6, 7] A prior research has found that mothers record lower mental and physical wellness than fathers; also child behaviour issues substantially contribute to maternal symptoms.[7, 8] Likewise, a study conducted in Iran has shown that 25.8 % of parents of an autistic child suffered major depression with mothers scoring significantly lower on mental health scales than their fathers.[9]

Although systematic solutions, such as parent-training sessions, have potential in increasing maternal health,[4] there are systemic obstacles present in Bangladesh that complicate the situation. One of the most important is the absence of social and family support, which proved to be relieved.[10] This is acute especially in the case of single mothers and families with low incomes, who experience increased psychological distress because of a lack of resources. HRQoL should be enhanced using multidimensional interventions, such as respite, counselling and community-based support networks.[11-13] Regardless, in Bangladesh, where ASD recognition and care have yet to be established, studies into the maternal HRQoL are severely lacking.[3] Some organisations provide diagnostic and intervention services but there are no research investigating the well-being of the caregivers.[14]

Thus, this study attempted to find out the determinants of HRQoL in mothers of children with ASD in Bangladesh, particularly focusing on socioeconomic status, social support, child behavioural severity and access of healthcare services. By using a developed SF-36 scale to evaluate HRQoL,[15] this study tried to offer a valuable insight about the physical and mental health of these caregivers. It is expected that the results may help policymakers and medical professionals by identifying the key stressors and protective elements and accordingly inform them to implement specific support programs. Filling this critical literature gap, this study can contribute to the improvement of the well-being of mothers, hence the subsequent positive effect on the development of ASD children in Bangladesh.

Methods

Study design

This cross-sectional research involved the investigation of the factors responsible for determinants of HRQoL in mothers of children with ASD in Bangladesh. The research was carried out over a six-month period from January to June 2023, across 16 selected service centres for persons with disabilities (Protibondhi Sheba o Shahajjo Kendra) under the Ministry of Social Welfare.

A two-stage sampling approach was employed to ensure a representative and relevant sample. First, to achieve extensive regional coverage and socio-demographic variation, a stratified random sampling technique was used to select sixteen service centres, two from each of Bangladesh's eight administrative divisions eventually. Second, within each selected centre, a purposive sampling strategy was used to recruit eligible mothers.

The required sample size was calculated using the formula for cross-sectional studies as $n = Z^2pq/d^2$. Based on a previous study[16] indicating a prevalence (p) of 0.075 for significant maternal HRQoL impairment, with q = 1-p (0.925), a 95 % confidence level (Z = 1.96) and a desired precision (d) of 0.05, the minimum required sample size was calculated to be 107. To enhance the statistical power for subgroup analyses and to have an equal number of participants from each of the 16 centres (10 per centre), the sample size was

increased by 53, resulting in a final target of 160 participants.

The study population consisted of mothers who were the primary caregivers for a child diagnosed with ASD. Inclusion criteria: Participants were required to be: (a) mothers of a child (any age) with a confirmed diagnosis of ASD; (b) residing in the same household as the child; and (c) willing to provide written informed consent. Exclusion criteria: Mothers were excluded if they: (a) had a self-reported cognitive impairment that would preclude them from understanding and answering the questionnaire; (b) had a history of substance use disorder; or (c) were the primary caregiver for any other individual with a disability (aside from their child with ASD).

Data collection and measures

Data were collected through face-to-face interviews conducted by trained researchers in a private setting at the respective service centres. Each interview lasted approximately 20–30 minutes. For participants with limited literacy, the researchers read the questions and response options verbatim and recorded their answers. The structured questionnaire consisted of four sections:

- Socio-demographic information: This section captured maternal age, educational level (no formal, primary, secondary, higher secondary, or tertiary), monthly family income and marital status.
- Maternal health and caregiving factors: Data were collected on the mother's self-reported chronic health conditions (comorbidities) and the average number of hours per day spent directly caring for the child.
- Child-specific characteristics: Information regarding the child's age, perceived severity of ASD symptoms (as reported by the mother, categorised as mild, moderate, or severe) and the presence of challenging behaviours was collected.
- Health-related quality of life (HRQoL): HRQoL was assessed using the validated Bengali version of the Short Form-36 (SF-36v2) health survey.[17] This multi-purpose, short-form health survey yields an 8-scale profile of functional health and well-being scores, as well as psychometrically-based physical and mental health summary measures: the physical component summary (PCS) and mental component summary (MCS). Higher scores indicate better HRQoL.

To ensure data accuracy, all completed questionnaires were reviewed daily by the research supervisor. Any inconsistencies or missing data identified were addressed by re-contacting the participant for clarification whenever possible. Each participant was assigned a unique identifier to maintain data confidentiality and consistency during entry and analysis.

Statistical analysis

Statistical analysis was performed using IBM SPSS Statistics for Windows, Version 25.0. The level of statistical significance was set at $p < 0.05$. Frequencies and percentages were calculated for categorical socio-demographic variables. Means and standard deviations (SD) were computed for continuous variables, including the SF-36 domain scores and the PCS and MCS. Independent-sample t-tests (for binary variables like marital status) and one-way analysis of variance (ANOVA) (for categorical variables with more than two categories like education level, ASD severity) were used to compare mean PCS and MCS scores across different groups. Chi-square test was used to examine the association between categorical participant characteristics and dichotomised HRQoL scores (eg above/below median), where appropriate.

Results

Study included 160 mothers of children with ASD, with a mean age of 32.78 ± 7.45 years (Table 1). The majority fell within the 30–39 age group (41.2 %), followed by 20–29 years (34.4 %), indicating that most respondents were relatively young to middle-aged. Nearly all participants were married (95 %), with very few being divorced (2.5 %), separated (1.9 %) or widowed (0.6 %). Education levels varied, with 29.4 % having primary education, 23.1 % higher secondary and 19.4 % secondary education, while 11.3 % were illiterate. A small proportion (16.9 %) had university-level education (Honors/Bachelor or Master's). Religiously, Islam was predominant (84.4 %), followed by Hinduism (10.6 %) and Buddhism (4.4 %). Family structure was nearly balanced between nuclear (55.6 %) and extended (44.4 %) households. Monthly family income averaged 17,781 ± 8,206 Bangladeshi taka (BDT), with 43.7 % earning 15,000–24,999 BDT and 34.4 % in the lowest bracket (5,000–14,999 BDT).

Most families had 4–7 members (75.6 %) and nearly half (49.4 %) had two children, while 28.1 % had only one child. Slightly more respondents resided in urban areas (56.9 %) compared to rural (43.1 %).

Table 2 provides important information on key health and caregiving patterns among the participants. No comorbidities were found among 46.3 % of participants, followed by unspecified chronic conditions (28.1 %), high blood pressure (15 %), diabetes (5 %) and heart disease (5.6 %). Very high proportion of respondents (70 % were not on regular drug regimens) although 30 % were on regular pharmacotherapy presumably related to underlying health conditions. Regarding home care responsibilities, only around 21.2 % of mothers took up extra caregiving roles in the house. Almost a half spent over eight hours daily in taking care of the child with ASD as compared to the rest who spent four to eight hours or less than four hours. These high-caregiving requirements would probably increase physical and emotional demands especially in mothers with comorbid medical conditions or when they had other responsibilities.

Table 3 outlines the features of 160 children with the ASD disorder. The average age was 7 ± 3.43 years of age, with the majority of them being in the 6-10 years (35.8 %), then they fall into 1-5 years (32.6 %) and then the 11-15 years (31.6 %) catego-

Table 1: Sociodemographic profile of mothers of children with autism spectrum disorder (ASD) (N = 160)

Variable	Category	Frequency (n)	Percentage (%)
Age group (years) (Mean ± SD: 32.78 ± 7.45)	20–29	55	34.4
	30–39	66	41.2
	40–49	32	20.0
	50–59	7	4.4
Marital status	Married	152	95.0
	Divorced	4	2.5
	Separated	3	1.9
	Widow	1	0.6
Educational qualification	Illiterate	18	11.3
	Primary	47	29.4
	Secondary	31	19.4
	Higher Secondary	37	23.1
	Honors/Bachelor	14	8.8
	Master's	13	8.1
Religion	Islam	135	84.4
	Hinduism	17	10.6
	Buddhism	7	4.4
	Christianity	1	0.6
Type of family	Extended	71	44.4
	Nuclear	89	55.6
Monthly family income (Bangladeshi taka) (Mean ± SD: 17781.25 ± 8206.20)	5000–14999	55	34.4
	15000–24999	70	43.7
	25000–34999	26	16.3
	35000–44999	9	5.6
Number of family members	1–3	24	15.0
	4–7	121	75.6
	8–10	15	9.4
Number of children	1	45	28.1
	2	79	49.4
	3	30	18.8
	4	6	3.8
Residential status	Rural	69	43.1
	Urban	91	56.9

Table 2: Comorbidities, medicine intake and home care responsibilities of mothers of children with autism spectrum disorder (ASD) (N = 160)

Variable	Category	Frequency (n)	Percentage (%)
Comorbidities	No comorbidities	74	46.3
	High blood pressure	24	15.0
	Heart disease	9	5.6
	Diabetes	8	5.0
	Other diseases	45	28.1
Medicine intake	No	112	70.0
	Yes	48	30.0
Presence of disabled or elderly at home	No	126	78.8
	Yes	34	21.2
Duration of time spent with child	Less than 4 hours	34	21.3
	4–8 hours	51	31.9
	More than 8 hours	75	46.9

Table 3: Characteristics of children with autism spectrum disorder (ASD) (N = 160)

Variable	Category	Frequency (n)	Percentage (%)
Age (years) (mean ± SD: 7.0 ± 3.4)	1–5	52	32.6
	6–10	59	35.8
	11–15	49	31.6
Gender	Boy	117	73.0
	Girl	43	27.0
Social communication and interaction skill	Good	10	6.3
	Somewhat good	91	56.9
	Poor	34	21.3
	Very poor	25	15.6
Restricted behaviour or interest	Good	13	8.1
	Somewhat good	91	56.9
	Poor	34	21.3
	Very poor	22	13.8
Offensive attitude	Yes	83	51.9
	No	77	48.1
Repetitive movement habit	Yes	101	63.1
	No	59	36.9

ry. The sample was composed of male participants (73 %) which is in line with gender distributions known in ASD populations. There was varied social communication and interaction proficiency among the cohort; 56.9 % had moderately adequate skills with the rest having poor (21.3 %) or very poor (15.6 %) skills. The same pattern of the restrictive behaviours or interests was similar; more than half of them were considered moderately adequate and the other participants were placed in the lower proficiency groups. Also 51.9 % of the children were offensive and 63.1 % showed repetitive movements that are commonly reported occurrences of the ASD.

The SF-36 scores that demonstrate HRQoL of the participants of the study are presented in the Table 4. The average score of physical functioning was 54.97 ± 26.14 that indicated moderate restrictions to the performance of physical activities. The meaningful constraints in roles were caused by physical and emotional disruptions and the mean scores were 19.83 ± 12.66 and 20.16 ± 13.12, respectively. There was also low vitality (35.79 ± 16.93), which is a sign of high levels of fatigue. Emotional wellbeing had a low score of 34.07 ± 14.31 indicating that participants were psychologically troubled. The social functioning scores were at 50.31 ± 16.35, signifying there

was partial impairment of social activities. It also affected bodily pain and general health perception, with a mean score of 43.75 ± 29.83 and 42.73 ± 16.82, respectively. The HRQoL in overall was 37.70 ± 18.27, which indicates a poor perception of health overall. On a disaggregated categorisation of the PCS into component summaries, the score was lower at 40.32 ± 21.36 and the MCS score was even lower at 35.08 ± 15.17, highlighting more difficulties in the mental health areas.

The analysis in Table 5 reveals that mother's age, educational status, monthly family income and type of family showed statistically significant associations ($p < 0.05$) with multiple HRQoL domains, including physical functioning, emotional well-being, general health and bodily pain, indicating that these factors influenced perceived health outcomes. Marital and residential status also demonstrated substantial impacts, particularly on emotional and physical role limitations. Additionally, the type of disease and medication usage affected nearly all HRQoL dimensions. The presence of disabled or elderly family members, the time allocated toward children and child-specific characteristics (such as age, gender, social communication skills and repetitive behaviours) significantly affected most HRQoL domains. Notably, children's communication skills and behavioural patterns had a profound influence on the mother's emotional well-being, energy levels and overall health perception.

Table 4: SF-36 scoring in mothers of children with autism spectrum disorder (ASD) (N = 160)

HRQoL domain	**Score** (mean ± SD)
Physical functioning	54.97 ± 26.14
Role limitations due to physical health problems	19.83 ± 12.66
Role limitations due to emotional problems	20.16 ± 13.12
Vitality (energy/fatigue)	35.79 ± 16.93
Emotional well-being (psychological distress and psychological well-being)	34.07 ± 14.31
Social functioning	50.31 ± 16.35
Bodily pain	43.75 ± 29.83
General health perceptions	42.73 ± 16.82
Total scale score	**37.70 ± 18.27**
Total PCS	**40.32 ± 21.36**
Total MCS	**35.08 ± 15.17**

HRQoL: health-related quality of life; PCS: physical component summary; MCS: mental component summary;

Table 5: Association between different parameters and health-related quality of life (HRQoL) in mothers of children with autism spectrum disorder (ASD) (N = 160)

Variables		**Domain**							
		Physical function	Limitation due to physical health	Limitation due to emotional problems	Energy/fatigue	Emotional well being	Bodily pain	Social functioning	General health
Mother's age	**M**	52.61	9.77	14.58	40.99	31.87	38.38	48.87	38.88
	P	< 0.001	0.609	0.017	< 0.001	< 0.001	0.023	< 0.001	0.041
Marital status	**M**	51.10	9.46	19.68	22.89	24.71	19.55	50.06	36.89
	P	< 0.001	0.042	< 0.001	0.001	< 0.001	< 0.001	0.162	0.005
Religious status	**M**	38.43	15.26	12.42	28.75	35.17	44.65	54.20	48.25
	P	0.12	0.075	0.085	0.658	0.852	0.185	0.096	0.097
Educational status	**M**	56.67	15.46	14.68	35.85	35.98	53.00	43.45	44.43
	P	0.012	0.029	0.002	0.035	< 0.001	0.021	0.012	0.041

Monthly family income (Bangladeshi taka)	M	57.80	14.72	13.12	34.51	33.62	49.32	45.62	44.74
	P	< 0.001	0.039	0.036	< 0.001	0.012	0.043	0.028	0.028
Type of family	M	54.89	12.91	12.37	35.45	34.03	50.78	43.59	42.20
	P	< 0.001	0.127	< 0.001	< 0.001	0.004	0.029	0.016	0.031
Number of family members	M	58.73	12.53	16.17	40.83	34.13	48.88	52.87	44.16
	P	< 0.001	0.627	0.065	< 0.001	0.052	0.029	0.036	0.011
Number of children	M	57.56	18.50	11.24	33.71	29.42	52.14	40.50	43.16
	P	0.032	0.005	0.005	0.041	0.006	0.036	< 0.001	0.011
Residential status	M	56.17	12.83	12.94	35.49	33.45	49.75	44.68	42.99
	P	< 0.001	0.339	0.023	0.023	0.041	0.002	0.031	< 0.001
Type of diseases	M	52.19	9.02	16.86	38.44	35.50	48.44	30.96	45.71
	P	< 0.001	0.01	0.001	0.041	0.033	0.003	0.024	< 0.001
Medication	M	54.90	12.63	13.15	35.80	34.05	50.33	43.56	42.67
	P	0.024	< 0.001	0.038	0.001	0.002	0.007	0.001	0.041
Presence of disabled/ elderly person	M	51.87	14.21	12.63	34.49	35.89	49.93	43.45	44.50
	P	< 0.001	0.048	0.009	0.612	0.014	0.001	0.012	0.041
Allocated time towards children	M	54.67	13.25	11.95	35.01	33.96	50.83	39.79	42.94
	P	0.002	0.004	0.203	0.013	0.041	0.003	0.032	< 0.001
Children age	M	54.61	12.43	12.90	35.83	34.26	50.31	43.35	42.55
	P	0.037	0.14	0.009	0.041	< 0.001	0.001	0.004	0.029
Children gender	M	60.27	13.07	15.10	36.21	34.04	52.14	43.34	42.46
	P	< 0.001	0.001	0.002	< 0.001	< 0.001	0.003	< 0.001	0.021
Social communication and interpersonal skills	M	52.94	14.57	10.88	34.50	33.72	53.18	48.03	43.57
	P	< 0.001	< 0.001	< 0.001	< 0.001	0.002	0.04	0.008	0.041
Restricted or repetitive behaviours or interest	M	59.70	12.83	8.23	31.64	30.86	48.13	43.08	43.32
	P	0.01	0.012	0.006	0.041	0.012	0.032	0.023	0.022
Offensive behaviour	M	55.08	12.77	13.21	35.77	33.93	50.37	44.13	42.75
	P	< 0.001	0.091	0.08	0.024	0.004	0.084	0.013	0.005
Repetitive movements	M	56.97	13.81	13.45	35.88	33.86	51.13	46.08	42.36
	P	< 0.001	0.005	0.043	< 0.001	< 0.001	0.302	< 0.001	0.021

M: mean; P: p-value;

Discussion

The current research offers valuable information on the sociodemographic diversities of mothers raising children with ASD in Bangladesh and its effect on the HRQoL. Mothers in this sample were relatively young (mean age 32.78 ± 7.45 years), younger than those reported in Western studies,[18] possibly reflecting cultural factors or earlier help-seeking. Most participants were married (95 %) in line with prevailing social norms[19] and the religious distribution (84.4 % Muslim) corresponds with national demographics.[20] However, the relatively low educational level and household income (mean BDT 17,781) compared with national[20] and urban data[21] indicate that many participants came from lower-income families. Combined with younger age and a predominance of nuclear families (55.6 %), this profile may increase vulnerability and negatively influence HRQoL by limiting social and financial support.

The study also highlights a substantial caregiving and health burden among mothers. More than half reported comorbid conditions such as hypertension and diabetes, consistent with findings from China[22] and evidence that comorbidities reduce functional status and quality of life.[23] Nearly half of the mothers (46.9 %) spent more than 8 h daily on caregiving, although this was lower than reports from the United States (59.2 % > 12 h/day),[18] possibly due to cultural differences in caregiving practices, support systems, or ASD severity. Additionally, 21.2 % of mothers had other dependents, further increasing caregiving demands. These findings present the need for mul-

tidimensional support systems addressing both maternal health and caregiving responsibilities.

Regarding child characteristics, the mean age of children with ASD was 7 ± 3.43 years, younger than reported in a previous Bangladeshi study,[21] suggesting possible improvements in early diagnosis. The male-to-female ratio of approximately 3:1 aligns with established biological patterns in ASD prevalence.[24, 25] Core ASD symptoms, including repetitive behaviours and social communication impairments, were commonly observed and are known to contribute significantly to maternal caregiving stress and reduced HRQoL.[26]

On the HRQoL, the results of this research demonstrate that both physical and mental HRQoL was highly impaired amongst Bangladeshi mothers having children with ASD. The scores of the overall HRQoL of 37.70 ± 18.27 reveals significantly impaired wellbeing, comparable with international studies showing a worse QoL in ASD caregivers than in parents of typically developing children[18, 27] or those with other disabilities.[28, 29] The low score of physical domain (40.32 ± 21.36) justifies the results of other studies[30, 31] and is probably associated with the high physical burden that taking care of children with ASD implies such as attending numerous therapy sessions, managing difficult behaviours and staying alert all the time.[22, 32]

The scores on the mental health section were also low, which fits the global trend[22, 32] but is possibly further aggravated by a poor mental health service infrastructure in Bangladesh. The fact that near absence of psychologists in primary healthcare centres and scarcity of psychiatrists in district hospitals also forms service gaps that are critical to such mothers. This gap in access to mental healthcare is most probably exacerbating the inevitable psychological strain of raising children with ASD, making it necessary to implement policy changes to ensure the inclusion of mental healthcare provision into the current healthcare systems.[22]

The results of the domain-specific analysis showed that the highest scores belonged to physical functioning (54.97 ± 26.14), similar to several findings on an international level,[33] whereas the lowest results were reported by role limitations due to physical health (19.83 ± 12.66). This trend contrasts other studies whereat vitality is consistently ranked lowest,[32] which may be an indication of cultural differences related to caregiving requirements or differences in methods. Unexpectedly harsh limitations of the role deserve special consideration, since it can be concluded that ASD caregiving in Bangladesh could limit access of the mothers in a disproportionate way to work and social roles and have cascading consequences in economic stability and social networks.

The current paper identified a number of decisive socio-demographic factors, which affect the HRQoL of mothers with children with ASD in Bangladesh. Large correlation coefficients between maternal age and HRQoL ($p < 0.05$ in all the domains) confirm other studies that older age is associated with a decreased quality of life[34] due to reduced physical ability and health burden.

Another very important factor was marital status, as a previous study found out that marital satisfaction was lower among ASD caregivers.[35] Based on presented findings, it can be seen that married mothers have distinct difficulties in preserving family harmony, meeting the needs of their children which may become a source of excessive stress and ultimately a decreased HRQoL. This throws light upon the importance of family-focused interventions to deal with the issues of marriage as well as inculcating positive coping skills within the family setting.

Contrary to a null relationship between educational attainment and HRQoL established by a group of researchers,[36] this study observed a positive relationship between these two variables. The discrepancy can be explained by the diversity in the study environment or the unique educational situation in Bangladesh where literacy has a direct influence on health literacy and access to the service. Better educated mothers probably possess more resources to find their way through complicated healthcare systems and put in place a good care plan and, therefore, caregiver education programs are important.

Financial burden played a particularly pronounced role; whereby household income had a strong correlation with HRQoL. This is concurrent with prior study evidence[37] and is an implication of being saddled with ASD costs as well as possible lost income due to lack of job.[38] Lack of economic security of these families requires policy responses like allowances to caregivers, tax incentives and workplace accommodations.

The structure of family was also showcasing considerable influence where the extended family support was seen to act as a kind of buffer to caregiving stress. This observation highlights protective value of the traditional network of kinship in Bangladesh[39] and gradual disappearance of such netting on the background of urbanisation. Surprisingly, there was a correlation between urban residence and worse HRQoL regardless of the improved accessibility of services that may indicate higher costs of living, social isolation, or unrealistic expectations regarding services. This inequality between the urban and rural areas deserves further research to be able to target specific support programs dependent on geographic characteristics.

Interestingly, religious affiliation did not relate meaningfully to HRQoL indicating that other forms of spirituality are no less likely to assist the coping process. The possible anti-stress effects of religiosity and its intervention on producing resilience[40] suggest that the faith-based organisations may offer effective collaborators in the caregiver support programs.

Future research should use longitudinal designs to better understand cause-and-effect relationships and examine how the identified determinants interact over time. Qualitative studies can provide deeper insights into the lived experiences of mothers, especially differences between urban and rural settings and how education may strengthen resilience. In addition, intervention studies should test integrated support models that address multiple determinants of HRQoL, simultaneously.

Finally, in order to provide a sustainable care pathway to ASD management in Bangladesh, mothers should be acknowledged as the recipients and the providers of care. Having identified the described socio-demographic conditions, it becomes possible to offer more efficient support systems that would maintain maternal wellbeing without compromising the results achieved in children with ASD.

There are a number of limitations in this study. The design used in this study was the cross-sectional, which is not conducive to the cause-and-effect determination of variables. It is possible that the convenience sample of certain clinics or communities could be biased and thus could not be entirely used to generalise the findings to the entire mothers of children with ASD in Bangladesh. Furthermore, the research was based on self-reports and this can introduce the illusion of recall bias and can also overstate correlations. The control group (eg mothers of children with other disabilities or neurotypical children, etc) is not provided thus limiting comparative analysis. Lastly, significant mediating or moderating variables that include social support, coping strategies, stigma, or access to interventions were not investigated in the study that would permit better understanding of the determinants of maternal HRQoL.

Conclusion

The paper reveals that mothers of children with ASD in Bangladesh have had a greatly impaired HRQoL and a highly significant burden on mental health. The results determine key determinants related to worse maternal HRQoL, ie lower socioeconomic status (education and income), nuclear family, increased burden in caregiving, maternal comorbidities, as well as, most importantly, the challenging behaviours of the child (eg offensive attitudes, repetitive movements) and ineffective social communication skills. The findings support the conclusion that specialised multilevel interventions are needed. The policy recommendations are to provide economic assistance, implement mental-health-caregiver services in primary healthcare and create community-based support programmes that provide respite and behavioural-management training. Further longitudinal studies that include a more enriched sample and measures of effective support systems have to be conducted in the future to validate these results and to determine the validity of these interventions in improving the health of mothers and children with ASD in Bangladesh.

Ethics

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board (IRB) of Daffodil International University (decision No: IERC/

MPH/2022/0178, dated 22 October 2022). All participants were provided with detailed information about the study's purpose, procedures, and their rights. Written informed consent was obtained from each mother prior to participation. They were assured of the confidentiality of their data and their right to withdraw from the study at any point without any consequences.

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Conflicts of interest

The authors declare that there is no conflict of interest.

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Data access

The data that support the findings of this study are available from the corresponding author upon reasonable individual request.

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