Designing Technologies for Managing Responsive Behaviour: A User Centred Approach

Andrea Wilkinson

Interactive Media Lab

University of Toronto

Toronto, ON M5S 3G8, Canada

andrea.wilkinson@utoronto.ca

Tiffany Tong

Interactive Media Lab

University of Toronto

Toronto, ON M5S 3G8, Canada

tiffany.tong@mail.utoronto.ca

Farzad Nejatimoharrami

Interactive Media Lab

University of Toronto

Toronto, ON M5S 3G8, Canada

farzad.nejatimoharrami@mail.utoronto.ca

Mark Chignell

Interactive Media Lab

University of Toronto

Toronto, ON M5S 3G8, Canada

chignell@mie.utoronto.ca

Abstract

We focus on innovative designs for managing problem behaviours in late stage dementia. Our participatory design involves ethnographic observation of behaviours, along with stakeholder (e.g., occupational therapists, recreational therapists, and geriatric psychiatrists) recommendations, followed by formulation of design concepts and prototypes that are tested and improved through iterative design and field testing in long term care homes. This methodology has led us to develop familiar interfaces that allow residents with dementia opportunities to self-initiate (trigger), and engage and interact with technologies that provide physical, cognitive and social stimulation. Our goal is to re-engage task oriented parts of the brain to the extent possible, and to assist people in attaining a 'state of calm', thereby managing problem "responsive" behaviours (e.g., screaming, hitting, pacing) and improving quality of life. We describe two new families of products for people with dementia: 1) Ambient Activities based on Montessori principles, where sensori-motor interactions are emphasized and 2) Rewarding activities (Centivizers) intended to strengthen or maintain physical and cognitive ability.

Ambient Activity Technologies (AATs)

Purpose: AATs - (1) help manage responsive behaviours (e.g., hitting and verbal abuse); (2) offer personalized content and experiences anytime (ambient); (3) exercise critical functions within the brain; (4) reduce caregiver burden by requiring minimal external involvement.

Image 1. Ambient Activity Technology (AAT) – called ABBY - designed for use by individuals with dementia in long-term care homes. For example, a resident can turn the wheel to activate the video content being displayed on the touchscreen, with audio output through the speakers.

Introduction
Rapid aging in many societies is leading to increasing prevalence of age-related conditions associated with abnormal cognitive status, such as delirium, and dementia [1]. Other aging-related issues that affect quality of life, and the ability to live independently, include frailty and loss of functional status. In Canada alone, 20% of people over the age of 65 are estimated to be frail [2], and over half of individuals living in long-term care (LTC) homes have dementia [3]. With one new individual diagnosed every seven seconds [4], and people with dementia often being unable to live at home, there is great pressure on LTC homes to meet the specific needs of this unique population.

In individuals with dementia, procedural/implicit memory remains relatively intact, along with motor skill learning [5]. Long-term memories tend to degrade more slowly than short-term memory, while priming, emotions, motor control, reinforcement/implicit learning, reward seeking, and sensing tend to be preserved relatively late throughout the progression of dementia.

Staff Workload
Ideally, people with dementia should be engaged in meaningful activities on a daily basis. However, methods such as relationship-centred care [6] create high workload demands exacerbating a situation where the ratio of recreational staff to residents is already poor, tending to vary between 1:25 and 1:28 [7]. How can technologies help provide better care without increasing staff workload?

Responsive Behaviours
Responsive behaviours (also referred to as behavioural and psychological symptoms of dementia; BPSD) include agitation, aggression (hitting, screaming), aberrant motor behaviour (e.g., pacing), anxiety, elation, irritability, depression (crying), apathy, repetitive verbalization, delusions and hallucination [8] [9]. Up to 90% of individuals with dementia exhibit these types of behaviours, which are commonly treated with antipsychotic medication or ignoring behaviour, and compromise quality of life for residents, as well as caregivers and LTC staff [9]. The most frequent responsive behaviour within a LTC setting is agitation, affecting 55% of residents in one study [10]. Managing responsive behaviours is resource- and time-demanding, as behaviours can occur at any time (24 hours a day, 7 days a week).

Ambient Activity
Ambient Activity Technologies (AAT) incorporate a person-centred approach with various technological interventions involving tablets, sensors, and hardware input devices such as wheels and switches ("tangibles") to create always available engaging activities. To facilitate personalized activities, and individualized stimulating experiences, ID technology recognizes the person using the AAT and responds accordingly. For example, a sing-along interactive game, customized to the resident's musical interests will play when he or she turns the wheel (*see Image 1*). The personalized

Centivizer Systems

Purpose: Centivizers reward task performance with applause, music, and verbal approval.

Image 2. Centivizer prototype showing a range of modules (lever, slider, large and small screens, pantry door, and lighted buttons) mounted as an all-in-one unit.

playlist will have been created by the resident and/or family member and/or staff and uploaded to the AAT. Games are also personalized and have been created using flexible and adaptable difficulty levels to meet the changing needs of individuals living with dementia. The AAT can be used in two modes: independently by individuals with dementia and/or as a tool used by family members and staff to help alleviate negative symptoms. The goal of the AAT is to:

1. Encourage meaningful engagement through access to appropriate and personalized experiences, memories, and activities
2. Reinforce familiarity and personal identity
3. Promote physical activity
4. Enhance confidence and promote independence
5. Adapt interactions to the mental and physical challenges faced by people with dementia

Centivizers

Our second approach involves reward-based activities, using a combination of inputs, outputs, sensors and software to create engaging physical, cognitive, and experiential activities. *Image 2* shows an early all-in-one Centivizer prototype that includes a variety of physical and cognitive activities. As an example, the large buttons with flashing lights were designed to provide shoulder exercise and reduce the risk of frozen shoulder for the target users. Centivizers are also available in more specialized configurations that focus on physical, cognitive, social, or experiential activities, respectively.

Modified Participatory Design

It is difficult for many people with late stage dementia to communicate their needs and interests effectively. Thus, to include their voices in design, we needed to modify the participatory design process. We did this by using a three phase process: 1) Determine aspirations and opportunities through direct and indirect observation. Direct observation involves a series of visits to different LTC units looking for informative behaviours (e.g., "exit seeking" where the person packs their bags and looks for the exit - showing a desire to get outside of the locked unit; or spontaneously pulling things apart or tying them together - showing a need to work with the hands and manipulate physical objects). Indirect observation involves focus groups, workshops and other meetings with all stakeholder (e.g., family members, recreational therapists, etc.) who have lived with and/or observed people living with late stage dementia; 2) Iterative design cycles of user testing in LTC followed by redesign based on problems found; 3) Field testing where prototypes are installed in LTC homes for prolonged durations to assess reliability and usefulness over time. Our design process seeks to address three goals in the following sequence:

1. Find the Function
2. Find the Usability
3. Find the Reliability and Maintainability

Conclusions

Innovative methods are needed to manage the behaviours of people living with dementia and to improve their quality of life. Here we described the development and use of Ambient Activities and Centivizers to provide engaging interactions for people living with late stage dementia, without increasing staff

workload. Our design process functions in three phases, ethnographic observation and stakeholder engagement, followed by user testing and finally field testing. The ABBY unit (an ambient activity) has been through all three phases for design and is now being sold and installed within LTC homes. Centivizers are now in the second phase of the design process with field testing expected to follow in the second half of 2018. We have found that the combination of ethnographic observation, stakeholder engagement, and user testing is an effective way to get people with late stage dementia to participate in the design process as much as possible.

Acknowledgements

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