Designing for the Person Living with Parkinson’s: A Focus on Wellbeing Beyond Functionality

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ABSTRACT
This paper discusses the importance of considering patient wellbeing as a primary focus when designing healthcare technologies. It highlights findings from a participatory design process with a group of people with Parkinson’s disease (PD) which motivates this view. The sense of stigma, social embarrassment and disempowerment felt by the people with PD had to be addressed in order for the technology to be accepted. Acceptance and engagement with the technology is needed to ensure that designed healthcare interventions, specifically those to support patient’s health and wellbeing, are effectively applied.

Author Keywords
Wellbeing, Parkinson’s disease, design, healthcare

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION
Enabling and promoting patient wellbeing is one of the markers of a quality healthcare service. Drives from local and national policy makers and procedural outlined within the UK National Health Service (NHS) aim to create a more patient centered level of care, with patient empowerment and wellbeing as core themes [2]. Interaction design, in the context of developing medical devices for healthcare intervention, has parallels to these pledges in NHS policy aimed at ensuring that patients are involved in all aspects of their treatment. It is the designer’s role to develop devices that people will actually want to wear, devices which will not become a source of stigmatization for the user but which will enable them to engage with the technologies, in ways beyond the clinical and functional aspects of what they provide.

Wellbeing in Parkinson’s Disease
Parkinson’s disease (PD) is a neurodegenerative disease which presents in both motor (e.g. tremor, slowness of movement) and non-motor symptoms (e.g. compulsive behaviours, such as excessive spending or gambling, and inhibition). Although the presence of anxiety and depression, alongside significant negative changes in emotional wellbeing, are identified to be highly prevalent in PD patients, findings have shown that these symptoms are not systematically recognized in clinical practice [6].

Sialorrhea, or drooling, is another significant symptom of PD, with around 70% of all PD patients experiencing this problem [3]. It can lead to speech difficulties, social embarrassment and a reduced sense of both social and emotional wellbeing [1]. At the core of the majority of social activity, which is central to wellbeing, is conversation and social engagement. A reduction in both the functional ability to communicate effectively, as well as a sense of social embarrassment, directly impacts on the social wellbeing of the individual. In addition, a decrease in emotional wellbeing caused by feelings of disempowerment can cause people who experience drooling to shy away from engaging in social interactions. This, in turn, can cause multifaceted difficulties in aspects of everyday life such as the maintenance of relationships, self-confidence and stress management.

Yet, would the treatment of the drooling itself solve the problems and therefore improve wellbeing? Should the primary focus be on the development of an effective intervention, with wellbeing as a secondary outcome measure, or should we be striving to place patient wellbeing at the forefront of treatment? Physical manifestations of a disease can be seen and managed, however, is it enough to simply design interventions which focus on functional features?

Designing for Parkinson’s Disease
Our work explored the design space for a cueing device to aid in the management of drooling problems in PD. The device emits a cue at regular intervals, to remind the wearer to swallow more frequently and thus reduce drooling.

To address acceptability it explicitly incorporated the needs and desires of people with PD into the design process [5]. To this end, a two stage design process was carried out: the scoping stage gathered qualitative accounts, from 8 people with PD and 4 of their carers (age range 41-77), on everyday issues related to PD that might affect technology accessibility (e.g. hand tremor making buttons difficult to control), which allowed for informed conceptualization of the types of features the device might have. High fidelity iterative design was then used to refine the device and ensure that the specifications were truly representative of the needs and desires of the PD population.

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**Key Findings for Design and Wellbeing**

Although wellbeing was not a primary focus for us at the beginning of the design process, markers of it featured heavily in the qualitative accounts gathered from the participants. The most prolific findings to come from the design process were the sense of stigma, social embarrassment and disempowerment felt by the people with PD in relation to public perception of PD as a whole;

**P2**, male: “they look at you and know that you’re different”.

Participants felt that the public did not understand PD or its physical symptoms and thus they felt unaccepted in general by unfamiliar people. One participant said;

**P1**, Female: “I feel there’s a lot of rejection to people with Parkinson’s”.

To be socially ‘well’ an individual must feel that they are integrated and accepted in society and that they provide a valuable contribution within their social roles [4]. The feelings described by people with PD around social stigmatization, alongside descriptions of the loss of independence and ability to carry out enjoyable everyday activities, like going swimming or driving, due to the motor symptoms of PD, greatly impact on the individual’s wellbeing. One participant commented that PD “changes your life. Really it just erodes your whole existence” (P1, Female).

For each aspect of the design, participants placed focus on ensuring that the design allowed for the development of a device which could be easily hidden from the public, so it did not lead to inquiries about the device. This shows the negative emotions associated with drooling as a symptom of PD. Participants considered that having a device, which could be seen or heard by the public, would be a great source of embarrassment and social unease for them.

The feeling of stigma being associated with the use of medical devices was also highlighted in a discussion about wearing panic buttons. Participants admitted not using such devices, even when at home alone, as they made them “feel disabled”. This shows the importance of design when developing medical interventions, in order to prevent feelings of stigmatization becoming associated with wearing them. One participant surmised this issue by saying,

**P8**, Male: “we have enough to cope with, without also having to wear a device that advertises greater disability”.

This comment further emphasizes the importance of taking a design approach that considers the feelings evoked when wearing a medical device and not solely its functionality.

**Implications for Healthcare Technologies**

The findings from this design study highlight the importance of interaction design for the development of medical devices. Although the core drive for medical professionals is to provide adequate treatment interventions, we, as designers within this domain, know the importance of placing the person at the center of the design.

Creating technologies which are not only usable, but also desirable, to the user can ultimately lead to improved usage compliance and sense of social acceptability, both vital components of patient wellbeing. Although wellbeing is a ‘hot topic’ in NHS policy and procedure and the term is used frequently throughout the healthcare literature, it is difficult to find a consistent definition. If the term is not sufficiently defined, how can staff be expected to monitor and improve on patient wellbeing, let alone consider it an outcome measure for good healthcare service?

Additionally, the practice of interaction design in healthcare fits in line with the NHS ethos of person centered care. To truly create a sense of patient wellbeing within healthcare we must strive to design technologies that consider the individual in every element of the process. Interaction design methodologies, within the healthcare context, have to ensure that designed technologies will not become a source of social embarrassment or stigma for the user, nor hinder the user’s motivation to engage in social activities.

Future research in this area will look at the clinical effectiveness of the cueing device, with a view to monitoring levels of wellbeing as an outcome measure of the treatment through traditional wellbeing measures and a device to monitor levels of social interaction, i.e. the amount of interactions the wearer has during a day, as well as their level of engagement within these interactions.

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**REFERENCES**