Expert-Driven Technology-Based Intervention to Improve Oral Health of Children with Autism Spectrum Disorder

(Technical Paper)

Analysis of Subjectivity of Mental & Behavioral Condition Diagnosis and Technology

(STS Paper)

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Prospectus

Introduction

Autism Spectrum disorder (ASD) is a developmental disability in which patients exhibit social and communication impairments, restricted interests, and repetitive behaviors (Christensen, 2016). According to the NIH, of ASD include (but are not limited to the following): failing to respond to verbal attempts to gain their attention, difficulty identifying facial expressions, resistance to (even slight) change, being overly focused on certain interests, repetition of words or phrases, above or below average sensitivity to external stimuli, and performing everyday tasks (NIH,2020). According to El Khatib et al.'s findings, children with ASD struggle with poor oral hygiene, which leads to an increased occurrence of conditions such as gingival disease and orthodontic problems (El Khatib, 2013). One of the reasons for said problem is the fact that children with autism have difficulty brushing their teeth or having a parent brush their teeth due to sensory processing difficulties (Zhou, 2019). In order to mitigate this problem, we will be creating an app that will use video modeling and 23-step chaining which will break down the process of toothbrushing.

As mentioned in the technical portion, many social stories (non-app based) have been successful in breaking down the steps for tooth brushing for children with ASD, and have also improved oral health in children with ASD. While the technical side discusses the improvement to ASD, there are also questions raised in the subjectivity of not only implementing interventions for children with ASD, but also in diagnosing people, which will then define the way that interventions are created. The STS portion will examine subjectivity not only in technology designed to treat a specific treatment of a lifestyle difficulty caused by ASD and diagnosis of ASD, but also in mental and behavioral conditions as a whole.

Technical

Autism Spectrum disorder (ASD) is a developmental disability in which patients exhibit social and communication impairments, restricted interests, and repetitive behaviors (Christensen et al. 2016). It was first identified as a unique clinical diagnosis in 1980 (Christensen et al. 2016). It is usually identified when a child is around 18 to 24 months old (Maenner et al. 2020). ASD is screened through behavioral & developmental monitoring and developmental screening (Maenner et al. 2020, Christensen et al. 2016). According to the National Institute of Health (NIH), symptoms of ASD include (but are not limited to the following): failing to respond to verbal attempts to gain their attention, difficulty identifying facial expressions, resistance to (even slight) change, being overly focused on certain interests, repetition of words or phrases, above or below average sensitivity to external stimuli, and performing everyday tasks (NIH,2020). Children with ASD struggle with poor oral hygiene, which leads to an increased occurrence of conditions such as gingival disease and orthodontic problems (Khatib et al. 2013). One of the reasons for said problem is the fact that children with autism have difficulty brushing their teeth or having a parent brush their teeth due to the complex nature of the process This project aims to develop using behavior analytic strategies (i.e., chaining and video prompting) to support skill acquisition in health related self-care skills, starting with tooth brushing.

Specific Aims:

1. **Develop web-based applications that use chaining and video prompting to support skill acquisition in tooth-brushing.**
2. **Evaluate the effectiveness and feasibility of technology-based behavior interventions using single-case research design**

To accomplish aim one, I will spend the rest of this semester and winter break getting the necessary training. Specifically, I will be learning about fundamentals of programming through video-based Youtube crash courses. I will also learn Responsive Web Design (CSS, HTML, JavaScript), Java Algorithms & Data Structures, and React through online tutorials from Coursera, FreeCodeCamp, and Udemy. Prior to helping with the creation of the app, my deliverables will be a portfolio website with a landing page, working navigation with detail pages, and a “Hello World” React Native project with a simple Countdown timer component. After learning the basic skills necessary, I will assist the Sartography design team in the creation of the app by using the principles I will have learned to create an iPad application. I will also be helping with designing the user interface. In order to accomplish aim 2, I will be meeting with Dr. Badgett and her team of researchers in order to be able to properly create the various videos plus a feedback system for the children and parents to ensure that the children master each step of brushing teeth, and it can be convenient for parents to track said step. Additionally, this app will be piloted with children with ASD (age range of 3-8) and their behavior interventionists. In order to do so, we will conduct a single subject multiple probe across participants design (Horner & Baer, 1978) to evaluate the effectiveness of the application in supporting skill acquisition in toothbrushing. We will also collect qualitative data through video recordings of research participants interacting with the tool, as well as through social validity (treatment acceptability) surveys at multiple points in the research process. Qualitative and quantitative findings from the pilot study will influence future iterations of the tool design. If we accomplish the aims outlined above, we will have initial data suggesting the effectiveness of the tool in promoting skill acquisition in toothbrushing.

Research Strategy

Significance Autism Spectrum Disorder (ASD) has become more commonly diagnosed among children throughout the past few decades (Johnson et al. 2007). Current data suggests that 1 in 54 children in the United States are diagnosed with ASD (Maenner et al. 2020). Given that ASD is a common condition, various public health, clinical, and behavioral health interventions have been implemented in order to mitigate some of the symptoms associated with it.

Symptoms of ASD include challenges with communication, social interaction, repetitions of specific behaviors, and abnormal sensory sensitives and needs (Blomqvist et al. 2015). People with ASD also struggle with "building flexible predictions and expectations," which is an impediment to thriving in the unpredictability of the social world and environment around them (Blomqvist et al. 2015). Additionally, children with Autism may have lower motor skills which can result in them struggling with performing complex health-care tasks such as brushing teeth (Smutkeeree et al. 2020). Tooth-brushing twice a day is extremely important to maintain oral health. However, due to the complex nature of the task (requiring many steps to perform), it is challenging for the child with autism spectrum disorder to perform this task, which results in the child displaying challenging behaviors or being resistant to performing the task (Smutkeeree et al. 2020).

Not brushing teeth can result in poor oral health which usually affects people in the form of tooth decay, dental caries, and periodontal gum disease (Campanaro et al. 2019). These conditions are detrimental to overall health because as it can lower a person's quality of life including affecting their ability to eat certain foods and to sleep due to pain, suffering and weakness of gums (Campanaro et al. 2019). Another problem, specifically for children with ASD and other developmental disabilities is difficulty in verbally expressing that they are in pain, which results in said pain going unnoticed, which can then lead to more serious conditions such as diabetes (Campanaro et al. 2019).

In order to mitigate this problem, we will develop and test the effectiveness of a web-based application that incorporates chaining and video prompting to support caregivers in teaching children with ASD to brush their teeth.

Innovation Cazaux et al. (2019) conducted a study titled *Toothbrushing training programme using an iPad for children and adolescents with autism.* The aim of this study was to "improve oral health of children and teenagers with ASD using an iPad-based training program" (Cazaux et al. 2019). In this study, 55 participants diagnosed with ASD, (aged 3 to 19) were recruited, with 52 participants completing the full program (Cazaux et al. 2019). Their application, cATED, was a digital diary that used 16 pictograms to outline the steps of toothbrushing, and the caregiver oversaw the process of the children brushing their teeth. There was a baseline measurement of toothbrushing skills, then a four-month measurement, and finally an 8-month measurement by dentists evaluating how well the children can brush their teeth on their (Cazaux et al. 2019). No child was able to perform all of the toothbrushing steps on their own in the beginning of the program, and after 4 months, 4 children were able to complete all of the steps of brushing their teeth independently, and after 8 months, 10 children were able to complete all of the steps of brushing their teeth independently (Cazaux et al. 2019). This shows that while visual pedagogy (e.g., video modeling, picture schedules) could be effective, there is a necessity for more interactive methods of training children (such as video prompting and immediate feedback after learning, both of which our application features).

The objective of my capstone project is to create a tool (iPad app in this case) to increase accessibility to evidence-based behavioral interventions through technology. There are two aspects that make this innovative. We are targeting complex behaviors with expert-recommended guidelines for practice, such as tooth brushing, hand washing, etc., as opposed to breaking down the steps of tooth-brushing based on general healthcare guidelines. We also

focus on health-related behaviors/self-care as opposed to daily living routines such as folding laundry, or doing other household chores.

Approach

Preliminary Work

In order to accomplish Aim one, I have completed half of the Responsive Web design certification course on freecodecamp.com. Additionally, due to my previous internships and programming classes, I am able to use workflows, shell scripting, version control software (namely Git), and apply some programming concepts such as loops and arrays.

Aim I - Develop the application which features chain-based video modeling to teach children with autism how to brush their teeth by breaking down the process into 23 steps

Rationale Previous studies have shown that children with autism spectrum disorder have greater instances of dental caries and other dental conditions among children with Autism, who have more trouble brushing their teeth (Pielbro, 2015). Specifically, we have chosen an app-based intervention as it would be more user-friendly for the children with ASD along with their parents. Additionally, this is an expert-informed technology-based behavioral intervention that seeks to promote agency among families and caregivers of children with ASD in that we seek to support them in their implementation of daily routines for their children.

Design Approach /Necessary Preparation In order to be able to construct the app, I have to first undergo training to be able to use the technologies such as HTML & HTML 5, CSS, JavaScript, React Native. I would still want to revise some programming concepts and undergo Git training in order to be able to design a part of the application. Sartopgrahy (the company that I will be working with to create the app), has started on some of the development work, and they are planning on conducting alpha-testing (testing for bugs and re-iterating) in mid-December, and are hoping to conduct beta-testing (having participants test the app) in mid-January. In

order to be able to participate in app creation, I will have to finish relevant training by the end of winter break, such that I will be able to finish all of my training and submit my end-of-training deliverables by winter break and contribute to designing the application after initial testing by participants. I will also be contributing to the data analysis during the spring semester.

Problems and Alternative Approaches The application is not guaranteed to yield positive results, and it may not necessarily be user-friendly right after beta-testing, which means that we will have to re-design the app based on user feedback to ensure that it could work and yield positive results.

Aim II - Evaluate the effectiveness and feasibility of technology-based behavior interventions using single-case research design to replicate the effect of research-based participation

Rationale We are conducting this study to evaluate the effectiveness of this intervention to see if we can break down tooth brushing (a complex skill) into discrete behaviors to promote skill acquisition among children with ASD.

Experimental Approach To implement single-case research design, participants must be recruited. Dr. Natalie Badgett and her team of researchers will be recruiting participants from applied behavior analysis clinics in central Virginia. Participants will be included if they do not demonstrate mastery on toothbrushing and are able to follow simple verbal demands. Potential participants will be excluded if they engage in severe challenging behavior, which includes behavior that poses an imminent threat of harm to the child or their caregiver. Upon recruitment of three participants along with behavioral technicians, we will run probes every two to three days until stable responding is established. After which, the participants will be given iPads which have the application. The application itself will collect data on two dependent variables in

each session (sessions should occur twice a day): percent of steps completed and percent of steps where challenging behavior occurred. We will also conduct cold probes about every 5 sessions. These will be the same as we used in baseline, where we will instruct the child to brush his or her teeth and then will record (using a checklist built into the app) what skills the child demonstrated and whether challenging behavior occurred. We will video record each session to gather qualitative data to better understand user experience for the adult and the child. Taken together, the qualitative and quantitative findings will inform future iterations of the tool.

Data Collection and Interpretation For this experiment, we will be using single case design, which is used for evaluating the impact of intervention on mastery of a particular skill (Kratochwill et al. 2010). The "case" is an individual participant whose data will be analyzed (Kratochwill et al. 2010). As mentioned earlier, we will be recruiting three to five participants for this study, in which the participants' baseline toothbrushing skill levels (prior to intervention) will serve as a control to compare skill levels post-intervention (Kratochwill et al. 2010). The data for this experiment will be analyzed using the multiple probe technique to record the percentage of skill mastery (in our case, the number of steps of toothbrushing mastered (out of 23) for visual analysis (Horner and Baer, 1978). The main features of the multiple-probe analysis for this study include the following: 1) initial baseline probe sessions which will be conducted as the measurement of skill mastery before intervention for each participant until there is a baseline has been established, and 2) measurements of skill mastery of toothbrushing after intervention has been implemented. The x-axis features the number of sessions, and the y-axis features percent of steps completed and percent of steps in which challenging behavior occurred. The Multiple-probe analysis will be conducted for each participant's data (Horner and Baer, 1978).

Potential Problems and Alternatives Participants may drop out during the middle of the study, in which case we would continue recruiting for new participants. We will recruit at least 5 participants even though we will only need three. One of the problems that may happen is that we won't see skill acquisition occur or challenging behavior decrease. In that case, we will need to introduce additional intervention techniques, which may include using adapted materials (to address sensory needs) or adjusting our task analysis (list of steps) to make the targets easier to acquire. One of the benefits of using single case design is that it allows us to make these kinds of changes to our interventions to promote learning in participants.

STS

According to Flore, the transformation for technology into mental health has 'social, cultural, political, and economic implications." Specifically, he names the need to use AI to automate healthcare interventions to minimize the need for humans to conduct care (Flore, 2020). Flore also claims that digital health has even changed the way that humans experience illness and health (Flore, 2020). To me, this begs two questions: "is there a right way to experience health? Does technology take into account the complexities of a person's healthcare experience? At first glance, according to governments and NGOs, technology-based interventions for mental and behavioral conditions proves to increase access to healthcare, lower patients' costs for healthcare access, and even reduce the stigma associated with these conditions (Flore, 2020). Some of the stakeholders include not just patients and their loved ones, but also MHPs, physicians, medical device manufacturers, the general public, pharmaceutical companies, friends and acquaintances of patients, and the general public as well (Flore, 2020).

Subjectivity in Diagnosis of Mental and Behavioral Conditions

The diagnostic standards module (DSM) contains guidelines to diagnose people's mental and behavioral conditions without taking social and environmental factors into account,

yet these conditions “produce important social consequences” (Nelson, 2019). Due to this, many mental health practitioners (MHPs), work around the DSM by undermining it, working around the “standardized” criteria, and factoring the social conditions of the patient (Nelson, 2019). A factor that determines the subjectivity of diagnosis that would not be accounted for in the DSM or technologically-based diagnostic/screening tools is stigmatization of behavioral conditions such as ASD. In fact, according to Russell and Norwich et. al, despite displaying behaviors indicative of ASD, many children do not get diagnosed due to barriers either by health professionals or by parents (Russell & Norwich, 2012). This is a significant topic to look at because it drives the subjectivity in diagnosis. People’s barriers to mental health diagnosis is a significant factor that is not accounted for in the DSM, but will greatly determine who receives treatment since people without a formal diagnosis cannot receive treatment. Additionally, creators of screening tests and behavioral interventions may only take into account populations the characteristics and environmental conditions of those who are diagnosed. Yet, there may be differences that algorithms cannot take into account for people who do not have a formal diagnosis, but have the condition. Additionally, on the other ,end of the spectrum, it also cannot take into account people who may be misdiagnosed with ASD or might have other conditions that are either diagnosed or undiagnosed.

Subjectivity in Design of Application

Flore et al. created a “framework to understand how subjectivity and knowledge of mental health can illness are transformed through the combination of technology and pharmaceuticals and entanglement of human and non-human actors.” (Flore, 2020). Similar to MyCite (analyzed by Flore), the application that I am creating for my capstone project is also an “assemblage of technologies:” software code, algorithms, iPad, and videos. I want to use Flore’s framework to examine subjectivity in designing this application as well. The example Flore uses is Wysa and Woebot, which are smartphone apps designed to track mental health and well-

being and offer mental health/therapeutic coaching using AI. He mentioned that algorithmic subjectivity is being used in this scenario to track the patients' everyday moods and daily mental health to then provide personalized counseling (Flore, 2020). The app that I will co-create with Sartography would also use data-driven and algorithmic subjectivity in order to focus on the correct step for the user (in my case, a child with ASD) when brushing their teeth, by asking the parent if the child has mastered the previous step. (In this situation, the parents are guiding the child and teaching the child using the app how to brush their teeth). Plus, patient data will also have to be collected for this particular project to test mastery level, which then brings the questions of subjectivity of data valency along with questions about the ethical collection of data.

Next Steps

As the above suggests, I will focus on analyzing not just the subjectivity behind designing the app for children with Autism to brush their teeth, but also on the process of diagnosing these children. I will also analyze the implications of the biases for/against diagnosis of mental and behavioral conditions and how that will affect the design of devices. Specifically, I will focus on the data collection process, subjectivity of the algorithm of the app I am designing with Sartography, and I also want to dive into the social factors and stigma against mental health when exploring diagnostic subjectivity. Then, I want to understand how diagnostic subjectivity plays a role in the subjectivity involving the app-design intervention using Flore as a framework.

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