




Designing for and with Neurodiverse Users: Wearable Applications for Self-regulation

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Abstract. Wearable Technologies have a large potential to provide assistance to neurodiverse users – thanks to their close proximity to the user, continuous usage, and discreteness. However traditional user-centric design techniques are not always suitable to attend the needs of this user population. In this paper, we discuss practical considerations for methodological approaches involving neurodiverse users front and center in the design of assistive wearables. The discussion is grounded on a longitudinal field study conducted with a cohort of eight young adults with Down Syndrome and Autism. We designed, developed, and evaluated an assistive wearable application that provides emotion regulation support on demand. Study participants provided feedback through questionnaires, weekly meetings, and interviews. This paper presents and discusses design considerations, as well as the challenges and recommendations for recruitment, design, and evaluation of the application.

Keywords: Assistive wearables · Neurodiversity · Emotion regulation · Design

1 Introduction

Wearable technologies have evolved in the past decades to include miniaturized hardware, energy-efficient batteries, and protocols for data transmission [5, 6]. Wearable technologies are well-suited to serve as assistive devices [3], first, due to their conventional look they can reduce potential stigmas; second, their on-body interfaces are beneficial for on demand interventions and timely assistance; third, the availability of development frameworks allow for customized solutions for hardware and applications as well [10].

Assistive technologies aim to provide support for users with diverse needs. Assistive technologies are able to augment human abilities and/or to replace those, helping users to achieve high quality of life and to live more independently. Although assistive technologies have been extensively researched and

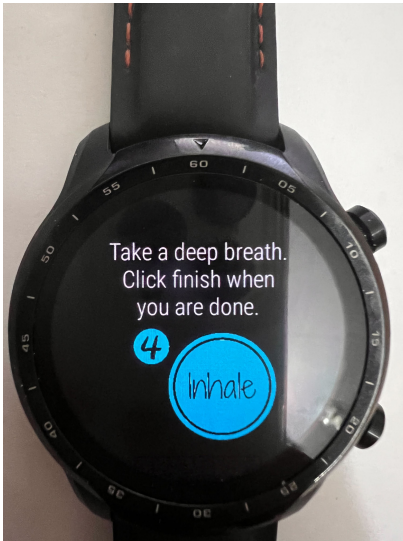
developed for many types of disabilities, including visual impairments, hearing impairments, and motor impairments [3], fewer technologies have been dedicated to meet the specific needs of neurodiverse users—a population that has been increasing in number and whose conditions largely vary.

Neurodiverse conditions include attention deficit and hyperactivity disorder (ADHD), Autism, Down Syndrome, and cerebral palsy. They are characterized by variations in cognitive abilities, information processing, and executive functions. They are lifelong and chronic, manifesting themselves in a spectrum, i.e. each individual has unique traits, abilities, assets, strengths, and limitations as well.

The field of accessibility has involved users with disabilities in the design of technology since its inception. Still, there are tendencies to focus on specific disabilities and to closely involve end users' peers (e.g., parents, caregivers, professionals) rather than users with diverse needs. Oftentimes users with diverse needs are not sufficiently involved in the design process to actively inform and iteratively shape the design of technology [4]. Moreover, several techniques employed conventionally in a user-centered design process are not suitable for neurodiverse users [2], specifically, think aloud requires participants to be verbal (which is not always the case for autistic individuals) and to concentrate on multiple tasks at a time (inspecting the user interface and describing their thought processes) [7]. Diaries for example require participants with cognitive abilities, literacy skills, and memory which may be impaired for users with Down Syndrome and dysgraphia.

To involve neurodiverse users front and center in the research and design agenda, we need to take into account their specific abilities [9], i.e. motor skills (for sketching tasks), visual thinking (for diagramming), communication skills (verbal expression), literacy levels (reading and writing), among others. Because no validated methods or best practices specific to neurodiverse populations exist in the field, we rely on recommendations from the research community [1]. Still, it is crucial to report and discuss the experiences of investigators conducting such studies in order to identify methodological approaches that have been proven to be successful to engage neurodiverse users in the design process [2]. Additionally, we must reflect on the potential sources of bias and address those [8].

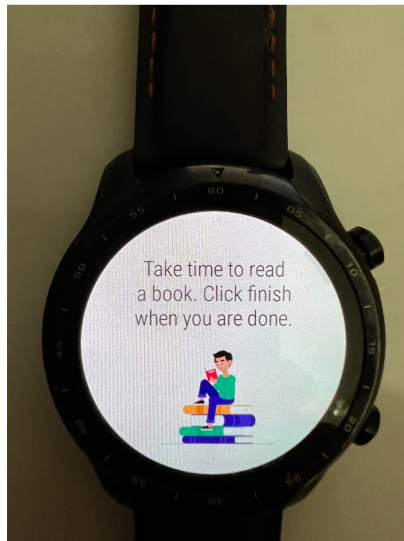
This paper reflects on the authors' experience, conducting user studies for and with neurodiverse participants for the past five years. The discussion focuses on the design, development, and evaluation of assistive wearables and a gender-balanced participant population of young adults. Application domains for the technology involved contexts that range from inclusive employment, independent living facilities, and postsecondary programs. Specifically, we focus on a case study involving the design and development of assistive smartwatch applications for emotion regulation. We present the challenges faced in recruitment, data collection, analysis, and deployment of the tool. We conclude with design implications for stakeholders investigating wearables as assistive technologies for neurodiverse users.



(a)



(b)



(c)

Fig. 1. Three strategic interventions displayed on the watch application: (a) deep breathing; (b) journalling; and (c) reading. Participants could suggest interventions in the beginning of the study, to customize the app. The interventions were triggered per time.

2 Methods

2.1 Recruitment

Upon Institutional Review Board approval of the study protocol by the university, we recruited neurodiverse participants. We advertised the study using flyers, emails, and word-of-mouth. Specifically, we relied on a network of contacts of alumni from a postsecondary inclusive program (email list), we also contacted the coach of the Special Olympics where the study has been conducted, and distributed the call for participation in social media channels (dedicated parent groups on Facebook). We reached out to the coordinators of independent living facilities in our region (Northeastern US) and other educational programs. More than 100 people were contacted—including neurodiverse adults, parents, and professionals, such as: coaches, analysts, therapists, and caregivers. The recruitment took place in the Spring 2021.

2.2 Experimental Design

The study consisted of three parts: onboarding, weekly meetings, and closure interviews. Initially, in the onboarding phase, we applied a demographic form, collecting profile information such as age, gender, condition, and preferred interventions. Secondly, participants joined a video conference call to watch a demo video about the watch app, and received the watch with a phone. The delivery of the devices was done via porch pick up or mail, to avoid issues related to COVID-19. A pre-paid data package was used to ensure all participants had a stable Internet connection to synchronize data. In the second phase, the participants started using the watch. The duration of their participation ranged from 4 to 8 weeks. Each participant received notifications and prompts on their watches at their preferred times (morning, afternoon, or evening) and frequency (5 to 10 times per day) as they indicated in the responses to the demographic form. Lastly, to give closure to the study, we invited participants to join a one-on-one interview and to recall the memorable events when they needed the watch.

2.3 Data Collection

We collected data using a brief questionnaire (demographic form) to characterize profile information, and gather their individual preferences regarding the types of strategic interventions (preferred regulation techniques). Also, the watch collected data about their responses (mood at the time of the notification, intervention chosen, heart rate and timestamp). We collected heart rate data in order to identify the potential success of the intervention in decreasing high heart rates. Also, we revised the transcripts from the audio recorded in weekly meetings. Lastly, for the individual interviews we asked participants to draw their ideas, describing their experiences. In case they were not comfortable with sketching or drawing they had the option to explain out loud their experiences using the watch application.

2.4 Data Analysis

We adopted a mixed-method approach for data analysis according to the nature of the data collected, amount, and research questions of interest. Specifically, to analyze the watch data (log files) we assessed the times in which the application was accessed, the choice of strategic intervention, the changes in heart rate. To analyze the video transcripts, we highlighted the comments related to their experience, suggestions for modification, challenges faced, among others. The analysis of the closure interviews was also based on review and annotation of the audio transcripts. The analysis was conducted in a collaborative effort by the research team, specifically, we meet weekly to discuss the study protocol, procedure for analysis, and key research findings.

2.5 Incentives

Each participant was compensated with a US\$25 gift card, delivered by email, after participation in the final interview and return of the equipment.

3 Results

3.1 WELLI

As Fig. 1 shows, the application was implemented for Android watches (using Wear OS). In the database we stored data about the user interaction as log files. All participants received the same version of the watch and phones. A brief training was provided to explain how to use the app, and weekly calls were held online to discuss the user experience. The next sections summarize major design considerations based on the analysis of field notes.

3.2 Design Considerations

Regarding the acceptance of the watch, participants who were already familiar with a smartwatch from another brand and model (e.g., an Apple watch), hesitated to switch to another device. As they became more familiar with the watch and learned how to use it, such a concern faded. A few participants would like to continue using the device after the study ended, stating for example “Should we return the watch in one month? Can I have it longer?” [P4]. This indicates a potential for long term adoption and acceptance of the app.

Regarding the strategic interventions, initially, participants could not easily identify and suggest their preferred interventions. However, as they became more familiarized with the app during the study, they recommended interventions and asked us to update the list of pre-defined interventions. As P3 asked: “Is it possible to put watching TV on my watch as one of my things? I don’t like storms, and it is storming and when the weather is like this, watching TV helps me be calm” [P3]. We observe that having their favorite interventions implemented

proved to be successful for participants, whereas not having those available led to the rejection of the app.

Regarding the participatory design and inclusion (designing for and with neurodiverse users), some participants were invested in the study, even offering to assist other participants with training. Also, they offered to further advertise the study and invited their friends to join it as well. As P3 mentioned: “Is it ok if I let P2 know how she should use the watch? I can help her to learn it. I know all the things about the watch, and I can help if you want” [P3]. Such recommendation suggests that participants were engaged with the study and took ownership to exert their agency, influencing recruitment and leading to a community-based approach for onboarding.

Regarding the utility of the watch, when participants were not using the app they felt the need to have it readily available. This was remarkable in situations of extreme stress, for instance when P3 experienced a shooting event during a football match and informed that she wished she had the watch with her to calm her down. She felt upset that she could not use the watch at that moment. Also, when they could not use the watch due to technical issues they felt frustrated. P4 for instance had problems connecting her watch to the Bluetooth. Because she felt upset she asked the researchers to assist her promptly, so that she could start using the app the next day.

Regarding the effectiveness of the app and interventions, we noticed participants were overall satisfied. In weekly calls, participants shared their experience using the watch and how it impacted their routines. For P4, a delay in her work schedule caused frustration, but she stated that the breathing techniques in the watch helped her to feel better: “Getting a notification that asks me if I am feeling all right and checking on me makes me happy. I expect to see some kind of rewarding quote in the notifications, like ‘you are doing great!’ I like some notifications that say you have had more than 500 steps so far. Excellent job. It always feels good to receive something like this” [P4]. Positive reinforcement has been identified as a key design decision for technology implemented for neurodiverse users, such a remark confirms findings from prior work.

As noted in previous studies, positive reinforcement is highly appreciated among neurodiverse participants. Hence, in the watch app WELLI, participants accumulate stars when the strategic interventions are completed. In the weekly meetings, participants expressed excitement about the stars they had received. The rewards system also encourages them to use the app. As P1 mentioned: “...it’s kind of sad because I got really excited with seeing the stars, but I haven’t seen my stars in a while...”. The watch app proved to be useful even during their holidays, as P1 stated “... me and my parents were on vacation at the home for a couple of days and I had to make sure to wear my watch every day and whenever we took some walk... For make star, I always click finish” [P1]. Such comments indicate that overall participants had a positive experience and enjoyed using the app.

3.3 Discussion of the Methodological Approach

Recruitment of participants during the pandemic proved to be more challenging. Specifically, it required more time and effort of investigators to find participants who were willing to join the study. Some participants already had a watch but of another brand/model (Apple Watch) and were not willing to switch devices. Also, some participants had vacation plans, and the lack of routine summed with travel prevented them from attending weekly meetings. Although more than 80 participants were contacted, the initial cohort consisted of 8 people. While no conclusive results can be obtained from a small sample size, we approach the analysis in depth investigating individual experiences longitudinally.

We observe in the findings that the technology interest of each participant influenced their device usage. In other words, participants who were more inclined to technology took the lead on training their peers, explaining how the device works, and inviting their friends to join the study. Such an appropriation is beneficial since participants took ownership of the study and engaged in a kind of community-based approach to engage others as well.

To address connectivity issues, we provided participants with a pre-paid data card since it proved to be easier than managing problems related to WiFi connections at various locations. Because we aimed at ecological validity in multiple sites, reducing the burden related to setting up devices became an essential requirement in the study.

Regarding social connections, the weekly meetings proved to be a great opportunity for participants to meet and talk to one another, even those who did not use the watch application regularly still enjoyed joining the weekly meetings as an opportunity to meet their peers, and talk to them. Still, reminders were needed to encourage participation in online meetings.

3.4 Participants' Experience

We observed in the study that the acceptance, adoption, and attachment to the watch app was tied to participants' levels of self-awareness about their emotions, or executive function, but not necessarily linked to a disability type or IQ level. Further studies with a large sample size are needed though to identify potential causation effects.

Regardless of the level of participant engagement in the study, we observed their enjoyment in interacting with other people in the call, in addition to technology use. Hence, the weekly meetings lasted longer than initially planned. Also, participants who were not using the watch app regularly, kept joining the call. This observation must consider the COVID-19 pandemic context, in which participants had their regular routines disrupted and remained in isolation, instead of going to classes, work, or practicing group activities.

Regarding need for training, the onboarding process was extended, with participants requiring reminders, prompts, and regular contact to troubleshoot watch app issues or to notify them to use the app.

4 Concluding Remarks

This paper reports on the design and evaluation of an assistive wearable application that provides support for emotion regulation for neurodiverse adults. The field study discussed involved 8 participants who used the app during 8 weeks. The analysis of the field notes yield design recommendations that can guide future research with neurodiverse users. Specifically, we discuss how we addressed challenges in recruitment, connectivity, user engagement, and adoption.

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