

Confronting Autism in Urban Bangladesh: Unpacking Infrastructural and Cultural Challenges

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Abstract

Autism Spectrum Disorder (ASD) is a critical problem worldwide; however, low and middle-income countries (LMICs) often suffer more from it due to the lack of contextual research and effective care infrastructure. Moreover, ASD in LMICs offers unique challenges as cultural misperceptions and social practices often impede effective care there. However, the recent growth in mobile phone adoption in many LMICs has created a timely opportunity for improving ASD care practices through digital means. We present qualitative findings on the challenges of designing mobile assistive technologies for ASD in Bangladesh. Our data reveals a set of technical, social, and cultural challenges with caregivers and care professionals for designing a meaningful technology for them. We show how those challenges are deeply rooted in the broader infrastructural and cultural tensions of the country. We also present embedded design implications to overcome these challenges.

Keywords: autism, Bangladesh, stigma, mental health, mobile health, understanding users, ecological design, ICTD

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1. Introduction

Autism is a global phenomenon with local implications [1]. Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder that is often characterized by impairment in verbal and nonverbal communication, deficits in emotional and social reciprocity, and repetitive behavioral patterns [2]. This affects more than 7.4 million people worldwide, with a 600% increase in prevalence in the last two decades [3]. Studies have shown that cultural perceptions affect diagnosis and treatment of

autism, shape familial beliefs about autism, influence intervention techniques, and are integral in the acceptance of persons with autism in society [1, 6]. Samadi and McConkey, who studied autism in Iran stress the “need to view autism within a cultural context and not just as a medical condition requiring standard interventions” [6]. Their claims are substantiated by a World Health Organization disability report that also recommends that culturally situated understanding of a disability is necessary in order to properly address it [7].

Research in autism, however, has hardly been contextualized in LMICs despite more than half of the

world's population is living in those countries. This dearth of contextual research in autism often leads to unreliable statistics of ASD prevalence, which significantly impacts the diagnosis and interventions [8]. For example, the Centers for Disease Control and Prevention (CDC) reports that 1 in every 68 children in the US is affected by ASD [9]. However, equivalently reliable statistics are unavailable in most LMICs [10-12]. This lack of contextualized data often creates unwarranted assumptions that neglect the prevalence and severity of autism in LMICs [6]. This issue was emphasized by Daley after investigating autism in India where "autism researchers have almost entirely neglected families of diverse ethnic backgrounds and those in non-Western countries" [13]. When research is thus skewed, technology stemming from it often suffers from blind transfer issues. Such blind transfers of technology often fail and negatively impacts on the local culture [14]. Therefore, there is a need for designing technology for autism based on the situated [69] needs of LMICs.

In this paper, we focus on the challenges in designing an appropriate mobile technology for autism care in Bangladesh, a low-income country in South Asia. Bangladesh provides a unique opportunity to identify the local stakeholders' needs, understand the social and institutional barriers, and empower persons with autism and caregivers by engaging in inclusive design and research in a situated manner. Besides the needs for understanding these non-trivial local challenges in Bangladesh, the timing of making digital interventions to local autism research there is becoming feasible. The country has recently embarked on a mission of transforming itself to a "Digital Bangladesh" and there has been a remarkable proliferation of smartphone use and a rapid growth of mobile internet. There has also been some notable progress in the policies around disability and autism recently in Bangladesh [15-17]. We aim to leverage this opportunity by contextually designing digital interventions that can positively impact autism care in Bangladesh. As a first step, we have conducted an extensive qualitative analysis in Bangladesh to gain a deeper understanding of the challenges and the opportunities associated with designing an acceptable digital technology there. In this paper, we present and discuss the findings of our study that reveal the situated challenges of developing such an application in a LMIC.

The contribution of this work is threefold. First, we present contextual data and analysis that enables a holistic understanding of the problems around ASD in Bangladesh—from both technical and socio-cultural points of views. The insights gleaned through our study reveal several gaps in the existing technological interventions and social practices in Bangladesh that warrant additional research to address the caregivers' and care professionals' needs. Second, we offer a value-sensitive design approach of deriving design implications that advocates viewing inefficiencies and deficiencies from a socio-technical perspective while designing mobile phone applications for such communities. Our research offers important insights into the voice of the stakeholders (both caregivers and care professionals) that often remain silent in designing health interventions. Third, the design lessons and insights would be helpful in building

an autism-related care framework that can be utilized in two ways: first, developing interventions in other LMICs endemic with similar infrastructural, cultural, and social challenges, and second, helping to transfer appropriate design aspects to matured environments (e.g., in developed countries) with similar challenges and potentially improve established practices through a "trickle-up" or reverse innovation mechanism [75].

We first review related work on the technological, infrastructural, and cultural aspects of autism care and diagnosis. In particular, we highlight the challenges of technology design in LMICs, especially Bangladesh. Next, we delineate current practices and policies around ASD in Bangladesh focusing on hospitals, private practitioners, policies, and special-needs schools. We then present methods and qualitative findings from the perspective of two main stakeholders—caregivers and care professionals. Finally, we discuss our findings under the lenses of socio-cultural and infrastructural challenges followed by a set of design considerations and implications for feasible and practical technological interventions in developing countries like Bangladesh.

2. Related work

2.1. Technology Interventions in Autism Care

Long-term monitoring and studying physiological aspects can reduce the likelihood of misdiagnosis of ASD [18, 19]. From facial affect detection to non-invasive screening methods, from behavior tracking to speech therapy, autism-tech research has been boosted by major advancements in mobile sensor and capturing tools (e.g., Apple's HealthKit and ResearchKit) [20]. Autism & Beyond uses facial affect detection from video responses to understand risk of autism in the viewer [21]. Gaze-Wasserstein is a non-invasive screening method that uses gaze-tracking technology and is deployable in any camera smartphone [22]. Behavior Tracker Pro and Autism Tracker Pro [23] are two more applications designed to monitor and track behaviors of children with autism (CWA). However, wearability challenges of sensors in daily activities have limited most autism-tech research to laboratory conditions [24] [37]. As a result, contextual data collection in practice is limited.

2.2. mHealth in LMICs & Transfer Challenges

LMICs often lack the healthcare infrastructure that is taken for granted in developed countries [25-27]. However, the proliferation of affordable smartphones has facilitated a growing ecosystem of mhealth apps. From maternity health (e.g., Gifted Mom [28]) to smartphone powered medical devices (e.g. Mobisante Ultrasound [28]) to telemedicine (e.g., AirStrip One [28]), mobile apps designed in an embedded context can account for the infrastructural affordances of the ecosystem [28].

Beyond infrastructural challenges, there is a shortage of trained medical professionals and awareness resources along with cultural factors that affect diagnosis and care [25, 26]. As a result, technology transfer from matured ecosystems to developing countries is non-trivial and requires adaptation and translation to infrastructural and cultural contexts. It poses a challenge because additional time and resources must be spent to hire individuals who can make these adaptations.

2.3. Mobile Healthcare Technologies in Bangladesh

Bangladesh is evolving as a mobile-first ecosystem with notable improvements in both internet penetration and mobile phone use. With 128 million mobile subscribers (76% of the country's population) [54], there is a thriving ecosystem of affordable mHealth solutions. In particular, social enterprises like Jeeon [29] and Dnet [30] along with mobile operators have created innovative interventions. Aponjon, an mhealth service for expecting and new mothers provided by Dnet, uses text messaging and interactive voice response technology to share personalized messages specific to the pregnancy cycle and age of the baby [31]. Jeeon uses human-centered design methodologies to create telemedicine solutions that connects rural patients with quality healthcare with the help of local intermediaries.

Telepsychiatry and mental health services have also started to gain traction in Bangladesh. A nationwide mobile based telepsychiatry service has been launched in 2016, mainly focusing on child development disorders [32]. Maya Apa is a digital wellbeing assistant where users can anonymously post questions around a range of topics from mental to physical help and a registered therapist or doctor can answer them [33]. Autism-related mobile interventions can leverage the momentum in the mHealth ecosystem in Bangladesh and create interest amongst the relevant user groups.

2.4. Autism Technology in Bangladesh

In recent years, technological interventions around autism screening, diagnosis, and awareness have been developed in Bangladesh. Beyond the technological challenges in terms of infrastructure, sociocultural perspectives and stigma around autism pose unique challenges; for instance, the hesitancy of parents to reach out and seek timely help for ASD-related symptoms at an early age of children with autism [35]. Autism Barta [34] is smartphone based automated screening approach that integrates the questions of M-CHAT screening tool [36] in Bengali with the help of animations and suggests nearby autism resource centers based on the data analyzed. The Bengali translation increases accessibility to caregivers who are not comfortable with English. Bangla Autism Severity Assessment App [37] has been developed to measure the severity of autism and bring them under regular monitoring.

While there has been advances in the autism technology space in Bangladesh, none of them focus on bridging the technological aspects with the sociocultural challenges of behavioral tracking of the CWA. Unlike mental health interventions (e.g., BeWell [38], MoodRhythm [39]) that require integrating sensors into high-end mobile phones, Bangladesh's ecosystems offer unique challenges that require embedded design. Beyond tracking, there is a distinct lack of bridging the technological behavioral tracking of the CWA with the mental health of the caregiver through peer support. Peer-based social support can play a significant role in autism care, especially amongst caregivers, and can act as a buffer against several crisis factors [40]. With these challenges in mind, the promising growth of technology in Bangladesh creates an opportunity for impactful technological interventions in autism care [24].

3. ASD in Bangladesh: practices and policies

The intervention for ASD typically involves various types of nonpharmacological behavioral interventions and training where a close collaboration between caregiver and care professionals is necessary. However, care professionals may also prescribe drugs to address severe symptoms. With no standard protocols in Bangladesh, every institution follows their own guidelines based on their experience. The psychiatrists normally follow The National Institute for Health and Care Excellence (NICE) and UK and American Psychiatric Association (APA) practice guidelines. Typically, families across the socioeconomic spectrum receive treatment from public (government hospitals or institutes) and private organizations (clinics/private practitioners). Approximately 200 psychiatrists and 50 psychologists are currently available for roughly 160 million people in Bangladesh [41]. Access in rural areas is poor since most of the practitioners are located in cities.

Bangladesh has a limited number of hospitals that are equipped with professionals and resources for initial assessment and diagnosis of ASD. Currently, mental health services are provided in 64 districts and 39 upazilas (sub-districts) of the country through the Institute of Paediatric Neurodisorder and Autism (IPNA) of Bangabandhu Sheikh Mujib Medical University, National Institute of Mental Health (NIMH), Psychiatry Departments of Medical College hospitals, 103 disability service and support centers, and 15 child development centers [42].

In terms of private clinics and practitioners, specialized professionals on autism are clustered in the capital city Dhaka usually charging BDT 320–960 (approx. USD 4–12) per visit. The fees pose a significant barrier to those who are at the lower end of the socioeconomic ladder, especially those in the rural communities, who based on our estimates need to spend BDT 800–1600 (approx. USD 10–20) for each visit to a major city. In addition, persons with autism require regular visits and involvement with multiple care professionals that can significantly increase the cost of care. Despite the high cost of care, private practitioners provide an essential support

system for an ecosystem that has a dearth of trained professionals compared to the need.

With respect to schools for CWA, we found the presence of approximately 100 registered schools in Bangladesh serving children with special needs. An official database listing all schools and associated services is currently unavailable. Typically, a care professional affiliated with the school handles health management of the students. Most of the schools are privately run and have a broader focus on differently-abled children that includes children with autism. For instance, the Society for the Welfare of Autistic Children (SWAC) is a prototypical example of non-profit special needs schools run and governed by caregivers. The schools are clustered in the major cities, namely Dhaka and Chittagong, and typically are run by nonprofit organizations and, most often, managed and funded by parents and grants. We identified a total six special schools in Dhaka and three in Chittagong.

In terms of policies, autism has taken center stage among mental health conditions in Bangladesh in recent years. The government has deployed action plans for children with special needs. For instance, the National Parliament of Bangladesh has promulgated two important acts to protect the rights and ensure safety of persons including autism—the Rights and Protection of Person with Disability Act-2013 and the Protection of Persons with Neurodevelopmental Disability Trust Act, 2013 [41]. However, many of these policies are not practiced.

4. Methods

We organize the findings around the perspectives of the main stakeholders – caregivers and care professionals. Caregivers include parents, guardians, relatives, or hired staff who are responsible for day-to-day care of persons with autism. Care professionals include general physicians, psychiatrists, neurologists, speech therapist, and psychologists.

The focus around these stakeholders' perspectives enables a multifactorial understanding of the issues against the backdrop of institutional and ecosystem changes currently taking place in Bangladesh. Caregivers, especially parents, are crucial for two main reasons. First, they are generally the primary caretakers for children with ASD, and they spend considerable amount of time with them. As a result, they develop a unique perspective on their child's condition that cannot be found elsewhere. Furthermore, they can inform technology design not only for improving the child's caregiving system, but also about integrating into their own lifestyle. Second, parents create the bridge to get access to required resources such as intensive educational, behavioral and health services. Care professionals provide situated perspectives around medical and therapy practices along with institutional and technological affordances.

We had a total of 46 volunteering participants - 18 parents and 28 care professionals, partake in our study. For the caregivers, we conducted 18 one-on-one interviews and one focus group discussion (FGD) while the care professionals participated in 4 separate FGDs. Both the interviews and

FGDs were conducted in Bengali by two Bengali speaking members of our research team. Audio recordings were used when possible with prior consent of each of the participants. The collected data was then transcribed, translated, and analyzed by three members of our team. We present our findings from the FGDs and interviews clustered around thematic insights that provide perspectives on both the sociocultural effects of autism as well as the medical implications of it in the following Section.

5. Findings

We present the challenges of improving the existing care system for the children with ASD in Bangladesh from technological, social, and cultural points of view. Combining challenges for both caregivers and care professionals, we present emergent themes on design implications.

5.1. Understanding caregivers' perspectives

All the caregivers interviewed were parents. The interviews took place from January through May of 2016. We utilized snowball sampling [43] to recruit the participants. First, we reached out to the caregivers of children with ASD that we knew in our family or social network. Then we expanded the pool of participants by recruiting other participants from the suggestions of the participants we had already interviewed. This process continued until we reached a saturation point [44]. Since it was difficult for most of the participants to meet us in person, we used phone or Viber calls for the interviews. The average interview lasted for 22 minutes. The demographic summary statistics for the participants is given in Table 1.

Table 1. Caregiver demographics

| | | |
|--|------------------|------------------------|
| Sex of Caregiver | <i>Female</i> | <i>Male</i> |
| | 12 | 6 |
| Age of Caregiver (years) | <i>Mean</i> | <i>Std. Deviation</i> |
| | 37.1 | 6.4 |
| Income per month (BDT) | < 30K | 30-60K |
| | 2 | 16 |
| Education Level | <i>Bachelors</i> | <i>Other</i> |
| | 14 | 4 |
| Age of child with autism (CWA) (years) | <i>Mean</i> | <i>Std. Deviation</i> |
| | 10.7 | 2.8 |
| CWA has neurotypical siblings | <i>Yes</i> | <i>No (only child)</i> |
| | 61% | 39% |

We qualitatively analyzed the interview notes using thematic analysis [45] and grounded theory [46]. With an open coding scheme, we formed a set of codes that highlighted different caregiver perspectives and underlying challenges. With the codes serving as analytic lenses, we grouped them under emergent themes, which shed light into the dimensions of caregiver perspectives. We iterated the process of clustering until consensus of a final set of emergent themes was reached. Finally, we distilled connecting themes into insights that can be used to unpack the multifaceted perspectives of caregivers on this issue. We refer to caregivers using the following notation: C1 refers to caregiver 1, C2 refers to caregiver 2, and so on, and CWA is used to refer to children with autism.

Dearth of reliable information

A lack of reliable information became one of the dominant themes from the interview data. Most of the parents that we interviewed reported that they did not find necessary information about the appropriate care practices for their CWA in many contexts. Those parents often looked for relevant information over the Internet, but failed. In some cases, even when relevant information was found, it was difficult for them to trust the source of information. One parent highlighted the dearth of trustworthy and verified information in online communities such as Facebook groups:

“The Internet is everywhere now... The problem is not information, but knowing if the information is right or wrong. I saw in one Facebook group that vaccinations cause autism. I don’t want to believe it, but wonder if it impacted my sweet child.” (C3, father of a 7-year old CWA)

This quote elucidates the prevalence of unverified (and often incorrect) information on Internet forum that many Bangladeshi parents frequent. Misconceptions perpetuated by such adulterated information sources can have a serious impact on the psyche of the parent.

Parents often want to know about nuances in daily childcare activities. For instance, how they should handle “episodes” or socially frowned upon child behavior in a particular context (e.g., a wedding ceremony, birthday party), how they should teach their children about a particular task (e.g., brushing teeth), what kind of friends they should allow their children to play with, what kind of television programs they should let their children watch, and what kind of dietary and travel restrictions they should maintain for their children. While some of these questions are very contextual and hence hard to answer without knowing the child and their social context, many of these questions can be answered more generally. For example, experts often suggest that CWA should neither be forced to behave “normally” as a neurotypical individual, nor should they be totally ignored. Due to the paucity of experts in Bangladesh, it is often difficult for the parents to receive such information. On the other hand, most of the non-expert information is unreliable. Furthermore, the nature of their information needs is often in-situ and requires an instant answer, which is hard to provide for an expert. For example, if a CWA starts banging his head

against the wall, the parents need to know what to do instantly, and they do not have time to research for trustworthy data.

Time constraints and digital connectivity

Severe traffic congestions (or “traffic jams”) is one indispensable yet painful part of life in Dhaka and other major cities in Bangladesh [47]. Our participants reported that they spend almost 3 hours a day on average in a traffic jam, which significantly reduces their availability for childcare. For context, Dhaka is the most densely populated city in the world, where everyday citizens lose 3.2 million total working hours in traffic and the average speed is 7 km/hr (slightly higher than typical walking speeds) [74]. While most densely populated cities suffer from traffic congestions, traffic takes a whole new meaning in Dhaka (Figure 1).



Figure 1. A typical traffic jam in Dhaka. The mixture of rickshaws, auto-rickshaws (often called 3-wheeler CNGs), motorcycles, buses, and cars can create chaotic and unpredictable congestions. The photographed traffic congestion lasted for around 2 hours, during which the researcher was able to get out of the auto-rickshaw, go to a pedestrian overpass (elevated road crossing), take the photo, and then return to the vehicle.

Moreover, traffic is unpredictable, which is why services like Google Maps often fail to accurately predict travel times despite significant user adoption. Another unique aspect of Dhaka is the hyper-centralization of good schools, hospitals, reputed private autism-counselling centers in one of two specific locations in a city that is home to almost 20

million people. Unlike many other cities where facilities are distributed and planned, this centralized characteristic of Dhaka imposes an extra burden on caregivers if they have to travel, making the ramifications of traffic jams worse. Such significant time expenditure not only hinders access to care, but also drains the energy of the parents. Moreover, coordinating in-person group activities with CWA, which is important for developing their social skills, is hard for the parents due to the time lost in commute. The problem is exacerbated in a multi-child family, especially for working parents. Granted working parents with multiple children face time-management challenges worldwide, the unpredictable compounding factors posed by traffic congestions in Dhaka manifest the severity of time management challenges in a unique way. Stress and frustration induced from the parental challenges were evident when one parent lamented:

“My heart is torn into two pieces, which son do I focus [and take them out]? The one doing excellent in school [for tutorials] or the one [autistic individual for therapy]? I only have so much time [in a day]!” (C6, mother of an 8-year old CWA and 12 year-old neurotypical child)

It should be noted that, stemming from a collectivist South Asian culture, there is an expectation for grown-up children to look after their aging parents and siblings in need as part of the nuclear family [48,49]. The social fabric is such that children can rely on the wisdom of elders. Long standing scholarship on South Asian and East Asian sociocultural norms sheds light on how seniority-based value systems, where older members of society are prized and valued for their experience, govern the circle of life, especially when it comes taking care of your parents in your home (compared to a senior-assisted living facility) [70-72]. This implies that our participants often have to decide whether they will invest for their future (by attending to the neurotypical child who is more probable to support them in their old age), or to listen to the call of taking care of their child with special needs.

While parents can be frustrated about the time they lose in traffic, they are also keen to learn if there is any way they can utilize that lost time in a productive way. All interviewed parents had access to and basic knowledge of using the Internet and apps on smartphones. 76% of Bangladeshis have mobile phones and 95% of all Internet users use mobile Internet [50]. When asked about using cell phones, one participant highlighted its increased affordability:

“Who doesn't have a smartphone these days? If you can't afford the foreign ones, you can buy from Walton [a local company]... I see even rickshawalas [rickshaw pullers] with smartphones these days!” (C4, mother of an 11-year old CWA)

Caregivers were asked to share their experiences with other caregivers using mobile phones while stuck in traffic. Despite some hesitancy around noise levels in traffic, all of our participants said they find talking or using an app while stuck in traffic a good way to utilize some of the time to do something productive. Interestingly, 94% of our participants do not drive — they use a combination of public transportation, private car with a driver, and carpooling. With

time lost in traffic and improved digital connectivity, parents see an opportunity to transform the “lost” time in traffic into useful cycles of caregiver peer learning and engagement with technology.

Stigma, stress, vulnerability, and resilience

Aligned with Gray's [51] explanation that parents perceive themselves to be stigmatized due to their child's condition, all participants acknowledged that there is cultural stigma in varying amounts. 76% of our participants felt they are directly impacted by stigma in their ability to openly talk about autism while 24% felt there were some other kinds of stigma that denied them full access to social support. All of them stressed that autism should not be stigmatized; however, the effects of internalizing stigma were palpable. The intensity of internalized guilt, frustration from others' judgments, and helplessness about the situation was clear from their responses. One mother said:

“Relatives make it [the experience] harder...side comments during family events hurt more than those from strangers. People tell me that late pregnancy is to blame...maybe they are right...but what could I have done?” (C2, mother of a 12-year old CWA and 6 year-old neurotypical child)

It should be noted that autism results from a complex interaction of both genetic and environmental factors [1]. Although a number of factors have been postulated, such as parental age, there has been no direct causal evidence so far [52]. However, due to sociocultural stigma and the lack of scientifically-informed public awareness, a person with autism and their family usually encounter such critical comments in Bangladesh.

From this comment and similar sentiment expressed in other interviews, it appears that negative comments from family members have a strong impact on parents, resulting in a feeling of vulnerability. All participants acknowledged the need to bolster the support network since many felt that they were alone in this journey. They also expressed that communal bonds and shared experience with others fosters resilience. A sense of activism driven by the desire to help others to combat stigma seemed to be giving rise to the resilience of this vulnerable community. One experienced parent, with a 14 year-old son with autism and passionate about autism rights, commented:

“My son's story needs to be out there...he is not alone...we need to know [the story]. The more we share, the less we feel alone. We may be vulnerable, and at times helpless in the face of our society, but we are resilient. We have to be...there is no other way..” (C17, mother of a 14-year old CWA and 4 year-old neurotypical child)

For this parent, the transition from a stigma-internalized passive state to an activist one occurred through the involvement in a local special needs school, SWAC, promoting education and inclusion of CWA. Peer support from other caregivers helped her tackle social and cultural challenges. The parents felt that storytelling can help others in coping with the feeling of loneliness. While the remaining

25% expressed some hesitation, mainly because of the associated stigma around autism, all parents were willing to listen and learn from others, preferring a peer to peer learning model.

Demography, hope, and resistance

Our participants came from different socioeconomic backgrounds. An interesting finding was the pattern when it came to the reluctance to combating ASD for their CWA. Both the lower and upper end of the socioeconomic spectrum (SES) exhibited this tendency, but for very different reasons. An auto-rickshaw driver (who considers himself to be a member of low income community) described an inconvenient reality:

“There is no support for the poor... what if my child has to pick up begging later?... I’d rather have him like this” (C12, father of a 10-year old CWA)

This parent (and other parents in the same socio-economic group) cannot envision a bright future for their children with autism. Many of these parents think that their CWA will end up being a beggar in the street, in which case, taking care of them is both futile and counterproductive, because the physical, psychological, and behavioral differences of an individual helps a beggar earn more. On the other hand, an industrialist (self-identified as a member of the high-income group) claimed:

“I can hire 4-5 people for my child... Why bother taking him outside when that causes problems?” (C13, father of a 9-year old CWA and two 14 and 12 year-old neurotypical children)

In this case, considering the financial resources at his disposal, the parent is less concerned by the impact of ASD on the child, mainly because he can “afford” to manage it by other means to support the child in future. This is how demographic conditions impact the perception of care in ASD, especially amongst the primary caregivers– parents.

On one hand, we have someone with not enough resources, mentally preparing for a painful harsh reality and on the other hand, we have someone with resources who is refusing to invest much effort in autism care. Interestingly, middle class parents seemed to have the right balance of hope and resources to expect a positive change in their CWA through appropriate diagnosis and interventions.

Distance from the care professionals

During the FGD with the caregivers, we discovered that social hierarchy between care professionals and caregivers prevents the caregivers from being comfortable in asking questions and openly sharing their thoughts. In most cases, our participants reported that they did not feel at the same social hierarchy while interacting with care professionals, which created a perception of being patronized and lack of mutual respect. This perceived disrespect often results into providing insufficient information to the care professional regarding CWA. At the same time, the parents are also deprived of the information that they expect from the experts. Thus, there is a communication gap between the caregivers

and care professionals impacts the interventions for the CWA. A parent said:

“It’s difficult when doctors are too busy and don’t have time to discuss every issue in-depth...I wish they made me feel like a partner. I don’t speak up as don’t want to offend...after all, he is a doctor.” (C15, mother of a 7-year old CWA)

This comment brings up some key issues in the doctor-patient relationship dynamics. Parents prefer an environment that facilitates equitable discussion instead of the perception of being ‘lectured at’. They want to feel like partners in the long-term care of the CWA.

5.2. Understanding the Care Professionals’ Perspectives

Attempting to understand the nuanced challenges of autism from the care professionals’ perspective, we conducted 4 FGDs in primary cities in the country: Dhaka and Chittagong from May 2017 to July 2017 lasting a total of 10 hours with an average length of 2.5 hours (Table 2). Care professionals were randomly selected from the convenience-sampled institutions [53]. With 28 total participants, the group was comprised of psychiatrists, psychologists, pediatrician, and pediatric neurologists with an average of 6.7 years of experience addressing ASD related issues. One researcher of our team (who is also a medical professional, and a professional care provider to mental health patients) moderated the FGDs. The moderator both conducted the discussion and kept notes of the discussion. Those notes were then translated and transcribed in a similar process that we used for analyzing the data from the parents.

Table 2: FGD Location and Participation Summary

| Institute/ City | No. of Participants | Duration | Date |
|----------------------|---------------------|----------|---------|
| IPNA (Dhaka) | 3 | 1 | 24/7/17 |
| NIMH (Dhaka) | 8 | 2 | 9/7/17 |
| NIMH (Dhaka) | 14 | 3.5 | 9/7/17 |
| Nishpap (Chittagong) | 3 | 3.5 | 5/5/17 |

Aggregated Participants Summary

| Experience of care professionals dealing with ASD cases | Years | Count |
|---|-------|-------|
| | 0-1 | 1 |
| | 1-3 | 5 |
| | 3-6 | 6 |
| > 6 | 16 | |

| Distribution of professional designation among the participants | Title | Count |
|---|-----------------------|-------|
| | Psychiatrist | 17 |
| | Psychologist | 2 |
| | Pediatrician | 2 |
| | Pediatric Neurologist | 3 |
| Other | 4 | |

Technological proliferation but lack of transfer

Similar to the uptake in smartphone adoption and internet usage amongst caregivers, care professionals exhibited an increased desire to use technology in their professions. Citing the ubiquity of smartphones, the need for contextually adaptive technology, and importance of connectivity afforded by technology, one participant commented:

“Smartphones are in everyone’s pocket these days. Technology can improve connectivity between us and them [caregivers]. The diagnostic criteria have changed in DSM-5, so an adaptive system will be great because who knows what will change in DSM-6.” (CP2, Associate Professor, NIMH, Bangladesh)

Despite their desire to extend the use case of mobile technology to the professional setting, it is still mainly limited to their personal use. One of the participants pointed out that there was no prevalent culture and established guidelines to introduce the use of mobile technology to the medical professional services. When probed if there is a lack of technology training for care professionals and whether they typically leverage technology beyond personal use, the same participant (CP2) commented:

“We know how to use our phones. It’s not the basic training we need. I use Skype and Uber, and other apps all the time. [However,] there is no established and standardized practice of using mobile phones to help with diagnosis and care. Without a culture of using it, we are not exposed to how to use it in [the diagnostic] context. That’s why we need to have a culture of using [technology] more.”

It should be noted here that many of our participants were aware of several mobile-health applications that were being used in many other countries, but they were not confident enough to use those in Bangladesh, mainly because those were not evaluated in the local context and not part of the community of practice [69].

Need for longitudinal monitoring and database

All our participants highlighted the need for and the various benefits of a context- and resource-aware centralized database that provides longitudinal data about symptoms and behavior for ASD. One of the participants highlighted the benefits of longitudinal monitoring and use of databases as follows:

“Due to societal stigma or denial or forgetfulness, caregivers often provide inaccurate information that we rely on for diagnosis. A reliable database with long term data can improve diagnosis precision. It will save

time from my end and theirs. Most importantly, when they need to come, they can as they didn’t waste visits.” (CP10, Associate Professor, NIMH, Bangladesh)

There are two notable insights: first, verifiable longitudinal data can address issues of under- or over-reporting of symptoms, enabling better diagnosis and care. Second, a digital tracking method can facilitate regular monitoring without the need for in-person visits. With time-constraints and traffic jams in mind, the reduced need for in-person visits can lessen the burden for both the caregivers and care professionals, as our participants opined.

Barrier of language

Highlighting how linguistic differences in symptom-reporting impact diagnosis, care professionals called for the need of technology to address a diverse set of sociocultural challenges. Advocating the need for the system being able to handle variances in Bengali and provide proper scaffolding for low-English literacy caregivers, one participant said:

“We need a way to account for linguistic differences in the dialects as they affect diagnosis. I think a central repository of different word usages and their agreed meanings would be useful. We can’t rely on English as many caregivers aren’t fluent and often misuse terms which adds to the confusion.” (CP14, Assistant Professor, IPNA, Bangladesh)

The linguistic differences have roots in dialects of the Bengali language as well as SES levels that affect English literacy. Based on the district location, Bangladesh has a diversity of dialects. As a result, the same symptoms may be described differently in different districts. With varied English literacy levels that is tied to SES, we cannot always rely on using English. As a result, any technological intervention should incorporate contextual research into the linguistic differences across geographic and demographic differences.

Generational impact of technology adoption

During our FGDs, we noticed that younger professionals had a higher affinity and trust towards technology than the older, more senior ones. This presents a unique challenge because senior members have more experience, making them an important stakeholder of any intervention. The comments of the following two participants, a medical professor and resident intern, aptly summarize the phenomenon and challenge:

“I am about to retire soon and my generation didn’t grow up with computers. Moreover, I prefer the in-person interactions. I don’t really trust the technology, but I think training senior practitioners can help.” (CP1, Professor, NIMH, Bangladesh)

“Technology makes sense to me...because I grew up with it. Laptops and smartphones are staple in my generation. A paperless digital tracking method can also facilitate seamless continuity of care even when the medical care provider is changed.” (CP10, Resident, NIMH, Bangladesh)

Given the affinity of the younger demography towards technology adoption, they can be targeted for early adoption of any intervention. The collaboration with early adopters not only facilitates iterative design evolution, but also has the potential to give rise to a culture of electronic health records, addressing a key issue of continuity of care as mentioned by CP10. While the digital divide between generations is not unique to Bangladesh, the severity of it and the confounding context around it makes it a noteworthy challenge. In fact, if we can address the challenge of generational digital divide in as extreme a case as it is in Bangladesh, the transferrable insights can also benefit interventions in other LMICs and developed ecosystems.

6. Discussion

Our findings reveal some important infrastructural and cultural issues that are crucial in understanding the challenges and opportunities of designing such technologies for ASD care in Bangladesh. Our findings are important to conceptualize some crucial challenges around designing a digital technology to support the ASD care in Bangladesh.

First, our data reveals a set of critical infrastructural challenges, specifically around digital and transportation infrastructures, that inhibit advancements in autism-related care. Like most other developing countries in the world, Bangladesh lacks a robust digital infrastructure. This weakness can be explained by the lack of an effective and efficient power, network, and Internet infrastructure. Such infrastructural vulnerabilities exacerbate when we start moving from urban to rural areas of the country. However, it is important to note that electricity and cellphone infrastructures are often weak and uncertain in urban areas too. These include regular power shutdowns and “no cellular network” situations. Internet connections, despite becoming cheaper and easier to get, are often very weak and infrequent. Often times, it is hard for the citizens to rely on these digital platforms for a mission-critical important task. Disconnections and interruptions limit the scope of any potentially ubiquitous digital services.

Furthermore, in terms of transportation infrastructure challenges, localization of care resources compounded by traffic congestions entail that both care professionals and caregivers have to spend a lot of time on the roads being stuck in traffic due to a weak and unplanned transportation system of the country. There is a sunk cost of lost time, which they cannot utilize in any meaningful manner. These infrastructural weaknesses limit the ways existing technologies could better address many challenges of their life, including ASD.

Second, Bangladeshi citizens are still new to digital communication platforms and online social networks. Their social media are often flooded with unreliable information which significantly reduces the credibility. Exposure to unreliable information (often called 'fake news') has emerged as a global phenomenon with several negative consequences. While this concern is prevalent world-wide, the impact of misinformation can be severe in LMICs. Because of language

barriers, unfamiliarity with technical knowledge to verify an information, and the culture of having a "blind trust" among the community members increases the chances that such information spreads rapidly and is believed by more people in these countries. At the same time, the Internet often appears to the local communities as a medium controlled by those in the "West", and because of a long history of colonization and forced domination, these communities often hesitate to suspect an information found over the Internet (such cultural imperialism over digital world is often reported in post-colonial computing research) [14, 73]. As a result, the parents of CWA in Bangladesh often struggle to find their required information on online forums. Similarly, although care professionals are using mobile technologies in their personal life, they are not able to use them in their profession. Like other non-western, non-English speaking countries, the care practice is also often affected by the language barriers which could likely be addressed by some digital translation platform (e.g., Google Translator Toolkit [55]), which is not in place here.

Third, our data shows that there are strong cultural factors that impact on the life of CWA and their parents, and also shape the use and non-use of digital technologies in Bangladesh. A big part of this cultural challenge comes from the stigma and misconceptions around ASD. Various misconceptions, unscientific and unfounded beliefs, and superstitions constitute a wide-spread stigma around autism. Religious beliefs intertwined in the cultural fabric also impact people's perceptions in Bangladesh like many other LMICs in the world. For instance, based on a belief that the individual with autism is supposed to be closer to spirituality or God, some cultures do not prefer seeking interventions that can improve high functioning symptoms [56]. On the other hand, some Latino mothers view autism as punishment from God [57]. Some have the unfounded suspicion that the age of the mother during conception is also the determining factor for child's ASD [39]. All these stigma and misconceptions limit CWA's access to many social resources, and make the life of their parents more stressful and difficult.

Fourth, the social hierarchy in many Bangladeshi communities also plays a vital role in determining the impact of a digital technology for supporting the care of a CWA. For example, the relationship between the caregivers and the care professionals is often very distant and aloof. This relationship is often affected by the care professionals' real or assumed higher social status in the community, and a cultural trend of “educating” the patients and their relatives. Such paternalistic and patronizing attitude in the Indian subcontinent is often attributed to their colonial history [58] and the politics of expertise [59]. Hence, any technology that conveys information between the care professionals and the caregivers must tackle this power imbalance. Besides this, the gender hierarchy in many Bangladeshi communities also plays an important role in childcare [60] and how technology is used [61]. While mothers are often the primary caregiver for a CWA, their use of mobile phones and other computing and communication devices is often conditioned, surveilled, and limited by the male members of the family [62]. Hence, the gender bias in a community is directly affecting the impact of

a digital technology on a CWA. A successful technology must need to address these internal politics of Bangladeshi families and communities.

Fifth, our data shows that people's socio-economic status, education, family structure, and life-opportunity impacts their attitude toward ASD care. People from lower socio-economic classes are often losing their hope about their CWA, and seeing the treatment "less profitable" for their future. On the other hand, people from very high economic status often consider the treatment unnecessary as they can make arrangements for all necessary supports for their CWA using their money. At the same time, people of middle-income vacillate between caring for their CWA or investing more into their neurotypical child. All these tensions and resistances are largely influenced by hopelessness that ASD can be cured or that it can be taken to a state where it is no longer a challenge for an individual to live in a society with others. Sharing the stories of successful therapies in a responsible manner, one that does not inspire false hope, may alleviate the stress and take people out of such resistance.

All these infrastructural and cultural challenges explain the role of contextual requirements of designing technology in LMICs – an issue that has been core to the scholarship of Information and Communication Technology and Development (ICTD). Researchers have come up with several ideas to overcome the challenges of weak communication network [63], information unavailability [64], tech literacy [65], and uncertain infrastructure [66]. For handling the cultural challenges, researchers have focused on situated design of technologies that align themselves with the local culture and norms [67].

While this paper presents some valuable insights of an understudied topic, the ASD and mental-health interventions in Bangladesh, there are some limitations in our study, too. First, our study only focuses on urban areas, where ASD care is significantly better than the other parts of the country. Our study, therefore, may not represent the situation of the whole country. Second, all our participants had mobile phones and they were fluent in using those, which is again not a generalizable scenario even in urban Bangladesh. There are many underprivileged and low-literate people in Dhaka and Chittagong who are not represented by our participant pool. Third, our study is also influenced by our social network which we used for recruiting our participants. As a result, despite our best efforts at impartiality, some unconscious bias may still remain in our data. Because of these limitations, we do not claim our findings to be generalizable. Instead, we rely on the strength of qualitative research that focuses on making situated arguments [54] to report a set of practices that are present in the ASD care ecology in urban Bangladesh. We believe that the lessons revealed through our findings can later be leveraged to create a broader and deeper understanding of this domain beyond the population we studied.

These studies and interventions offer important lessons on how technology can be designed in a resource-constrained environment by factoring in the situated values and practices. Taking inspiration from ecological design philosophies that take an asset-based and value-sensitive approach to

ecosystem affordances [4, 5], we present a preliminary design considerations and implications for a voice-based peer-to-peer system that connects caregivers in the following section.

7. Design considerations & implications

Our findings shed light on the stigma around autism and highlight the need for social support amongst caregivers. Caregivers shared how peer support can strengthen communal bonds and foster resilience through shared experiences. Moreover, they also shared how time lost in traffic significantly impedes their abilities to adequately seek autism-related care. We also discussed the notion of transforming lost time in traffic into useful cycles of information exchange and learning. Based on this understanding, we facilitated 2 exploratory participatory design (PD) sessions with 6 caregivers where researchers and parents ideated around spaces for interaction that can address some of the challenges. Below, combining insights from the sessions, we present preliminary design considerations and implications. We share the motivation behind the design, share an outline of the user journey, and avenues for evaluation-based iterations of the design.

7.1 Voice-based, peer-to-peer, and moderated interaction spaces

Design motivations and considerations

The ideation sessions led to the concept of a social support system that can help the parents of CWA by leveraging the efficacy of peer-to-peer learning, exchanging relevant information, raising awareness, spreading empathy, and fostering resilience.

Caregivers were unanimous in their preference for a digital interaction space, mainly because the heavy traffic in Dhaka made in-person support groups impractical. In terms of methods of communication within the digital space, purely text-based approaches (such as web forums) were unfamiliar and considered impersonal while exclusively video-based approaches (such as skype calls) were classified as too forward from a sociocultural perspective, resource intensive, and privacy-invasive. Interestingly, voice-based approaches (phone calls) had the perfection of the right balance of personal touch and privacy. Caregivers mentioned how affective qualities of voice (tone, pace, pauses, etc.) could help establishing empathy. From a logistics perspective, partnership with telecommunication companies and social enterprises like Dnet, who have prior experience in phone-based services, can facilitate toll-free numbers and user-side integrations reducing burden of cost and resources for both the end-user and researchers.

Moreover, a voice-based approach can target the time caregivers lose in traffic jams in Bangladesh. In addition to other time slots, sessions (like conference calls) can be scheduled during the times of the day when most parents are in traffic (self-reported to be between 5-7pm). Caregivers were enthusiastic at the prospect of transforming this (self-

reported) “boring” lost time into useful cycles of potential engagement with peers on a shared journey.

In addition to addressing the infrastructural challenges, there were design considerations addressing cultural challenges. Cognizant of the sensitivity of autism-related topics and with the intention to buffer against insensitive dialogue, we thought of adding a moderator who can be a trained volunteer or a public health official from a potentially collaborating social enterprise like Dnet or BRAC. The moderator can facilitate the interactions between the speakers and passive listeners, keep the conversation relevant, buffer against insensitive language, and take notes that can provide invaluable grounded data around conversation topics and nature of interactions enabling proper analysis. The inclusion of a moderator can also reduce the risk of spreading incorrect information by pointing caregivers to proper resources.

In addition to moderated sessions that involve both mothers and fathers, caregivers highlighted the potential for separate discussion channels for males and females in order to better address their different needs. Mothers were interested in the option to have “moms only” sessions where they can openly discuss caregiver challenges specific to motherhood while fathers were keen on discussing how Bangladeshi conceptions of masculinity impacts their role as a parent of a CWA. Figure 2 represents a digitized version of a preliminary sketch our participants conceptualized about the design of the voice-based peer-to-peer support system.

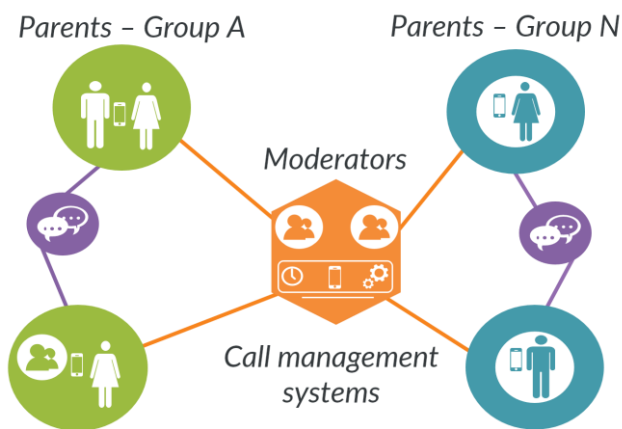


Figure 2. A (digitized) version of a sketch by our PD participants outlining the basics of the voice-based peer-to-peer support system. This schematic diagram depicts parental groups connected to each other through moderated conversations that can facilitate peer-to-peer learning and information sharing.

User journey outline

Based on the design ideas and considerations, a preliminary outline of potential user journey that emerged in the PD sessions is as follows: caregivers register with the project providing verifiable IDs, preferred times to talk, topics they would like to discuss, and address in Dhaka (at a region

level). Each user is assigned an alias which is tied to their real credentials. This pseudo-anonymization allows for anonymity in the chat room with accountability should unwanted things happen (for instance, use of abusive language or inappropriate actions). Once users are matched by their schedules, a group introductory call is made with ice-breakers and moderators setting the context. Given the cultural norms, PD participants felt the introductory group calls are essential to set the tone for the rest of the journey. Users are strongly recommended to stay with their group for the entire duration of the pilot study (helps in estimating any pre and post study impacts). After the introductory call, caregivers dial in at the designated slots to reach other members. If users wish to continue the conversation over other platforms, such as WhatsApp or Telegram, we can work with them to hand over the conversation. In addition, users can mutually agree to connect one-on-one should after the group chats—taking the relationship from a group context to a one-on-one can also signify fostering of rapport and trust, which can be an interesting avenue to study in the future.

Evaluation-based iterations

In terms of evaluation-based iterations of the interaction space, focus group discussions can be carried out pre-, post-, and mid-way through a pilot phase of 8-10 weeks, seeking feedback and iterating on the design. One of the biggest challenges will be to evaluate the efficacy of the voice-based peer to peer support system, especially since recorded calls are unlikely due to the sensitive contents of the discussion. This is where notes from the moderators can be invaluable to analyze overall efficacy. Based on the notes, follow-up interviews with participants and pre and post surveys can also flesh out areas that are working well, those that need tweaking, and ones that require major changes.

While considering the technological design considerations and implications, we want to highlight the need to avoid any kind of technological determinism in designing contextual interventions. Technology, alone and for the sake of technology, will not be able to address complex sociocultural challenges around ASD. The issues around it are critical and sensitive, especially in a resource-constrained ecosystem like Bangladesh. In addition to technological development and innovation, we need other aspects of the ecosystem to improve: social awareness, education, law, and policy. News and social media can play an important role here by creating awareness amongst people. Necessary facts about ASD can be taught in schools so that the society can slowly get rid of the misconceptions and stigma around it. The government should impose strict laws against any kind of unfair discrimination against the persons with autism. The government should also make policies to protect their human and civil rights. Such a holistic effort can not only help in autism-related care, but also catalyze successful integration of persons with autism into the workforce and their contribution to the society at large.

8. Conclusions

Autism is nuanced, and its challenges are unique and situated in the sociocultural framework. As a result, a culturally embedded design is essential for any successful technological intervention for ASD, especially in LMICs. Taking Bangladesh as an analytic lens and focusing on the challenges of caregivers and care professionals, in this paper, we have presented the findings from our original qualitative study in Bangladesh that highlight the design challenges from infrastructural and cultural perspectives. Based on our findings, we have also presented technology design considerations and implications using the concept of a voice-based peer-to-peer support groups for caregivers. We advocate that we should focus on leveraging the increasing proliferation of mobile technology in Bangladesh to address the sociocultural and infrastructural challenges around ASD. We believe that our findings and design implications will help future development of appropriate technologies to support the care practice for ASD in Bangladesh. We hope that the lessons gleaned through this study will also be beneficial for advancing autism-related health services in many other LMICs around the world and potentially improve established practices in other matured ecosystems (e.g., in developed countries).

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