Blurred Lines: A Reflection on the Ethical Dilemmas Encountered during the 'Google Glass for Parkinson's' Project

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Abstract

In this paper we reflect upon the ethical dilemmas we faced during our research looking at the potential for using Google Glass as an assistive device for people with Parkinson's (PwP). We report findings around the issues participants had during the trial and how these led to feelings of lowered self-confidence, and in one case self-worth, and how prior positive publicity around Glass led to levels of hope which were not founded by the research. We also take the opportunity to reflect upon how researcher vulnerabilities can be exposed throughout the research process by discussing concepts around professional roles and how these can become blurred when working with participants over longer periods of time within the home context.

Author Keywords

Ethics, Google Glass, Parkinson's, Self-Management

Introduction

Research within the field of HCI often centres around the application of existing technologies, developed for mainstream consumers, into novel domains such as healthcare. In the case of heavily used and

commonplace technologies such as personal computers [5], Smartphones [1] and gaming systems [6] this transition can occur with minimal issue. However, in the case of extremely novel platforms- like Google Glass- where the devices being trialled are still to all extents and purposes very high fidelity prototypes, yet are highly publicised as the newest 'must have', we need to be careful about how we present working with these technologies to participants. Furthermore, there is also increased pressure on researchers to publicize results and findings at the earliest opportunity—be this through media outlets, as a way to provide a measure of research impact, or locally during recruitment activities to promote future research within the area. While these are positive activities, it can raise ethical dilemmas when working with participants with heightened vulnerabilities or when preliminary findings become decontextualized.

In this paper, we describe our experiences within the second stage of the 'Google Glass for Parkinson's' project. We explain how, while the results of our first stage exploratory field trials with people with Parkinson's (PwP) were highly positive [7], our later trials were plagued by problems related to the reliability and predictability of the Glass technology. While the problems participants faced were fundamental breakdowns of the technology (e.g., failure to reboot following updates) or basic usability problems (e.g., the operating system changing the interaction qualities of the device), many of our participants experienced these as personal failures and inadequacies. We reflect upon the impact that previous promotion of Glass as a system had on our participants and discuss some issues we had around maintaining professional boundaries during the trial. Our reflections lead us to question the ethical implications of conducting this type of research with a 'vulnerable' group experiencing a range of physical, social and emotional difficulties due to their condition [2].

Parkinson's and its impact on life

The three major symptoms of Parkinson's are tremor, rigidity and slowness of movement—however there are a range of other symptoms that lend to the overall impact the condition can have on people's lives. Problems initiating movement can lead to episodes of gait freezing, where movement is suddenly halted, usually when additional attention is required—such as manoeuvring through a narrow space or turning—leading to an increased risk of falls [3]. Speech, voice, facial expression and swallowing problems are also extremely common and can impact on socialisation [8]. A range of non-movement issues are also seen, including fatigue, depression, and obsessive-compulsive behaviours [2]. Another factor leading to the diversity of Parkinson's is the on/off phenomenon, a side effect related to the extended use of Parkinson's medication. Over time, as medication resistance begins to accumulate, a PwP may find that they suddenly switch between periods of good response to medication (on) to their symptoms being uncontrolled for portions of time (off). A further classification of this side effect is known as 'wearing off' whereby an individual might find their medication does not last as long as it had previously and they begin to feel their symptoms return before their next dose is due [9]. It is unsurprising that a combination of these symptoms can cause a huge impact on the daily lives of PwPs. Daily activities such as washing, dressing, feeding oneself, writing a note or household chores can be affected, as can carrying out leisure activities or driving. These factors can also

impact on life enjoyment, independence and relationships with family and friends [9].

The Research

In our research we were interested in exploring the potential of Google's Glass technology as a means for providing assistance and support to PwP. Our initial exploratory research focused on general acceptance of the Glass technology (see [7]), while also highlighting a number of potential avenues of enquiry for future work focusing on specific application areas. This included the potential for this new technology to provide 'in situ' real-time cues and feedback to PwP wearing the device, which might provide them with the necessary visual cues to negotiate episodes of freezing of gate. This initial research also highlighted the great potential for the Glass to simply allow a PwP to quickly and simply contact a loved one or caregiver and share their location with them, should they suddenly experience disorientation or their medication wearing off.

Based on the positivity of our initial research, we conducted a follow-on study that focused more explicitly on the themes and potential use cases identified at the end of our first trial. We provided participants with a Google Glass (and a Google Nexus 4 mobile phone for internet tethering purposes) for a period of 7 to 10 days each. As with our prior study, a researcher visited participants in their home to deliver the Glass and provide a demonstration of its use. Participants were also provided with a user manual to refer back to if necessary during the field-trial. They were informed that they could use Glass as much as they wished in any setting they chose and felt comfortable wearing it in. Unlike our prior trial, however, we also provided participants with a diary

with a set of structured activities for them to perform each day (photo/video capture and sharing, making video calls, setting up and receiving reminders, using the Sat Nav, receiving updates from the technology based on speech quality and eye drowsiness). Each of these activities related to a further co-design activity, which was to be completed as part of the end of study interview with the researcher. Each of these activities was designed to support reflection on the specific tasks we had asked them to complete during the week and to identify opportunities for designing new Glass applications. The activities had a dual purpose—first to engage participants in reflecting deeply upon their everyday life and their use of Glass, secondly to act as ways of encouraging 'talk' which would be recorded and used as part of our qualitative analysis.

All of the co-design session were audio recorded and transcribed. This data was then thematically analysed using methods outlined by [4], to enable the construct of a set of common themes across the dataset. While a great many themes emerged directly related to the opportunities that Glass presented for our participants—and also highlighted continued enthusiasm for the technology as noted previously—the manner in which the technology operated during this phase of the trial also highlighted a number of ethical concerns. For the purposes of this workshop submission, we focus on three themes explicitly related to these concerns in the following sections.

Ethical Dilemmas Arising from the Research
Just take it away

During the trial it became clear that our participants experienced a range of difficulties in using the Glass technology that we had not come across in our prior study. On further analysis, it appeared that a great

many of these problems stemmed from updates to the Glass operating system (OS). During the study period the OS of Glass went through a number of frequent—but unpredictable—over the air updates which were impossible to stop without disconnecting from the Internet and, thus, severely reducing functionality of the device. Updates led to several undesirable participant experiences. The most extreme of these was an inability of the device to reboot following new software installation—requiring a researcher to reset the device, install the operating system and re-add applications. On other occasions, it meant that the device still functioned but a range of its attributes changed. These included losing charge more quickly, changing the list of voice commands, and altering the manner in which screens were navigated through both voice command and swipes of the touchpanel. As such, the instruction booklet provided often became invalid, as did the demonstration performed by the researcher at the initial home visit.

These updates and breakdowns in expectations of how the device should work had significant implications on participants during the trial. There was a feeling that the system required large amounts of time, energy and effort to get used to it. Morris explained how *"It starts to consume a lot of time"* and how he adopted a piecemeal approach to his engagement with the technology: *"Well, I've only done a couple of hours, and then put it down and try again later."* On two occasions the amount of effort Glass appeared to require led to participant withdrawals through the study, with Allen saying *"he couldn't find the time to engage with it properly"* and Cara, being so deeply frustrated with the Glass following two updates in a week, stating: *"I just want you to take it away, and be*

rid of it." In the case of these participants, they left the study with no issue, as outlined in the original ethic procedure that we had submitted to our board. However, the levels of frustration they felt were shared by other participants who persevered with the project because, as said by Ethel *"I didn't want to let you* [the researcher] *down".*

Ethel's statement is something that is likely experienced across a variety of domains when working with participants and it lends the question; is it enough to simply say (in our information sheets and during initial meetings) that "participants are free to pull out of the study at any time without giving a reason"? Should we be giving participants more explicit chances to leave the study if they are feeling undue levels of frustration? Also, is it really fair to leave a participant unsupported for a period of time with a new technology? In HCI, we often wish to uncover the intricate difficulties that participants face so that we can make things easier for them in the future—however, the revealing of these difficulties, or perhaps the acceptance that participants might have difficulties with a deployed technology—might, in itself, be an ethical quandary for research involving potentially vulnerable participants like ours.

This also raises a question as to how can we ensure that we support participants to an appropriate degree during trials of technologies like these. On reflection, while our first study yielded much less pronounced difficulties, we did phone each participant every night to discuss any problems with them. Based on the general positive feedback, and an increase in the length and scale of the research in this second study, the researchers reduced the amount of contact with participants during the trial. However, with many of our participants unwilling to contact the researchers to tell

them about their problems, perhaps from a feeling of embarrassment or not wanting to disappoint, this meant many of the problems were not picked up until the end of trial interviews. As such, while participants are informed that they can contact a researcher at any time if they need to, we have come to realise from this study that this assurance might not be enough.

It's not you it's me!

Returning to Ethel's experiences, she also encountered problems with the system that impacted her personally. She expressed an extremely positive attitude at the start of the trial: *"I was full of hope […] I just was too excited to take it in"*. However, she quickly experienced difficulties. On some days she found it difficult to get mobile connectivity, meaning many functions would not operate. Her, perhaps over-estimated, perception of what Glass would do for her stemmed from discussions with other participants who had already tested Glass in the project with success. This caused further declines in her self-confidence when using the technology as she felt she was a failure: *"I was just rubbish; absolute rubbish. […] She was telling us how brilliant it was […] I think, "Well, I must be thick if they had such a brilliant time with it."*

Ethel highlighted an extreme case of where participants blamed themselves for what was, mostly, failings in the technology itself. On our first visit with this participant she revealed that she was experiencing a slowing in her thinking and a loss of outdoor independence, due to Parkinson's related falls. The issues she had using Glass caused many of these concerns to resurface and be placed in the forefront of her mind during the study. These problems were also echoed, albeit less severely, by others: *"I was obviously doing something wrong.*

[…] *You feel inadequate don't you when it's the machine."* (Sue). Like Ethel, this same participant expressed great joy and satisfaction when she was able to get it to work: *"it made me feel a bit better because I got something right at last."* (Sue). Expectations about Glass were raised by the close contact participants had with each other, as members of local and regional volunteer networks. As such, the perceived successes of some participants - expressed in social encounters, local Parkinson's meetings and in highly publicized press work - reinforced individual reflections of inadequacy and incapability that other participants experienced in reference to using Glass and the impact their condition was having on their daily lives. Whilst we did not intend to expose these issues during our research we did originally hope that word of mouth about the project would entice new participants into joining, given that Glass was such a new entity. This shows how important it is, ethically, not to oversell the products we are testing during research and, again, to ensure that appropriate levels of support are put into place where more complex systems are being trialed.

Can't we just be friends?

A further challenge during the trial was the blurring of the relationships one of the researchers had with participants. One participant was well known to the researcher through their participation in a prior clinically-oriented technology trial. Prior interactions between the researcher and participant were mostly structured as a therapist-patient relationship, mostly due to the demands of that trial. Visits would be focused on capturing clinical outcomes related to the trialed technology, and there would be relatively little time for informal conversation. The second Glass trial was rather different—the co-design sessions were

extensive (up to two hours long) and often involved participants discussing more intimate and private details about their lives. In this one instance, it started to become clear that this participant had feelings of isolation and loneliness, and familial concerns that were impacting on him greatly. After the study, this participant continued to attempt to make an unnecessary contact with the researchers outside of the scope of the project (via Facebook and SMS). It appeared that the researcher became a friendly face for him to talk to and he perhaps was not ready to let this go after the study was over.

While an important attribute in any sort of qualitative research is to build a rapport with participants so that they feel comfortable during the research process, the lines between our professional roles as researchers and simply being friendly can become blurred at times. In particular, when working with groups of people who may be socially isolated and lonely, how do we manage the intricacies of the relationships we build? How do we ensure that professional boundaries are not crossed? Are these boundaries static or do they in fact differ between participants? In the case of the participant described, the researcher receiving the contact felt particularly confused about how to manage the situation—not helped by a lack of institutional support on what to do when such situations occur.

Conclusions

During our study we found a disconnect between the ways that we were *formally* protecting our participants (informed consent, appropriate debriefing, risk management) and the intricate social and emotional factors that arose during the research process. For this reason, this study led us to question the static nature of formal ethics and consider that we, as researchers, should be providing a more fluid and stepwise approach within our research protocols. Through the Ethical Encounters workshop we wish to draw out concepts around the issues reflected upon in our paper—managing contingencies around exiting a study, preparing participants appropriately for the issues that previous participants have had (without completely dissuading them from taking part), maintaining professional boundaries without making participants feel uncomfortable—in order to inform future practice.

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