Designing to support wellbeing in dementia: Experiences with participatory design in the KITE project

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ABSTRACT
This paper examines the concept of wellbeing, mental health and the relationship between “tertiary symptoms” and wellbeing. We present an examination of a design led research project in the context of wellbeing and look at the challenges that were encountered designing to promote wellbeing in people with dementia. Finally, we reflect on and discuss how these challenges can be addressed.

Author Keywords
Wellbeing, dementia, participatory design.

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

INTRODUCTION
A definition of wellbeing is rather difficult due to the concept being complex and the many different existing perspectives on it. Broadly speaking, it refers to a state of healthiness and happiness beyond the presence of illness. For example, the UK National Health Service (NHS) draws a distinction between health and wellbeing [2]. However, the NHS clearly values both qualities in their patients and frequently refers to promoting “health and wellbeing” in policy documents. The World Health Organisation (WHO) also discusses wellbeing [3] closely relating the concept to the idea of mental health and quality of life. The concept of wellbeing is also seen in more general venues with the UK government suggesting that they could start to measure the wellbeing of UK citizens [6] and value this measurements as much as more conventional measures.

We understand wellbeing to be a state of mental health that reaches beyond physical illness. However, the concept is more complicated than this as people with mental health problems can still have a sense of wellbeing. A related concept is that of secondary and/or tertiary symptoms. While primary symptoms are acknowledged as the physical symptoms of a disease, that appear in medical literature, secondary or tertiary symptoms are discussed in some notable disease charities literature [1] where the term refers to problems that occur as a result of the primary symptom. For example, conditions that affect someone’s ability to communicate such as certain forms of dementia might be said to have a tertiary symptom of social isolation or depression as people avoid social situations because of their disease. These tertiary symptoms can be seen as antonyms to the concept of wellbeing.

THE KEEPING IN TOUCH EVERYDAY (KITE) PROJECT
The following section describes our attempts to design a digital technology to address a tertiary symptom in order to promote wellbeing, the issues we encountered in this work and issues we foresee occurring in design for wellbeing. The aim of the KITE project was to promote safe walking activities among people living with dementia. Safe walking is defined as occurring when people with dementia walk alone outdoors without becoming lost or anxious [5]. However, this activity is threatened by disorientation as a result of dementia (a primary symptom) and, more frequently, fear of becoming lost on the part of either a person with dementia or their caregivers (a tertiary symptom) [5].

The work that we did was heavily influenced by the ideas of Tom Kitwood [4] who discussed the need to place respect for the personhood of someone with dementia at the centre of dementia care. We attempted to realise this through a participatory approach to design that leveraged concepts of democratisation and respect on the part of the designer for experts in the domain area (in this case their expertise was in the field of their own personal experiences).

In working directly with the people with dementia, we found that we became focused more upon their needs rather than their caregivers so there was a natural emphasis on supporting the activity, not management of symptoms. In addition, the participants in the process actually enjoyed engaging with the design process and felt empowered because they were being consulted about potential healthcare/wellbeing interventions.

The underlying cause and effect of primary symptoms is well understood and documented but the tertiary symptom of anxiety about walking alone is less well understood.
Specifically, the experiences of the people with dementia and their caregivers with this tertiary symptom are not well documented. Therefore, the first step in designing a digital technology to help with this problem was to talk to these groups and gather their experiences. This was done in small focus groups working with established support groups. These accounts gave the interaction designers working on the project insights into the problem domain that could not be found elsewhere in literature and allowed them to start theorising about potential interventions.

The next stage of the work was to engage in more focused workshops with the support groups with a focus on refining, reducing and re-envisioning potential solutions to the problem. Finally, we progressed to building personally tailored prototypes for our participants (see Figure 2 for examples). This stage focused on the personal needs of the participants with dementia and, by producing physical, working prototypes, removed the need for them to envision how their devices might work.

DESIGNING TO PROMOTE WELLBEING

Designing for wellbeing seems to be easier to define than wellbeing itself. We propose that designs for wellbeing are those that support people with a mental health condition but which do not, as their main goal, aim to address or to treat primary symptoms of a disease. A number of questions or issues around design for wellbeing occur to us in context of the KITE project work and our experiences working with people with dementia.

Challenges in design for wellbeing

There are some obvious challenges to designing to promote wellbeing. Understanding the needs of the population being designed for is an immediate challenge. As the concept of a tertiary symptom is not widely used and, in our experience, these issues are often poorly documented, designers can find themselves starting from scratch. Similarly, understanding others experiences are challenging. We found it was necessary to create strong personal relationships with those we designed for to help us understand their points of view but this process was both time intensive and tied us to individuals with each iteration of the prototypes. Another major challenge in the process was creating suitably high fidelity prototypes for the individuals with whom we worked. The impact of our devices on them was often effect by, to us, trivial factors and this meant that the final devices had to be very carefully crafted.

Measuring Wellbeing?

Measuring a devices impact on wellbeing appears to be an extremely challenging proposition. Wellbeing is an inherently contextual, longitudinal phenomenon, and for a novel device to have a measurable, meaningful impact on it, it must be deployed in the real world as part of a long term study. In the KITE project the process of evaluating designs was particularly difficult because we did not know how to measure their impact on people’s lives and experiences and we did not have a suitably high fidelity prototype to conduct a real world evaluation with.

In addition, the question of how to measure wellbeing is an open one. Is survey data suitable or do we need to engage in richer qualitative interviews? And, if we do engage in such interviews, is there a way to quantify the result? Finally, how do we compare the result to the situation prior to the intervention’s introduction? It may be the case that any work in the field of promoting wellbeing needs to start with extensive research into the existing conditions in order to determine the right questions to ask about interventions.

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REFERENCES