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Design with Older Users and People With Dementia – Methodologies, Practical Lessons and Challenges

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Abstract

We present design guidelines constructed on a strong theoretical basis for working with Older Users (OU) and older People With Dementia (PWD). The guidelines are illustrated with experience earned through work with groups of OU and PWD which came about in the course of two medium scale design exercises conducted as parts of the Keeping In Touch Everyday (KITE) project and The OASIS Participatory Analysis Framework (OPAF) project conducted with PWD and OU respectively. Simple techniques are identified and we discuss challenges we believe are the most significant and must be addressed in design frameworks for OU.

Keywords

Older Users, People With Dementia, Participatory Design, Invisible Design, OPAF, KITE

ACM Classification Keywords

H5.2 [User Interfaces]: User Interfaces---User Centered Design; H1.2 [Models and Principles]: User/Machine Systems ---Human Factors

General Terms

Design, Human Factors

Introduction

Whilst there is no doubt that the phenomenon of the ageing population is a testament to the general increase in the quality of life in modern society, it also means that we are faced with new issues such as design for older individuals and those afflicted by diseases associated with older age. Dementia is one example, a global decline in cognitive function meaning all the mental faculties of a PWD can be impaired and is a rapidly growing issue in public health. By 2020 there will be over eighty million people with the syndrome. In attempting to address the issue of design for PWD we found that design for OU, even without considering the possibility of cognitive deficit, can be challenging for a variety of reasons. Many designers recognize the obvious challenge posed by the normal ageing process that leads to diminished eyesight, poor hearing and reduced physical co-ordination but beyond this there are more subtle challenges. Paradigms of interaction we take for granted such as file structure and desktop organization are confusing for many OU who grew up in a time when the overarching paradigm for interacting with technology was mechanical rather than software based [2]. Another widely observed phenomenon we believe to be a dominant issue in this type of design, is their struggle to envision future systems and technologies. The KITE and OPAF projects encountered this and it has been observed in other work [4] noting that OU were good at criticizing a piece of technology placed in front of them, struggled when helping design screen interfaces and that they had little ability to envision future technologies. Dementia adds another layer of design challenge to this area as the experience of dementia remains poorly understood, especially amongst twenty-something technology savvy designers. In healthcare there is a tacit

acknowledgement of this and a move towards holistic Person Centered Care [3] which designers can emulate through a Participatory Design (PD) process as it shares many values and properties. Both essentially state that the only person whom truly understands the life of a PWD is the PWD them self.

The OPAF Project

The OASIS (Open architecture for Accessible Services Integration and Standardization) Participatory Analysis Framework (OPAF) is a three-phase guide for planning and running PD exercises with OU. The process is a typical PD activity that helps OU with aspects of design they struggle with through *specialist prompts* and establishing a common frame of reference.

OPAF-1: Working with OU deals with general issues around working with OU and how one goes about performing the recruitment of OU. The process must be carefully conducted in order to avoid excluding anybody accidentally and to ensure a relevant diversity of users. Further guidelines are focused on providing the proper environment for OU to work in. We found recruitment was the most challenging and variable aspect of the design process with OU. When developing very user group specific applications, such as transport advisers, obtaining a *relevant diversity* amongst focus group participants was challenging, the process took months to gather participants together.

OPAF-2: Feature and Scenario Envisionment is an Information Gathering and Envisionment Process for two-hour workshops. This is a specific structure for one to two hour meetings with OU designed to build a common frame of reference for everyone involved and to lay groundwork for envisioning future technologies:

- Information Gathering – Involves eliciting basic information regarding the relevant domain.

- Scenario Generation – Taking output from stage one and constructing shared scenarios.

- Claims Analysis – Asking users why things are the way they are, looking for emotive and social issues as well as purely physical ones.

- Feature Envisionment – Asking the OU how s/he can change the scenario they have outlined positively, again not restricting answers to technical solutions.

- Scenario Envisionment – Users look at their potential solutions and critique them, often the most productive part of the process [4].

To address the difficulties with getting OU to envision future technologies we use *specialist prompts,* videos produced by professional filmmakers and actors dealing with various issues around the design topic. Videos are short, humorous and, importantly, ambiguous with respects to the issues they raise. The story is set in a scenario where characters have the device being designed, cameras are manipulated to avoid displaying devices, a process we refer to as *Invisible Design* [1].

OPAF-3: Low-Fidelity Prototyping is the final phase comprising of another workshop using low fidelity prototyping material to mock up potential interfaces. The workshop is filmed in order to capture the transient relationships developed and shown by the participants.

The KITE Project

The KITE project worked with PWD and caregivers tackling issues with conducting design exercises with PWD and the concern that the voice of PWD was heard. The domain we tackled, Safe Walking for PWD, was not fully understood and heavy emphasis was placed on scoping the area to facilitate designer understanding.

Scoping Focus Groups were conducted with groups one to four in Table One. This stage was kept free of technological discussion unless volunteered by participants, discussion focused on experiences of becoming lost and emotional responses to the issue. Many PWD mentioned their concern about the stress their caregiver experienced rather than fear for their own safety. Participants who had been lost identified distinct stages they went through when they were lost.

Design Workshops were conducted with groups one, two, five and six aimed to bring technological solutions into the discussion. Meetings began with a summary of the scoping stage which served to establish a common frame of reference and aid participant's memories [5]. Various examples of current technology were presented to the participants and their opinions were elicited. The project used these stages as a way to identify PWD that were particularly engaged and recruit them for the final stage. The process developed a variety of heuristics revealing issues not typically considered in development of technology grouped into three categories, PWD's circumstances, issues they had with technology and specific needs for tracking.

Iterative Development and Field Trials checked and refined the designs for acceptable personal socio-technical tracking systems. Designs were guided by heuristics developed in the design workshops and tailored to suit each individual with rapid turnaround on the development process and constant re-evaluation.

Group	Number Of Caregivers	Number of PWD
Group One	2 Alzheimer's Soc. (AS)	2 PWD
Group Two	2 Caregivers, 1 AS Volunteer	3 PWD
Group Three	3 Caregivers	4 PWD
Group Four	6 Caregivers	---
Group Five	1 Professional Caregiver	5 PWD
Group Six	---	2 PWD

Table One: Group Compositions

Conclusion: Key Lessons and Challenges

Through the course of the two projects we have identified key issues that need to be addressed in any design process that seeks to work with an OU base as well as some aspects of working with OU that seem to actually make a design process easier.

- *Pre-existing groups* – Working with existing support groups made discussing sensitive personal matters easier and helped when PWD struggled to recall an event they wished to talk about, other participants in the group had heard the story before and could help.

- *Common frames of reference* – We found it was important to establish a common frame of reference early in all our design activities. When this was not achieved participants talked at cross-purposes.

- *Recaps* – Recapping the events of a previous design meeting frequently served to establish a common frame of reference for the groups and helped keep the memory of events and concepts.

- *Prompts* – The use of physical or video prompts to provoke discussion was one of the most successful aspects of the processes we detail.

- *Facilitator / Developer Separation* – One issue that perhaps should have been expected was that OU were often reluctant to critique the solutions we placed in front of them, separating the builders of the technology from those presenting the technology helped with this.

Currently our primary concern is the need for more concrete prompts to be presented to PWD and the potential for this to overtly shape their ideas about the design process. Tied to this was the difficulty of presenting more intangible concepts in design, something that might be addressed through the use of video for work with PWD in the future. A second difficulty is eliciting information from both groups about the aesthetics of a device, the only solution we have arrived at to date is presenting them with multiple aesthetic themes but this doubtless heavily shapes their expectations.

Acknowledgements

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