“Monday Feels Like Friday!” -Towards Overcoming Anxiety and Stress of Young Adults with Autism During Pandemic

Ashima Shrivastava, Roberto Palma, **Moushumi Sharmin, and Shameem Ahmed**
Department of Computer Science, Western Washington University, Bellingham, WA, USA
{shrivaa, palmar, sharmim, ahmeds}@wwu.edu

1. ABSTRACT

The COVID-19 pandemic has substantially impacted lives all over the world. Existing research suggests that COVID-19 has increased levels of stress and anxiety among the entire population. Autistic young adults are at a higher risk of experiencing elevated levels of mental and psychiatric distress during this pandemic due to challenges related to uncertain living conditions and abrupt changes in every aspect of daily life. In this research, we aim to develop participant-centric interventions for assisting autistic young adults in addressing their anxiety and stress issues during this current pandemic. We first conducted an extensive literature review and system analysis to gather design requirements of an effective stress management technology. We designed our initial high-fidelity prototype, named MindBot, based on our findings. We then conducted semi-structured interviews to understand the issues at a deeper level and to receive feedback on MindBot. In this paper, we report insights from our in-depth qualitative study.

Keywords - COVID-19 Pandemic, Autism Spectrum Disorder, Mental Health, Stress & Anxiety, Young Adults.

2. INTRODUCTION

It is estimated that 1 in 54 children in the USA has been diagnosed with Autism Spectrum Disorder (ASD) [1]. Moreover, almost half a million children with ASD will be in adulthood in the USA by 2025 [2]. This transformation to adulthood can be challenging for individuals with autism because of their core social communication impairments, overreliance on family, high rate of mental health conditions, and struggle of dealing with unexpected changes in activities, situations, or expectations [3].

The SARS CoV-2-virus (COVID-19), with over 1.7 million infections worldwide, is pushing national and international healthcare structures to their limits and it is especially proven burdensome for individuals with stress, anxiety, and mental health conditions [21]. A recent study conducted in 2020 stated that 70% of the study participants reported moderate or serious mental distress (i.e., frequently feeling sad, nervous, or hopeless) during this pandemic compared to 22% of respondents two years earlier [20]. For young adults with autism in addition to challenges resulting from their autistic traits, COVID-19 brought new challenges: the abrupt change in their daily routine and structure, the sudden transition to remote learning and remote work, lack of access to needed resources (e.g., online therapy sessions vs. face-to-face sessions), social isolation, and financial insecurity. These changes prompted health experts to predict a marked increase in stress, anxiety, and other mental health problems [20].

Many times adolescents and adults with autism inherit co-occurring psychiatric disorders with one in two individuals on the spectrum experiencing co-occurring anxiety or depressive disorder. The uncertain and unpredictable living environment persisting during the current COVID-19 pandemic, along with pre-existing impairments in social communication and social behavior in young adults

with autism, resulted in peer interactions that are difficult and fairly limited [14].

Due to the prevalence and impact of anxiety in young adults with ASD, techniques for addressing anxiety have received increased empirical attention [5]. Two major approaches that are extensively used to overcome anxiety and stress are Mindfulness Cognitive Behavioral Therapy (MCBT), a subpart of Cognitive-Behavioral Therapy (CBT), and the usage of an AI chatbot during Covid-19 [20, 23].

Our current research aims to develop participant-centric interventions for assisting young adults with autism to address anxiety and stress issues during high-stress situations such as during this current pandemic. As the first phase of our research, we conducted an extensive literature review and system evaluation to understand the existing approaches, elicit the needs of our target users (young adults with ASD), and gathered design requirements of an effective stress management technology. Findings from this stage indicated the potential of a mobile-based solution in aiding young adults with ASD in better managing their stress and anxiety issues. As the second phase of this research, we designed an interview-based study to understand the challenges, needs, and experiences of young adults with autism surrounding stress management technology, and evaluate the design of a prototype AI chatbot and mindfulness Cognitive Behavioral Therapy application (MondBot) that aims to aid the resilience and emotional intelligence of autistic adolescents during but not limited to the COVID-19 epidemic. In this paper, we report MindBot - our prototype design, discuss the methodology for gathering data from our target users, and findings from this study for addressing mental health issues utilizing mobile technology.

3. RELATED WORK

The World Health Organization defines well-being as "*the state in which an individual realizes his or her own abilities, can cope with normal stresses of life, can work productively, and is able to make a contribution to his or her own community*." Resilience is directly connected to wellbeing. It is about developing the ability to intervene & cope with stress and adapt to new and/or challenging situations [19]. As mentioned above, autistic individuals are unable to manage such situations, which dramatically escalate their stress level. To provide better interventions in these situations, prior research showed the effectiveness of AI chatbot and Mindfulness CBT. This section gives an overview of these two methods offered as a form of intervention and support.

3.1 Cognitive Behavior Therapy (CBT)

Cognitive Behavioral Therapy (CBT) involves exposure, modeling, and parental involvement and has been labeled a "well-established" evidence-based treatment for anxiety disorders among adolescents and adults [2]. This is a psychotherapy where the affected person works with a health counselor in a structured way, attending a limited number of sessions. Participants are directed to work through a minimum of five modules over three sessions (60 minutes each) [4]. Online CBT studies have been conducted in group and/or individual modalities. Several systematic reviews and meta-analyses have recently been conducted, generally finding moderate to large treatment effects [4]. A recent meta-analysis of RCTs (Random Control Trials) examining CBT use in individuals with ASD found that most studies only emphasized anxiety [6]. To overcome this limitation, mindfulness techniques were employed, resulting in the emergence of Mindfulness-CBT (MCBT).

3.1 Mindfulness (MCBT)

Mindfulness has been described as "*the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment*" [15]. Mindfulness-based interventions teach individuals to observe, acknowledge, accept and decenter from thoughts, feelings, and emotions that come into awareness, and do not aim to change the direct experience but rather encourage a changed way of relating to it [7]. Within the array of MCBT online programs, individuals with autism have demonstrated tremendous improvement [10]. Also, the results from various studies suggest that MCBT may positively impact internalizing and externalizing problems, Autism symptomatology, and psychological well-being of individuals with Autism [6]. Online MCBT has been proven to perform better than

traditional CBT and reduce stress, anxiety as well as depression altogether [6]. For immediate impact, short-term structured mindfulness meditation is also practiced among young adults, lasting for just 1-2 weeks [17]. Short-term mindfulness also increases coping flexibility and helps improve managing stress in only two weeks of an intervention [18].

Mindfulness also has few applications which are different from traditional meditation. It is called Guided Imagery. This technique involves purposefully and consciously inducing mental images to obtain the desired outcome [12]. This technique has strong roots in health care settings; however, it can be used in many diverse settings to overcome a multitude of diverse obstacles [11]. It is also proven that perceptions of cognitive and emotional stress decreased due to our brief guided imagery exercise [13]. To perform this, participants take part in a workshop on guided meditation, including psycho-education on how mindfulness is helpful during stressful times led by mindfulness experts [16]. As cultivating the practice of mindfulness and guided imagery is devoid of side-effects, it is safe for individuals with ASD to practice this irrespective of their health conditions.

3.3 AI Chatbot

A conversational user interface or chatbot is "*a computer program designed to simulate conversation with human users, especially over the internet*" [23]. Empathic and AI-enabled chatbots have been used to provide supplementary or complementary emotional support and assistance. Prior studies reported the promise that conversational agents hold as interventions for treating mental health problems in terms of efficacy and acceptability [22]. It is expected that chatbots will make a positive contribution to addressing the shortfall of mental health care. They are known to facilitate interactions with those who are reluctant to seek mental health advice due to stigmatization and allow more conversational flexibility [24]. While dealing with a mental health condition, it is vital to understand the emotional state and respond with simple micro-interventions such as suggestions for a deep breathing exercise or a friendly conversation. Micro-interventions can be useful in increasing the positiveness of a user's mood. The main advantage of these bots is to provide a practical, evidence-based, and attractive digital solution to help fill the gap of the support the young adults require.

During adolescence, it can be hard to share stressful feelings even with loved ones as the fear of being judged can overpower one's emotions, resulting in suppressing thoughts. Chatbot helps young adults deal with such situations and relieve the burden of carrying stress within themselves. A chatbot can provide an alternative avenue for students to freely share the stressful situations they are experiencing [22].

4. RESEARCH METHODOLOGY

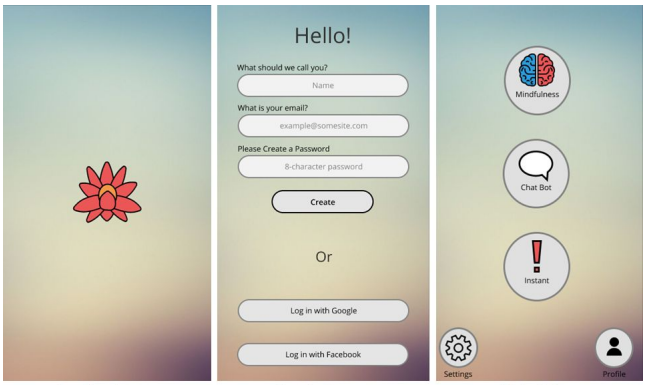
4.1 Phase 1 Study Methodology

We conducted exploratory research to identify papers focused on designing and/or delivering interventions to young adults with ASD to overcome anxiety and stress. We primarily used Google Scholar, ACM Digital Library, and IEEE Xplore to find relevant papers. Our initial search resulted in 35+ articles related to CBT and MCBT, chatbots in mental health, and the effect of Covid-19. However, not all the research and study were specific to autistic individuals. In addition to the literature review, we performed an extensive system analysis that primarily focused on web and mobile-based technological solutions for mental health support and interventions.

4.2 Prototype Design

Our literature review and system analysis led us to include Mindfulness CBT and chatbot features in our initial prototype design, dubbed as MindBot. MindBot consists of three primary stress management features (Mindfulness CBT, AI chatbot, and Instant) and other secondary features.

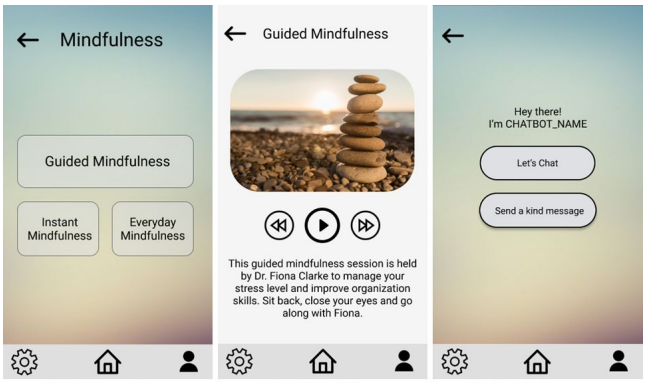
In MindBot, a user will be first greeted by a welcome page, along with a login/sign-up page. After signing in, the main menu will be displayed (see figure 1).



Loading Screen | Sign in Screen | Main Menu

Figure 1. Home and main menu of MindBot

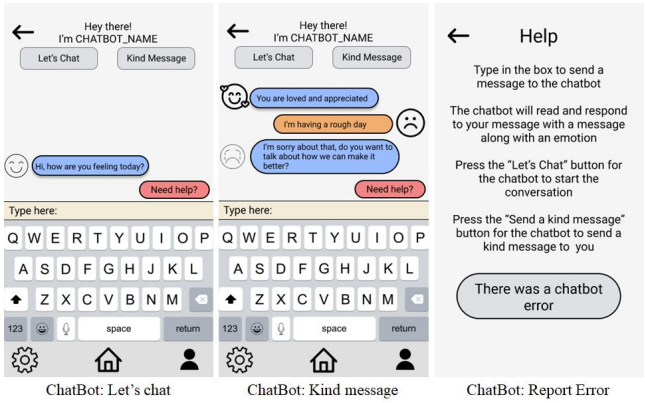
The first major feature included in MindBot is the mindfulness CBT (see figure 2). This page will direct users to choose what kind of mindfulness therapy they would like to perform. The page will also provide access to audio sessions, where a therapist guides the users on a mindfulness session.



Mindfulness Page | Guided Mindfulness | Chatbot: before screen

Figure 2. Mindfulness and Chatbot (Before Screen)

The second important feature is an AI chatbot (see figure 3) which will lead the user to a page that gives the option to either begin chatting or receiving kind messages. Both options will lead to a text conversation window where the user can commence a conversation with an AI chatbot. If the user chooses to receive a kind message, the AI chatbot will send a kind message. If the user chooses to chat, the AI chatbot will begin the conversation by asking the user about their day. To improve the quality of the AI chatbot, this page enables sending a message to the application developers if a particular chat response is deemed inappropriate by the user.

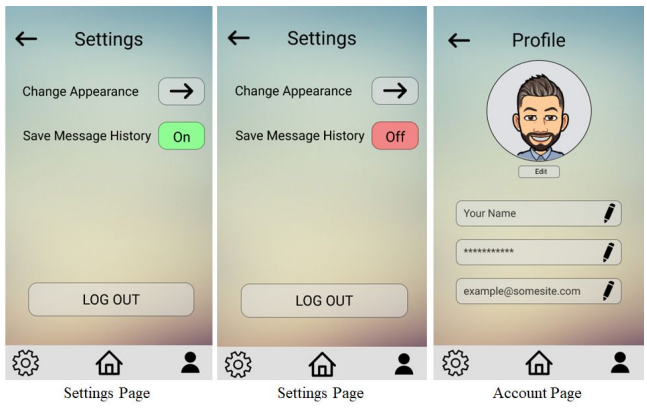


ChatBot: Let's chat | ChatBot: Kind message | ChatBot: Report Error

Figure 3. Chatbot

In addition, during a conversation, the avatar of the AI chatbot will change to reflect the emotion associated with the user's input. Finally, the user will be able to access the 'Let's Chat' and the 'Kind Message' options during a conversation. The user can also receive a kind message during their conversation with the AI chatbot.

The third important feature is the Instant page (see figure 1). This is intended to provide instant intervention to the users who feel elevated stress and anxiety at a given moment. At present, this feature "Instant Intervention" is still under development.



Settings Page | Settings Page | Account Page

Figure 4. Profile & Settings

Additional features included in MindBot is the ability for users to edit their profiles and also providing a way to change the chatbot's avatar to fit the users' preferences (see figure 4). MindBot prototype also includes the following options: 1) change the app's appearance, and 2) save message history. Changing the appearance will change the app's look for the users, while the save message history is intended to keep archives of the user's conversations with the chatbot. If the user prefers not to save the chat history, they have the option to turn this feature off.

4.3 Phase 2 Study Methodology

We designed our study to understand the challenges faced by young adults with ASD related to mental health conditions, current coping strategies, and their needs and expectations from any stress management technology. Another goal of this study was to evaluate the MindBot prototype aiming to identify features that are considered useful, features that are considered limiting, and any additional feedback from the users about this prototype. We submitted the study design to the Institutional Review Board (IRB) process of Western Washington University to get their approval and upon receiving the approval, we started our recruitment procedure. We reached out to autistic young adults via email, various social media platforms, including Discord, Reddit, and Facebook, and informed people about our research. Due to the pandemic, at this point, we were unable to recruit as many participants as we aimed for. We were able to recruit three participants to date and we are continuing to recruit more participants. All three participants are in the age group 20-25 and are diagnosed with ASD. All three participants are college students majoring in computer science and living with their families ever since the beginning of the pandemic.

We conducted semi-structured interviews via zoom to understand the current situation and effect of pandemic on their day-to-day lifestyle and their mental health issues. Each interview duration was 60-90 minutes, where we asked 12 questions. We allowed tangents during the interviews to get a holistic experience of the users. Table 1 shows a sample set of interview questions. Towards the end of each interview, we walked through our design (see section 4.2) to the participants to know their thoughts and ideas.

Table 1. Sample Interview Questions

How was your last year? How did the pandemic affect your life, if at all?
Many people suffered from anxiety and elevated levels of stress during this pandemic. Did you go through anxiety or any mental health issues because of the pandemic?
What was your coping mechanism to address stress and anxiety issues, and how did you manage your stress and anxiety?
Do you believe any technology could help you intervene through your stress and anxiety? Why or why not?

Upon completing the interviews, we transcribed the audio recordings of interviews and imported those transcriptions into Atlas.ti Cloud [32], an online platform. We applied thematic analysis to perform qualitative coding. During our qualitative coding, we went through all interviews again and read each transcript line by line. We performed an in-depth analysis to understand the participant's thought processes and emotions associated with their responses. In the open coding phase, we created 22 initial codes. Some of the codes we used were - Pandemic: daily-schedule, Pandemic: changes-due-to-pandemic, Stress: sharing-issues, Stress: Stress-due-to-pandemic. In the axial coding phase, we utilized these codes to link interview data from each participant and perform a systematic comparison in their answers to understand their situations and emotions better. We discussed the codes among ourselves to identify common themes. We finalized some of the major themes in the selective coding phase that we will report in the next section.

5. FINDINGS

Our research and analysis led to a number of interesting findings, manifesting how specific qualities of the intervention corresponded to the needs of every other individual. For this study, we aim not only to provide interventions but also to understand the challenges people went through during Covid-19.

5.1 Effect Of Pandemic

Our participants reported that the pandemic had impacted their lives in multiple ways. They have experienced uncertainties, social and physical isolation, and substantial changes to their daily routines. In the traditional in-person education system, students observed that their peers work hard, which encouraged them to stay motivated and perform well. However, due to the class being online, there is a lack of positive competition, which results in a lack of motivation. Not being able to go outside in social gatherings has changed their lifestyle, resulting in loneliness. All of our study participants felt disconnected from their friends during the pandemic. Participants 2 and 3 stayed in touch with their friends and were able to speak to them regularly, while

participant 1 suffered through losing them due to lack of communication. In adolescence, lack of social connections can have a significant impact, making a huge difference in their mental well-being [27]. Autistic individuals suffer from social anxiety, making it harder for them to make new friends or open up to others. Hence, losing friends can be stressful for them. Also, due to lockdown, the feeling of being trapped inside made them feel suffocated. Distracting from such feelings became very difficult and challenging. Everyone's day-to-day lifestyle changed, which resulted in unorganized thoughts and a lack of concentration. The distinction between weekdays and weekends became blurry; hence, keeping track of the activities became very difficult. To quote participant 3:

"Nowadays, Monday feels like Friday!" (P3, 21 years).

Surprisingly, participant 2 looked at the pandemic from a different perspective and expressed that it was easier to save time during the pandemic due to fewer physical interactions with friends and online classes. Hence, the saved time can be utilized in something productive, i.e., better performance in the course work and classes. Moreover, reduced interaction with people resulted in reduced social anxiety and helped them reconnect with themselves and their families. To quote participant 2,

"Since minimal interaction and hanging out with friends, I still talk to them regularly (phone or social media), but now I save that time. This gives me time to do more research and study" (P2, 21 years).

5.2 Stress During Pandemic

According to WHO, almost 18% of the United States population suffers from some form of mental health issues, and during the last year, it increased to 40% due to Covid-19 [30]. Recent assessments of college students on the spectrum and mental health symptoms have shown an increased level of stress and depression in the wake of the pandemic [26]. Along with our aim of providing intervention, we also focused on understanding some of the major causes and issues behind this elevated stress and anxiety that they are going through. Autistic individuals are prone to a higher risk of being mentally affected due to Covid-19 and feel insecure about getting affected by the pandemic [30]. Apart from the stress of being directly affected and catching the virus, there have been multiple reasons for elevated psychological conditions. The fear of permanently being stuck in this lifestyle and adapting to these changes has overpowered their positive emotions. Our participants described this changed daily routine as a "*never-ending infinite loop*" where they had hope and a positive attitude at the beginning of a pandemic. As the days passed, they feel they will forever be in this loop with no end to it. Participant 3 mentioned that:

"[It] feels like the loop. And it feels like I'll never get out of the pandemic and like self-quarantine and stuff." - (P3, 21 years).

This thought process has resulted in severe stress and made it exhausting to feel motivated and incorporate positive thoughts and emotions. On top of this, not being able to meet friends added to their feeling of being alone. Although being in touch with friends is still possible over online social platforms, our participants claim a huge difference between meeting in person and online. To quote participant 1,

"Yeah, I actually lost one of my best from I guess loss of engagement, and that was a stressful patch I had to go through." - (P1, 24 years).

Due to remote classes, indulging in group projects and group activities has been a big reason for stress. As face-to-face interaction with project/group partners is impossible due to lockdown, this situation has amplified the chances of miscommunication, resulting in increased course load and performance pressure for a better grade. Not every student has access to the hardware required for online education and additional resources that a university or college provides. Due to lack of educational resources, it has become more challenging for students to barely make it through the course if not excel. This increased the feeling of self-doubt and has further stoked anxiety in regard to academic pressure.

5.3 Coping Mechanism

Prior studies show that autistic individuals demonstrate their resilience through coping despite heightened stress and anxiety due to uncertainty and limited opportunities for in-person social interaction [29]. Despite all the psychosocial challenges that they are going through, our participants found the courage to make efforts to move past this situation. Our participants applied various coping mechanisms.

Our participants used technology such as online streaming, video gaming, and video conferencing in

their regular lives. Playing online games helped them to divert from stress. They could escape from reality and they could be whoever they want to be and whenever they could. The inclination toward the world of gaming also seems to help them relieve their tension. Other than this, Participant 3 indulged in coursework, tried to do more than expected in their school assignments, and focused all the negative energy on something productive. Apart from this, participants 2 and 3 used online streaming or binging and watching movies as a coping mechanism. Participants 1 and 2 watched horror movies as they built up the tension and made them forgetful about their own stressful situations. Participant 2 mentioned that -

"The reason I like horror movies is the kind of tension that you have when watching the movie, so that's the most enjoyable part of watching horror movies for me!" - (P2, 21 years).

Therapies played a vital role to our participants in surviving during the pandemic. Different therapies are known to release stress, and sharing emotions and feelings related to stress and anxiety is a big part of the coping mechanism. Therapies helped our participants organize their thoughts. The feeling of not being alone helped them intervene in their mental health issues. They also felt that having a pet such as fishes and dogs could be helpful during the pandemic. Taking care of the pets made them responsible. Also, seeing the pets happy made them satisfied, giving them a wholesome feeling and a sense of fulfillment. They considered taking care of pets as their "*personal therapy*." Extending the discussion on therapy, participant 3 also practiced meditation and watched youtube videos of guided meditation. It helped the participant to release his anxiety and stress. To quote participant 3,

"I like [to] meditate often, that helps me relax. That's very good for stress, just like 20 minute meditation, you know deep breathing and stuff." - (P3, 21 years).

Indulging into household work such as cleaning the room or eating a favorite food or talking to parents about their day also helped our participants to create a diversion from their anxiety. For some people, the pandemic was hard as they lost touch with their friends [27], but for others, talking to their friends on social platforms and having conversations made them feel supported and less alone. When they realize that they are not alone in this and their friends feel the same, as well as the entire world, is in a similar situation, it gives them a sense of hope.

5.4 Technology For Mental Health

The current situation, Covid-19, has shown the entire world that there is a lack of mental health care and awareness, and it is high time that we use technologies by bringing the IT industry into mental health care[31]. According to recent post-pandemic research, the US was already facing a mental health crisis before the pandemic: less than half of those with mental illness receive the care they need[31]. Along with autistic individuals, underserved populations, such as low-income or ethnic minority populations, are disproportionately affected; they show the lowest mental health services utilization [28]. Hence, it is of utmost importance to make universally-accessible software to provide mental health interventions.

We also asked our participants to know their opinions about technological solutions for reducing stress and anxiety. They showed extreme enthusiasm for such technologies. Prior studies showed that autistic young adults feel more comfortable on online tools than face-to-face interaction; hence, having technology that provides intervention for stress and anxiety would be extremely beneficial [8].

We showed our MindBot prototype (see section 4.1) to the participants. After walking through the features in detail, all three participants liked the platform. They considered our idea very noble and mentioned that they would be interested in using such software. To quote the participants,

"This whole idea and project are so good. I almost feel jealous not to be a part of research like this myself. This seems really well thought the way it is designed." - (P1, 24 years).

"For me, for this one, I will give it 100% and say, Bravo! Because for me, as I said earlier, I don't share most of my problems with people. So considering my knowledge on chatbots, this is a perfect idea." - (P2, 21 years).

"*This is really cool. I really like this application and will use something like this.*" - (P3, Age 21).

Apart from such enthusiastic encouragement, we also received some insightful suggestions discussed in the next section.

7. DISCUSSION AND DESIGN IMPLICATIONS

As part of our research, we aim to understand the effectiveness of a chatbot and MCBT as effective intervention techniques to reduce anxiety and stress of young adults with ASD. Our findings suggest that an effective platform for delivering interventions would be web/mobile-based applications since young adults with ASD feel more comfortable with technologies than face-to-face solutions [8]. More than 65% of the young adults in the USA go through psychosocial issues and anxiety disorder making it even harder for individuals with ASD to seek traditional treatment for such conditions. As a result, a mobile-based platform could play an essential role in providing easy access to interventions to support young adults with ASD to manage their anxiety and stress better. Although not a replacement for face-to-face intervention, this technological platform could be a promising complement or accessible alternative to other support and treatment options. In this section, we will also discuss some of the design implications which indicates our user suggestions for the design.

Making the AI chatbot a friend

One clear implication that participants recommended ways to make the AI chatbot more friend-like. They implied that instead of a separate app, it would be nice to communicate with the bot via the phone's message application like they would do with their friends with actual phone numbers. They also suggested that a typing symbol should appear to demonstrate that the bot was listening when it was typing a response. In addition to this, having a delayed response could make the messages from the bot feel more genuine and thought-out. Participant 1 mentioned that:

"I feel like if it replies right away, right when I say something, it would almost be a little less genuine." - (P1, 24 years).

Participants 1 and 2 talked about how it would be a nice feature if users could put in hobbies and interests, and the chatbot would later follow up with the user asking about these interests. There was also some emphasis placed on the bot's avatar, where participant 3 said they would not like the bot to appear "*like a cold robot*." In the interest of making the bot more human-like, participant 1 offered that maybe the bot could follow up with you after a conversation and send reminders to come back and speak with it. Similar to how a friend would act.

Accessibility

Participant 2 suggested that the application should be available on web browsers as well. They often like to put their phones aside to take a break. Hence, having the application both on mobile as well as the web would be helpful.

Empathetic Chat Conversation

Participants were curious to add more empathetic responses and have a continuous conversation over multiple days. They mentioned it would be nice if the bot could send a follow-up message the next day asking how they are holding up in the morning after a stressful night.

The participants enjoyed the idea of having the option of saving the chat history. Having greater control over what specific chat messages were saved would empower users to protect their sensitive messages. To quote participant 3:

"It'll be cool to have the option of saving specific messages. Personally, I like saving messages but not all so that I would remember the conversation afterward." - (P3, 21 years).

Others

Our participants provided additional suggestions to improve the design of MindBot, such as keeping the app clutter-free. For example, participant 1 noted that the big red help button on the chat page seemed to be

out of place and distracting. There was some interest in personalizing the user interface, such as personalizing font, backgrounds, the chatbot avatar, and the look of elements.

8. CONCLUSION

Nearly two-thirds of the autistic youth reported moderate-to-severe levels of psychological distress [26]. Our research highlighted the effective intervention methods to reduce stress and anxiety of young adults with autism during the pandemic. By designing MindBot, we incorporated Mindfulness Cognitive Behavioral Therapy and an AI Chatbot to help autistic individuals to manage their stress and anxiety. This research is still a work in progress, and we aim to recruit more participants in the near future to gather more data and feedback on the MindBot prototype. Our study highlighted the burden of COVID-19 and the many changes it brought to the lives of autistic individuals. We identified various problems that autistic individuals are currently experiencing due to the increased mental health issues. We also shed light on specific reasons that caused stress in autistic individuals because of the need to adapt to the pandemic lifestyle. The pandemic's greater impact on the mental health of autistic individuals highlighted the need for convenient and affordable support from mental health providers to manage their mental health. We believe that applications such as MindBot that focus on the constructive and optimistic coping mechanisms and building positive energy is vital in initiating a holistic approach to addressing autistic young adults mental health conditions both during and after the pandemic.

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