StammerApp: Designing a Mobile Application to Support Self-Reflection and Goal Setting for People Who Stammer

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ABSTRACT
Stammering is a speech disorder affecting approximately 1% of the worldwide population. It can have associated impacts on daily life, such as loss of confidence in social situations and increased anxiety levels (particularly when speaking to strangers). Work exploring the development of digital tools to support people who stammer (PwS) is emerging. However, there is a paucity of research engaging PwS in the design process, with participation being facilitated mainly in testing phases. In this paper, we describe the user-centered design, development and evaluation of StammerApp, a mobile application to support PwS. We contribute insights into the challenges and barriers that PwS experience day-to-day and reflect on the complexities of designing with this diverse group. Finally, we present a set of design recommendations for the development of tools to support PwS in their everyday interactions, and provide an example of how these might be envisioned through the StammerApp prototype.

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User-centered design; Speech and Language Therapy; Stammering; Mobile applications; Self-management

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H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION
Stammering (or stuttering) is a multifactorial speech disorder affecting approximately 70 million people worldwide [36]. It is caused by regular disruptions in the natural flow of speech [20]; from repetitions of a word or sound, to less obvious interruptions such as regular use of injections like 'um' or 'ah'. The verbal characteristics of the stammer often co-exist with secondary features such as facial grimacing, loss of eye contact and excessive physical tension (e.g. in the shoulders) [20].

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There are a range of psychosocial impacts related to the experience of living with a stammer. For example, negative experiences associated with being mocked or teased can lead to the development of low self-esteem, poor confidence levels, anxiety and social isolation [9]. This can, in turn, cause long term challenges around the avoidance of particular situations that may be construed as challenging (e.g. using the telephone), forming lasting relationships, and finding and keeping a job [8, 14]. However, for many individuals, stammering is an integral part of their identity, and to whom the concept of 'curing' their stammer might be seen as offensive. These somewhat polarized viewpoints exist widely within the domain of disability rights and can be particularly likened to the deaf community and the debate surrounding cochlear implants, and sign language culture [34].

The small, but emerging, HCI literature around stammering seems to center mainly around the solutionist domain, with several examples looking at the development of tools to improve speech fluency [16, 40]. In addition, there is a distinct lack of any research (that we could find) which has attempted to engage people who stammer (PwS) themselves in the design of digital tools to support their needs (with preference being to work with speech & language therapists (SLTs) [10, 19]). Given that technologies to support communication are supposed to help the user in having a voice, as it were, there is a need to ensure that the voices of PwS are being adequately represented in research that is aimed at developing solutions to be used by them.

In this paper, we describe a series of engagements conducted with 39 participants over the course of approximately 12 months. First we conducted a set of online surveys with 20 PwS, to gain an insight into the overarching issues that PwS currently face and the types of support they would like to have, as well as gathering an understanding of the types of apps PwS currently use to support them. We then conducted a small user-centered design workshop, with 3 PwS, to gain a deeper understanding of the extent that challenges surrounding stammering can impact their everyday lives, and scope the potential places that a mobile app might support them. We then took the ideas that emerged from this workshop to a larger group of PwS (n=15), by running a final workshop at a national stammering conference. Through this, we were able to explore the breadth of shared experiences that the

wider community had, and gather final insights on how a mobile app might be received and used. Drawing from insights gathered during the initial design stages we developed StammerApp, a mobile application to support goal setting, practice and reflection around situations seen as challenging for PwS in daily life. Finally, 3 PwS (2 from workshop 1 and another participant who had nothing to do with the design phase) conducted a preliminary evaluation of the eventual app that was developed, using it in-the-wild for 1 week and providing feedback on their experiences.

Our contribution to HCI is threefold. First, we deliver insight into the challenges and barriers that PwS can experience in their day to day lives, and the highly personal ways that different people engage with self-management strategies to overcome these. Second, we reflect on the complexities of engaging with this diverse group. Finally, we present a set of design recommendations for the development of tools to support PwS in their everyday interactions, and provide an example of how these might be envisioned through the StammerApp prototype.

BACKGROUND

Stammering and its associated impacts

Stammering (also known as stuttering) is a speech disorder which can present in a multitude of different ways, including prolongations (where a sound is prolonged for several seconds e.g. b----aby), repetitions (of the whole or part of a word e.g. b-b-baby), injections (such as 'um' or 'ah'), broken words (where there is a gap in the middle of words b….aby), and blocking (where the sound does not come out at all for a few seconds) [20, 21]. The severity of stammering can vary depending on the time of day (e.g. feeling tired later in the day), the situation (e.g. a new experience or environment) and who the person is speaking to (e.g. a stranger, or an intimidating manager at work) [27]. Stammering often occurs in similar places in words and sentences, or on the same sound or word [13, 15]. PwS are also more likely to stammer on words beginning with consonants, initial words and longer words [13].

Individuals can attach negative thoughts or emotions to particular words or sounds due to negative past experiences [15, 39], and this can influence how they approach these in the future. This 'anticipation effect' [13] can cause increased social anxiety in some people [4, 10, 13, 15, 28, 22], which can lead to covert tendencies. People who are covert will commonly use avoidance techniques such as circumlocution (using multiple words where one would do) and/or replacing certain words which might elicit a stammer during conversation [4, 10, 39]. Avoiding eye contact [10] or avoiding situations entirely due to concern about their speech [10, 13, 18, 35] is also common.

In modern practice, stammering is not viewed merely as a speech disorder, but as a far more complex condition which can also include deeper psychological effects such as loss of confidence, lower self-worth and increased anxiety levels [5]. PwS can be subjected to negative stereotypes, prejudice and discrimination, as well as victimization and bullying [3, 5, 13, 28]. They are also at an increased risk of having a lower quality of life, particularly in social and vocational spheres, and in terms of their emotional and mental health [27]. In addition, PwS will often have a high level of awareness and concern over their speech [22], which can lead to hyper-vigilance and increased error monitoring, regardless of whether more errors are actually made [7, 13]. Individuals commonly perceive their stammer to be a speech error in itself and their attempts to minimize the number of errors that they make can ultimately cause more dysfluencies [7, 13].

Management of Stammering

While speech and language therapy can be helpful for children, there are fewer success stories for adults, as they are less responsive to its effects and less likely to seek out help if they need it [28]. As such, adults are more likely to require strategies to help them to self-manage their stammer, such as using learned techniques and strategies, practicing breathing, altering volume or speech rate, using positive self-talk or taking pauses to aid relaxation [15].

As it becomes more widely accepted that there is more to PwS than just their dysfluencies [39], more holistic models of therapy are being used, such as Cognitive Behavioral Therapy (CBT) [28] and Acceptance and Commitment Therapy (ACT) [1]. Behavioral therapies help PWS to re-evaluate their standards [7], and it has been noted that people who have received therapy are less likely to experience setbacks with their speech [2]. CBT targets negative personal thoughts, encouraging positive attitudes, improving social skills, reducing avoidance, improving everyday functioning, and managing emotional reactions to dysfluency [28]. It involves challenging PWS to put themselves in situations which they would usually avoid, predicting the outcome and assessing how realistic their predictions were, based on the real event. Similarly, ACT encourages the individual to focus on their own personal value and remain psychologically flexible [1]; accepting that there are things that cannot be changed and focusing on the present, rather than the past, to attain goals. Both therapies are strongly related to mindfulness, a tactic designed to manage and reduce negative thoughts [28], allowing people to focus on more positive aspects of their life, and control where their attention is placed.

Just as professional approaches to stammering have moved towards an ethos of acceptance and management as opposed to cure, national stammering charities are also taking a more holistic, less fluency-focused angle to stammering. For example, the British Stammering Association state that "it is possible to lead a happy and fulfilled life, even if fluent speech does remain elusive. We have a voice" [6]. Similarly, the Scottish Stammering Network seeks to help PWS "to build confidence, gain skills, manage stress and learn to live well with stammer, as having a stammer doesn't have to stop you from doing what

you want in life" [33]. While both charities still support speech and language therapy, the greater emphasis is placed on the individual and helping them to be happy and successful in their everyday lives, whether they stammer or not.

Technology Mediated Support

There is a minimal, but emerging, HCI literature considering the use of technology to help PwS [10, 16, 19, 31, 32, 40]. Most of this focuses on the development of fluency aids (to improve the severity of stammering), reflecting the clinical focus found in the literature. A common fluency aid, for which there are many applications currently available, is Delayed Auditory Feedback (DAF)—a well-known SLT technique to reduce stammering, that involves playing an individual's speech back to them, at a delay, to help them regulate their speech [38]. Voigt et al. [40] studied a DAF smartphone app and reported improvements to fluency. However, they noted that it was difficult to filter out environmental sound, meaning that there were other sounds on the recording alongside the speaker's voice.

Another study by Kalwed et al. explored a speech completion app, which employed a process of predicting what word will come next based on the previous sound [16]. The authors claimed it was designed to boost confidence by prompting the word most likely to come next. This style of system caters to repetition-style stammering, and is able to detect stammering by checking if a word or sound has been repeated multiple times before or after a pause. The system then calculates what the rest of the word (if unfinished) or the next word (if finished) is likely to be, and the results are returned in order of likelihood. The audio output is intended to act as a prompt for the user and help them to say the word, however the application was limited in scope as it was only usable by people who had a specific form of stammer. It was also found to be unhelpful if it prompted at the wrong moment or with an inaccurate suggestion.

There are also examples of websites and apps to support self-management of stammering. For example, Scenari-Aid [30] is a well-known Australian website that contains a list of video based scenarios that PwS can use to practice specific situations (e.g. a job interview). I [am] Aware [of] my Stuttering (IAmS) [19] and its later iteration Brothers in Stuttering (BroiStu) [10] were designed to allow PwS to register a 'stuttering-related situation' (SS) [19]. The individual can self-monitor their speech by charting their problems and progress, as well as allowing an SLT to link up with their account in order to understand which situations cause stammering, so that they can tailor their treatment. This allows SLTs to motivate their patients by encouraging them to practice their speech and reflect on their progress, so that they can better engage with therapy sessions. Users are encouraged to input a stuttering-related situation as soon as possible after the event and may change their mood settings at any time. Any new SS will then be linked to their current mood. The user can also select parameters such as context, who they were speaking to, whether they chose to speak or not (and why), whether they stammered or not, the intensity of the stammering, the reaction of the person they were speaking to and the emotions that they experienced. When tested, the overall reaction to this application was positive, judging it easy to understand, with a good flow of actions. Personalization was also considered to be very important to users.

Whilst these examples speak more to the socio-emotional needs of PwS, as opposed to aiming to improve fluency in an objective manner, they are limited in scope in terms of the type of reflection they allow, and focus on monitoring improvement throughout the course of an SLT program (thus requiring SLT support to be useful). In summary, although there is an emerging interest in HCI around the space of digitally supporting stammering, there is a distinct lack of research examples which have engaged PwS in the design process; 2 PWS and 5 PWS were involved in user testing only in [10] and [19] respectively, and none were involved at any stage in [16] or [40].

Through our work, we aimed to explore the specific needs and values of PwS, to ensure that their voice is represented in the design of future digital tools to support them. We first describe our design process, and the findings that emerged from this. We then discuss the StammerApp, which was developed in response to the design requirements gathered. Finally, we discuss a preliminary, in-the-wild evaluation of the StammerApp, and the feedback that users provided.

ENGAGEMENTS WITH PEOPLE WHO STAMMER

The first stage of our research involved a series of engagements with PwS, to understand the needs and values that they would like to see represented in an app to support them in their daily lives.

Survey

We first conducted an online survey, to gather an understanding of the types of apps PwS currently use and the type of support they would like to receive. We recruited 20 participants, via advertisements posted on a series of stammering related Facebook groups. Individuals of any age or stammering severity were welcome to take part.

Participants followed a link to an online form where they were asked 5 questions: 1) Have you ever used an app to help with your stammering? If so, what did it do and was it useful? 2) what features would you like to see in an app for people who stammer? 3) what type of speaking situations would you like to practice? 4) what type of things would you like to have some feedback on; and finally 5) who would you like to have feedback from? All responses were provided in free text format.

Survey responses were collected online via free-text input. Data was then collated into a spreadsheet and a content analysis [29] was conducted to look for emergent themes relating to each specific question. Following analysis of the survey data we generated a set of 60 "I want" statements which we developed into cards. These were later used as materials in our workshop.

Design Workshops

The next phase of the design process involved conducting a workshop with PwS to further discuss and refine the ideas which had emerged from the survey data. With recognition of the communication and confidence issues that PwS can face, we wanted to keep this workshop small, to ensure that we could facilitate participation of all members to an appropriate degree [11]. We recruited 3 PwS (1 female), through personal contacts and a call for participation, posted on the local British Stammering Association Facebook page for Newcastle Upon Tyne. Participants were aged between 26 and 35.

The workshop was held during the evening at Newcastle University and lasted 3 hours. Participants were not paid for their time but we provided food (as they were attending immediately after work). We started the session by asking participants to tell us about themselves and how their stammer affected them, as well as any specific situations where they felt their stammer was worse or where they felt they might need support. We then asked participants to discuss the types of places they usually go for advice or support for their stammering and any strategies they used to help themselves day-to-day.

We then moved to a card sorting task, which aimed to uncover the priorities that the application should focus on. We asked the group to sort through the 60 "I want" statements derived from the surveys and add a colored sticker to the top 5 things that felt reflected what they would most like to have in the application. We then discussed these, as a group, and decided on the top 3 priorities together, selecting option of importance to multiple participants and resolving disagreements as we went along. Finally, using the top 3 statements as prompts, we discussed how we might initiate feedback or learning opportunities for each statement using a mobile application.

In order to explore whether or not the findings from this workshop would be applicable to a larger group of PwS, we decided to conduct a second, larger workshop. Where workshop 1 aimed to provide a deep engagement with a small group of participants, workshop 2 focused more on scoping the types of advice that might be useful to PwS in specific situations and whether or not the priorities we identified in workshop one were shared by the wider community. Despite success recruiting participants for the online survey, we had significant difficulties recruiting participants to engage in workshop 2. However, through a personal contact from one of the researchers, we were

Figure 1: The card sorting activity conducted during workshop 2

offered a slot to host a workshop at the 2016 British Stammering Association National Conference held in Manchester, UK. We recruited 15 participants (2 female, ages 19-62) via email advertisement sent to the delegates.. We then carried out a 2-hour workshop prior to the beginning of the conference, as part of their opening activities. Participants were broken up into small groups of 5, with a researcher positioned on each table. We started the session by asking each table to read through a persona that we had created based on the experiences identified as challenging by the workshop 1 participants. These were centered around the workplace (giving a presentation, having a job interview), transport (getting the bus across town) and using the telephone (calling a broadband provided). For example:

Kate needs to phone her internet provider to fix a problem with her WiFi. She normally uses substitution to help her to be more fluent, but she won't be able to do this when giving her personal information to the company. She is very nervous and worries that they will not give her the time she needs to speak, hang up on her or interrupt her because they think there is something wrong with the line.

We asked participants to discuss a) How they would suggest the person should approach the situation; b) what advice they would give to help the person prepare for the situation; and c) where they would suggest the person should go for advice to help them. We then asked each table to feedback what they had discussed, writing emerging themes on a flipchart.

We then repeated the card sorting task from the first workshop (see figure 1). We asked each table to sort through the "I want" statements and decide on top 3 things that felt reflected what they would most like to have in the application. We then discussed these as a whole group and decided on the top 3 priorities, discussing the potential for using a mobile application to support these as we went through each one.

Data from both workshops was audio recorded and transcribed verbatim for later analysis. Two members of the research team analyzed the data independently, conducting an inductive thematic analysis on the transcripts. Coders then worked together to consolidate any discrepancies. Data was summarized with short one or two word codes, at the sentence-to-paragraph level. Codes were then compared to one-another and grouped, which led to the construction of themes that captured the core topics and concerns emerging from the data.

A total of 17 themes emerged from the workshop data, which were then synthesized into the 4 wider theme headings that we used to explicate our findings. We first report the broad findings taken from the survey responses, to provide insight into the themes of discussion that we further explored in the workshops. We then move to discuss the workshop findings, which led to the generation of a set of design requirements for StammerApp.

SURVEY RESPONSE FINDINGS

Previous Application Experience

The majority of our respondents reported that they had not used an app to support their stammering (n=14). Of those who had, two had used an app for social and information support. The other three participants had used apps to aid in the practice of their speech (e.g. DAF app and the coastal breathing technique).

Desired Features in an App to Support Stammering

When asked about what features respondents would like to see in an app to support them, we had a wide range of suggestions (n=33) which could be grouped into 5 broad themes. The first related to the provision of information (n=5) and how an app could support PwS in finding associations and SLTs, and describing coping methods or treatment ideas depending on individual desires. The second theme groups desired features for practicing situations (n=8), which includes encouragement; reminders (to practice, stutter openly, or use coping mechanisms); practical demonstrations of coping strategies; and speaking exercises. The third theme lists features for journaling (n=8), which included real-time note taking; note taking to reflect back on a situation; recording who you interact with; rating stuttering moments and stress levels for the day; and a personal goals checklist. The fourth theme is around social features (n=8), which includes connecting and communicating with other PwS (or others to develop speaking skills); positive feedback, encouragement, and reassurance; and a reward system (to recognize brave moments). The fifth and final theme groups remaining miscellaneous desired features (n=4): Translating stammered speech into another language; DAF with multiple customizable settings (according to stutter severity); a screen or card that states “I stutter, please be patient”; and listening to speech to inform the user which letters or words impact the stutter the most.

Scenarios to Practice

The survey respondents were asked which speaking situations they would like to practice. Several situations were provided, which were grouped into 3 groups: e*veryday tasks*, *work-related*, and *social*. Most of the suggestions were grouped into *everyday tasks*. Most of the respondents (n=7) suggested practicing phone calls or placing and order in a bar/restaurant. Other suggestions included introducing yourself (n=3); asking directions (n=2); and basic small talk (n=2). The remaining scenarios were suggested once each: saying important information; ordering a taxi; assertive speaking situations; public speaking; talking on video; and talking in loud or distracting situations. The next group of practice scenarios were *work-related*. Job interviews were suggested the most (n=8), followed by presentations and speeches to small and large groups (n=2). The remaining scenarios were each suggested once: conference calls; elevator pitches; speaking in the workplace; and speaking on the phone in an open-plan office. The last grouping of practice scenarios were *social*. Some respondents suggested meeting new people or strangers (n=4), and a couple suggested dating (n=2).

Receiving Feedback on Speech

The respondents were asked about what elements of their speech they thought would be useful to receive feedback on. There were several suggestions (n=22), with their responses grouped into 3 themes: *Physical*, *vocal*, and *attitude*. The *physical* elements received the most discussion, mainly around posture and poise (n=9), and eye contact (n=10). Some stated that feedback on secondary or involuntary features of stammering would be useful (n=2), whilst the remaining features received minimal coverage (n=1): video recordings to assist assessment, appearing to struggle, body language, breath control, and heart rate. There were more *Vocal* elements, but they received less focus from the respondents. The more prominent features in this category were speaking speed (n=3), and tone and number of stuttering episodes (n=2). Other features (n=1) include: voluntary stammers, whether a stutter is visible or audible in any way, clarity and understandability, continuity, volume, and where stuttering occurs (any letters or words that give the most trouble). The responses grouped as *attitude* elements received similar levels of attention as the vocal elements. The most common element here was confidence (n=4), followed by other features (n=1): speaking within ear shot, avoidance behaviors, engagement with subject matter, and mindfulness.

Whom to Receive Feedback From

When asked about whom they would prefer to receive feedback from, most of the respondents stated SLTs and SLPs (n=11), especially those with a specialization in stuttering, which was closely followed by PwS (n=9). A smaller number said they would prefer feedback from strangers (n=4), whilst others suggested they would prefer to receive feedback from someone with experience of stuttering (n=3), or anyone (n=3).

WORKSHOP FINDINGS

This section describes a synthesis of findings from both workshops. P1-3 took part in workshop one, with P4-18 taking part in workshop two.

Experiences and workarounds

Participants represented a diverse range of experiences and attitudes, particularly in their self-presentation and work lives. For example, P1 demonstrated a level of shyness within their workplace: *"I never speak first at work"* and described themselves as working *"behind the scenes",* where P2 had a forward-facing job: *"I spend a lot of time speaking to volunteers and corporations"*, and P3 was heavily involved in several national stammering charities, serving as vice-chair for one. They all had different situations that they found particularly challenging. Many of these centered around interacting with strangers day-to-day. For example, P1 described how, before automated ticket machines became commonplace, buying a daily train ticket caused much anxiety and how he had developed a workaround to overcome this challenge, a solution he viewed as an avoidance technique *"I used to have a post-it note in my hand at the train station… I would attempt to ask, but if I got really blocked I used to just go back with the post-it note…it was avoidance really"*.

There was much discussion around challenges relating to phone calls. P2 described how it was the sole focus on speech that caused anxiety *"face-to-face you've got the body language and the person's there and you see them and…on the phone, you can be more nervous*". P3 described how anxious she felt when making phone calls at work *"whenever I pick up the phone in work, I'm representing that workplace…if I stammer and disgrace the organization, it's so much more pressure for me"*. Both P1 and P2 described how important it was to have privacy when making a phone call. For P1 it was his self-consciousness that caused him stress: *"I get really stressed having to phone restaurants and book a table…I need to go into a room by myself*", where for P2 it was distraction through external noise that caused his stammer to worsen "*if I have to phone a volunteer…I'll walk out the room and down the corridor to where it's quiet, because the noise can be distracting and when you're distracted then you stammer more"*.

Phone calls were also seen as a challenge by participants in workshop 2 but participants had a wide range of workarounds that they used. The main comments centered around accepting the stammer was going to happen *"just make the call as soon as possible…if you're gonna stammer on your name your gonna stammer on your name"* (P14)—P05 described 'deliberately stammering' on a word *"so when I get to the more difficult words my system is more relaxed"*—and self-advertising the stammer to the other person *"You don't have to apologize for it…you just say 'I have a stammer'"* (P04). Several of the participants also had some innovative techniques that they used to support them, for example P13 suggesting *"playing background music, to let the other person know the caller is still there"* in cases where a block happens, while P12 knew people who used audio files *"they know the words they will get stuck on and have audio files to say it for them"*.

Workarounds to avoid stammering in the workplace was also discussed in the context of meetings and delivering presentations. P3 talked about how challenging it was to read aloud: *"one of my hardest situations is reading aloud. If you hand me a book or a sheet of paper and someone says: "Read that out." Can't do it"*. Both P3 and P2 discussed how they had to "freestyle" work presentations.

It was clear however that the challenges and workarounds experienced by participants were highly heterogeneous. There were many examples of differences in opinion around what works and what doesn't work for individuals. For example, P2 described *"try and relax and think about what I'm gonna say before I say it",* where for P3 *"I sometimes find that the more I think about what I'm gonna say, the more likely I am to stammer on it"*. This concept of individual needs and, as such, personalization within digital technologies to support such a diverse group of people, was seen as important to participants. P1 described *"I think that everybody is different… for me, calling up a restaurant is a lot more stressful than picking up the phone at work… for somebody else that might be vice-versa, total opposite"*.

Stammering Acceptance

Participants described how other people's reactions to their stammer made them feel, particularly when other people finished their sentences *"if someone finishes your sentence, which I absolutely hate, then afterwards you feel a lot worse… compared to if you've managed to do it yourself"* (P2) or guessed a word they were struggling with *"when you're trying to say something and they try to guess and they get it wrong. And you're like: 'Well, now we're just taking longer because you're making incorrect guesses at me'"* (P3) Conversely, the importance of having successful interactions, through engagements with friends and family was highlighted: *"I think it's kind of reassuring if you have a bad day, that there's still people you can talk to…It's kinda reassuring yourself that not every communication experience is going to be bad"* (P3).

There was much discussion around stammering acceptance and having the confidence to embrace that a stammer was part of their identity: *"I think if you stammer and you're out in public, which 99% of people are gonna have to be, you can't hide it…it's more about getting confidence to embrace it and to accept it. Even if you don't like it"* (P2). Participants felt this actually led them to be more fluent: *"I find that if I openly disclose my stammer to somebody then after that I can go on to have a fluent conversation with them"* (P1), with P3 echoing *"It takes the pressure off"*.

This was of particular relevance in the discussions around job interviews in workshop 2. While there was a general

consensus that PwS should disclose their stammer to *"release a lot of the tension"* (P07), there was also a sense of fear that employers might discriminate again PwS, and that the timing of self-disclosure was important*: "first you sit the online test…and then once they arrange the interview, you tell them…you've already trapped them"* (P08). While it was seen that having stammering *"put down on your CV as a disability"* (P05) could allow for reasonable adjustments to be made during the interview and selection process, others felt this would make employers *"disregard your CV straight away"* (P08) because *"it's illegal to discriminate but they do"* (P12). However, P04 described how she disclosed her stammer through her CV: *"on mine it's in the context of, I go to events, I run support groups, I'm involved in a national charity…I'm taking this negative and turning it into a positive"*.

There were differences in opinion around the extent to which stammering entered in to identity formation, and participants' perceptions around 'curing' their stammer. *"I don't know what life would be like for me without having a stammer. I've had it for so long"* (P1). P3 echoed this:

"if somebody said: 'You could go back in time and not have a stammer', no way would I take that, because it's very much made me who I am today. I don't know who I would be without it. It's kinda formed my character. It's formed the decisions I've made in life, the places I've been I wouldn't have been without it" (P3).

P2, however, felt differently: *"if I had a chance not to have a stammer? Then yeah. Definitely. Then I would I would quite happily get rid of it right now. And if I could go back twenty-odd years and not have it, then yeah"* (P2)

This also linked with discussion participants had around terminology relating to stammering and whether or not it should be 'reduced': *"I wouldn't say reduce my stammer better. I'd say manage my stammer better"* (P1). P3 echoed this statement:

"for me, it's not so much reducing my stammer as becoming more comfortable with it, meaning- even if I do stammer- I'm not completely panicking and thinking that I've completely messed up a situation just because I've stammered. It's more like managing my own expectations of the stammer rather than reducing the 'percentage of syllables stuttered', sort of thing. It's less clinical".

This highlighted the importance to participants in feeling in control of their stammer, as opposed to letting the stammer control their actions or experiences*: "I'm always gonna stammer, and that's okay, the most important thing for me is what I do with my stammer, rather than have it totally go"* (P1). But not at the expense of losing other aspects of their speech*: "there is a Russian speech technique which is if you talk with no intonation at all and slow yourself down and talk like a robot… you're fluent, but it's not worth the trade-off, in my opinion"* (P3). One way of remaining in control was seen to be to challenge oneself. There was much discussion around how this was done day to day in different ways: *"I do try to phone a place rather than just pop in and book a table face-to-face. Just to expand that comfort zone a little bit. I'd feel it was a bit of a cop-out if I was to go in in person and book a table"* (P1).

Community/ Social

Throughout the workshops the concept of community and the importance of social support arose as a strong theme. P3 described *"I'm very much in favour of peer-support and coming together… It's the case of having people who you can turn to, you can hear their stories, and you can reassure yourself you're not alone in it"*

Advice from peers was seen as something that could support the learning of a range of techniques and strategies from supporting stammering *"Things like the techniques and practising can come off your peers, because you know you might find someone who has the exact same issue as you and they might be able to suggest something"* (P2). It was also seen as an element that could almost become a therapy in itself: *"I've known people who have joined a peer support group and, through being there, they've gone from not speaking in any meetings to joining in in every meeting, so there can be development"* (P3). P2 highlighted *"it's more the fact that you're engaging with people who you socialise with and you can relax"*.

Specific techniques and training

Monitoring one's speech in order to make personalized changes was seen to be an important element for future technologies to support stammering. P2 stated: *"I think being able to monitor your own speech is invaluable… being able to monitor where you're having your ups, where you're having downs with your speech"*. Personalization and the ability to try different techniques was also seen to be key: *"if you tried it three times, and three times it didn't work, then you might be like, Okay, that's not working for me, try something else"* (P2).

In addition, being able to self-reflect on particular situations or settings was seen as an important way to monitor challenging situations and *"rating the interaction and how you feel"* (P2). This was seen as a way to help manage expectations and predictions around specific situations: *"You maybe had predictions about what you think's gonna happen, then you come out the other end and you're like: Well, okay, the world didn't explode"* (P3). P1 suggested monitoring *"maybe your top three most stressful situations, such as picking up the phone, going for tickets, speaking to new people. Again, it'll be different for everyone else"*. However, as P07 stated, lengthy interactions could be off putting to users: *"it is important to minimise any interactions with the device"*, with P13 following *"not too much typing, a quick interaction"*.

The top 3 statements that participants in workshop 1 wanted the application to reflect were: *1) I want to be able to monitor and manage my stammer effectively; 2) I want to*

be able to track my stress levels around stammering situations; 3) I want to be able to link with other people who stammer for peer support. For the participants in workshop 2 the statements were: *1) I want to progress my speaking skills; 2) I want to be able to monitor my speech (in very simple ways); 3) I want to challenge myself in real-life situations.*

STAMMERAPP DEVELOPMENT

StammerApp (see figure 2) was developed using the Xamarin framework [42] allowing it to be produced on multiple platforms easily by sharing a common codebase. Although Android was chosen as the launch platform (due to its 70% device market share and ease of development [17]) the shared codebase would allow for a much faster development of versions of the app on other platforms. The app was composed of four tabs: Practice, Challenges, Advice and Community.

The *Practice* page was made up of a list of scenarios, drawn from the workshop data, developed as a way for the user to train and challenge themselves for real-life situations (workshop 2). There were 6 pre-existing scenarios that we created; 3 video based scenarios, which were filmed in real world settings by members of the local community ("Having an appointment", "Ordering food" and "Buying a train ticket"); and 3 audio scenarios recorded by the research team ("Calling your internet provider", "Booking a table", "Booking a taxi"). Each scenario was composed of at least three mini clips, each containing a question or statement that would lead to a response from the user (e.g. "Hello, how can I help you?" or "What time would you like to book that for?"). A written description of the scenario context was provided to prompt the user with how to respond (e.g. You have an appointment with Mr. Jones at 3pm) and they had the option to audio record and listen back to themselves if they so wished. The user could also create their own written scenarios to help them practice for a specific situation that was not on the list. Once they had reached the last question of the scenario, they could rate themselves out of 5 stars according to different ratings that they assign when setting up their account. This feature was created in response to participants' desire to track stress levels relating to specific stammering situations (workshop 1) and to monitor and progress their speech in simple ways (workshop 2). The categories of "Anxiety", "Confidence" and "Preparedness" are provided as suggestions but the user could create their own personalized rating scales. There was also space for the user to write personal notes and reflections on their practice tasks. All ratings and comments were saved into a rating history which could be easily accessed by the user in a dropdown menu.

In order to support participants' needs around challenging themselves in real-life situations (workshop 2) we created the *Challenges* tab, which consisted of a list of goals that the user would like to achieve. An initial set of challenges, directly relating to the pre-existing scenarios, were selected when the user first set up their account, but they could add as many challenges as they wished. Users kept a record of the challenges they had achieved by ticking a checkbox.

In response to participants' desires to link with other people who stammer for peer support (workshop 1) we created the *Advice* and *Community* tabs, which provided the users with direct links to a variety of trusted webpages (from the British Stammering Association, the largest national charity for people who stammer). These webpages depicted a wide range of advice relating to stammering, as well as many links to find support groups and forums, where PwS can connect with one another for advice and guidance on a range of different topics.

PRELIMINARY EVALUATION

We evaluated StammerApp with a group of 3 PwS. Two of the participants who were involved in the first workshop (P2 and P3) agreed to evaluate the app (P1 was unavailable at the time of testing). To balance the perspectives of the participants who were centrally involved in the design process, we recruited another participant (P19) who had nothing to do with the design phase, through an internal email call at Lancaster University. Participants were asked to download the StammerApp application to their personal handsets to use over the course of a week. They were asked to fill in an online daily feedback form, which asked them to indicate how they had used the application and whether or not they had created or completed any practice scenarios or challenges. At the end of the week, participants were interviewed about their experiences of using StammerApp and the potential for the app to support them longer term. Please note that our intention with this preliminary evaluation was not to test the effectiveness of the application on treating stammering, but to understand how the design process translated into a usable and useful prototype for participants, to provide guidance about future refinements which may enhance user experience and engagement, and the design of further applications begin developed for PwS in the future.

Evaluation Findings

Participants used the app in a range of different ways, both practicing with the pre-existing scenarios and creating their own (e.g. asking a stranger for directions (P19), cancelling an appointment (P19), and making a specific phone call (P2)). Most notably, P3 used the app regularly to help her practice certain phrases she found challenging:

"I found that it was a really good thing to practice the certain things that make me really nervous, such as ordering the coffee that I actually want …The little things that are so small, but can make you feel awful and nervous while you're waiting to say them, those were the ones that I found the most helpful, and I found myself coming up with new bits that I wanted to practice fairly regularly"

P19 also noted how practicing with the app helped her to feel more confident when conducting the challenge in real life "*In*

the beginning, I stammered at the time I was thinking of what to order, which usually happens in my real life. But after I practiced this again on another day, I felt more confident to tackle that"

Listening back

Participants all used the listen back function when practicing their scenarios. This function was received with mixed feelings. P19 described: *"When I listened to the first answer, I was a bit impatient as I was expecting a more fluent answer…I felt if I am the listener I may be impatient"*. However, she described then using the app to reflect upon and modify her practice *"So, in the next practice I tried to shorten my response by avoiding repetitive phrases…After 1-2 times when I listened to myself again, I felt more comfortable as I made an effort to reduce the stammer bit."*

P3 also described using this function, but how for her it caused new insecurities to arise:

"It was useful because it helped me to hear myself back, and hear how it actually sounded (as opposed to how I imagined that it sounded). Many times, I found that the stammer itself wasn't too hard to listen to, but that all of my little quirks that I've developed as fluency aids were more problematic. At the beginning of the week, it actually made me feel a little worse about my speech, as it introduced this new element of 'well, the stammer's fine, but what's all this?', and I felt really paranoid about speaking for that reason. However, towards the end of the week, I was starting to force myself to slow my speech a little and take out some of my little additions in order to clear up other elements of my speech"

In addition to this, P3 highlighted how a future version of the app should ensure that auto-lock functions were turned off, to ensure that further negative emotions were not evoked, something that we had not even considered in the development process: *"is there a way to override the auto-lock on devices while recording? I had a few times where I stammered so much that it locked while I was still talking, so the recording was corrupted and I had to start again…again, for the more insecure, the idea that your stammer is so bad that a device will time out on you might be an issue…"*

Practice to prepare

Participants all described using the app to help them feel prepared when executing their challenges in real life. P19 described: *"The app allowed me to practice again and again without someone else saying 'sorry I don't understand'--this usually makes me nervous and start stammering…when I did it in real life I felt 'oh I've practiced this before, I can do this'."*

For P2, it was helping to prepare for a specific phone call: "it was nice to use before actually making a real phone call. *As it give me chance to practice and work out exactly what I was going to say... it identified any possible difficult areas"*

DISCUSSION

Through our study, we have delivered insights into the challenges and barriers that PwS can experience in their day to day lives, and the highly personal ways that different people engage with self-management strategies to overcome these. We also presented a set of design recommendations for the development of future tools to support PwS in their everyday interactions, and envisioned this through the StammerApp prototype. We now reflect on the complexities of engaging with this diverse group, and need for future work in this space to move beyond solutionist approaches of self-management, to inform future designers wishing to work with this diverse population in the future.

Engaging People Who Stammer in Design

Our design process uncovered the importance that the stammering community place upon being given a voice, whether it be a voice that stammers or not. This concept of giving voice to people with communication difficulties is echoed throughout the, somewhat limited, HCI literature which has attempted to engage people with communication impairment in design [11, 24, 25, 26, 41].

However, as we have reported, gaining access to the close-knit stammering community was not an easy task. We were lucky enough to have a researcher who was already heavily engaged in the stammering community. As such, we were able to rely on her personal contacts throughout local stammering groups and conferences. When attempting to broaden our search for participants however, we were often met with reservation, or in many cases ignored altogether. Whilst many people from the broader stammering community were willing to engage with us online, textually, many people were unwilling to engage with us face to face in verbal exchanges.

This highlights the importance of leveraging existing networks of people who know, and feel comfortable around, one another, as well as engaging PwS in environments where they feel they can retain a sense of control [3, 8]. Our workshop participants were recruited from local stammering networks and, as such, many of the participants knew one another. A level of support and a respect for each other's opinion within the workshops allowed even those participants with particularly severe stammer to have their say. This echoes findings from Lindsay et al [18] in their study of designing with people with dementia, in which they describe how the recruitment of existing groups and caregivers can facilitate the sharing of personal narratives in a comfortable and sympathetic space.

In addition, we kept our group sizes small to facilitate the participation of all members (3 in workshop one and groups of 5 in workshop 2). Smaller groups sizes allow for greater time and attention to be placed on encouraging people with communication difficulties to express themselves

effectively and could prove a beneficial consideration for future designers wishing to work with people with communication difficulties [11]. Most importantly however, throughout our discussion based design work, was the aspect of giving time to participants to have their say. As described by Massimi [23], it is the researcher's job to ensure all participants are being heard within the design process. This was difficult at times, particularly when considering the fact that there are always participants who are more dominant than others in discussion. The researchers therefore had to carefully observe the participants and look for indications that they were attempting to engage in discussion.

Balancing Concepts of Identity

There was much discussion in our work around stammering acceptance, and the stammering voice as a key aspect of identity. For most people who stammer, they have had their stammer since childhood [20]. This means that their stammer becomes part of their identity and the way that they speak, rather than being an external condition. For this reason, stammering can be considered to fall under the social model of disability, which would recognize stammering as an impairment, only becoming a disability if there were societal restrictions placed on the individual. However, this was something that caused somewhat polar opinions amongst the stammering community, evidenced in both our survey and the workshops.

There was much discussion around whether or not stammering openly and disclosing one's stammer was a beneficial thing to do. For many situations, this was seen to be a strategy to enable the individual who stammers to remain in control of their speech and relieve tension, by making the listener aware that they might require more time. However, in certain situations, particularly in the context of finding and keeping a job, participants were often fearful that they would be discriminated against for having a stammer. Butler [8] highlights the socio-cultural nature of employability which emphasizes 'excellent communication skills', and highlights the challenges and routine discrimination faced by PwS when attempting to gain employment in positions that require this skill.

However, for the majority of participants, finding a way to stammer openly and feel more confident and relaxed with their own voice was an important value that they would like to see expressed in tools to support them. The desire for support with the emotional elements of stammering, was somewhat surprising to us, as we went into the initial workshops a little naively, envisioning tools that would deliver interventions to objectively improve stammering (e.g. reducing percentage of syllables stammered on). Future work should be mindful of the fact that stammering is not simply about speech output and 'improving speech'—indeed we found that for our participants many of these terms were laden with negative connotations—but encompasses a range of socio-emotional tensions. Whilst our StammerApp relied on reflection and practice as a tool to support PwS in feeling more confident within certain speaking situations, existing work from Tanveer et al [37] (focusing on public speaking), and McNaney et al [26] (focusing on monitoring volume in people with Parkinson's), has explored how technologies such as the Google Glass might provide in-situ support during speech. Both discuss the use of real-time feedback on aspects of speech production such as volume and rate which are provided to the user in real time. Future work with PwS might consider how real-time aids such as these might support aspects of communication, such as monitoring stress and anxiety levels, that our participants felt were important to them.

CONCLUSIONS

Through this study we have offered a deepened understanding of the specific needs and values of people who stammer for the development of digital tools to support them in their day to day lives. Our study has highlighted the homogeneity of stammering as a condition and the need for personalizable tools that support individuals within the settings and situations that they require most. Future research is required to further scope the potential for tools such as StammerApp to make a difference in the lives of PwS. While showing promise in the support of PwS, larger field trials of StammerApp, over longer periods of time and with a wider sample of the stammering community, is required. Whilst outside of the scope of this paper, future evaluations to determine the effectiveness of apps like StammerApp should consider the use of informal attitudinal rating scales (e.g. such as the Overall Assessment of the Speaker's Experience of Stuttering [43], or the situational anxiety hierarchy [12]), as well as considering methods such as experience sampling, to understand day to day improvements that users might be experiencing. The collection of telemetry around app use would also add depth to future trials.

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