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Study Results of mCARE: Developing, Deploying, and Analysing the End-to-End Results of a Mobile-Based Remote Monitoring Tool for Children with Autism Spectrum Disorder in Bangladesh

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Abstract

Mental health is one of the most neglected healthcare issues in developing countries. The situation is worse in the Global South due to stigma, superstitions, and many other social-cultural-financial constraints. Lack of mental health professionals and regular monitoring has deprived families raising children with Autism Spectrum Disorder (ASD) of the desired care and support. However, the overwhelming adoption of mobile phones in Bangladesh has created an unprecedented opportunity to overcome these various constraints. To leverage this opportunity, we designed, developed, and evaluated mCARE (Mobile-Based Care for Children with Autism Spectrum Disorder Using Remote Experience Sampling Method), a mobile application that integrates the Experience Sampling Method (ESM) with the local healthcare practice by putting the caregivers in the loop. mCARE collected behavioral and developmental progress parameter values from the caregivers of 300 children with ASD periodically (daily/ weekly/ biweekly/ monthly) along with sociodemographic data of the family. This paper reports: (a) the context and challenge identification phases that validate the requirement of a mobile based tool; (b) evolution of mCARE following Value Sensitive Design; (c) short term and long-term impact analysis (qualitative and quantitative) of mCARE, and; (d) broader implications of these findings for the HCI scholarship along with the impact of mCARE during COVID-19.

Keywords: Autism Spectrum Disorder, mHealth, symptom monitoring, COVID-19.

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1. Introduction

Autism Spectrum Disorder (ASD) is a highly prevalent neurodevelopmental disorder affecting about one percent of the population in the U.S. and abroad [55, 76], including Bangladesh [83, 85, 98]. However, this is likely an underestimate due to many unaccounted cases [86, 98]. The worldwide predominance of Autism Spectrum Disorder (ASD) has expanded 20 to 30-fold during the last 50 years [90]. Most of the previous research on autism has been limited to Western or wealthy Asian countries [30, 31, 48, 62, 77]. Research in the domain of ASD in the Low and Middle

Income Countries (LMICs) is mostly done in the area of screening [8, 23, 45]. Although a few mHealth tools exist that, in a limited capacity, serve for monitoring mental health diseases in LMICs [6, 17, 80], these cannot accommodate the rich variety, individual nuances, and the uncertain patterns of ASD. Also, most mHealth applications for health data collection are built assuming that the health data will be collected by physicians or health care workers [21, 22, 52, 73]. Moreover, values embedded in a cultural setting impact the perception, diagnosis, and treatment of ASD [28, 39, 64]. Thus, a carefully designed mHealth application that considers the socio-cultural values, norms, and perception of ASD, and can be easily used by caregivers (based on literacy level and mobile use experience) themselves to address the aforementioned constraints, is an important need.

Regardless of remarkable progress in ASD screening and raising awareness in recent years, the healthcare support system is limited for families raising children with ASD in Bangladesh [88]. Like many other low and middle-income countries (LMICs), social-cultural-financial constraints and a scarcity of mental health professionals (MHPs) have deprived families raising children with ASD (CWA) from regular monitoring, care, and support in Bangladesh. Existing practices depend on traditional 'on spot' evaluations of the behavior of children with ASD or caregiver recollections during their occasional and infrequent visits affect the evidence-based decision making of MHPs, resulting in inaccurate and unreliable care.

The objective of our work is to dynamically improve the care system with an accessible and easy-to-use mobile-based application called mCARE for evidence-based decision making. mCARE is designed to address three major constraints in the care system for children with ASD in resource-scarce contexts – financial hardship for parents to arrange frequent visits and to accurately report to MHPs, lack of availability of MHPs, and lack of availability of longitudinal data on behavioral changes. mCARE, developed following the socio-cultural and existing care process norms, is being used by 8 mental health professionals (MHPs) and 300 caregivers of CWA for over a year. Caregivers of CWA use mCARE (mCARE-APP/mCARE-SMS version) to routinely submit customized behavioral and developmental progress parameters as selected by the MHPs for that specific child. MHPs utilize the web-based data visualization platform known as mCARE-DMP (Data Management Platform) to view and compare the submitted data and support evidence-based decision making.

The contribution of this paper to HCI literature is threefold. First, this paper describes the design, development, and evaluation of mCARE, which is the first mobile-based tool to routinely and systematically collect behavior and developmental parameters for children with ASD in LMICs. The evaluation of this application demonstrates how the collaborations between the care professionals and caregivers are crucial for such technologies to work properly. Second, this paper reports a novel way to capture the impact of COVID-19 on CWA by using mCARE. We report how COVID-19 had a wide range of impact on various CWA based on their familial circumstances, socioeconomic condition, and geographic location. Finally, this paper describes how the impact of such a digital behavior monitoring platform is shaped by the familial values of the children and caregivers. We demonstrate how the use of this application was impacted by the patriarchal social structure and other social norms. Thus, this paper makes an important contribution to the HCI scholarship on designing mental health technologies with the people in LMICs (especially in the Global South).

2. Background

Though a multilayered, widespread network of health care facilities exists in Bangladesh, starting from 'Community Clinics' (35000+) to tertiary level specialized hospitals (25), the scope for the multidisciplinary specialized ASD care is available in less than 20 centers, mostly located in Dhaka and several other urban cities [60]. Though there is no specific official data, care professionals working in mCARE estimated that the average number of ASD care provided throughout the country would be 500 per day. Approximately 200 psychiatrists and 50 psychologists are currently available for 160 million people in Bangladesh [89]. The situation is even worse in rural areas since most of the practitioners are in urban cities. Families visit ASD practitioners infrequently, which forces the practitioners to make intervention decisions based on a few unreliable, recall-biased [74, 95, 98] data points. In addition, the practitioners hardly receive any feedback once the caregivers leave the clinic. People from the low socio-economic spectrum mostly come to the government hospitals/centers since the treatment is almost free. Most of the private clinics or chambers specialized in treating CWA are clustered in Dhaka (capital) and Chittagong (port city and the second-largest city). These centers typically serve the rich, where each visit costs around BDT 320-960 (approximately USD 4-12) [26]. When asked about the care practice continuum, one mental health professional (MHP), serving in a government institute, summarized the process as follows:

"*We really rely on behavioral therapies and suggestions. These patients come to us because they have nowhere else to go (since other places require money). But even then, they come may be twice or thrice a year. I don't normally prescribe drugs until and unless I find some symptom extremely severe (since I don't have enough data to make a confident decision).*"

Irrespective of this scenario, the Government of Bangladesh has initiated multiple steps to acknowledge and support mental health and neurological disorders. In 2011, Bangladesh organized a convention titled "Autism Spectrum Disorders and Developmental Disabilities in Bangladesh and South Asia," known as the Dhaka declaration [65] and praised by the UN as a role model for autism awareness [1]. Bangladesh has also included autism, neurodevelopment disorders, and disabilities related issues with the National 7th Five-Year Plan for 2016-2021 [1]. The parliament also passed the 'Protection of Persons with Neurodevelopmental Disability Trust (NDD Trust) Act', 2013 [89] and is planning to open a mental health cell in all 64 districts under NDD Trust.

3. Related Work

ASD is a widely researched topic that has drawn attention from various angles. The relevant research on the topic is summarized below.

In recent years, due to the vast explosion in smartphones used in both developed and developing countries, the popularity of using smartphones to monitor children with ASD is increasing [21, 32, 40–42, 73]. Besides smartphone technology, several other technologies are also used to monitor and support children with ASD [48, 89]. Autism and Developmental Disabilities Monitoring (ADDM), an active surveillance system [14], is used for prevalence assessments for children aged eight years. Our thorough review revealed the use of different technologies as follows: (i) wearable devices like a smartwatch [37, 66, 82], wrist/chest/ankle bands[11, 13, 16, 18, 54, 75, 93], GPS [69, 79, 92], head-mounted displays [33, 57, 58], and cameras [25, 51, 94] (51 papers); (ii) Tablet [43, 61, 78, 91], iPad [46, 47, 96] or mobile applications [3, 20, 81] (58 papers); (iii) Virtual Reality (VR) [12, 57, 58, 97] (11 papers), and; (iv) Robots [19, 29, 44] (14 papers). Multiple web-based mobile health (mHealth) apps are proposed to continuously monitor the symptoms and progress of children with ASD, including My JAKE (Janssen Autism Knowledge Engine) [7, 50, 100].

Early identification of ASD symptoms is crucial for the ASD treatment process [8, 23], and hence research in the domain of ASD in LMICs is mostly done in the area of screening [8, 23, 45]. Examples of this category include Prottoy [6] (Bangladesh), Autism Barta [56] (Bangladesh), Autism Severity Assessment App [63] (Bangladesh), Autism&Beyond [49] (South Africa), 12m [10] (India, Pakistan, Zambia), ACCESS [99] (Uganda, Sri Lanka), AHC-DMAT [59, 71, 84] (Cambodia), and MDAT [34, 35] (Malawi). A 2018 cross-sectional study [36] in Bangladesh emphasized the importance of early detection and decentralization of healthcare service delivery in the domain of ASD care. In low and middle-income countries (LMICs) like Bangladesh, many unique challenges, including cultural and social practices, often impede effective care of Autism Spectrum Disorder (ASD) [45, 90].

mCARE addresses the shortcomings of the aforementioned projects in multiple ways: i) it has been developed considering the socio-cultural-financial aspects of the population; ii) it includes module to be used by both caregivers and MHPs; iii) to include the mass population, both app and SMS version of mCARE are developed and deployed in 4 institutes (public and private), and; iv) it monitors both behavioral and milestone parameters using locally accepted scales. Successful completion of this project served as a proof of concept that persons living in an LMIC can effectively use a carefully designed mHealth application and that such applications can improve overall outcomes and quality of care of ASD.

4. Methodology

Any technological intervention to support ASD in LMICs needs close involvement of both caregivers and MHPs from the very beginning of the development. In this paper, considering Bangladesh as a case study, we completed multiple field studies to understand the hidden dynamics of the stakeholders, which will be crucial in designing the technological intervention to be followed.

4.1. Challenge identification

First, we interviewed 20 parents of children with ASD (12 female, 8 male) in Bangladesh and learned about their challenges in understanding their child’s progress and in reporting those to the MHPs. Snowball sampling [38] was used to recruit these participants and continued until a saturation point [67] was reached. Since it was difficult to reach the participants in person, who are distributed all over the country, we used phone or Viber calls for the interview that lasted for 22 minutes on average. The mean age of the parents was 37.1, and the mean age of children with ASD was 10.7 [26].

Second, we conducted 4 focus group discussion (FGD) sessions in Dhaka and Chittagong, Bangladesh to identify the challenges faced in the current treatment process and find the potential of an mHealth tool to address these challenges.

Table 1. Focus group participants summary

Institution Name	IPNA	NIMH	Nishpap	AWF
Location	Dhaka	Dhaka	Dhaka	Chittagong
Duration (hours)	1	2	3.5	3.5
No. of Participants	3	8	14	3
Aggregated Participant Summary				
Experience of Participants Dealing with ASD (years)	0-1	1-3	3-6	>6
	1	5	6	16

Distribution of Professional Designation of Total No. of Participants	Psychiatrist	Psychologist	Pediatrician	Pediatric Neurologist	Other
	17	2	2	3	4

28 MHPs, 2 government officials, and 10 parents of children with ASD participated in these sessions (detailed in table 1). The MHPs were selected on a random basis from the convenience-sampled institutions [87]. One of the clinical coordinators of the research team moderated the FGDs, which are audio recorded and later transcribed and analyzed. These FGDs frequently highlighted the current situation of scarcity of skilled mental health professionals. We qualitatively analysed the interview and FGD notes using thematic analysis [5] and grounded theory [24]. The interviews and FGD sessions revealed the following challenges faced by the caregivers regularly: 1) lack of time during visits to express the condition of their children; 2) lack of regular communication with practitioners, and; 3) lack of knowledge in general (what to focus on, what to achieve next etc.). In contrast, that of the practitioners were: 1) lack of data points to get the whole picture; 2) irregular visits with commonly exaggerated information; 3) failure to answer questions with clarity; 4) limited time window during visits, and; 5) lack of communication (no feedback) between visits. From heretofore, we will use PC# and CC# to refer to practitioners' or caregivers' challenge number. Along with the aforementioned challenges, three themes came up again and again as the major constraints in the care system for children with ASD in resource scarce contexts - a) financial hardship for parents to arrange frequent visits (a visit to major cities typically requires patients to spend BDT 800-1600 (approximately USD 10-20) [26]) and to accurately report to MHPs; b) lack of availability of MHPs, and; c) lack of availability of longitudinal data of behavioral changes. We included participants from the family welfare department of the Government of Bangladesh to take their input in terms of the Government's willingness and priority is such a project to make it a scalable and sustainable project in the future. One interesting observation from this two-step challenge identification process was the unanimous acceptability among the caregivers of an mHealth tool that might help them to improve the quality of care. As one caregiver said, "*I always carry my phone with me. Actually, all the adult members of my family have mobile phones. If spending some minutes for my son helps me to get better treatment, get better attention, and doctors are ok with it, why not?*"

4.2. Identification of parameters

This project adopted a systematic and comprehensive procedure for identifying a set of demographics, behavioral, and developmental progress parameters (also known as milestone parameters) that - i) are feasible to incorporate in existing treatment practice and ii) might help the practitioners in decision making if monitored longitudinally.

Identification of behavioral parameter

With the help of a group of ASD care practitioners (n = 7) and parents (caregivers) (n = 9), we identified a set of questions to put into the preliminary data (e.g., demographic and contact information, height, weight, sibling information, ASD severity, and number of years of being diagnosed) and a set of behavior parameters based on two internationally recognized autism monitoring routines (Indian Scale for Assessment of Autism (ISAA) [15, 68] and DSM-5 [24]). Both the DSM-5 and the Indian Scale of Autism Assessment (ISAA), used for developing the list of behavior parameters to be monitored, are validated in Bangladesh. ISAA has already been adopted by the Bangladesh government for autism screening. The data collected using mCARE followed the same unit and scale as suggested in ISAA to avoid confusion.

i) Fine tuning behavioral parameters: Later, we used a Qualtrics survey to receive feedback from the MHPs and caregivers on the necessity of selected parameters and frequency of submission (daily/weekly/monthly). Based on the 39 recorded responses (detailed in table 2), we updated the language of the questions asked, frequency of input, and other features (e.g., addition of a free form field for caregivers to provide context against any parameter) as summarized below:

Table 2. Qualtrics participants summary

Gender	M	15
	F	10
	Unidentified	14
Role	Professional	17
	Parents	7
	Unidentified	15
Experience (years)	0-1	4
	0-1	6
	0-1	1
	>6	6

ii) Addition of frequency category: Initially, we had three possible submission frequencies against each behavioral parameter. But 7 MHPs asked to add a 4th category, biweekly/15 days. One of the proponents added the justification as follows:

"I tend to ask the parents to record some of the behavioral parameters in every 2 weeks and I am very accustomed to

that. So, it would be great to see these parameters submitted the same way."

iii) Simplification of the behavioral parameter list: One of the behavioral parameters of the ISAA scale was 'sleep problem'. Several MHPs asked that to be divided into multiple specific questions like 'hours of sleep per night', 'No. of times the child woke up during night sleep', etc. Also, multiple survey respondents (both MHPs and caregivers/parents) were asked to clarify several parameters ('Understands personal care routine') mentioned in ISAA with an example. One of the caregivers responded as:

"Even with a bachelor's degree, I had a hard time understanding some of the questions (parameters). I think it should be as clear as possible. You can add examples to show what you are looking for or make things more quantitative."

For two of the parameters (self-injurious and aggressive behavior), ISAA has both intensity and frequency questions. The survey showed that MHPs are more interested in frequency rather than intensity. Also, 'Unusual sensitivity to light' has been suggested to be represented as 'Unusual sensitivity to shadow/light'. According to one of the MHPs: *"Typically, when I ask my patients (caregivers/parents) about intensity even during face-to-face visits, they have a hard time explaining that. So, I (and I think most others) rely on the frequency to decide. Also, several of my patients mentioned the issue of shadow or darkness, which is missing in the current ISAA scale."*

All these suggestions are accommodated, and finally, a pool of 32 behavioral parameters was finalized. This pool is later used by the MHPs to create a customized monitoring plan for each participating child.

Identification of developmental progress/ milestone parameters

Based on Vineland-II adaptive behavior scale [32], the MHPs and parents also identified a set of developmental progress parameters categorized by age in the domain of communication (e.g., says first and last name when asked), daily living skills (e.g., brushes teeth), socialization (e.g., shares toys), and motor skills (e.g., color simple shapes).

The Vineland scale, used for identifying developmental parameters, has been validated and used frequently in India for similar settings [53]. The MHPs and parents discarded/altered multiple developmental progress parameters mentioned in the Vineland-II scale, as those either do not culturally fit or are not considered as priorities. For example, most of the caregivers discarded the 'memorize the address' parameter, saying "*...we never let our kid go outside the house alone. Even the gate is under lock and key all the time. So, I don't think it is as important as other parameters.*" Also, sometimes the MHPs and caregivers have conflicting opinions in terms of the importance of certain parameters. As one of the MHPs said: *"We consider self-hygiene (like cleaning themselves after pooping), self-eating, or getting self-dressed are very important from childhood whereas many parents consider these will be learnt by the kids later because it is very common for parents in Bangladesh to do these things for their kids (even for normal ones) for long period. Parents are more concerned about education (learning colors, alphabet, etc.)."*

Just like the behavior parameter pool, a pool of developmental progress parameters to be monitored is created for two age groups: 3-6 and 6-9, accommodating the aforementioned issues. The number of parameters adapted from the Vineland-II adaptive behavior scale and selected for each age group is summarized in table 3.

Table 3. Number of developmental progress/milestone parameters by categories

Domain	Age (3-6)	Age (6-9)
Communication	13	11
Daily living skill	9	10
Socialization	6	5
Motor skill	10	6

A complete list of the milestone parameters used in the study has been added in Appendix A. The form used by clinicians to choose the behavioral parameters (from the potential pool of 32 behavioral parameters) to be monitored for participants, including frequency of data submission and baseline value, is shown in Appendix B.

4.3. Study site and population

The mCARE study took place in 4 major institutes of Bangladesh in two geographical locations - Dhaka and Chittagong. We collaborated with two of the largest government ASD research and treatment institutes, the National Institute of Mental Health (NIMH) and the Institute of Pediatric Neuro-disorder & Autism (IPNA), to recruit 100 caregivers of ASD kids from each. The participants from each institute are divided into two groups - mCARE-APP (50) and mCARE-SMS (50), who will later be using the app and SMS version of mCARE. Each group is further divided equally into test (25) and control (25) groups. Typically, in Bangladesh, families with low and high socioeconomic resources receive treatment from public and private organizations, respectively. To include participants from all socioeconomic classes, we included two private organizations - Nishpap (means sinless) and AWF (Autism Welfare Foundation). 50 participants are chosen from each of these schools, divided into test (25) and control (25) groups only for the mCARE-APP study.

Table 4. Participants overview (P: Mental Health Professional, C: Caregiver)

	NIMH	IPNA	AWF	Nishpap
mCARE-SMS	50 (C)	50 (C)		
mCARE-APP	50 (C)	50 (C)	50 (C)	50 (C)
mCARE-DMP	5 (P)	5 (P)	3 (P)	3 (P)
Status	Public	Public	Private	Private
Location	Dhaka	Dhaka	Chittagong	Dhaka

Our FGD sessions revealed that all the parents/caregivers of these children have smartphones, and so mCARE-SMS is not applicable in this scenario. A total of 16 MHPs used the web-based mCARE data management platform (mCARE-DMP) to monitor and utilize the data submitted by the caregivers in their treatment process. A summary of the participants recruited from these 4 sites is given in table 4.

4.4. Eligibility, recruitment, and enrollment

This project involved a total of 300 children, aged 3 to 9. We incorporated diversity in terms of age, sex, ASD severity, and family socioeconomic resources. The power analysis yields that the sample size of 300 is sufficient to discover a difference among mCARE-SMS, mCARE-APP, and the control groups with the power of 0.97 at $\alpha = 0.05$ and the medium effect size. The power analysis was performed using GPower 3.1 based on the ANOVA with all covariates including all demographic variables, care facilities, and MHPs. Recruitment was subjected to voluntary participation by the legal guardians and was conducted through the MHPs. We did not use children with serious illnesses or who are otherwise unable to participate. The recruitment was performed over 7 months from March 2019 to September 2019. All the caregivers read and signed the consent form in Bangla. After signing the consent, the participants are asked about their access to types of mobile phones and comfort using mobile apps. Based on their answers, they are classified into the mCARE-APP or mCARE-SMS study group. Later, they are randomly classified into either the test or control group. The consent and data collection methods were approved by the Bangladesh Medical Review Council (BMRC). It should be noted that the caregivers were approached by the MHPs during their regular visits. All the test group subjects are given 50 BDT (USD 0.60) per month as data cost.

4.5. Preliminary data collection

We performed the following tasks with the help of one MHP/clinical coordinator (clinical coordinators are MHPs who are assigned to supervise the issues of each site. Four clinical coordinators were assigned, one for each site) and one researcher:

Demographic data

Each caregiver filled out a demographic questionnaire with 28 questions categorized into two domains: socio-demographic information of the child (10 questions) and birth and developmental history (18 questions). This took around 30 minutes on average to complete. Most of the questions (22 out of 30) were organized in a combo box ('choose one of the options from the following') category to minimize the burden on the caregivers.

Baseline value of behavioral and milestone parameters

At this step, MHPs, who are already familiar with the medical history of the child, selected 6~23 behavioral parameters that are appropriate for the child in question and would be most helpful if longitudinally monitored. This required 6-8 minutes by the MHPs. Most of the caregivers are assigned 6~13 parameters (67%) with varied frequency of submissions (daily/weekly/biweekly/monthly) as requested by the MHPs. Later, based on the discussion with each caregiver, MHPs selected one or two developmental progress/milestone parameters from each of the four categories (communication, daily living skills, socialization, and motor skills). This selection process of milestone parameters took around 15 minutes. The frequency of submission for milestone parameters is selected as monthly and justified by one of the MHPs (MHP 9) saying:

"These developmental progress parameters do not change in days or weeks. So, monthly should be fine. Also, we don't exactly need too many data points on these since we do not use them for treatment purposes, unlike behavioral parameters."

Finally, caregivers are asked to put in the current parameter values for each of the selected parameters. For behavioral parameters the scale was from 0 to 10 (with 0 means never and 10 means almost always as mentioned in the ISAA scale) and for developmental progress parameters the scale was from 0 to 2 (with 0, 1, and 2 stands for never, sometimes, and always respectively as mentioned in Vineland-II scale). While MHP was recording this information on paper, one researcher recorded the values in the mCARE database. Demographic and baseline values of behavioral and milestone parameters are collected from all 300 participants. Along with this, we also collected baseline information regarding satisfaction level (towards MHPs and quality of care), basic knowledge of ASD, and travel time and cost for each visit from all participants. The same set of data is also collected from all 300 participants at the end of the study. It should be noted that this portion of the data collection was done by the researcher only, since we felt that caregivers would not feel comfortable putting the satisfaction level value for MHPs/quality of care in the presence of an MHP.

Installation of mCARE and training

After the data collection is done and recorded in the database, a text with an installation link is sent to the mobile phone of the caregivers of CWA who are selected for the mCARE-APP test group. One researcher helped the caregivers install the app. It should be noted that each caregiver received a customized version of mCARE-APP, which will show only the selected behavioral and developmental progress parameters with the chosen frequency for the child. After that, each caregiver is trained on how to submit values using the mCARE-APP. Caregivers of the mCARE-SMS test group are also trained on how to check and send SMS with parameter values multiple times until they feel comfortable. The usability test result is shown in figure 1.

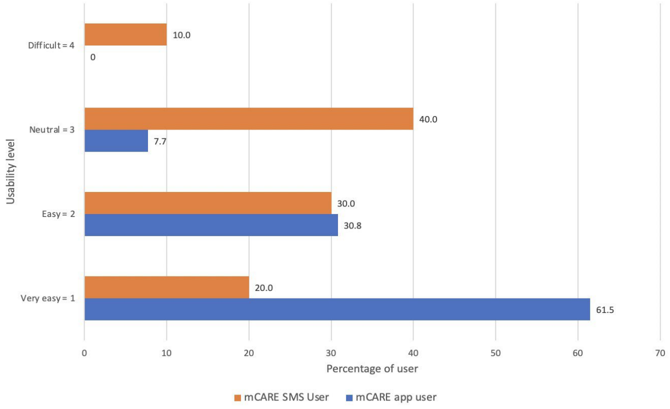


Figure 1. Usability analysis of mCARE-App and mCARE-SMS users

4.6. Training of MHPs

We organized training sessions in all four sites (NIMH, IPNA, Nishpap, AWF) to show all the features available for the MHPs while using the web-based data management platform, mCARE-DMP, which visualizes the longitudinal data submitted by the caregivers. Since the actual submission did not start by that time, two researchers showed the demo using dummy data.

4.7. Data collection and coordination methodology

All the caregivers who belonged to the mCARE-APP or mCARE-SMS test group submitted data from Nov. 2019 to Nov. 2020. All the researchers and MHPs met every week for 30 minutes to discuss the day-to-day operations of the study. A larger (2 hours) group discussion is scheduled quarterly to discuss the experience of long-term use of mCARE-DMP and its impact on the quality of care of CWA. We also had an end-of-study interview with 30 caregivers to collect their experience of using mCARE-APP or mCARE-SMS.

5. MCARE Development

5.1. Design and Development of mCARE

As pointed out in our detailed related work and methodology section, this is the time for technological innovation and adaptation of validated methods to address the burden of ASD in LMICs. The barrier to technological breakthrough mostly lies in the form of sociocultural challenges in the form of acceptance, ability, and adaptation. Design lessons learned following the perception of caregivers and MHPs helped us to design a user-oriented and culturally acceptable technological intervention.

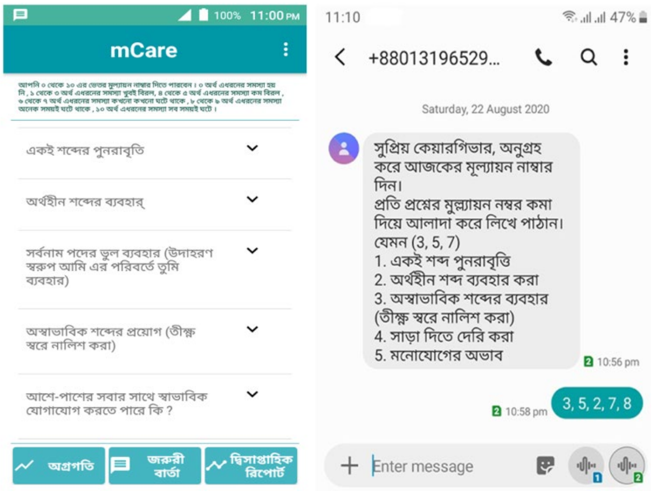
mCARE adopted the three-step methodology of Value Sensitive Design (VSD) for the design process. For the 'Conceptual' (identify the stakeholders and their cultural values based on theoretical concepts/previous studies/stories from local people) and 'Empirical' (collect empirical data to underpin the understanding of local values and practices of the stakeholders) step, we relied on exhaustive field visits, FGD discussions, face to face and phone interviews, online surveys, and long experience of the mCARE team members in providing care to children with ASD, and designing, developing mHealth applications for targeted communities in Bangladesh [23, 28, 30, 36, 40–42, 48, 64, 80]. For 'Technical' (build technologies according to the stakeholders' values, deploy the technology with them, and gradually improve the system based on feedback from the users) step, we developed mCARE-APP and mCARE-SMS following a user-centered and evolutionary approach (Agile development method) [22] constantly integrating feedback from users [15, 48]. mCARE has adapted to Fogg's Behavior Model (FBM) by providing bi-weekly reports and hopes of better care as 'motivations', its simple as possible design ensures 'ability' to use, and regular prompts for reminders will act as 'triggers'.

mCARE-APP

We developed mCARE-APP for active parental monitoring of behavior and developmental progress parameters of CWA. Caregivers used mCARE-APP to submit selected parameter values, send emergency SMS to the MHPs, and view a bi-weekly summary report. The bi-weekly report summarized the performance of the child in the last month and outlined any odd values, if represented. This allowed the caregivers to reflect on the status of their child. Software development for mCARE-APP has occurred in three cycles over three months. For each period, the first step was to analyze the stakeholder challenges and requirements (as identified during the FGDs, interviews, etc.). Next, the software program was designed with the research team's input and vision. A minimal viable product of the software system was built and showed to 3~5 caregivers of the mCARE-APP test group. Based on the feedback, adjustments were made, and the process of analysis, design, coding, and building a prototype was repeated. Further, we evaluated options for providing written instruction, audio guidance in the local dialect, or video in which a mother of a child with ASD showed the steps [31, 48]. We also considered different design trade-offs, such as login-based (more secure but less user-friendly) method vs. IMEI-based authentication method (less reliable but provides ease of use). We conducted a formal heuristic evaluation and cognitive walkthrough of mCARE-APP using Nielsen's heuristic evaluation to ensure the usability and navigability of the developed tool [21]. We also used the System Usability Scale (SUS) to validate the user interface design with questions on the usability, learnability, complexity, navigability, and confidence of use [72]. Five caregivers (different from those who gave feedback during the development phase) were randomly selected for this usability study.

mCARE-SMS

For SMS communication between the mCARE service and the caregivers of CWA, we needed 2-way communication (all the SMS are sent from a certain number and received in that specific number). An SMS is sent to the caregivers with the names of the parameters for which values need to be submitted for that day, and the caregivers are required to reply with the sequential values separated by a comma. But we could not find any service that supports 2-way SMS communication; rather, all of them are just 1-way from mobile operators to users for advertising purposes. To overcome the situation, we had to build a separate Android app that works as an SMS gateway to serve our requirements. It is a background service app, and it always fetches the SMS to send from the server and sends it through the mobile network. When a caregiver replies, the app reads the SMS from the device and notifies the server about it. Figure 2 shows the sample screenshots of mCARE-APP and mCARE-SMS.



আপনি ০ থেকে ১০ এর ভেতর মুল্যায়ন নাম্বার দিতে পারবেন। ০ অর্থ এধরনের সমস্যা হয় নি, ১ থেকে ৩ অর্থ এধরনের সমস্যা খুবই বিরল, ৪ থেকে ৫ অর্থ এধরনের সমস্যা কম বিরল, ৬ থেকে ৭ অর্থ এধরনের সমস্যা কখনো কখনো ঘটে থাকে, ৮ থেকে ৯ অর্থ এধরনের সমস্যা অনেক সময়ই ঘটে থাকে, ১০ অর্থ এধরনের সমস্যা সব সময়ই ঘটে।

একই শব্দের পুনরাবৃত্তি

অর্থহীন শব্দের ব্যবহার্

সর্বনাম পদের ভুল ব্যবহার (উদাহরণ স্বরুপ আমি এর পরিবর্তে তুমি ব্যবহার)

অস্বাভাবিক শব্দের প্রয়োগ (তীক্ষ্ণ স্বরে নালিশ করা)

আশে-পাশের সবার সাথে স্বাভাবিক যোগাযোগ করতে পারে কি ?

সুপ্রিয় কেয়ারগিভার, অনুগ্রহ করে আজকের মূল্যায়ন নাম্বার দিন।
প্রতি প্রশ্নের মুল্ল্যায়ন নম্বর কমা দিয়ে আলাদা করে লিখে পাঠান।
যেমন (3, 5, 7)
1. একই শব্দ পুনরাবৃত্তি
2. অর্থহীন শব্দ ব্যবহার করা
3. অস্বাভাবিক শব্দের ব্যবহার (তীক্ষ্ণ স্বরে নালিশ করা)
4. সাড়া দিতে দেরি করা
5. মনোযোগের অভাব

3, 5, 2, 7, 8

Figure 2. Screenshot of (a) mCARE-APP (b) mCARE-SMS interface

mCARE-DMP

We developed mCARE-DMP is developed as a visualization and analysis tool for the MHPs based on the data submitted by the caregivers. Here, a key challenge was to present this data to the MHPs in an easy-to-use and meaningful way. Based on the FGD sessions conducted, we identified the following features to address the challenges and requirements mentioned by the MHPs: a) Longitudinal view: Single or multiple parameters of a selected child can be monitored over time to show the changes in the behavioral pattern over time; b) Real time SMS feedback: MHPs can create customized triggering events for each child through mCARE-DMP (e.g., send a SMS if the aggressive behavior is more than 8 for two consecutive days); c) Multi-subject comparison: Single or multiple parameter comparison of multiple children over time; d) Time-feature based query: MHPs can select specific data to visualize based on date range, parameter name, and parameter value. This feature is useful to find outlier values and identify specific contexts that contributed to those values; e) Zoom in a particular segment of data based on MHP's interest to add more information (time of the submission, contextual information provided by the caregiver if any etc.), and; f) Dynamic customization: Practitioners can add/delete new parameters to be monitored and change the monitoring frequency based on the situation. Figure 3 shows a drawing sketch of the mCARE-DMP interface created during a meeting with MHPs.

5.2. Evolution of mCARE

The caregivers and MHPs started using mCARE in November 2019. We collected feedback from the MHPs and caregivers every week for the first 4 weeks. Here we summarize the adjustments and lessons learned as part of the evolution of mCARE as a final product.

mCARE-SMS technical challenges

From our end, we were trying to send an automated SMS to each of the 50 mCARE-SMS test group participants within a certain time period. During the very first week, many caregivers reported to the MHPs that they did not receive the expected SMS. Later, it was found that, as the mCARE-SMS system uses generic SMS sending from devices (not any purchased service from operators), it has limitations on the sending frequency (not more than 1 message per minute). We resolved this issue by creating two SMS gateways on two Android devices. This customized system allowed us to send one SMS every 5 minutes from a single Android device. We resolved this issue by creating two SMS gateways on two Android devices. Another limitation is, the Android OS sometimes makes the gateway process in sleep mode, resulting in failure to deliver. To overcome this, we implemented a regular status check for the gateways on the server.

i) Update the SMS acceptance pattern: mCARE-SMS test group users received an SMS with the name of the behavioral parameters for which they need to submit values. The reply text is expected to have the symptom values (between 0 to 10) separated by a comma as shown in Figure 2(b). Within weeks of the data collection phase, MHPs complained that they called multiple caregivers to notify them about missing data and got the reply that they had submitted the data (SMS reply). Later, it was found that the SMS server received the reply, but the database code (parser) was not able to parse that

SMS and record the parameter values in the database. This is because the parser used a comma as the delimiter, and many of the SMS received from the caregivers were not in the correct format. To resolve this, we updated the parser code to parse SMS where parameter values are separated by comma (e.g. 3, 4, 5, 6, 4), semicolon (e.g. 3; 4; 5; 6; 4), dash (e.g. 3-4-5-6-4) or mixed format (e.g. 3, 4; 5, 6- 4.). We also updated the SMS sent to the caregivers to include a sample correct pattern (comma-separated) at the top, as shown in Figure 2(b).

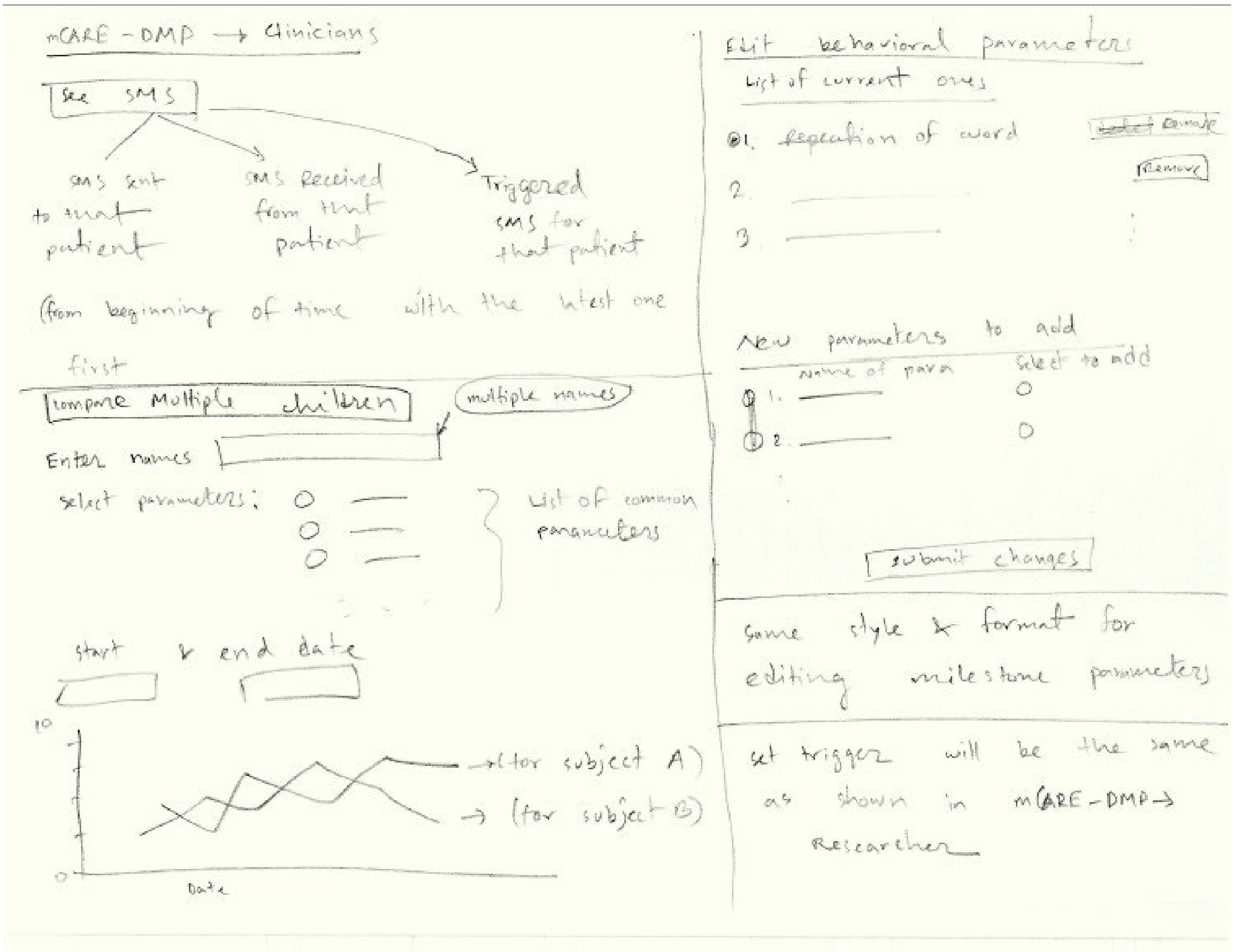


Figure 3. Planning phase pencil sketch of mCARE-DMP

ii) Dynamic customization of behavioral/developmental progress parameters: Once the MHPs started using mCARE-DMP for longitudinal monitoring, they found that some of the selected behavioral parameters are no longer helping in their decision-making. This happened mainly due to receiving low scores (1~2) over a while for those selected parameters. Also, two MHPs asked to add a new behavioral parameter that was not in the pool of behavioral parameters to choose from. One MHP complained as follows:

"This caregiver (IPNA 101) is submitting 1 or 2 for aggressive behavior for almost a month. And I do not think I need to monitor that parameter anymore, at least for the moment. Rather, I would like to add some other parameter to monitor. Also, for some other subject (IPNA 134), I would like to monitor 'sensitivity to specific color' since that is mentioned by the caregiver several times recently. But I couldn't do that since this parameter is not in the list of parameters. Autism is a spectrum, and that changes dynamically, and the software should be able to cope with such issues."

As a result, we added the features of add, delete, or edit (change frequency of submission) for existing parameters. Along with that, we created a feature that allows the MHPs to create their own parameters to be monitored (if that is not available in the pool of parameters created).

iii) Addition of data submission adherence interface: Data submission adherence was one of the biggest challenges. As per protocol, MHPs called the caregivers to motivate them to submit data, especially those who are missing data regularly. Based on MHPs' request, we provided an interface to give a data submission history for the last 7 days of all caregivers under that MHP's care. Also, MHPs can query to show a chart of only those caregivers who missed data more than a specified number of days in a week. This helped the MHPs in prioritizing the list of caregivers they would like to call.

6. Discussion, Lessons Learned, And Impact Of COVID-19

To understand the performance, issues, and challenges of mCARE, we met with the mCARE-DMP team quarterly for group discussions and discussed the following questions.

1. What is your experience so far using mCARE-DMP (positive or negative)?
2. Do you think it saves you time?
3. Which features of mCARE-DMP do you use most?
4. Can you give a case example for each feature you used?
5. Do you think it is helping you in managing your patients?
6. Can you give any example where mCARE-DMP helped you in making evidence-based decision-making?
7. Can you please elaborate and compare your experience pre- and post-deployment of mCARE in terms of patient management?

6.1. Discussion and Lessons Learned

"What's my benefit" and data submission adherence

After the initial enthusiasm of getting involved in a new project was over, we saw a sharp decline in terms of data submission adherence. Though the benefits of participating were articulated during the consent signing, many of the caregivers echoed the following sentiment of a caregiver (Nishpap 14):

After the initial enthusiasm of getting involved in a new project was over, we saw a sharp decline in terms of data submission adherence. Though the benefits of participating were articulated during the consent signing, many of the caregivers echoed the following sentiment of a caregiver (Nishpap 14):

"I have been submitting the data for 3 months now. But I don't see any noticeable improvement in my child's behavior. I somehow thought there would be a miracle and my son would get better once I start (..and hence do not have the motivation for regular submission). Also, it is too many (parameters)."

Based on this, MHPs asked 20 caregivers (10 mCARE-APP and 10 mCARE-SMS test users) two specific questions: i) what number of parameters they would feel comfortable submitting, and ii) what we can do to help them benefit. Then we discussed the findings during our weekly meeting (with all researchers and MHPs) and made the following changes in our protocol: i) maximum number of parameters to be monitored would be restricted to 5~7 parameters; ii) Monthly call from clinical coordinators, and; iii) Monthly free face to face meeting with senior mental health professionals (director of IPNA, director of NIMH, and ex director of NIMH) who served as site principal investigators for mCARE. We also trained the clinical coordinators (who keep regular contact with the participants) to repeat the benefits during their conversation. For example, the clinical coordinator of NISHPAP explained to one of the caregivers as follows:

"We know it is hard to see any notable improvement in behavioral parameters in a short period. But as you see, when I call you, I know the exact status of your kid since you have submitted data regularly. Others (who are not participating) do not get regular calls from us. Please take the opportunity to meet with Professor X (the senior professional overseeing NISHPAP participants) end of the month. Also, you can send me an SMS (text message)) and get help in any situation instantaneously."

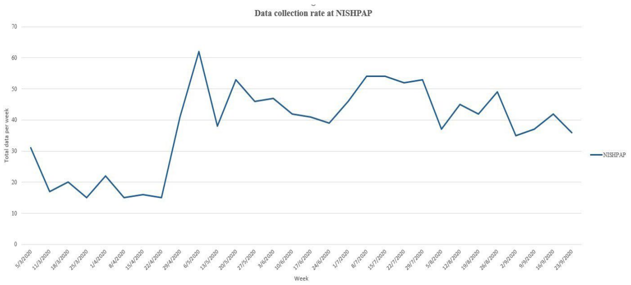


Figure 4. Data collection rate at NISHPAP over the study period

Finally, MHPs suggested providing some kind of instant feedback right after the caregivers submit data. So, we provided a link once the data is submitted, which, if clicked, would show the longitudinal representation of the submitted data for the last 7 days. This would provide instant feedback to the caregivers regarding how their child is doing over the past week. All these steps helped us to improve the data submission adherence rate as shown in Figure 4. Before these steps, the average data submission rate over all 4 institutes was 39.05% (Nov 2019-Apr 2020). And after implementing the changes, the corresponding rate increased to 54.43% over the period of six months (May 2020 - Oct 2020).

Milestone parameter – the 'sense of achievement'

One of the challenges mentioned by the caregivers is that they do not have an idea of what to achieve next (CC3). As a solution, we added developmental progress parameters as part of the longitudinal monitoring. These would be used as individualized milestones to be achieved by the caregivers, and MHPs would update these with different ones once achieved, thus continuously engaging the caregivers with small targets. Each caregiver was given 8 developmental progress/milestone parameters (2 from each of the 4 categories mentioned in the Vineland II scale) to work on. During the monthly call, clinical coordinators specifically asked about the progress on milestone parameters and guided the caregivers regarding how to achieve the next level for the selected parameters. Once the value of any of the milestone parameters reaches 2 (which represents always), that is replaced with a new target. One of the caregivers (NIMH 03) said:

"I have tried really everything to improve (the symptoms), but I don't see much (for behavioral parameters). But for these (milestone parameters), I try to teach them and take advice from the madam (clinical coordinator of NIMH). I taught my son the names of 5 colors. I felt that I really accomplished something, some positive change that I can see. I think this is helping me not to lose hope and carry on."

Overall, out of total 1200 (150 test group participants X 4 domains X 2 parameters per domain) developmental progress/milestone parameters (over 4 domains) selected for mCARE test group members, improvement was seen in 732 of them (61%) and the rest (39%) remain unchanged (neutral). This analysis is based on comparing the data collected at the end of the study with the baseline value. If the baseline value of the selected parameter changed from 0 to 1 or from 1 to 2, we have considered that as an improvement (with 0, 1, and 2 standing for never, sometimes, and always, respectively, as mentioned in the Vineland-II scale). For the mCARE control group, the percentage of parameters that improved (over all 4 domains) is 21.05%. The summary of the change in developmental progress/milestone parameters is shown in table 5.

Table 5. Percentage of participants with improved milestone parameters.

	Communication		Daily Living Skills		Socialization		Motor Skills	
	Test	Control	Test	Control	Test	Control	Test	Control
NIMH	19.9	1.4	20.4	8.1	19.0	3.6	21.3	6.3
IPNA	10.9	2.2	34.8	12	15.2	1.1	20.7	3.3
AWF	13.8	9.7	17.2	9.7	15.9	11	13.8	9
Nishpap	6.9	0.0	37.9	3.4	20.7	0.0	27.6	3.4

As seen from table 5, the average percentage level of participants with improved developmental progress/milestone parameters for the mCARE test group (78.82%) is significantly higher compared to that of the mCARE control group (21.05%). Unlike the mCARE-APP test group, the mCARE-APP control group did not submit regular data or receive calls from the clinical coordinators with suggestions regarding how to work on the selected milestone parameters. This indicates the impact of mCARE in improving the developmental progress/milestone parameters.

This table gives an interesting insight into the prioritized focus of the caregivers. The percentage of mCARE test participants (all four sites) with improved milestone parameters is 34.33 (Communication), 73.53 (Daily Living Skills), 47.2 (Socialization), and 55.6 (Motor Skills). The corresponding values for the mCARE control group are 8.87 (Communication), 22.13 (Daily Living Skills), 10.47 (Socialization), and 14.67 (Motor Skills). This indicates that caregivers from both test and control groups put most of their efforts into 'Daily Living Skills', followed by 'Motor Skills'. One of the caregivers (AWF 17) said the following:

"I have tried for his other skills (like eye contact), but I am mostly focusing on the basic things so that he can do these things by himself. I want to make sure he can have his food by himself, dress by himself, can hold a pencil, etc. These are the must-haves for him. I am worried what would happen to him when I am not here if he doesn't know these skills."

Single SIM (subscriber identity module)/mobile number registration issue

At first, all the caregivers were registered with one mobile number, and mCARE-SMS test users would receive and reply to their feedback from that mobile number. This created the following issues:

Case 1: A specific caregiver (IPNA 186) failed to submit data for several days, which was pretty unusual for her.

When called by the MHP, she said that the SMS comes to the mobile phone of the father, and the father is away due to office purposes for some days. Since the mother did not get an SMS from the system, she wasn't able to reply. It should be noted that, for most cases, both father and mother visited the day when consent was signed, and baseline data collection was done. And in Bangladeshi culture, when a question is asked, typically the father, as the head of the household, answers the question. And once the mobile number is asked for, in all cases, the mobile number of the father is recorded. This resulted in multiple missed submissions, since typically mothers play the role of primary caregiver, and they are the ones who submit the data. As one of the caregivers (IPNA 186) said:

"As long as my husband is at home, I try to submit it. Sometimes I submit it late at night if he comes late from the office. On the weekends, I try to submit early before he goes out for family needs. He knows I submit the data from his phone, but he never does it by himself. That's why when he was out for several days, I could not submit."

Case 2: In several cases, the MHPs communicated with the caregivers, and they said that they did not receive the SMS. But our automated system showed that SMS has been sent. Later, it was found that they had changed their mobile number. In Bangladesh, it is very common to have multiple SIM (Subscriber Identity Module) cards. People tend to just buy a new SIM whenever a new promotional offer comes from one of the mobile carriers. To limit this situation, Bangladesh Telecommunication Regulatory Commission (BTRC) capped the maximum number of SIMs allowed against a specific national ID to 15 [2]. It should be noted that, in Bangladesh, the mobile number is not transferred when you take a new SIM. But due to socio-cultural impact, mothers tend to be less interested in changing their mobile numbers. To resolve these case scenarios, we updated our system and added the mobile number of the mothers in the records and sent SMS to both the numbers (father's and mother's). We initially thought of sending the SMS only to the mother. But considering the socio-cultural context, we decided to send the SMS to both parents. As one mother said:

"Please do not just send it to me. I have to go through a lot just because I have this child (suffering from ASD). He might think he is not being given enough importance if you send the SMS only to me. I need to keep him happy just to participate in this."

Evidence-based decision making

Lack of data over time has been identified as the single most important factor hindering the evidence-based management of ASD care (PC1). This is now available through mCARE-DMP, and so MHPs can make more informed, data-driven decisions. During the quarterly group sessions with participating MHPs, we identified cases where longitudinal data (or other features of mCARE-DMP) helped them in making evidence-based decisions.

These quarterly sessions are centered around 4 questions:

(1) Do you think it is helping you in managing your patients?
(2) Can you give a case example for each feature you used?
(3) Can you give any example where mCARE-DMP helped you in making evidence-based decision-making?
(4) Can you please elaborate and compare your experience pre- and post-deployment of mCARE in terms of patient management?

Along with the availability of longitudinal data, MHPs identified four specific visit scenarios that they regularly experience, where mCARE-DMP was helpful. Some use case scenarios are given below that came up during these discussions:

Case 1: Focusing only on certain parameters: According to the MHPs, many parents are only interested in talking about certain parameters or issues that they think are important. This happens due to socio-cultural impact and personal belief. As MHP 2 said:

"Many of the parents come to me and spend the whole time on a couple of specific issues, like does he respond when called by name, or does he smile socially, or does he avoid eye contact. These are important parameters, but their kids have other important issues to talk about, too. But they are simply not interested."

When we asked certain caregivers about this, we got a different context. This caregiver (Nishpap 11) said:

"I live in an extended family, and people want to make sure kids respect the seniors. As you know, in our culture, not to smile or respond when a senior calls is considered very rude. I want to make sure my child learn this first. Also, it is not the case that I do not want to discuss the others (parameters). They (MHPs) simply do not have that time. If I have 5 minutes, I first like to talk about these priority points." But now, MHPs can simply select the other important parameters and monitor them using mCARE.

Case 2: Suppressing certain parameters: When caregivers visit with their children, many times, MHPs do not see some of the features that might be important. This is because sometimes parents do not want to show things to the clinician that they find embarrassing and even coach their children not to do things during visits. MHP 3 detailed one specific experience as follows:

"..I was about to finish the visit and then all of a sudden this kid banged his forehead so hard on my table that I was afraid his skull had been fractured. But I saw his parents were not that concerned. This gave me an idea that this is not the first time. They never reported this issue before, and hence I did not select this parameter to be monitored. Then I asked them to be open with me. Initially, the father said that it is not a big deal, but later he said he did not want others to know about this issue, especially when the door is open and others in line just outside my door can see. Once they are submitting the values from their home, they are typically honest (since no one else is seeing that except me)."

Case 3: Over-emphasizing symptoms/outliers: Caregivers travel to IPNA and NIMH, which are the two most renowned public institutes in Bangladesh, from all around the country, typically 3 or 4 times a year (according to our field study). There is this common belief among caregivers that they would get better attention and treatment if they exaggerated the symptom values. Also, they inadvertently highlight certain parameters due to recall bias. MHP 7 summarized this common experience as:

“Any parameter that the caregivers like to prioritize would get a higher value. And you know, whatever they say, that is the gold standard. Sometimes I am not sure what to do (to stick with my feeling or accept what the caregiver is saying). But now I can verify the actual average of any parameter, looking at the historical data (mCARE-DMP).”
MHP 6 shared her experience with outlier values, saying:

“This caregiver (mother) spent half of the visit time talking about aggressive behavior. But when I checked the longitudinal history, I was confused since I did not see high values there. When I shared this, she explained that the kid was aggressive on the way here. And they took 3 transports (bus, rickshaw, and scooter), and the bus was full of people. She also mentioned that some people on the bus were even taunting her son. Because this had happened just before the visit, she was upset and wanted to focus on this. Without the longitudinal history feature of mCARE-DMP, I would never be able to verify this.”

Case 4: The complete picture: During our field visit, the lack of data resulting from infrequent visits came up again and again. MHPs mentioned the term ‘complete picture’, which they often miss, but very important for treating CWA. MHP 1 said the following:
“Sometimes I used to feel shaky to prescribe since I was not confident to prescribe with so little and seemingly exaggerated or vague (PC2, PC3) information (received during the face-to-face visits). But now I can see the whole timeline of how it went once they left my office last time. Also, if I feel, I can simply add a new parameter or discard a parameter not needed anymore. I feel more powered and more confident.”

Utilization of ‘otherwise wasted’ time

As per the Value Sensitive Design (VSD) approach, we wanted to make sure mCARE-DMP is not adding any burden on the MHPs but rather merged seamlessly with their current care protocol and helped them overcome the challenges they face. We were especially interested to know about the extra time spent using mCARE-DMP. All the MHPs agreed that other than the initial training and learning curve, this has been very helpful. A common consensus was that they like to use it when they are stuck in traffic jam. As MHP 2 said:

“Typically, I see one or two caregivers (from the mCARE project) daily. And now (after almost 9 months) it is very common for the caregivers to call us to notify us that they are going to come that day. I simply take a look at their longitudinal data while going to the center on my phone. Otherwise (if not looking at the data), I would just waste that time on something else. Thanks to you that it (mCARE-DMP) works in mobile phones.”

It should be noted that MHPs spend 2 hours/day in traffic jams on average [26].

Improvement in satisfaction

Overall, we found that the average satisfaction level towards quality of care and MHPs has been improved for both mCARE-APP and mCARE-SMS test group participants (compared to baseline data). The average satisfaction level of the mCARE participants is detailed in figure 5.

Figure 5. Change in satisfaction level pre and post-deployment of mCARE

The average satisfaction level on quality of care and MHPs has been improved by 0.8 for mCARE-SMS users, whereas that of mCARE-APP users stands at 1.69 and 1.84, respectively. The answer lies in the mindset of these two groups of users who come from very different socio-economic classes. mCARE-SMS users, belonging to the lower socio-economic class, were happy even to see an MHP in a public hospital, whereas mCARE-APP users always expected more compared to what they received in public hospitals. As a result, there was a big gap in the satisfaction level between these two groups before the deployment of mCARE (6.6 vs 6.08 and 7.8 vs 6.85). mCARE-SMS users simply submitted selected behavioral parameter values with no other features. Hence, their satisfaction level improved by a simple margin (0.8) post-deployment. But mCARE-APP provided many features (longitudinal view of submitted data, biweekly report, developmental progress/milestone parameters, etc.) that helped the mCARE-APP users and that resulted in a big jump in terms of improved satisfaction level (average satisfaction improved by 1.69 and 1.84, respectively). We interviewed a total of 30 caregivers (20 mCARE-APP and 10 mCARE-SMS test group users) and found 3 major reasons that positively impacted the satisfaction level of mCARE test group users.

(i) Technology - the miracle healer: Some mCARE-SMS test users from rural areas credited any improvement in their child's performance on mCARE and thought that it happened because of this 'foreign' system. Caregiver of NIMH 56 said:
"Foreign people are coming with a foreign system. This has impacted her (the MHP) and my son positively. It is a miracle."
The mCARE-APP users, being relatively higher educated and socio-economic class, were more concrete in identifying the relationship between mCARE and better outcomes of their children. As one caregiver (father of AWF 19) said:
"I regularly provide my child's data to the system, and when I consult with the doctor regarding my child, the doctor always observes the previous data and suggests therapy or medicine based on the previous data. So, I noticed a very good and positive response in my child in a short period, which I think was possible by using this mACRE-APP. I have noticed one more thing that I have a relative who has a child with ASD, but his child's improvement is not noticeable. For this reason, I will recommend other parents to use this APP for their ASD child monitoring."

(ii) Personal touch - 'She is like family': Before the deployment of mCARE, caregivers used to consider MHPs as untouchable figures who would spend some minutes with them during each visit. It was unthinkable for caregivers to call the MHPs for any reason. On multiple occasions, we found cases where caregivers did not provide the correct picture or hide issues from the MHPs. All these changed when a bonding beyond the caregiver-MHP relationship was established as a result of regular communication. Mother of NIMH 20 said:
"I cannot express how it changed. At first, she used to call her if there were some issues. Later, I started to call her when I felt any emergency. I even shared my family issues with her. I was able to see the motherly side of her (beyond her MHP figure). Now, I kind of consider her as my elder sister."
Another caregiver (IPNA 41) added that, *"I even called her when I was having difficulty during COVID-19. I was not sure how he could help, but I just felt that I should share my situation with him."*

(iii) Notice of tangible changes: Caregivers repeatedly mentioned noticeable improvement in their child's behavior and credited mCARE for this. Two of the caregivers expressed their happiness as follows:

Case 1: "*I have used it (mCARE) for the last ten months, and I have observed some major behavior changes. At present, my child can indicate a vague sound for his needs. For example, when he gets thirsty, he sounds 'mum mum' or when he is hungry, he sounds 'aub aub', which he could not do before. Besides, now he can bring something if we tell him to do so.*" - (Father of NISHPAP 3.)

Case 2: "*I feel very lucky that I can use this app. I have no complaints, and I am very satisfied. My child's behavior has improved. I always tried to follow the questions that are given by this app and consult with the doctor regularly based on the questions and the outcome of my child. As a result, he can now respond (when called) and also eat by himself using a spoon. In the past, he could not do it even though he was scared to see a spoon. Secondly, he can now take his bath by himself. For his improvement, I credit mCARE*" - (Father of IPNA 110)

The behavioral report for IPNA 110 for the symptom 'Does s/he respond when called by name?' is shown in figure 6.

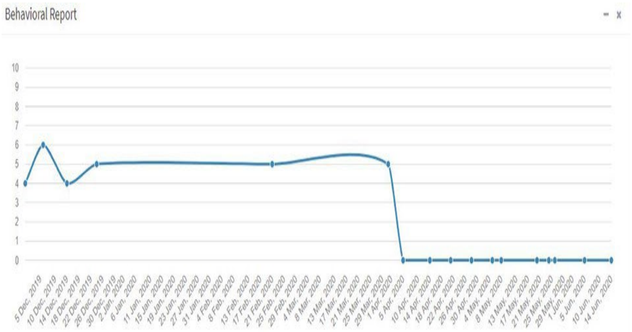


Figure 6. The behavioral data report for IPNA 110 on 'Does s/he respond when called by name?'.

Proactive agent of change

MHPs reported that they have found the caregivers, who submit data regularly, are relatively more aware of their child's situation and many times act proactively. This includes asking for change based on a specific contextual scenario, taking actions based on their judgment (helped by longitudinal data), recording changes of abnormal behavior, etc. According to MHP 11:
"I see that these parents are much more knowledgeable and proactive now. They are asking me questions with examples. Like, my child ate rich food, and the next day he had these issues. Should I be aware of this? Even one mother came with a notebook showing me that when she notices some abnormal value (while entering that value in mCARE), she tries to record what happened that day to show me. I have not seen this before."

Caregiver of AWF 21 said how mCARE is helping in boosting the positive behavior, as:
"I regularly check the longitudinal graph of my children and take necessary steps accordingly. This also helps us keep our motivation high in taking care of our child. If you check (mCARE data), you will see that I followed the

advice of the doctor, and after months, my kid started making eye contact. I made sure I continue doing the things that helped him in achieving this (as shown in figure 7).”

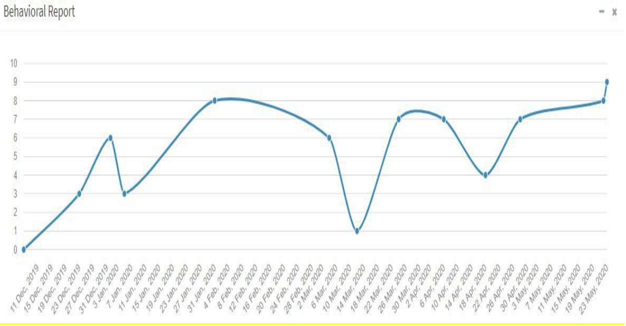


Figure 7. The behavioral data report for AWF 21 on ‘Avoids eye contact’.

Improvement in basic ASD knowledge

Though it is clinically preferred to be diagnosed as early as possible [27], the situation is quite the opposite in Bangladesh. The average age of being diagnosed with ASD is 4 years [9] in Bangladesh, whereas that of in the western world is 18~24 months [70]. Our focus group sessions revealed that the primary reason is a lack of knowledge regarding ASD. Along with that, belief in different myths and lack of available support information also create a barrier in asking for professional help. To address this challenge, we collected answers pre and post deployment of mCARE for 11 basic questions in 3 domains – i) symptoms and treatment (e.g. Do you know what are the primary symptoms of ASD?); ii) support and facilities (e.g. Do you know the government facilities for children with ASD?), and; iii) superstitions (e.g. Do you think it is a punishment from God?). All the answers are recorded as yes or no. The correct answers to these questions are added as special feedback below the biweekly caregiver report. It should be noted that the feature ‘biweekly report’ is only available for mCARE-APP test users. Caregiver of IPNA 141 credited the biweekly feedback mechanism as follows: *"As a parent of an autistic child, I had no idea about the symptoms of autism. I first learned about the autism symptoms when I took my child to the doctor, and he was diagnosed with autism. I believe that many of the parents in Bangladesh do not know about the symptoms, and I think all parents should know them, even though their children are normal. It will help in the early identification of an autistic child, which will help in the long run. I also do not think that it is a curse of GOD. But I used to think it was infectious. Then from the biweekly report, I came to know that that is wrong.”*

The pre-post change of percentage of correct answers for mCARE-SMS test group users stands at 16.5%, whereas that of mCARE-APP test group users is only 4.6%, as shown in Figure 8. Though being more educated, mCARE-APP users answered 77.7% of the answers correctly at the baseline, we expected more than a mere 4.6% increase in correct answers since mCARE-APP test group members received the correct answers to these ASD questions at the bottom of their biweekly feedback report. When asked, one of the caregivers (AWF 1) said, “I just saw the top portion that visually shows if the behavioral symptoms of my child are improving (or worsening). I did not scroll down to read those basic knowledge answers.” We were also pleasantly surprised to see the big jump (16.5%) in the percentage of correct answers among the mCARE-SMS test group participants. It should be noted that, unlike mCARE-APP test group members, mCARE-SMS test users did not receive the correct answers through mCARE.

We asked multiple caregivers and MHPs regarding this and got the following answer:

“I think I know the answer (why there is a big change in percentage of correct answer for mCARE-SMS users). Based on the baseline data (and also from my personal experience), I knew that these people (mCARE-SMS users) are not highly educated (thus not aware of symptoms and facilities available), and they believe in superstitions. That’s why, whenever I called them, I repeated these things because they are the people who suffer most from superstitions and a lack of awareness. I think we all did the same thing, and that resulted in this big change.” (MHP 13)

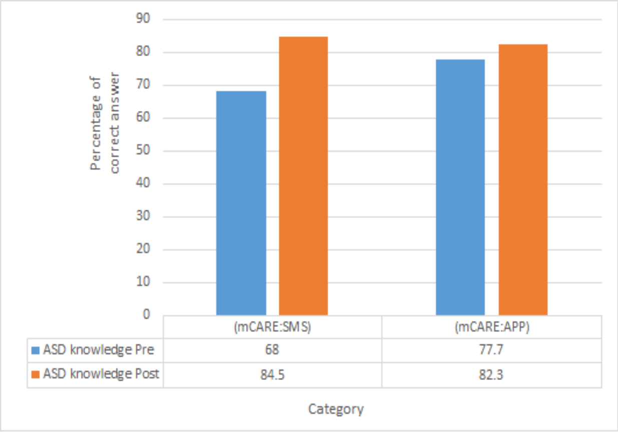


Figure 8. Change in percentage of correct answer regarding ASD basic knowledge pre and post-deployment of mCARE

Real-time monitoring and feedback

The current ASD care treatment process does not involve any feedback mechanism. This leaves practitioners with virtually no knowledge regarding the condition of the children with ASD until the follow-up visit. This challenge has been mentioned by both the practitioners and caregivers (PC5, CC2). mCARE helped to address this by virtually connecting the caregivers and MHPs daily through their submitted data. The caregivers were also able to send SMS to MHPs, and MHPs can send a reply SMS based on the SMS query or triggered events. This denotes a paradigm shift compared to the care mechanism before mCARE. This overall approach closed the missing feedback and monitoring loop. Interestingly, multiple caregivers mentioned the ‘sense of security’ while appreciating mCARE.

"Using mCARE, I feel secure that my child is observed all the time by a healthcare professional, and it creates a bridge between doctor and me for easy communication, and I feel so relieved.” (caregiver of Nishpap 3)

“Before using this app, there was no one to take feedback from my child, and no one took any updates from me. Now, every week, I can give feedback through this app and can also take help from the health care professional if I need it.” (caregiver of AWF 9)

We noted an interesting observation here. Caregivers, who received the reply to their SMS, were appreciative. But several caregivers mentioned that their SMS has not been replied to. On the other hand, MHPs noted that many times those SMS do not warrant immediate attention, rather they termed them as ‘borderline irritating’. One of the MHPs (MHP 3) said:

“Initially, I used to reply to all such messages, but later it started to bother me. One (caregiver) started to send me messages every other day. Sometimes I felt that they were more motivated to send these messages because I replied. Hence, I only reply to the messages that I feel are important. But I always communicate back when a trigger occurs because I know those triggers are set by me and important.”

Visit time analysis

When patients visit the hospitals, they first stand in long queues to buy tickets for outdoor patient visits with MHPs. Then they would come in and stand in line again in front of the door of the MHPs. Our field study revealed that it takes almost 4~5 hours to complete these two processes. During the visit, MHPs ask some behavioral and milestone parameter-related questions of the child based on a ‘physical health-related book’ where the previous health history and treatment process are recorded. On average, it takes around 8~10 minutes for each visit. We noted several issues during our visit observations: i) it is common for the caregivers to forget to bring the ‘physical health-related book’; ii) the door of the doctor’s office typically remained open and others can hear the conversation happening inside; iii) on several occasions, we found parents became impatient due to the long wait and started knocking the door if the MHP took more time to deal with any child, and; iv) sometimes MHPs would cut short the story/detail description of the caregivers to make sure they can attend all the patients waiting in line within the time (which is typically 2:00 pm). The situation was quite different for mCARE test group participants. Since MHPs do not need to ask regarding the behavioral and milestone parameters (they can already see it based on the submitted data through mCARE-DMP), the caregivers have more time to speak freely about other issues. Also, the caregivers no longer need to carry any physical documents. On average (based on 25 observations), the visit time lasted for 6 minutes for mCARE test group participants. Another important issue regarding the visit came up during our end-of-study interview, as expressed by the mother of IPNA 51:

“My daughter would do weird things (like shouting, howling, banging, etc.) every time I would bring her here. But she never does this at home. Because it would happen during every visit, he (the MHP) got a wrong diagnosis of my daughter. Now I understand that this happened due to many factors: long commute, wait time, lots of unknown faces, loud noise, etc. Now with mCARE, I do not come that often since I am getting regular feedback from the doctor from my home settings. mCARE helped me get good care with a smaller number of visits. It also helped my child (this overall situation).”

6.2. Impact of COVID-19 on CHW

The first outbreak of COVID-19 was detected in March 2020 in Bangladesh [4]. The Government of Bangladesh declared an emergency and lockdown (except emergencies) was enforced starting end of March. The hospitals closed almost all non-emergency services, including mental health services (or running with very limited support). But during this lockdown period, mCARE played a very effective role. During the first week of lockdown, the clinical coordinators contacted everyone over the phone and asked them about their situation in this lockdown scenario, but did not remind them to submit data. Later, we interviewed 20 caregivers (10 each from the mCARE-APP and mCARE-SMS test group) to get more information regarding the overall impact of COVID-19 on the caregivers, CWA, and overall quality of care. From the discussion and submitted data during this period, we were able to see distinct changes in terms of data adherence, behavioral and milestone parameter values, and attitude of caregivers (due to the impact of job loss, change of location, financial stress, etc.).

Impact on treatment and acceptance of telehealth as a whole

Mental health support, being considered as kind of non-essential in Bangladesh, suffered greatly during the COVID-19 pandemic. Most of the caregivers stopped coming to meet the MHPs. Many caregivers were especially worried about the potential impact of COVID-19 on their CWA. Mother of IPNA 23 said:

"I will think about meeting the doctors if we survive this (COVID-19). I think my son (being an ASD kid) has a higher chance of getting infected. He would not be able to handle this like other kids. I would rather stay home. Moreover, I am at least getting regular feedback from the doctors (others are getting nothing)."

When we discussed the situation with the MHPs, they noted that though the Government and private organizations promoted telehealth-based support for many cases, they failed to provide the longitudinal historical data that was available to the MHPs through mCARE-DMP. MHP 11 said:

"We are lucky to have mCARE in such a unique scenario. Many of my colleagues from other departments are always talking about how critical patients are missing the treatment. But for us, we became more dependent on mCARE. I used several of the features (of mCARE) during this period (that I haven't used before). And the best thing is, the caregivers are accepting the fact that face-to-face meetings are replaceable, and they are accepting mCARE as the new normal."

Impact on ASD status: better or worse?

One of the questions discussed during the interview with caregivers was the impact of COVID-19 on the health status of their children. Interestingly, we found that COVID-19 impacted the health outcomes of CWA in both positive and negative ways, as detailed below:

i) Negative impact: Case 1: "*Due to not going outside for the coronavirus, my child was at home all the time. He missed going to school or the park. For this reason, my child shouted and cried loudly. His tendency to scream went up. We are being locked down in our congested (small) apartment, and our neighbor's house is very close to our flat. They complained to us when my child got hyper, and sometimes they quarreled with us. For many nights, I could not sleep*" - (Father of IPNA 167)

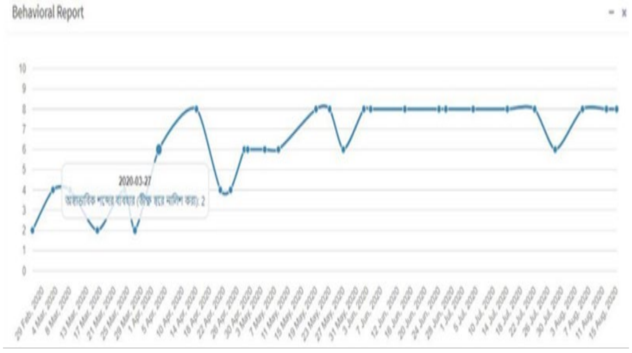


Figure 9. The behavioral data report for IPNA 167 on 'Use of unnatural sounds (e.g., high pitch squeal)'.

ii) Negative impact: Case 2: Multiple caregivers reported stress due to financial situations as a result of COVID-19. At least 5 head of households lost their jobs due to the pandemic. The majority of the participating families are affected in some way. For many families, survival became the priority, and that hampered the care of the CWA. Mother of NIMH 97 (whose husband lost his job) said the following:

". . . my husband lost his job. It became impossible to talk with him. He is continuously thinking about how to support the family. We don't have enough savings. I don't know what's going to happen. He shouts at home and is always in an irritated mode. I also don't have the money to buy medicine. All these have impacted my son. He became more aggressive in his behavior."

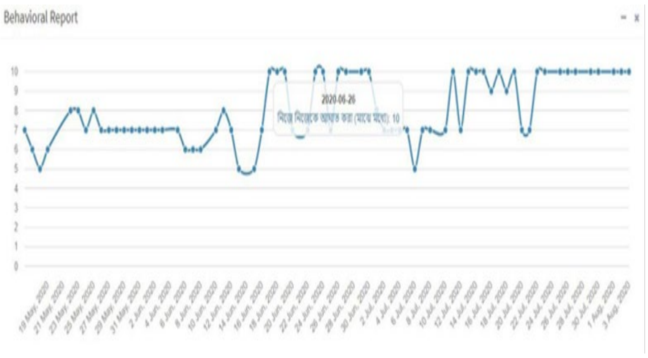


Figure 10. The behavioral data report for NIMH 97 on 'Self-injurious behavior'.

iii) Positive impact: Case 1: *"This COVID was a good thing in disguise for me. I worked remotely from home. I was able to spend quality time with my kid. Before, I would leave for the office early morning and come back late in the evening. Also, I would be too tired to take care of my kid. But now I am talking and playing with him regularly. Sometimes, we go to the roof in the afternoon. I think all these helped him to do better."* - (Father of AWF 24)

iv) Positive impact: Case 2: *"We came to the village (hometown) because it is much cheaper here (you don't need to pay rent). My husband has started a small shop here. We have a large family here. My kid is playing with her cousins and getting the chance to spend time with her grandparents. There is also a big field here for him to play. I would say my kid is doing better overall during this period."* - (Caregiver of IPNA 49)

Impact on data submission adherence

Data submission adherence took a hit as a result of COVID-19. Other than the interviews, the clinical coordinators called many caregivers who missed data regularly and tried to motivate them. We have identified the following reasons based on the discussion:

(1) Several families went to their rural hometowns with intermittent mobile network connections.

(2) In some cases, for job purposes, the father had to stay separate from the family in this situation. Families possessing only one phone could not submit data in this situation.

(3) Due to loss of jobs or income, several families faced difficulty. However, we kept providing them with the monthly incentives (for data submission) regularly.

(4) For at least 3 cases, father and mother had to be in isolation in separate rooms because of COVID-19 or exposure to someone having COVID-19. This also hampered the family from submitting data regularly.

(5) Caregivers also told the clinical coordinators of multiple issues: i) the mobile phone they used to send data

was broken (AWF 15); ii) zero balance (IPNA 101), or; iii) got some problem (NISHPAP 38) and they couldn't repair it during the lockdown situation. As the father of IPNA 101 said:

"Due to the long lockdown in my area, there was no shop or any agent open to load taka (money) into my mobile. And I couldn't travel a long distance to refill my mobile balance. That's why I could not provide data regularly during the middle of the lockdown situation. But when the clinical coordinator asked me the reason for not providing the data, I told him. And then he managed and provided the balance in my mobile."

7. Prediction Modeling

Our final approach for the data analysis falls under the domain of utilization of machine learning models in predicting symptom parameter values. We have followed the following steps.

7.1. Measuring The Improvement Level Of Selected Parameters

At the beginning of the mCARE project, the care practitioners obtained the baseline value for every selected behavioral and developmental progress parameter from the participant. Then, during the data collection timeline, the caregivers continuously submitted the selected parameter values using the mCARE tool. By comparing the baseline data with the end of project data, we can calculate the change (better/worse/unchanged) level for every parameter.

7.2. Data cleaning

We have observed some noisy data (out of range or negative values) in our dataset. We also observed some missing data, especially the age and family expenditure columns. We have utilized the popular "the attribute mean value" method [14], to handle these missing values.

7.3. Symptom parameter identification and feature selection

Of the 32 total symptom parameters, only 5 were chosen for analysis within our research. This was largely due to the need for variability in the data. We needed to select parameters that had a vast number of distinct users reporting on them. Selecting symptom parameters this way would allow us to be left with an acceptable number of distinct users for our machine learning models once data cleaning was completed. After selecting our 5 symptom parameters and cleaning our corresponding data, we were ready to perform feature selection. Upwards of 40 predictor variables were associated with each of our symptom parameters, which is too many to perform any meaningful machine learning method. To scale down our network of predictor variables, we utilized principal component analysis for mixed-data datasets. Around 7-8 important features were selected for each symptom parameter in our mixed-data principal component analysis. Table 6 shows the most important features for the symptom 'Use of meaningless word' following the aforementioned methodology.

7.4. Deployment of machine learning models

We have utilized four machine learning models (logistic regression, decision tree, K-Nearest Neighbor, Artificial Neural Network) to predict the changes in a behavioral parameter in 3 categories: the symptom value gets better, worse, or unchanged. For example, if the base value for the symptom, 'Use of meaningless word' was 5, then the situation has improved if the value at the end of the project becomes less than. Similarly, it would be considered worse

Table 6. Feature selection for the parameter 'Use of meaningless word'

	Parameter 2: Use of Meaningless Word	
Feature 1	Registration Type (Test vs Control)	This feature was used because we wanted to determine if the test group had any impact versus the control group.
Feature 2	Data Collection Type (App vs SMS)	Like the Registration Type feature, we wanted to see if app users and sms users had differences in improvements.
Feature 3	Family Expenditure (Numerical Values)	We included this feature because we thought that family expenditure would be important in telling the level of care provided, as higher family expenditures could mean better care.
Feature 4	Mother Occupation (Housewife or Not)	We included this feature because families report the scores via the app or sms (text), and most of the time the mother is the one reporting scores. We thought that whether the mother was at home or not could have a big impact on scores.

Feature 5	Residence Area (Rural vs Urban)	This feature was included for two reasons. The first reason is that it combined multiple complex variables into one simpler feature. The second reason is that this feature was deemed important after running PCA.
Feature 6	Education (Never, Usual, Usual_Failed, Specialized, Specialized_Failed)	This feature was included because it was deemed as a principal component in principal component analysis.
Feature 7	Birth Complications (Yes or No)	This feature was included because it was deemed as a principal component in principal component analysis.
Feature 8	Father Education (Primary, Secondary, Undergrad, Grad, PostGrad)	This feature was included because it was deemed as a principal component in principal component analysis.

if the value becomes greater than 5 and unchanged if it remains at 5. The accuracy level of predicting such changes of selected parameters using these four machine learning models has been summarized below.

Table 7. Accuracy summary by different machine learning models

Parameter	Logistic Regression	Decision Trees	K-Nearest Neighbor	Artificial Neural Network
Use of a Meaningless Word	50.00%	50.00%	75.00%	37.50%
Response when Called by Name	50.00%	57.14%	50.00%	64.29%
Avoiding Eye Contact	61.54%	69.23%	69.23%	61.54%
Understands Personal Care Routine	68.75%	87.50%	62.50%	75.00%
Repetitive Activity	42.11%	63.16%	52.63%	52.63%

7.5. Justification of poor accuracy

Any machine learning model works by finding hidden patterns in the data. When we manually analysed the user data, we found the following issues:

a) Many parents did not submit data regularly. Missing data was one of the biggest issues. COVID-19 made the issue of data submission adherence worse, as stated by the father of IPNA 101:
"*Due to the long lockdown in my area, there was no shop, or any agent open to load taka on my mobile. And I couldn't travel a long distance to refill my mobile balance—That's why I could not provide data regularly in the middle of the lockdown situation. But when the clinical coordinator asked me the reason for not providing the data, I told him. And then he managed and provided the balance in my mobile. Then I can provide the data again regularly.*"
b) Many parents submitted data that doesn't make much sense. For example, if 3 is submitted for a certain behavioural parameter on a certain day, the next day's submission showed 9 followed by 5 without any explanation.
c) Many parents continued to submit the same symptom parameter value for the whole period.

8. Conclusion

This paper describes the design, development, deployment, and evaluation of mCARE, a versatile and accessible technological system to allow caretakers to log and monitor the behavioral progress of CWAs and communicate with MHPs. This project's success relied on the improved collaboration between caregivers and MHPs. This work demonstrates how consistent data logging is integral for more informed and confident MHP decisions, and motivation and observable progress are essential for caregiver data submission adherence. In addition, this paper depicts how remote data collection aids in streamlining and optimizing infrequent in-person visits with MHPs. The system was also valuable in gathering notable data on the diverse impact of COVID-19 on CWAs. This paper emphasizes the complexity and nuances of mental health technological care, especially within the context of LMICs in the Global South. Societal structures, values, and knowledge differ greatly between cultures, accentuating the need for systems like mCARE to account for these distinctions in the design process, including gathering the necessary research and receiving and implementing user feedback throughout the deployment phase. This work generates a better adjusted and thus more effective method of supporting the mental health of people in diverse global environments.

Appendix A.

Pool of all possible milestone parameters by age group.

Age 3-6	**Age 6-9**
Communication	**Communication**
Possible Parameter	Says month and day of birthday when asked
Points to at least 5 body parts when asked	Modulates tone of voice, volume, and rhythm appropriately (eg. Does not consistently speak too loudly, too softly or in a monotone)
Listens to a story for at least 15 minutes	Can give simple direction (eg. How to play a game or make something)
Follow instructions in if-then form (eg. If you want to play outside then finish your food first)	Writes own 1st and last name from memory
Says 1st and last name when asked	Reads at least 10 words
Identifies and names most common colors	Writes at least 10 simple words from memory
Ask questions beginning with who or why	Can have conversation that lasts 10 minutes
Identifies one or more alphabet letters	Says own phone number when asked
Can distinguish letters form numbers	Says complete home address when asked
Recognizes own name in printed form	Writes simple sentences of 3/4 words
Ask questions beginning with ‘when’	Writes at least 20 simple words form memory
Tells basic parts of a story	
Identifies at least 10 printed letters of the alphabet	
Writes at least 3 simple words (eg. Cat, hat, see)	
Daily Living Skills	**Daily Living Skills**
Urinates in toilet/potty	Brushes teeth
Aks to use toilet	Buttons large buttons in front, in correct buttonholes
Can zip zippers that are fastened at the bottom (eg. Pants or backpacks)	Is careful around hot objects
Put shoes on correct feet	Looks both ways when crossing the street
Brushes teeth	Bathes or showers him/herself
Washes and dries face using soap and water	Takes medicine as directed
Wipes or blows nose using tissue or handkerchief	Is careful when using sharp objects
Is careful around hot objects	Says current day of the week when asked
Uses fingers to eat	Tells time using a digital clock
	Discriminates between bills of different denominations (1, 5, 10, 20, Taka notes etc.)
Socialization domain	**Socialization domain**
Answers when familiar adults make small talk (eg. If asked ‘how are you?’ says ‘fine’)	Keeps comfortable distance between self and others in social situations
Uses words to express emotions (eg. ‘I am happy’, ‘I am scared)	Talks with others about shared interests (eg. Sports, tv shows, cartoons)
Shares toys or possessions	Recognizes the likes and dislikes of others (eg. ‘A likes cricket’, ‘B likes noodles’)
Takes turns when asked while playing games or sports	Ends conversation appropriately (eg. ‘goodbye’/‘khoda hafez’)
Follows rules in simple games (eg. Ice-tag)	Says sorry for unintended mistakes (eg. Bumping into someone)
Says ‘thank you’ when given something	
Motor skills domain	**Motor skills domain**
Runs smoothly without falling	Glues or pastes 2 or more pieces together
Jumps with both feet off floor	Draws circle freehand while looking at example
Throws ball of any size in specific direction	Uses scissors to cut across paper along a straight line
Walks up/down stairs	Cuts out simple shapes (eg. Circle, square, rectangle)
Catches tennis or baseball-sized ball from at least 10 feet away	Draws square/triangle freehand while looking at example
Opens doors by turning doorknobs	Draws straight line using a ruler
Unwraps small objects (eg. Candy)	
Completes simple puzzle of at least 2 pieces of shapes	
Turns book or magazine pages one by one	
Color simple shapes (may color outside lines)	

Appendix B.

Form used by clinicians to select behavioral parameters and frequency is shown below

Pool of behavior parameters to be monitored	Daily	Weekly	Bi-weekly	Monthly	Current value
Repetition of same word					
Use of meaningless word					
Use of pronouns inappropriately (such as "I" instead of "you")					
Use of unnatural sounds (e.g. high pitch squeal)					
Can s/he start social interactions?					
Can s/he maintain social interactions?					
Does s/he respond when called by name?					
Does s/he smile socially?					
Delay in response (social/motor/interactive)					
Avoids eye contact					
Difficulty tracking moving objects/people					
Participation in imaginative games					
Understands personal care routine					
Mood swing					
Self-injurious behavior (how often)					
Self-injurious behavior (intensity)					
Aggressive behavior (how often)					
Aggressive behavior (intensity)					
Intense interest in objects/parts of objects (e.g. toy or eyes of a doll)					
Inflexible to change					
Repetitive activity (such as spinning a pencil/ hand flapping)					
Fails to express basic needs (e.g. hunger)					
Hyperactive					
Lack of concentration					
Sleep problems					
Hours of sleep/night					
Unusual sensitivity to light					
Sensitivity to pain					
Sensitivity to sound					
Aversion to smell					
Sensitivity to touch					
Other (Specify)					

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