
SIGCHI Workshop on Designing For-and-With Vulnerable People: The Dem@Care “Toolbox” Approach

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Abstract

We describe the challenge set to us within the Dem@Care project, of designing a multi-component system to support safety, enablement, and diagnosis for older adults with dementia. Specifically we discuss the system as it relates to home-based enablement. Person-centred care is the gold standard in dementia care, which we incorporate into technology design by engaging in a user-led, participatory approach. The result of our considerations is the Dem@Care “toolbox”, a solution which addresses the challenge of providing home-based, person-centred care and enablement for older adults with dementia, utilising sensor technologies. The current text describes the toolbox and the terms of its future deployment.

Author Keywords

Dementia, person-centred, enablement, ageing-in-place, older adults, technology, sensor, ICT

ACM Classification Keywords

H3.4, H.5.2, I.2.1, I.2.9, J.3, K.4.1

General Terms

Experimentation, human factors, reliability

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Introduction

Individuals with dementia represent a vulnerable clinical population. Dementia entails a progressive cognitive deterioration, and resultant functional impairment. Loss of autonomy and independence can arise during dementia progression, and this can further impact an individual's quality of life. One major factor in maintaining autonomy and quality of life is the facilitation of "ageing in place", a notion connoting the typical preference to remain in the family home, with all of the dementia-related adjustments that might imply, rather than being placed in an institution. Ageing in place has been operationalised as being an older adult's response to the question, "what is the ideal place to grow older?" [17] and evokes strong associations with the maintenance of independence, social ties, and autonomy into late life. While institutionalisation may be unavoidable for some individuals approaching the end of life, the ageing-in-place concept acknowledges the preference to remain in familiar and private surroundings, and prioritises the enablement of this scenario. Ageing in place has economic implications; the cost of institutionalisation on any already-burdened national healthcare system is significant, but the projected costs of formal care provision for individuals with dementia in coming decades are unsupportable. Home-based care, involving informal, family caregivers, must be made a workable solution to this projected healthcare shortfall. The "pull" of technology also predicts the future proliferation of home-based care, since increasingly intelligent and reliable technologies are being introduced to the market, under the collective term of "telecare" [3].

Technology represents a means of engineering the requisite adjustments to make the average home suitable for an individual with dementia. The Dem@Care project's aim is to create, with input from individuals with dementia, a technological dementia support system. While the Dem@Care project also caters for diagnostic laboratories and nursing homes, here we focus on the private home-based deployment of the system. The focus is on enabling the individual to remain at home, maintaining independence and autonomy, and optimising the individual's wellbeing, with the aid of sensor technologies and feedback. We ground our system in a person-centred, user-led philosophy, which we discuss alongside the ethics of dementia research. Finally, we outline the evolution of the "toolbox" system, which is our solution to the provision of enablement for older adults living with dementia in the home. The toolbox system is our novel approach to the provision of person-centred care for older adults with dementia.

Person-centred care

Person-centred care as it relates to dementia was defined by Kitwood [7], after the work of Carl Rogers and others [12]. This approach states that the person with dementia, and their subjective reality, should be the primary focus of care. Care ought not to be task-oriented, but rather the experience of the individual with dementia is paramount. For older adults in general, care is effective insofar as it supports autonomous functioning and the retention of personal identity [4]. Person-centred care does not mean a lack of consideration for other stakeholders in the dementia care scenario, such as family members and formal caregivers; rather, it re-emphasises the priority of the

individual with dementia, and ensures that their needs are placed as the most important consideration.

There are several strategies we can take to ensure that person-centred care is being delivered [5]. Edvardsson and colleagues [5] gathered these strategies and defined them to be;

1. Having a degree of biographical knowledge about the individual, and about their past life, and incorporating this knowledge into their care.
2. Reminiscence – allowing the individual to reminisce, facilitating this reminiscence with appropriate stimuli.
3. Acknowledging the individual's own interpretation of their subjective reality to be the most important.
4. Ensuring that the subjective experience of the individual is always placed at a higher priority than anything else, e.g. tasks to be completed.
5. Ensuring that all routines for the individual are flexible and can be adapted according to the wishes of the individual.

The Dem@Care home deployment adheres to these strategies, and places the subjective experiences of the individual with dementia as the top priority. This means that the system is deployed only with the acceptance of the individual with dementia; if the opinion of the individual towards the deployed technologies changes over the course of the project, the system will be changed accordingly. At the design phase, also, the opinions of the individual with dementia will be prioritised.

Technology, Ethics & Dementia

Delivering person-centred care necessitates an ethical treatment of the proposed work. Individuals with dementia are a vulnerable population and as such research needs to consider the ethical implications of deploying sensors into typically private, home-based care situations. Among the ethical issues to consider are issues of informed consent and how it is sought; working with older adults with cognitive impairments; surveillance; and processes of care and how it is delivered [3]. Having a rationale for data collection, rather than collecting data opportunistically, is another identified issue. Issues of maintaining privacy, and avoiding the use of obtrusive sensors, have also been highlighted as being relevant to technology deployments for older adults with dementia [13]. These ethical issues have been considered at length by the Dem@Care researchers, and internal guidelines have been developed to ensure that any deployment is ethically sound. These investigations highlight the importance of consistently obtaining informed consent with a progressively deteriorating participant group, ensuring security and privacy of the personal data, including outlining provisions for the incidental collection of data pertaining to other individuals, and ultimately, consistently adhering to the wishes of the individual with dementia [8].

Dem@Care: System Design

One way of ensuring that the end system is person-centred in its goals is by including end users in the system design. User-centred design has previously been used successfully with older adults, including those with dementia [11]. User-centred design involves including the end users of a technology in its design process, to give developers an accurate and

ecologically valid idea of the usefulness, acceptability and effectiveness of the technology. There are certain caveats accompanying this type of research, however. Roger Orpwood warns that while the input of the individual with dementia is valuable, it may be too great a taskload to involve them too early in the design process [10] when aims and processes are typically ill-defined. We collated 12 principles governing good dementia design from the previous work of Orpwood and his colleagues, as follows;

1. User interaction should be kept to a minimum [9; 10; 2].
2. The technology should appear familiar to the individual with dementia [9; 10; 2].
3. The technology should be empowering, helping the individual with dementia to solve their own problems and complete their own tasks [9; 10; 2].
4. The technology should reassure the individual with dementia [9; 10; 2].
5. Algorithmic applications should be based on large datasets to avoid overreliance on small and therefore non-representative datasets [10; 15].
6. The technology should be tamper-proof and robust [9; 10; 1].
7. The technology will reside in a person's home and therefore should have an aesthetic [15].
8. The technology should be person-centred and not carer-centred [2].
9. The technology should provide the person with dementia with a feeling of independence [2].
10. The technology should acknowledge the person with dementia as being an individual with abilities [2].

11. The technology should engage caregivers at the first stage of development, and be refined somewhat before it is presented to the individual with dementia [10].
12. The technology should emulate carer behavior, by providing reminders, support, and reassurance to the individual with dementia [9; 10].

The use of sensor technologies to monitor lifestyle and functioning in the home may help to promote independence for the individual living at home with dementia. Provision of feedback regarding their own lifestyle habits and functional status may improve motivation for change and self-reflection. This necessitates a clear and easy-to-navigate user interface, providing relevant and interesting information for the individual. Furthermore, while this is a person-centred design, the system also caters for the clinician, as it has been proposed that continuous monitoring of daily activities can provide a better measure of functional status than one-time clinic-based assessments [16]. This, coupled with the fact that user needs were defined in the first instance by clinicians, means that the system design is not entirely user-led.

Dem@Care Toolbox

We propose a 'toolbox' approach to providing technological solutions for the individual with dementia. Providing a choice of solutions addressing different functional difficulties is both person-centred and empowering to the individual with dementia. The toolbox approach aims to deliver a system which focuses on person-centred care, by utilising the strategies set forth [5]. Both the design and the deployment of the Dem@Care system adhere to

person-centred care principles, and it is hoped that this approach will best provide for each unique situation of the participants with dementia.

The toolbox approach arose from the wish to create a highly personalisable system which could also be deployed to multiple situations. Individuals with dementia are a highly heterogeneous group, but some functional disability is common, and forms part of the diagnostic criteria. Based on focus groups held with formal caregivers, and on a literature review, we propose that most functional difficulties experienced by individuals with dementia fall into one of five categories; sleep, eating and activities of daily living, physical activity and exercise, mood, and social interactions. We took this first step in order to establish some structure to the project before engaging in the user-centred design process, in accordance with the recommendations of Orpwood and colleagues [9;10]. Based on these functional areas, technical partners designed a system employing sensor technologies to monitor activity over time, and provide relevant feedback. This system is currently in development. When the system and its proprietary ontology and architecture are complete, the clinical researchers will have a "toolbox" of system functionalities to present to participants. The participants can then choose the solutions they wish to have deployed in their homes, thus empowering them, and involving them in the solution of their functional limitations.

We plan to present the different domains of functioning to the participants to acquire their confirmation that these are in fact relevant to older adults with dementia, and we introduce the sensor technologies, the feedback they are likely to receive, and the form of the user

interface to be used. Based upon these, participant feedback will be elicited on the initial prototype of the system. Following this interview, a second assessment interview will be performed with the participant. In this assessment, the researcher will, using semi-structured interview format and relevant validated questionnaires and scales, identify areas in which the participant is having trouble. It could be the case that this could be in the areas of sleep and exercise, for instance. If this is found to be the case, we will offer modules from the toolbox relevant to these functional areas, and the participant will be encouraged to reflect upon the acceptability of these modules. From the remaining pool of acceptable sensors, then, the participant can decide to have some or all deployed to their homes. The individual can receive support in any or all of the domains. In this way, the personalised system is controlled entirely by the individual with dementia and their wishes, thus constituting an empowering, person-centred approach to care.

The toolbox approach is developed with a user-centred design process, involving a 3-stage participatory design as previously described [11]. Initially a scoping exercise was conducted, where focus groups of professional and informal caregivers of individuals with dementia reported participant needs and system requirements. This was conducted in 2011, in the first year of the project. In year 2, we will conduct preliminary interviews with persons with dementia and their families, to access their input on particular aspects of the system design, thus representing the participatory design stage. These issues include the acceptability of sensor technologies, familiarity with technology, prioritization of system functionalities, and confirmation of the relevance of the needs reported by

caregivers in the scoping stage. Stage 3 is the prototype development stage, due to start in April 2013, whereby systems will be deployed to the homes of lead users and participating nursing homes, and refinement and development of the system in conjunction with the aid of the individual with dementia and their families and formal carers will commence.

As the design illustrates, the individual with dementia is an active participant in the project, rather than a passive individual to be cared for. This important difference is well described by Irving and Lakeman [6] in their description of mental health recovery and its implications for personal responsibility in individuals with dementia. The current project takes this model into account by emphasizing the individual's own role in designing their own Dem@Care system. As Orpwood states, we must improve upon the extant skillset of the individual with dementia rather than replacing functionalities which they can still perform for themselves. Individuals with dementia represent a vulnerable population, and historically, have not been included in dementia care research. There is a danger, then, in providing solutions for this population, that a didactic, unidirectional provision will be made, rather than a dialectical exchange regarding individual needs and wishes. The Dem@Care system acknowledges that

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every technological system development runs the risk of designing “for” rather than “with” a vulnerable patient group, since it can be perceived to be difficult to elicit and incorporate the opinions of individuals with cognitive impairment. We propose our “toolbox” approach to ensure that the wishes of this vulnerable population are kept at the fore of Dem@Care priorities, and argue that this is the only truly ethical and effective means of conducting fruitful technological research with this population group. We are confident that including the patient group in the co-design of the system will lead to an ecologically valid and flexible support system.

The focus in the Dem@Care study is the enablement of individuals with dementia in both nursing home and private residential settings. In a review of the literature there is a paucity of research investigating technology use for individuals living in the community with dementia [14], and therefore the current paper focuses more so on this deployment. The toolbox approach is designed specifically to allow a highly individualized, enabling system for individuals with mild to moderate stage dementia, and to facilitate ageing in place. The system will be flexible and modifiable as the deployment progresses, since the needs of the individual are likely to change over time [16].

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