Design for dementia: Making spaces for uncertainty

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Introduction

This paper presents research undertaken as part of the LAUGH project to explore design processes and design of hand held playful objects for people living with advanced dementia. A series of six co-design workshops were carried out with experts in relation to dementia and design. This paper reports on a workshop with designers that enabled them to draw on their experience and training in design, provided creative opportunities to reflect on their personal values, and challenged preconceptions about designing for dementia care.

Dementia is a complex, highly emotive disease, requiring sensitivity, empathic understanding and compassion within a design context. Globally, the number of people with the disease is expected to double every 20 years. By 2050 it is projected there will be 115 million people with dementia worldwide (Prince et al. 2014). Dementia affects memory, perception, cognition and behaviour and as yet there is no cure for the disease. Current care practice involves physical day-to-day care but often neglects a holistic approach that considers a person's emotional and psychological wellbeing. Each person's experience of dementia is different and varies individually through the progression of the disease.

Designing appropriate, safe and beneficial products and services presents a challenge for designers with limited knowledge of dementia. Designers who have not had direct experience of the disease are often informed through medical and clinical viewpoints and are unaware of the embodied nature of the condition, the variations that exist from person to person, and the limitations and possibilities. Further challenges arise for designers exploring co-design approaches when engaging with people living with advanced stages of the disease, who are chair or bed-bound and may have severe communication difficulties.

Co-design events throughout the project brought together design professionals, family members, carers and health professionals who work directly with people in the advanced stages of the disease, to contribute their expert knowledge to the research (Treadaway et al. 2016a). Designers engage in co-design approaches where they become one of many expert voices as they work alongside and accommodate the ideas of other non-design specialists. As the process develops, the skills and technical

expertise of design specialists are also required to hone and refine co-produced concepts being developed and give them physical form and robustness. This critical phase in the design process was an essential part of the study discussed in this paper.

A Design Challenge event was held in which designers and technologists (who had not all been involved in the earlier workshops) were invited to contribute their expertise. A multidisciplinary group, with different approaches to the creative process and differing viewpoints on design, was brought together. The aim was to explore design for dementia and 'disrupt' or challenge existing design thinking. Qualitative data was gathered via audio and video recordings, photography and concept boards. A thematic analysis, informed by a literature review and interviews was used to interrogate the data and inform design development (Treadaway et al. 2016b).

The event was divided into three activity sessions using envisioning techniques to generate ideas. These included: association exercises, dot voting and storyboarding. Each session was followed by a group discussion with opportunity to reflect and focus ideas ready for the next activity. The intention was to move from the broad themes identified by the experts in previous co-design workshops and generate sketches or paper prototypes for playful products. The activities encouraged participants to think divergently and the structure of the event was designed to challenge each designer's established patterns of thinking, design processes, deeply held values and unconscious bias.

The design event had been set up with the intention of creating a secure 'space for uncertainty' for the design participants. However, the activity sessions were familiar to many of the designers and they were confident about moving forward with design concepts. Nevertheless, it was evident from the outset that, apart from the research team, understanding of the disease was limited, which had implications for product design and development. The 'place of uncertainty' that was being sought in the design process actually coalesced in the debrief session at the end of the workshop through discussion of language use and the appropriateness of terminology inherited from scientific, clinical, medical, technological, and design fields and applied to people living with dementia in a care environment (rather than a clinical one). It became evident that it could not be assumed that the use of ethically sensitive language would be viewed as positive and productive and that language use was an issue that needed to be dealt with as part of the learning, understanding and communication process. Discussion around language use provoked deep reflection on the ethical issues around design for dementia and highlighted how language shapes understanding and therefore influences outcomes (products, designs). This was crucial learning for designers new to the field, who had not previously considered the wider ethical implications of language used in a design context.

Several design concepts resulted from the activities including an idea based on a vintage telephone (see Fig.1). This concept provided a platform for broad discussion about services, technology and social media, and helped participants understand embodied issues related to dementia care. The telephone concept was developed further and informed by preferences and life history of a person in the advanced stages of the disease.

Figure 1. Vintage telephone concept

Analysis of the data yielded by the Design Challenge reveals ways in which designers working in the area of advanced dementia benefit from opportunities to disrupt their thinking and reflect on their personal values and unconscious bias in the early stages of design concept generation. Making space to explore their uncertainties in a safe environment with others who have deep subject knowledge facilitates shared language and deeper understanding to inform the development of appropriate design concepts.

Acknowledgements

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