

Cueing Swallowing in Parkinson's Disease

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ABSTRACT

We present the development of a socially acceptable cueing device for drooling in Parkinson's disease (PD). Sialorrhea, or drooling, is a significant problem associated with PD and has a strong negative emotional impact on those who experience it. Previous studies have shown the potential for managing drooling by using a cueing device. However, the devices used in these studies were deemed unacceptable by their users due to factors such as hearing impairment and social embarrassment. We conducted exploratory scoping work and high fidelity iterative prototyping with people with PD to get their input on the design of a cueing aid and this has given us an insight into challenges that confront users with PD and limit device usability and acceptability. The key finding from working with people with PD was the need for the device to be socially acceptable.

Author Keywords

Parkinson's disease, swallowing, drooling, participatory design.

ACM Classification Keywords

H5.m. Information interfaces and presentation: Miscellaneous.

General Terms

Design, Human Factors

INTRODUCTION

We are currently living within an ageing society. New advances in medical treatments, as well as a drive from the UK National Health Service (NHS) to implement initiatives around public health education, mean that life expectancy is increasing. Alongside this comes an increase in the prevalence of age-related diseases such as Parkinson's disease (PD), which currently affects approximately one in 500 of the UK population [11]. A significant symptom of PD is drooling, which has been found to be a problem for

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CHI 2011, May 7–12, 2011, Vancouver, BC, Canada.

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70% of people with PD [3]. The existing literature suggests that drooling is associated with muscle rigidity and bradykinesia (slowness of movement) of the oral structures [9] coupled with a deterioration of the swallowing reflex rather than over-production of saliva. Drooling is not an incidental problem without consequences. The problem can impact an individual's quality of life socially, emotionally and physically. Drooling can cause social embarrassment for the person with PD and adds to the risk of aspiration (when food or liquid enters the lungs) which can result in choking or pneumonia [2]. Excessive loss of saliva can also cause related difficulties with eating and oral hygiene as saliva acts as a lubricant during chewing and swallowing and contains proteins with antibacterial effects [2]. Most current treatments for drooling in PD aim to decrease saliva production, predominantly with the use of pharmaceuticals or Botox injection into the salivary glands [6].

Previous studies have focused on testing the clinical effectiveness of using electronic cueing devices to manage drooling [7, 8]. These studies used a commercially available device in the form of a brooch which emits an auditory cue or prompt (beep) at regular intervals, to remind the wearer to swallow, thereby reducing drooling. Although such a device was found to be effective in the control of drooling problems, wearers reported several aspects that reduce their acceptability. For example, the auditory cue was a significant source of embarrassment for many wearers. In addition, hearing impaired people – who form a large percentage of the older population with PD – cannot use the device. The product used also incorporated a switch to turn the device on and off, yet many users needed assistance to operate this due to fine motor skill degeneration resulting from PD. Our work explored the design space for cueing devices and, to address the device's acceptability, explicitly incorporated the needs and desires of the PD population into the design process. This approach has been shown to be effective in previous work [1, 4]. The method also coincides with current pledges in NHS policy aimed at ensuring patients are involved in all aspects of their treatment, to promote their empowerment and motivation [5].

DESIGN PROCESS

The design process had two stages, scoping and high fidelity iterative design. The scoping stage was used to gather qualitative accounts from participants about

everyday issues that affect accessibility such as hand tremors making small buttons difficult to operate. This stage allowed for more informed conceptualisation of the types of features the new device should have. High fidelity iterative design was then used to refine the device. Participants were recruited through the voluntary organization *Parkinson's UK* [11]. Twelve participants, eight with PD and four caregivers (age range 41-77 years old) took part in the scoping stage of the study. Three people with PD, who had taken part in the scoping stage, participated in the high fidelity iterative design (Table 1). Analysis of the discussions from the scoping stage revealed several recurrent themes. The consensus in the opinions expressed throughout all of the groups led to a set of design requirements being formulated.

Participant	Sex	Age	Years Since Diagnosis
One	Male	60	2
Two	Male	74	4
Three	Male	66	18

Table 1: High fidelity prototyping participant profiles.

SCOPING STAGE: PROCESS

This scoping stage discussion lasted approximately one hour. Participants were organized into three small groups of three to five people. Focus Groups were carried out in an exploratory manner using open ended questioning to allow free flowing discussion to develop and mature into topics of interest. Participants discussed PD and the impact its symptoms could or did have on their use of technology. They also discussed their feelings towards medical devices and previous negative and positive experiences with them. Within the same session participants brainstormed the types of features they would or would not want in a drooling management device. They discussed specific features, collectively deciding on the best options for them and the reasons behind their choices. At the end of the workshop the participants were shown two prototypes to act as prompts intended to stimulate or provoke discussion about concepts such as device size or appearance. Prior to prompt showing, these concepts were abstract for the participants



Figure 1. A prototype device shown as a prompt to elicit discussion about abstract concepts. Black and red buttons control vibration frequency on either side of an LED.

and many of them struggled to articulate their thoughts. One prototype was a rudimentary custom built device (see figure 1) and the other was an application that ran on a mobile phone. The scoping sessions were video recorded and the discussions transcribed. Subsequently, themes and sub-themes were extracted and used to develop a set of requirements for the first high fidelity prototype. Participants were contacted by telephone in the week following the data analysis to validate the requirements. This step was important as without it there was potential to obfuscate individuals concerns about the device.

SCOPING STAGE: RESULTS

Participants discussed the different modalities for **cueing** such as visual (a flashing light), auditory (a beeping noise) or vibration. The participants unanimously felt that the most acceptable modality for cueing was vibration because it reduced the attention drawn to the wearer if the device was worn in public. By contrast visual and auditory cues were considered potential sources of embarrassment in public.

In relation to **size**, participants' comments indicated that they would like to have a device that was small enough to be hidden to reduce embarrassment or social unease that might come about wearing it in public. However, they also commented that they would need a device that is large enough to be easily handled by a person with a tremor (a common symptom of PD) or other age-related conditions like arthritis in the hands.

Participants indicated that they would require help to change a **battery** due to their PD. They discussed the sense of dependency or disempowerment that this often caused when using other devices because they had to rely on someone else. As the design team considered it important to avoid this disempowerment and produce a device that someone with PD could use unassisted they built a large, easy to use plug in charger and a socket for it on the device.

In terms of **where to wear** the device most participants indicated a preference for a wrist worn device. They commented that it could then be designed to look like a commercial wristwatch, to avoid stigma that might be associated with a medical device. Discussion in one group produced the idea of using a hook and loop Velcro fastening. This eliminated many of the steps involved in putting the device on, thus making it more accessible for the user with PD further empowering them.

Participants said that pressing **buttons** on small devices like wristwatches could pose a significant problem for them. The groups felt that there needed to be some other way to operate a device. This theme was echoed throughout all of the Focus Groups and it was decided that a motion sensor feature would be employed to switch the device on and off. An accelerometer was used to recognize any form of motion and this served as a signal to put the device into 'on' mode and to switch off when the device was absolutely stationary (i.e. remaining on a stationary surface) for more than ten seconds.

Participants commented regularly on how much **stigma** they felt there was associated with the public's perceptions of PD. Because of their concern with this they believed it was vital to consider how the device's design related to potential stigma. The main issue that arose was that the participants were worried other people might see or hear the device when they were out in public which would lead to embarrassment. The feeling of stigma, from using medical devices, was highlighted during a discussion about wearing panic buttons (a medical device designed to alert emergency services if the wearer has a fall or medically dangerous incident). The participants involved in this discussion admitted not wearing these devices, even when alone at home, as it made them "*feel disabled*". This showed the importance of designing a device that does not look like a disability aid, to prevent the feelings of being stigmatised becoming associated with the device. As one participant commented individuals with PD have:

"Enough to cope with, without also having to wear a device that advertises greater disability."

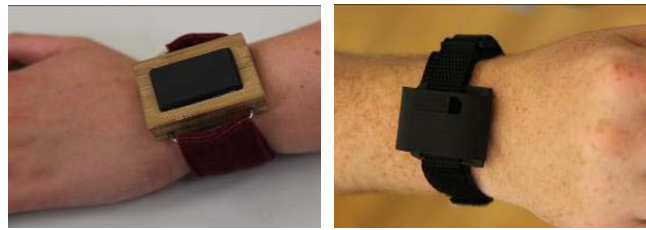
Stigma being associated with a device was felt to be a clear problem and, as part of this, so was the need for a device that could be worn somewhere discreet or disguised as an everyday piece of technology. Overall, these comments emphasize the importance of taking a design approach that more equally weights feelings evoked wearing a medical device with the device's actual functionality.

HIGH FIDELITY ITERATIVE DESIGN: PROCESS

This stage began two months after the scoping stage. Using the design specifications, a high fidelity prototype was made and given to three participants with PD so they could report their experiences of using the device over the course of a week. The participants were asked to use the device as they pleased. The design team was interested in the reasoning behind their choices e.g. when and where they chose to wear the device. The choices could then be analyzed to provide broader insights into their experiences using the technology. They each filled out a daily diary detailing the situations they had worn the device in and their feelings towards it. They were also interviewed at the end of the week. Recordings of the interviews were transcribed and, along with the diaries, thematically analyzed to identify aspects of the design that might impact the device's acceptability, usability or desirability. In response to this, alterations were made to the prototype and the process was repeated for the same participants. Interviews were transcribed and analyzed and further (more minor) improvements on the prototype were identified. A second device was then built in response to these perceived needs.

HIGH FIDELITY ITERATIVE DESIGN: RESULTS

The results and analysis in the scoping stage was used to construct a set of specifications that were then followed in the construction of a prototype. The prototypes that were produced vibrated once every minute independent of



Figures 2: First (left) and second (right) versions of cueing device produced in the iterative design process.

swallowing actions to prompt the users to swallow any excess saliva. The time period was selected to correspond with the normal swallowing rate of adults. Once constructed, high fidelity prototypes (see figure 2) were given to three participants (see table 1 for their characteristics) for one week. Information regarding both their experiences with the device and their opinions about its design were then gathered through interviews.

This first in-situ study revealed several recurrent themes regarding specific device features that were expressed by all three participants. The consistency between their opinions made it simple to pinpoint the aspects of the device that needed to be improved. Only one negative aspect of the device itself was identified: that the vibration was too noisy and thus caused embarrassment in public contrary to the requirement for avoiding stigma discovered in the scoping work. All other faults discussed regarded the wrist worn band, within which the device was held. Participants felt that the band was too bulky causing it to catch on clothing, that it was too short making it difficult to put on and that it was aesthetically unpleasant (design shown in figure 2). Only one of the three participants said they would consider using the device in its current format and this same participant was the only one to wear it in public.

"I went shopping today and I was very pleased, I could talk to people much better than before."

He shared the opinions of the other participants about negative aspects of the device format. However, he experienced a reduction in his drooling problem and this was much more important to him. The main effect the reduction had for him was the improvement he experienced in his speech and he commented that other people also noticed a positive change.

"We were out with our friends and they were surprised at how much better my speech was."

His confidence increased dramatically whilst using the device. For him, the benefits it had given managing his drooling surpassed any problems he might have had with it. These comments show how much of a valuable contribution a device such as this could make to someone's life.

Changes to the prototype were made in response to participant critique and a second in-situ study was conducted with the same people. The same process was carried out using a second version of the high fidelity prototype (see figure 2). When discussing this new

prototype all three participants said that they would use it again and all wore the device out of the home environment over the course of the week. The participants also all said they felt comfortable discussing the device with members of the public and that they preferred the second version of the device. When discussing the second device participants were also more likely to mention its effectiveness. One participant stated that the device “controlled” his drooling problem and that he felt “more confident” when using it. The only fault identified with this prototype version was that they still felt it was slightly too bulky.

REFLECTIONS

Whilst the research and design revealed interesting aspects that contributed to the acceptability of cueing aids for drooling in PD the study did not conduct quantitative work to evaluate the efficacy of the devices that were built. As such, we can only speculate on whether or not the perceived increase in efficacy actually correlated with a decrease in drooling. However, this study has contributed to our knowledge of how the emotional and physical aspects of living with PD can effect interactions with technology. Although there are commercial products for use in the management of drooling, there are aspects which make them unacceptable for users. The opinions of the participants in our study echoed those expressed by users of one such device [7, 8]. They wanted a product which was discreet and could be used independently, a product which would not draw attention to their drooling or incite curiosity from the general public.

During scoping we showed participants a mobile phone based cueing device. We considered this a cost-effective, simple solution to the issue. Our participants dismissed the idea as unrealistic. They listed multiple difficulties that might arise such as: the fact that a mobile cannot be used within hospitals, confusion that may occur when trying to distinguish between cueing vibrations and incoming SMS or calls, and the fact that female users often keep a mobile in their handbag and may not feel the cue. Although these comments seem obvious on reflection, they were not things that we had considered before. A noteworthy point was the increase in perceived effectiveness experienced by all participants with the second design. The functionality of the device had not changed which demonstrates the importance of having a desirable device that people want to interact with. There was also a shift in perception of the device, shown by the change in the way participants talked about it. Initially there was an overwhelming sense of being “embarrassed” because participants felt members of the public would associate it with a medical condition and in turn the stigma around PD. However, in final interviews all the participants were comfortable talking about the device. Participants did not make the same negative associations with the aesthetically pleasing device. Our findings agree

with Norman’s (2002) commentary on aesthetics. “*When we feel good, we overlook design faults. Use a pleasing design, one that looks good and feels- well- sexy, and the behavior seems to go along more smoothly, more easily and better. Attractive things work better*” [10, p.41].

ACKNOWLEDGEMENTS

This work has been funded by an Engineering and Physical Sciences Research Vacation Studentship and the Research Councils UK Digital Economy Research Hub SiDE: Social Inclusion through the Digital Economy (EP/G066019/1).

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