

# Parenting in context: parents' experiences of caring for a child with autism in Bangladesh



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## Abstract

Although research on children with autism, their parents, and family-provider relations has substantially increased around the world, there has been a paucity of qualitative studies conducted on autism in developing countries or cross-cultural contexts. This qualitative study aims to explore parents' experiences of raising a child with autism, as well as how autism is framed in everyday cultural contexts in Bangladesh. Using a semi-structured interview schedule, the study conducted interviews with four fathers and eighteen mothers of children with autism. The findings of this study reveal that parents who care for a child with autism experience emotions of sadness, frustration, and isolation. Despite the immense challenges that come with raising a child with autism, many parents report that their stress and anxiety are compounded by the stigma, avoidance, and disparaging remarks they receive from their own family members and neighbors. The findings of this study may help researchers and healthcare professionals understand better as to how local cultural beliefs, experiences, and understandings influence, how parents and families care for and view the development of their children with autism, and how they look for support and treatment services.

**Keywords** Autism · Stigma · Isolation · Parenting · Qualitative research · Bangladesh

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## Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder marked by qualitative difficulties in social and communication skills, along with a tendency to engage in restricted interests and repetitive behaviors (American Psychiatric Association [APA] 2013). Autism is typically a pervasive developmental condition that becomes evident after 12 months of age and persists throughout an individual's life (Dawson 2008). Since autism is a heterogeneous disorder, symptoms can manifest differently in many basic areas of development, including social, language, and interest patterns (APA 2013). Some of the common co-occurring conditions of ASD include hyperactivity, self-injurious or aggressive behavior towards oneself or others, cognitive impairment, changes in sensory perception, frequent outbursts, and sleep disturbances (Aman 2004; Novaes et al. 2008).

Epidemiological surveys indicate an upward tendency in the annual prevalence of ASD, with reported rates of 1%-2% (Arora et al. 2018). Baxter et al. (2015) reported that globally, the prevalence of ASD is 7.6 cases per 1000 people, equivalent to one in every 132 people. In the United States, one in every 54 (1.9%) children aged 8 had autism in 2016, but this number rose to 1 in every 44 (2.3%) children in 2018 (Centers for Disease Control and Prevention [CDC] 2021). Although the South Asian region accounts for more than one-fifth of the global population, the exact prevalence of ASD remains unknown. The documented occurrence of ASD in South Asia exhibited a range of 0.09% in India to 1.07% in Sri Lanka, which suggests that one in every 93 children in the region has ASD (Poovathinal et al. 2016; Perera et al. 2009). Autism is thought to have a high prevalence in Bangladesh; however, until recently, there have been no official prevalence rates available for autism in the country. The majority of cases go unreported due to the stigmatization faced by children with autism and their families. According to some studies, prevalence rates range from 0.15 to 0.84 percent, with Dhaka having a significantly higher (3 percent) prevalence rate (Hossain et al. 2017).

Empirical evidence suggests that providing care for a child with autism is considerably more taxing and challenging than raising a child with a developmental disorder or typical development (Griffith et al. 2010), particularly in countries with few support resources available. Parents of children with ASD often report experiencing increased levels of anxiety (Stein et al. 2011; Machado et al. 2016; Lim and Chong 2017; Grinker 2007), depression (Stein et al. 2011; Hayes and Watson 2013; Zablotsky et al. 2013; Falk et al. 2014), and poorer physical and mental health (Stein et al. 2011; Dykens and Lambert 2013; Allik et al. 2006; Fairthorne et al. 2015). Multiple studies have reported that raising a child with autism causes financial hardships, higher divorce rates (Järbrink et al. 2003; Allik et al. 2006), and strains relationships among siblings, extended family, friends, and neighbors (de Aguiar and Pondé 2019).

Comparative studies further find that parents of children with autism experience more stress and lower well-being than those of the parents of typically developing children (Dabrowska and Pisula 2010; Estes et al. 2013; Hayes and Watson 2013), as well as parents of children with other neurodevelopmental disorders,

such as Down syndrome (Dabrowska and Pisula 2010; Dykens and Lambert 2013; Estes et al. 2013). Moreover, parents of children with autism have recognized a range of stressors associated with raising children with autism, such as (a) the intensity of their children's autism symptoms (Stuart and McGrew 2009), (b) the challenges their children encounter in developing self-regulation skills (Davis and Carter 2008), and (c) feelings of stigma and inadequate assistance (Osborne et al. 2008).

Mothers of children with autism may experience distress levels that are up to *four* times higher than those of mothers with children in other groups (Silva and Schalock 2012). Research further suggests that mothers of children with autism experience double the stress compared to those of children with developmental challenges (Estes et al. 2009; Silva and Schalock 2012), with stress levels in some samples reaching as high as the 90th percentile (Mori et al. 2009). Some research teams expressed concern that mothers of children with ASD frequently abandon their personal lives and individual goals, limiting their own development and career (Järbrink et al. 2003). Another effect of raising children with autism is the isolation of primary caregivers, particularly mothers (Bromley et al. 2004). This isolation is often reinforced because caregivers avoid social interactions to avoid stigma (Woodgate et al. 2008). However, some studies have found that the quality of the bonds and attachments between a parent and a child with autism is equivalent to that of other groups of parents and young children (Buerkens et al. 2013). There is also proof that, in some cases, raising a child with autism can enhance family life (Hunt-Jackson 2007; Lutz et al. 2012).

Although research on autism has increased globally, the bulk of the existing literature on ASD is produced in Western nations (Daley 2002). Professionals have underscored the importance of raising awareness about the influence of cultural factors on ASD (Dyches et al. 2004; Welterlin and LaRue 2007). However, there is a scarcity of information on ASD in a cross-cultural context and how it is perceived in different cultural settings (Jegatheesan et al. 2010). It has been demonstrated that parental beliefs about ASD can influence their intervention preferences (Blacher et al. 2014; Stahmer et al. 2011). A study by Bagatell (2010) revealed that in Western culture, the biomedical community has a strong influence on perceptions of ASD, and they tend to see it as a problem that requires "fixing." On the other hand, in Indian culture, where beliefs in *karma* and fate/destiny are more prevalent (Gabel 2004), and therefore, ASD matters are treated in accordance with traditional Indian culture. However, the findings of a recent study on Indian parents who have adopted Western culture indicate that traditional beliefs have been eschewed, resulting in the use of a blend of behavioral and biomedical therapies for their children in conjunction with some complementary and alternative treatments from the Western world (Ravindran and Myers 2013).

In his study on the "lay conceptions of ASD" among Australian parents, Gray (1995) found that they held various beliefs and explanations for the diagnosis of their children, such as birth trauma and pregnancy-related illness, some of which were associated with magical or religious ideas. Additionally, some parents believed that ASD was caused by past transgression or *karma*, a belief that was also found among Indonesian parents (Riany et al. 2016).

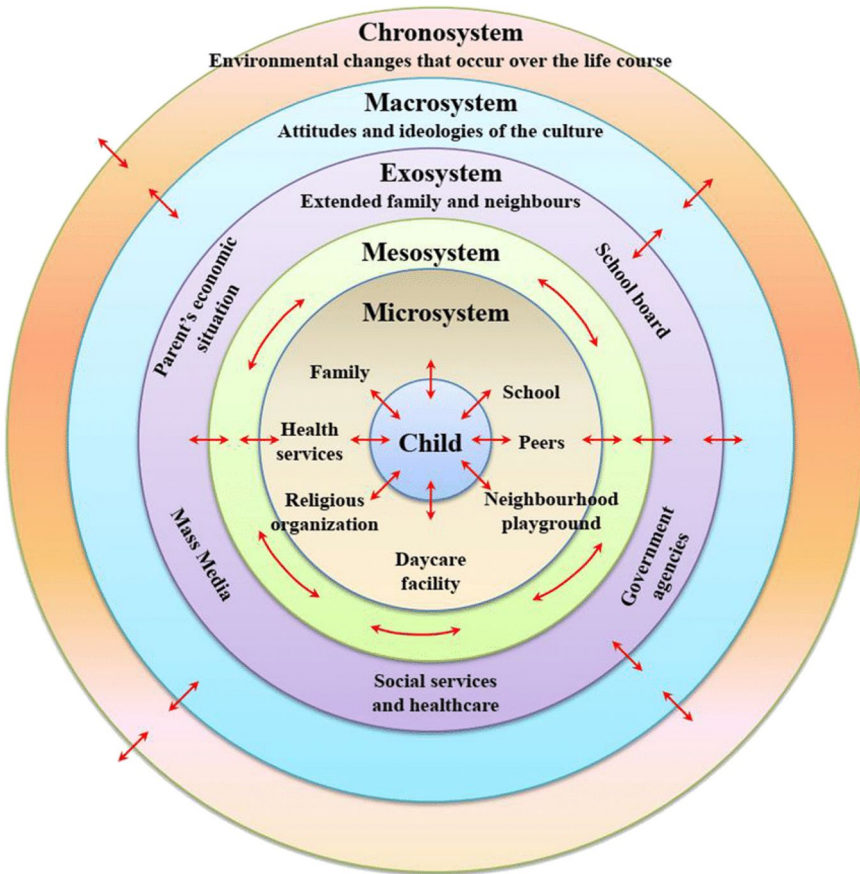
In Bangladesh, there are only a few studies on autism, all of which are quantitatively rely on secondary data and are primarily concerned with policy analysis and recommendations (Rahman et al. 2016; Rabbani et al. 2009; Ehsan et al. 2018). The present study contributes to our understanding of the parents' lived experiences of caring for a child with autism in Sylhet, Bangladesh. To achieve this, the following research questions are addressed in this paper: What are the participants' lived experiences when it comes to parenting a child with autism? How is a child with autism perceived in everyday social interactions?

## Theoretical framing

Although a variety of theoretical frameworks can be used to organize the exploration of parents' experiences with their children with autism, we flexibly adhere to Bronfenbrenner's Ecological Systems Theory and Goffman's Labeling Theory. To gain a deeper understanding of the context surrounding the initial stages of child development, and how various ecological factors impact this process, Bronfenbrenner (1979) introduced a pioneering conceptual framework during the 1950s. This framework highlights the significance of environmental influences on child development and delineates these influences as a series of interdependent ecological systems. The ability of a parent to support their child's development is affected by ecosystems in either a positive or negative way. A child's development takes place within a complex network of interrelated social, economic, and cultural ecologies that impact both the child and the family. Some variables have a direct and immediate influence, while others have an indirect impact that is more distant. The ecological model emphasizes the importance of studying the dynamic interplay between the environment and the individual; whereas, as per the organism-environment system, "autism is not a static condition existing within a person, but a developmental process that can only be understood as taking place through the interaction of person and environment" (Loveland 2001). Figure 1 portrays these processes and delineates a range of factors that exert an influence on the development of a child.

The labeling theory, as already mentioned, is another theoretical lens for this research. Hacking (2004) defines labeling theory as follows: '[It] asserts that social reality is conditioned, stabilized, or even created by the labels we apply to people, actions, and communities.' Erving Goffman is a well-known sociologist who has written about labeling theory. In his book titled *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) defines stigma as a multifaceted construct and as an attribute that is "deeply discrediting" because it is perceived by others as an "undesired differentness from what we ["the normal"] had anticipated." Goffman provides a variety of examples including homosexuality, prostitution of women, drug addiction, persons who have spent time in a psychiatric hospital, and members of minority religions. Stigma can also result from having a psychiatric diagnosis. Such a stigma, in Goffman's opinion, damages one's social identity since "normal" people stop taking them seriously.

The main similarity of both theories is that they both lay a strong emphasis on the social and cultural environments in which people live. Scholarly literature has



**Fig. 1** Bronfenbrenner's Five ecological systems (Source: Guy-Evans 2020)

extensively documented the influence of culture and knowledge systems on parental comprehension of their child's impairment and their selection of appropriate interventions (Brown and Rodgers ). To gain insight into the experiences of parents caring for a child with autism, it is crucial to consider the social and cultural contexts in which they operate, as cultural norms and expectations can significantly influence beliefs, attitudes, and behaviors. The ecological systems theory posits that the development of neuro-typical children, those with developmental disabilities, and specifically those with ASD is influenced by a range of social and ecological environments. As such, these same factors are likely to impact parents' experiences of raising a child with ASD. Labeling theory suggests that the labels that society assigns to individuals, especially children with ASD, may have negative effects on their mental and behavioral health, as well as on the lives of their parents and family who are actively involved in their care. Therefore, examining parental care of children with autism through the lenses of both the Ecological Systems Theory and Labeling Theory may help answer key research questions about how socio-ecological factors (beliefs,

values, and actions) influence parenting of children with autism and how individuals with autism and their parents are labeled in everyday life in Sylhet, Bangladesh.

## Materials and methods

This qualitative study employed a narrative approach. The empirical data of this study were collected from the parents of children attending two special-needs schools located in the Sylhet city corporation area, Bangladesh, where there were 55 children with autism. We collected data from four fathers and 18 mothers of children with autism between June and August 2019. A purposive-convenience sampling process was followed to include the study participants. The primary inclusion criterion was that the participants who took part in the study were living with their children with ASD and actively involved in the care of their children. This inclusion process was aided by key informants and special needs school teachers.

Data were collected through in-depth interviews and case studies to gain insight into parents' experiences with the diagnosis, the implications for daily activities and responsibilities, and the challenges they faced with their children with special needs in their own families and society on a day-to-day basis. The one-to-one interviews were flexibly semi-structured; as a result, the respondents were able to express their experiences in their own words. The experiences of parents with a child with autism revolved around the identification of problems, seeking assistance, receiving a diagnosis and intervention, parenting, and addressing challenges in everyday life. Accordingly, the semi-structured interviews were divided into three sections: (1) problems, diagnosis, and interventions (2) parenting experiences in everyday life, and (3) societal challenges.

The in-depth interviews conducted in this study began with collecting socio-demographic information from the respondents. Of the participants, 17 were Muslims and five were Hindus. The mean ages of the fathers and mothers were 46 (SD: 6.4, Range: 37–60) and 37 (SD: 3.7, Range: 30–52), respectively. All children in the study were within the age range of 9 to 14 years. In terms of education, around 61% of the fathers of children with autism had a graduate degree, and about 32% had a secondary school diploma or higher. Among the mothers, 50% had obtained a graduate degree, while the rest had completed secondary school or higher. The majority of families (72%) lived in a joint or extended family setting, and all families resided in the City corporation area.

The findings of this study are expected to provide not only an understanding of the unique experiences of these parents, but also what Stake (1995) referred to as "petite generalizations" - generalizations that are qualified by the contexts in which the parents' burdened, frustrated, and happy experiences were found.

The verbal consent of the respondents, who had been told about the study's goal, was obtained prior to data collection. The participants were assured that their involvement in the study was completely voluntary; their interviews would be taped, but their opinions would remain confidential, and no personally identifiable information would be included in the transcripts. The duration of the interviews varied between 50 to 90 min, with an average duration of 60 min. In accordance

with ethical practices, the respondents' identities were kept confidential by using pseudonyms in this paper. The majority of the interviews took place on the school grounds, but three participants chose to conduct them at home. The interviews were transcribed verbatim by the members of the study (M.J.U., L.A.). The author leading on analysis (M.J.U.) synthesized data and checked transcriptions back against the original recordings for accuracy. Following a thorough reading, comparisons were made across the in-depth interviews and cases, and narrative fragments were marked and related to the themes in each interview. Common themes identified in the narratives included a child-centric lifestyle, evil spirits, over-burdened-ness, isolation, sadness, financial difficulties, and societal harassment. These themes were categorized into four groups: From symptom recognition to diagnosis and intervention; Parenting experiences in everyday life; Feelings of social isolation i.e., pity, sympathy, and avoidance; and Autism labeling in everyday life i.e., mad, thick-headed, and foolish. The analysis aimed to provide a comprehensive and detailed depiction of the data-driven categories.

## Findings of the study

### From symptom recognition to diagnosis and intervention

When my son, Sajib, was born, all of my family members were overjoyed. His complexion was as bright as a yellow duckling . . . he was in excellent health. When Sajib was approximately a year old, I realized that he didn't communicate in the same manner that other boys and girls his age did. I tried to smile at him all the time, but he rarely smiled back. When we called him, he hardly looked at us. I collected sacred red threads (*dhaga*) and sanctified green coconut water (*dab pora*) by performing religious rites (*puja*) for him . . . We thought our son's problem was only temporary . . . My mother-in-law frequently told me that boys spoke late and I should avoid spending money on doctors . . . Sajib was diagnosed with autism when he was four and a half years old . . . It felt like someone had stabbed me in the heart when the doctor said my son had autism. I sobbed uncontrollably in front of the doctor. It was a total shock to me and my family. I could not picture my child being unable to speak verbally. (A mother, 35-year-old)

The preceding story depicts a mother's bereavement of a perfect and healthy child. Like this case, all participants shared their journey from the first inklings of concern for their child to the final stage of diagnosis. They spoke about how difficult it was to identify and diagnose the exact problem in the context of their own child. Almost all of our participants confirmed that they noticed behavioral or developmental difficulties in their child before their child's first birthday or early childhood (18 months on average), but autism was rarely diagnosed before a child's fourth or fifth birthday. Respondents described their children's difficulties as the inability to respond to physical demands such as hunger and illness; sleeping and emotional disorders; constant crying, difficulty with speech and language,

repetitive repertoire of behavior, hyperactivity, and attention deficits. A few parents claimed that their children did not initially exhibit any abnormal symptoms but were later diagnosed with autism—a finding that is consistent with previous research from other populations (Desai et al. 2012). Here are some excerpts from the parents' statements on their children's problems:

When my son was an infant, he didn't like to sleep. He is hyperactive and has trouble remembering anything . . . He has a habit of beating up other boys in the school his age. This is a terrible tragedy for my family and me. (Mother, 34-year-old)

My son always avoided making eye contact. He can't communicate with us by words. He can't express himself verbally when he is unwell, hungry, or upset. He utilizes particular signs to describe his needs that only his mother understands, but the others do not. (Father, 45-year-old)

When my son was about 8 months old, I noticed he didn't look at us . . . He has a habit of rolling around on the floor, putting spit all over his face and the floor. If we try to stop him from doing so, he yells and throws household items around. For safety reasons, I always lock the refrigerator and kitchen. (Mother, 48-year-old)

Respondents' attitudes toward the causes of their children were mixed. They attributed different meanings to beliefs regarding the causes, symptoms, and therapies. All parents reported that they initially tried to come up with their own explanations, which were largely based on mental images and embedded socio-cultural beliefs about disabilities and mental disorders that they had observed in society. The following statements reflected the views of the majority of the parents:

My son, Tanim, can't speak because my in-laws cast evil eyes (*ku najara*) on him. It was a conspiracy . . . they did it because they don't like me. (Mother, 34-year-old)

We used to believe that our son's mental illness was caused by evil spirits (*batash laga/ ufri-laga*). (Father, 55-year-old)

My affinal family blamed my child's autism on my late marriage, but I was only twenty-three when I married, and I had my child after a year. I am getting tired of it all. (Mother, 40-year-old)

My mother-in-law and some family members believe that my son's disability was the result of being born under the bad influence of the planet (*graha*). (Mother, 36-year-old)

A few parents believed their infants were suffering from genetic predisposition or pregnancy complications. A possible cause of ASD was mentioned by one respondent as the improper use of injections for the treatment of pneumonia:



I must say that my child was in good health. My son got pneumonia when he was about 3 years old and had to be admitted to the hospital. When Sayem returned home, his mother noticed that he had speech inertia. I immediately sought medical advice, but the doctor assured me that the condition was merely temporary . . . The doctor gave him a high-dose injection for pneumonia treatment, and as a result, I am sure my child lost his ability to speak. I took him to India for better treatment, but the Indian doctor came to the decision that my son had autism. Still, I couldn't accept it. (Father, 40-year-old)

In our study, all parents reported actively seeking help for their children's difficulties as soon as they became aware of it. However, they had trouble getting a diagnosis and struggled for years to identify the root of the problem, as Gobrial (2018) also observed in Egypt. Throughout the narratives, we found that parents initially relied solely on traditional therapeutic practices such as amulets, sanctified water, and sanctified water of green coconut administered by local religious people, and herbal medicine administered by the doctor of alternative medicine to heal their children. When traditional therapeutic methods proved ineffective, most parents sought the advice of professional medical doctors. The following statements reflected the views of the majority of the parents:

We collected an amulet (*tabiz*) and sanctified water (*pora pani*) from a religious person (*hujur/Imam*) and took him to a shrine (mazar) for the treatment . . . We tried everything that people suggested to heal our baby, but our efforts were futile. (Mother, 34-year-old)

We sought treatment from herbalists (*kabiraj*), homeopathic doctors, and finally medical doctors . . . I am not sure why Allah chose my son to suffer from this disease. We are confused about what to do now. (Father, 55-year-old)

Even if the parents' efforts are fruitless, what matters is that they are concerned about the health and well-being of their children. All participants reported being shocked and disappointed when their child was diagnosed with autism. They experienced emotional pain, grief, and mourning as a result of the loss of a perfect child and the disruption of their hopes. As parents, they felt insignificant and helpless. They felt a sense of loss since their children do not fit into society's definition of normalcy. They lived in a state of anxiety as a result of their children's future life trajectories. Some participants claimed that their other family members were more likely to overlook their problems and did not provide them with honest advice or assistance.

### Parenting experiences in everyday life

Parenting a child with ASD in the family appears to be a challenging journey. All the narratives have produced a broad consensus that mothers are the primary caregivers who are responsible for all aspects of caring for their children with ASD in everyday life. Being the mother of a child with autism has a significant impact on her daily and social life. The mother prioritized caring for her children due to

gender roles and social expectations associated with child-rearing in society. All mothers spoke about the huge load they carry in their daily lives. In addition to household chores, these mothers devote almost all of their time to caring for their children, leaving very little time for themselves which adversely impacts their time, energy, and self-care in particular. Their personal life and everyday routines have been disrupted. In most cases, they were either without assistance or didn't have faith in anyone else to take care of their children. To care for their children, these mothers forego their hobbies, recreation, and relaxation. Mothers' accounts indicated that they are exhausted, but they have accepted their child as an integral part of their lives and cannot imagine life without him or her. The affection and obligations of mothers towards their children with autism are found to be closely interwoven. Some of the mothers' feelings and physical fatigue as a result of caring for their children are as follows:

My daughter insisted on having me with her at all times . . . I do everything I can for my daughter—feeding, bathing, assisting with sleep, and providing emotional support—but she is not developing normally, which is heart-breaking for me as a mother. (Mother, 42-year-old)

I have to do everything for my son, from feeding him to taking him to school. When he was an infant, I had to keep him in my lap at all times, even when cooking or going to the bathroom. Now, whenever I go outside, I have to bring my son with me. Otherwise, he yells and cries as loudly as he can. If he goes outside, he never stays quiet for more than a second. I can't abandon him because I am a mother. (Mother, 37-year-old)

Consistent with the findings of Fletcher et al. (2012), some mothers in this study conveyed their discontentment with their limited personal time.

It is a huge responsibility. Right now, I am physically exhausted and weak. It is not a 1-day duty. If a family does not have a child with autism, they do not understand the amount of stress that comes with dealing with a child with autism. (Mother, 44-year-old)

Nothing is normal these days, from the moment I get up until the time I go to bed. I can't eat, bathe, or sleep on time. To be honest, I don't think I would be working in this manner if I didn't have a child with a disability (*prothibondi*) in my life. (Mother, 36-year-old)

Some mothers are required to be with their children late at night, which prevents them from sleeping well, resulting in a variety of health problems. One mother (46-year-old) reported:

My lifestyle has drastically changed. I used to enjoy going out a lot before having this child, but now I do not. With my son needing care, I have to do all the household tasks. Since my son has trouble sleeping, there are nights when I only get 2 to 3 h of sleep. Thus, I have been suffering from a headache all day. I am not sure how I am managing to stay alive.

Parents have to sometimes choose between careers and child care, and it is common for the mother to sacrifice her career while the father abandons caregiving accountabilities. For example, one mother (42-year-old) stated:

I had employed a babysitter for my daughter, but I found that she had frequently beaten my daughter while I was at work . . . The attendant treated my daughter as a mentally ill patient. I had to give up my career to care for my daughter because my spouse was so focused on his work . . . I can't picture life without my daughter.

Parents of children with autism must look after their own physical and psychological health to maintain their resilience and continue their parenting journey. Some of the mothers indicated that their husbands did not provide adequate support in dealing with their children. Their behaviors with their children with autism are often unacceptably bad. One mother, for example, claimed that her son is often subjected to inappropriate behavior from family members. As a result, the son has become increasingly arrogant and rambunctious. The mother's subsequent words were loaded with sadness, nearly to the point of depression:

My husband couldn't accept our son's problem. He (husband) humiliates and physically assaults our son. In everyday life, my mother-in-law despises my child as well. I put up with them in silence. This is taking a toll on my mental health and well-being. I am depressed but I have no choice other than to live for my child. (Mother, 33-year-old)

Some fathers have admitted to sharing their time and taking responsibility for their children with autism. They can't always devote their time because they have to work outside the home. They do, however, take their children out to communicate and play with other children when they have free time. One father expressed his inability to care for his daughter, but he acknowledged that it was his responsibility to do so: "It becomes increasingly difficult for me to care for my daughter as she grows older and physically develops, but my other daughter steps up to the plate."

Parents go through a spectrum of emotions when it comes to caring for their children. They wanted to make sure their children were handled equally, but they often failed. Some mothers expressed their dissatisfaction with not being able to devote enough time to their other children since they must invest a substantial amount of time in caring for their children with ASD. The other children were unhappy, according to some parents, because they did not receive as much affection and attention as their brother or sister with a disability did—these findings are also consistent with earlier studies (Aylaz et al. 2012; Divan et al. 2012).

### **Feelings of social isolation: pity, sympathy, and avoidance**

Respondents' narratives revealed how having a child with challenging behavior causes social isolation, embarrassment, grief, and the loss of relationships. They shared their experiences with unfavorable social interactions such as overly sympathetic attitudes, chit-chat, compassion, avoidance, and disparaging remarks in

everyday life. The following narratives were soaked in grief, almost to the point of anguish:

I take my son to school every day, so I know how people always look at us negatively. They don't even ride with us on public transportation or sit next to us. My son always babbles for no apparent reason. A few days ago, an elderly woman asked whether my son is insane. This is a question I am frequently asked . . . It is heartbreaking . . . If a family does not have a child with autism, they will not understand the pain that comes with parenting a child with autism. (Mother, 41-year-old)

When people notice my son is disabled, they look at us with pity. They treat us as if we are the most despicable people in the world. (Father, 48-year-old)

Some participants claim that some of their relatives and neighbors have turned a blind eye and cut ties with them. These relatives and neighbors keep their distance from these families out of fear that their children may be negatively impacted if they keep their relationships with them. Children with autism were excluded from peer groups, mothers reported:

Some relatives do not allow their children to interact with my child. They are scared that their children may get disabilities if they play with my son. (Mother, 30-year-old)

Some of my neighbors' parents have forbidden their children to play with my son because they think their children will end up like him. (Mother, 55-year-old)

Some parents stated that they are subjected to a barrage of inappropriate questions, which they find exhausting, but that they have managed to keep up with everything in their everyday life. As depicted by a respondent:

People, both familiar and strange, have become overly concerned about my son's health and have bombarded me with unwanted questions and advice. They are unaware of their limitations. They frequently ask who will look after my son in the future if he is not normal. What will I do to help him? When I tell them that it will take time for my son to be normal, they look at me as if they pity me. (Father, 39-year-old)

As an adaptation strategy, parents often choose to avoid public gatherings and family events with their children with autism. Instead, they prefer to keep their children at home. In some cases, parents may even sever ties with friends and relatives due to negative comments and attitudes they encounter. Interactions with neighbors and family members have largely been passive, which can be seen as a reasonable approach to evade criticism and pursue a meaningful life. For clarity, the following statements from parents are included:

I have been living in my family's domain for over a year and have avoided visiting my neighbors because their criticism and chit-chat about my son mentally upset me. (Mother, 33-year-old)

We try to avoid public places as much as possible with our child because people stare at us with a bad attitude, which we find difficult to bear. My child enjoys playing with a select group of his classmates, and we now have a wonderful relationship with those families. (Father, 43-year-old father)

Some of our relatives and neighbors ignore us at family functions and events. When my child is there, they feel anxious and worried since he has a habit of touching things. (Mother, 45-year-old)

The narratives revealed that many people in our society don't know how to act in the presence of a child with ASD. People who are unaware of or do not understand how to interact with children with challenging behaviors are often found avoiding or mistreating them in public.

### **Labeling in everyday life**

Having a child with autism is often viewed as a tragic event from which a family can never recover (Kearney and Griffin 2001). The day her daughter was diagnosed with cerebral palsy, according to Green (2002), was the worst day of her life. Green went on to say that the diagnosis categorizes parents as social outcasts. All of the respondents in this study expressed their dissatisfaction with others' lack of awareness about ASD, which they believe is a contributing factor in people's negative perceptions of children with autism and their families. People typically link autism to punishment or curses given by Allah or God for parental personal malfeasance or wrongdoing (*pap*) in the past. Other researchers have also pointed out that in Indian culture, having a child with autism is often associated with the concepts of *karma* and fate/destiny (Gabel 2004; Pinto and Sahu 2001). Some parents have expressed their dissatisfaction with Allah/God for giving them a child with ASD. They blame God for their bad luck, while some believe Allah is putting them to the test. These aspects are reflected in the parents' statements, which are mentioned below:

I believe Allah is putting our family to the test in this way. It is a misfortune that we must accept. Is it possible for us to abandon our son? (Mother, 40-year-old)

My mother-in-law despises me in everyday life, accusing me of having given birth to a disabled child. (Mother, mother of 33 years)

Many people, including our neighbors, believe our child is disabled because we did something bad (*pap*) in our lives, but so far, we did nothing wrong. (Father, 52-year-old)

I am currently praying to Allah to make everything right. It is a fate determined by Allah. I am not sure why we have to go through this misfortune. (Mother, 45-year-old)

Participants stated that they are stressed and disrupted not only because of their child's condition but also because of negative or insulting comments they encounter in everyday life. The term "*prothibondhi*" (handicapped/disabled) was widely used

by parents to describe their child's condition. Many of the participants stated that individuals with autism are feared because of their difficult demeanor or activities. It is clear from the responses that a child with autism is treated/labeled in society as "mad" (mentally ill or defective), "abnormal" (unpredictable/psycho), "foolish" (*arhua/boka*), "thick-headed" (*matha-mota*), "stupid" (*biyakkel*), and "handicapped" (*prothibondhi*). These labels are also extended to the child's family, which is often dubbed as a handicapped family or a crazy family. Such guilt-inducing remarks, which Green (2002) refers to as a "catastrophe," have put parents in a vulnerable position and exacerbated their sadness. Some statements from parents are given below:

Some of our neighbors have referred to our family as a foolish (*arhua*) family. They don't understand our unbearable pain (*kostho*) with our son. (Mother, 52-year-old)

People commonly ask if my daughter is insane (*pagol*). (Mother, 38-year-old)

Research from the West (Barnes 2003) also shows how parents are constantly bombarded with negative, often clichéd ideas of impairment as a tragedy to be pitied. Some parents have described how their children are teased and ostracized from peer groups and community activities.

My son prefers to go outside . . . He always likes other boys his age, but others don't like him. I take my son out to play and interact with other children, but they frequently ignore and bother him. They despise my son and regard him as dim (*matha mota*). (50-year-old father)

Our neighborhood children dislike my son; they often tease him. They beat him up and smear mud on him when they find him alone; treating him like a fool (*biyakkel/gobet*). (Mother, 37-year-old)

Some mothers vehemently assert that not only outsiders but also close family members abuse them and their children. They have also heard a slew of disparaging remarks about their children from family members, friends, and neighbors.

## Discussion and conclusion

The study provides insights into the experiences and challenges of parenting a child with autism in everyday life in Sylhet, Bangladesh. As mentioned earlier, the ecological systems theory and the labeling theory of Bronfenbrenner and Goffman respectively have had a general influence on our thinking throughout the study process. Both the ecological model and the labeling theory are supported by the results of the thematic analysis of this study, which may be interpreted in terms of various cultural and social environments.

The first theme that was addressed went from symptom recognition to diagnosis and intervention. The majority of parents' narratives revealed that they understood there was something wrong with their children's growth and behavior at an early age

(18 months on average), but autism was not diagnosed before their children were 4 or 5 years old. These parents spoke of a lengthy, difficult journey they had to go through to recognize their children's impairment, and in some cases, they found that doctors failed to provide a definitive diagnosis. Many parents even acknowledged that they were not familiar with the term "autism" before their children were diagnosed. As previously stated, all of the parents resided in the city corporation area, and the bulk of them had higher secondary or higher education. Even so, there was a time lag between parental concern about their children's problems and the diagnosis of autism. This finding is congruent with international reports (Daniels and Mandell 2004).

The most commonly stated impairment that parents experienced was their children's inability to speak orally. The second most-often stated item was behavioral problems, which were illustrated by examples including restlessness, hyperactivity, unceasing crying, odd and stereotyped behavior. All these areas of impairment aligned with DSM-5 diagnostic criteria for autism and related disorders (APA 2013). The existing literature recognizes the influence of society and knowledge systems on how parents perceive their child's problem and the intervention they opt to use (Brown and Rodgers 2003; Harkness et al. 2007). Ecological theory also notes that social, economic, and cultural environments have an impact on child development (Bronfenbrenner 1979). In line with theory and literature, this study also found that most parents' perceptions of the causes of their children's problems and interventions were deeply rooted in their cultural norms, traditional beliefs, religious values, and social environments in which they lived and interacted. More specifically, they attempted to make meaning of their child's problems using both modern scientific knowledge and ways as well as indigenous, traditional, and religious knowledge and practices. The study found that the majority of the parents initially linked their children's problems to supernatural forces and beliefs, such as the possession of evil spirits (*ufri-laga*, *batash laga*, *jiin*), being subject to the malevolent gazes (*ku najara*) of their neighbors and relatives, and being born under the bad influence of the planet (*grahera prabhaha*). Some parents also aligned themselves with hereditary, biological, and doctor's maltreatment to make meaning of their child's problem and intervention.

The majority of parents sought remedies as soon as they noticed there was something different in their child's development. This study found that the majority of parents gave strong priority to religious support, local rituals, folk medicine, and homeopathy in addition to Western modern medicine. They reported turning to fasting, prayers, ceremonies (such as arranging *milad/pujas*, giving out sweets [*sinni*] in the mosque, and visiting shrines), feeding their children blessed foods and holy water, and wearing religious adornments like amulets (*dhaga*, *tabiz*) for the well-being of their children with autism. Some parents stated that they had faith in God to handle the condition. One mother stated: "I was repeatedly told by my mother-in-law that boys speak late and I should not worry about wasting money on doctor visits." This is consistent with international empirical findings. For example, Gabel (2004) conducted a 2-year ethnographic study of 20 Asian Indian Hindu households in the US who had children with mental retardation. The parents, following Hindu beliefs of reincarnation and karma, believed that their child's disability was a divine

blessing, bestowed upon them as punishment for misdeeds committed in a previous life. Similarly, Jacob (2004) conducted research on American families with South Asian backgrounds and found that parents, regardless of their religious background, resort to spiritual practices such as praying, embarking on pilgrimages, and using sacred items such as amulets and saffron threads to ensure the well-being of their children with autism.

Consistent with de Aguiar and Pondé (2019) research, this study found that when parents' idealized children were diagnosed with autism, their hopes and expectations for a perfect or society's notion of the normal child were shattered, leaving them distressed and depressed. Parents used words like 'helplessness,' 'shocked,' 'heart-broken,' and 'misfortune' to depict their emotions and feelings. They admitted to feeling worried, despair, remorse, and rage as a result of having a child with autism. Some respondents admitted that they felt guilty and embarrassed even about disclosing their child's impairment to others. The present study serves to corroborate the findings of prior meta-synthesis investigations on the topic of parental caregiving for a child with autism (De Pape and Lindsay 2015). The earlier studies discovered that parents tended to experience feelings of guilt and self-blame during the initial stages of diagnosis while trying to understand the causes and reasons for their child's autism. However, the majority of the participants in our study acknowledged that their own attitudes and beliefs about their children's problems had changed over time, from believing that their children were possessed by evil spirits or subjected to malevolent gaze to understanding that their children were psychologically/mentally different and lived in a different way. These parents appeared to be more problem-solving-oriented and optimistic about their child's future, which was driven by their interactions with medical professionals and therapists, as well as by their decision to enroll their children in special needs schools and their interaction with other parents at the school. The result of the study demonstrated that, in line with ecological theory, there was a shifting of the focus of the respondents from the inner circle to the outer/expanding circles.

The second theme that was covered was parenting experiences in everyday life. This study found that children with ASD not only experienced significant challenges, but their condition also had a substantial impact on the family's interpersonal relationships and household operations. The presence of a child with autism was found to have effects on the emotional, psychological, and physical well-being of the family, with some interviewees considering it traumatic and a misfortune for the family. A few stated that it was a test from Allah for them as parents. Some mothers stated that their in-laws chastised them for having a disabled child. One mother (33-year-old) reported receiving threats of divorce from her husband's extended family because they blamed her for the child's impairment. In her own words: "My in-laws used to say that because I am a bad woman, Allah has punished me by giving me this child."

It became clear from almost all of the respondents that parenting a child with autism was very challenging and stressful. Parents' narratives made it clear that they, particularly mothers, embraced a child-centric lifestyle to provide their children with the best care possible. This finding is consistent with many empirical studies (Silva and Schalock 2012; Järbrink et al. 2003). Participants in this study, particularly



mothers, expressed greater caregiver burdens for their children than fathers, confirming the long-held gender stereotype in Bangladeshi culture that mothers are responsible for raising their children. Islamic cultures also value women as primary caregivers for their children and families, while encouraging men to be sole breadwinners (Stewart et al. 2000). Some mothers in this study appeared to be mentally, emotionally, and physically exhausted as a result of juggling daily household chores alongside caring for their children with ASD. They described the taxing effects of parenting a child with ASD, such as feelings of burnout, making personal sacrifices, and facing social stigma. These factors impeded their capacity to care for their overall well-being and compromised both their physical and mental health. However, the narratives of these mothers conveyed their unwavering commitment to the care of their children, with their daily lives revolving around promoting the physical and emotional well-being of their children. Regardless, these mothers' narratives suggested that they were completely committed to caring for their children and their daily lives revolved largely around the physical and mental well-being of their children. Many mothers mentioned in their narratives that their devotion stemmed from a sense of unconditional love and care for their children, along with a societal and cultural responsibility to raise and protect them. One mother even cited having left her job in order to care for her daughter. This result is consistent with Bronfenbrenner's ecological systems theory, which posits that the exo-system (in this case, the parents' workplace) can have an impact on and be affected by the microsystem (the innermost circle of the ecological system).

The next theme that was addressed was parents' experiences of social isolation with a child with autism, and it was found that a child's ASD had a substantial impact on the social functioning of the parents. The respondents' narratives revealed that parents of children with autism were commonly perceived as aloof, depressed, anxious, and that even their relatives often exhibited a lack of warmth towards them. Previous studies have similarly reported that parents of children with autism frequently experience higher levels of stress, anxiety, and depression (Machado et al. 2016; Lim and Chong 2017; Grinker 2007). Some of the respondents reported that they often avoided social gatherings and visits to relatives' homes due to the apprehension of encountering insensitivity, dismissiveness, and derogatory remarks. To shield their children from the stigma and harassment that is commonly associated with autism, these parents often confined their children to private domains and refrained from participating in social events. This private realm is referred to as "zones of social abandonment" (Dhar 2009). Parents who struggled to integrate their children into the community's peer groups expressed that they often felt disregarded or looked down upon, and this issue was consistent with the findings of previous studies (Gray 1993, 2002; Kinnear et al. 2016).

The final theme that emerged from the narratives was parents' experiences with stigma in everyday life. The parents' accounts revealed that there is a pervasive social stigma, superstitions, myths, and misconceptions surrounding autism in our culture. The participants relayed that children with autism are often misunderstood and are thought to be the result of *karma*, a curse from God, or divine punishment for the transgressions, illicit wealth, and immoral deeds of their family members, or even ancestors. Such beliefs carry cultural shame, and family members, as well

as the child with autism, are often blamed, as reported in other studies (Park et al. 2010; Samadi 2020). Some parents even admitted to thinking that their children had autism because they were imperfect parents, and they felt humiliated by their child's condition. This result is consistent with Gray's (1993, 2002) research, which revealed that parents and family members of individuals with autism also encountered stigmatization.

Stigma is a "deeply discrediting" trait that makes the person who has it "tainted" and "discounted" (Goffman 1963). Participants in this study widely mentioned parenting stress and frustration, but they underlined that there were other factors at play besides the child's autism. They asserted that it was much more upsetting when neighbors and members of the immediate family often assumed their child was naughty, mad (mentally ill), thick-headed, foolish (*arhua/boka*), or dumb. These labels not only restricted their activities but also alienated them, leaving them with a negative self-image and a sense of helplessness and burden to others. Also, a family with a child with autism experienced social stigma since the immediate family was seen as part of the autism and the family was labeled as a disabled or psycho family in their community, an observation that supports Goffman's labeling theory that public stigma extends to the child's family members (Goffman 1963). Divan et al. (2012) and Desai et al. (2012) found that societal attitudes toward autism can make parents more stressed and negatively impact their coping mechanisms.

The results of this study suggest that social stigma, misconceptions, and mistreatment related to autism need to be addressed methodically. Furthermore, the study highlights the significance of recognizing autism as a unique life experience for the child, rather than viewing it as an unfortunate, traumatic, or divine punishment. Parents of children with autism should have access to counseling or training to help them cope with the challenges of raising a child with autism and overcome the stigma they encounter in everyday life. This study highlights the urgent need for social intervention in Bangladesh, including initiatives to promote the social and emotional well-being of families, foster supportive social environments, and encourage positive social interactions. Public awareness campaigns about autism need to be conducted, especially in schools, to promote healthcare services and combat discrimination against those with physical or mental challenges. Children with autism require access to quality education, therapy, and opportunities for skill development, which should be available in good schools. Better services, special needs schools, public and private sector recruitment, and social representation of children with autism are all necessary to dispel prejudices associated with autism in Bangladesh.

The findings of this study are comparable to those of earlier studies on ASD and developmental disabilities in Bangladesh, which are extended to Sylhet. However, this study, like any narrative research, is limited by questions of validity and generalization (Riessman 1993). Conclusions may not be generalizable due to the small sample size, but the concepts may apply to other parents in comparable situations. Narrative research, it is stated, does not seek to arrive at decisive conclusions, but rather to arrive at well-founded and evidence-based conclusions (Webster and Mertova 2007). Larger sample sizes and persons from a range of backgrounds could be used in future studies. A comprehensive study with numerous stakeholders, including parents, siblings, family members, friends, and professionals, as well as

the child, can be conducted to gain a better understanding of the subject. Despite its limitations, the results of this research were generally consistent with other theoretical and empirical findings. This study significantly broadens our understanding of ASD and ASD intervention, as there are few studies conducted in Bangladesh and some of the findings diverge from those of earlier studies.

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## Declarations

**Ethics approval and consent to participate** Verbal consent of the respondents was obtained prior to data collection.

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## Comments

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