

Journeys to Engagement: Ambient Activity Technologies for People Living with Dementia

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ABSTRACT

Caring for individuals with dementia living in long-term care environments requires the management of responsive behaviours (e.g., screaming, hitting, wandering), which affect 60-80% of residents with dementia. Responsive behaviours are commonly treated with antipsychotic medications, and they compromise well-being of residents as well as staff. Our multi-disciplinary team seeks to develop technological solutions to help minimize agitated and aggressive behaviours by creating familiar and appropriate activities that allow residents with dementia opportunities to self-initiate (trigger), engage and interact with Ambient Activity Technologies (AATs) and Centivizers (reward-based learning). Once engaged, these technologies should provide the resident with individualized and stimulating experiences that are meaningful to the resident, facilitating the development of a calm and engaged state, thereby managing responsive behaviours (e.g., agitation and aggression) and improving quality of life. In this paper, we review the etiology of dementia and responsive behaviours to elucidate the rationale behind the design and development of AATs and Centivizers for individuals with dementia living in long-term care, using a person-centered technological approach. Our goal is to utilize technology to minimize caregiver burden and help to improve well-being related outcomes in residents, staff and family members.

Keywords: Alzheimer's disease; dementia; ambient technology; person-centered care; Montessori; meaningful engagement; quality of life; caregiver burden; gamification; human factors

1. INTRODUCTION

Dementia is a devastating neurodegenerative brain disease. According to the world health organization (<http://www.who.int/mediacentre/factsheets/fs362/en/>) close to 50 million people worldwide currently have dementia and there are almost eight million new cases each year. Prevalence rates are expected to reach over 135 million by 2050 [1].

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In Canada, over half of individuals living in long-term care facilities have dementia [2]. With one new individual diagnosed every seven seconds [3], and with people having dementia often being unable to live at home, there is great pressure on long-term care environments to adapt more precisely to the requirements of people with dementia.

In this paper, we introduce Ambient Activity Technologies (AATs) and the Centiver (reward-based learning) as tools for dementia care. These technologies are intended to: (1) assist with the management of responsive behaviours (e.g., hitting and verbal abuse) using a non-pharmacological approach; (2) offer personalized experiences to residents that are always available in the environment (24 hours a day/7 days a week) for anytime use (ambient); (3) exercise critical functions within the brain to slow the progression towards increased cognitive frailty and loss of functional status; and (4) reduce caregiver and long-term care staff burden by offering activity solutions that require minimal external involvement.

In the following sections, we will (1) Describe the morphology of dementia, including an outline of the abilities that remain intact; (2) Discuss long-term care environments, including the issues surrounding caregiver burden and responsive behaviours. We will also describe the unmet needs model as an alternative to the use of antipsychotic medications for the treatment of responsive behaviours; (3) Discuss Montessori as an approach to designing person-centered activities for individuals living with dementia; (4) Introduce AATs and reinforcement learning technologies, Centivizers, as novel approaches to addressing responsive behaviours by providing engaging interactions, while making minimal demands on long-term care staff and caregivers.

2. DEMENTIA

Alzheimer's disease (AD) is the most prevalent form of dementia, affecting half to three-quarters of people with dementia [4, 5]. One key feature of AD is the presence of amyloid plaques and neurofibrillary tangles, which have variously been attributed as causes or symptoms of brain cell death (although the utility of these markers as diagnostic criteria for dementia remains elusive [6, 7]). The spread of brain pathology (neurofibrillary tangles, but not plaques) has been shown to follow a predictable pattern, initially affecting brain areas involved with memory function (hippocampus and entorhinal cortex) and its presence has been

shown to impact performance on memory tests [8-10]. The involvement of the medial temporal lobe memory system in AD begins in the entorhinal cortex – an area located deep inside the brain with connections to the hippocampus, which plays a key role in explicit learning and converting short-term memories into long-term memories [11].

Key symptoms of AD and dementia include: memory loss, disorientation to time and space, problem-solving difficulties, as well as a breakdown in language functioning [5, 11, 12]. The changes in cognition are severe enough to impact an individual's ability to perform activities of daily living (ADLs), which results in loss of independence [13]; however, it is important to note that individuals with AD can live up to 20 years post diagnosis [5].

Although there are many downsides to a dementia diagnosis, it is important to focus on the abilities and capacities that remain. Individuals with dementia maintain the capacity to feel joy and happiness [14]. Their memory for past and future may be compromised; however, their experience of the current moment remains, and moments of joy and happiness are particularly important. Feelings of happiness can be facilitated in multiple ways, including social interactions, being listened to in an attentive manner, or through engagement with meaningful content, such as hearing/singing an individual's favourite song or participating in hobbies and skills learned long ago [14].

Favourite music has been demonstrated to be a powerful therapeutic tool in dementia care. In particular, evidence suggests that some long-term memories (e.g., music) remain intact in individuals with dementia [15]. In one study, musical memory for common tunes was compared in 12 individuals with mid- to late-stage AD vs. 12 healthy controls. When comparing individual performance to the group, almost half of the individuals with dementia (five) performed at the same level as healthy controls [16]. There were an additional four experimental participants who performed worse than controls but better than chance, demonstrating some sparing of musical memory.

Although explicit memory and the ability to learn new information deteriorates with the progression of dementia, implicit memory and procedural learning – such as hobbies learned long ago – appear to remain intact. As an example, despite having late-stage AD, older individuals demonstrated retention of their well-known abilities to play musical instruments [17, 18] – likely because this skill was so well ingrained into their procedural (automatic) memory system.

The act of engaging in activities that are skill- or hobby-based also reinforces a sense of self and helps individuals to maintain their personal identity [14, 15]. There is a human need to remain a person of value – even post diagnosis [19], which can be accomplished through the continued use of old skills and well-learned abilities. Long-term care environments can help to create positive emotional experiences for their residents by focusing on the strengths, and highlighting the remaining abilities, of those residents.

3. LONG-TERM CARE ENVIRONMENTS

According to the Continuing Care Reporting System (CCRS) in a 2014-2015 report, there were 1304 residential continuing care facilities (nursing homes, personal care homes, long-term care

facilities) across Canada (Newfoundland and Labrador, Nova Scotia, New Brunswick, Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, Yukon and Northwest Territories) with 631 of those being in Ontario [20]. In Ontario, these facilities included 78,100 long-term care long-stay beds, which are primarily filled with individuals suffering from dementia. At the time of this writing, around 50,000 individuals or about 60% of residents living in not-for-profit long-term care facilities in Ontario have dementia – a rate that is growing by 2.5% per year [21]. Also on the rise is the cost of care for individuals with AD and other dementias. Expenditures attributable to dementia, including both the Canadian health care system and caregiver (out-of-pocket) costs, were approximately \$10.4 billion in 2016 – projected to hit approximately \$16 billion in 2031 [see 22, 23]. Given the high prevalence and rapidly growing number of individuals suffering from dementia who are living in long-term care environments, their needs, as well as the needs of the long-term care facilities and its staff, should be paramount.

3.1 Caregiver Burden and Responsive Behaviours

Technological interventions have great potential for use in long-term care environments, because dementia care is labour intensive and resource demanding. As a result, it is not feasible to provide the dedicated round-the-clock attention and interaction that people with dementia might benefit from. In Canada, the resident to staff ratio is 9:1 in long-term care environments [24, 25], limiting the amount of individualized care that can be provided. Furthermore, caring for someone with dementia creates physical, psychological or emotional burden [26], and levels of stress are reported to be high among nursing staff in long-term care environments. One-third of long-term care staff report high emotional stress (37%) and physical burden (32%), in particular as it relates to end of life in dementia care [27]. A contributor to this stress may be responsive behaviours (definition below), because they can occur at any time (24-hours per day, 7-days a week), always take priority, and are a burden not only to the residents that experience them, but also to long-term care staff, caregivers, and family members. In particular, aggressive behaviours that were perceived as threatening (e.g., screaming), were shown to be particularly stressful for staff [28]. When residents are aggressive, staff feel more frustrated, anxious and angry towards those residents and as a result wish to distance themselves from them [24]. In this way, responsive behaviours may lead to disruptions in care.

Responsive behaviours (also referred to as behavioural and psychological symptoms of dementia or BPSD) include agitation, aggression (hitting, screaming), aberrant motor behaviour (e.g., pacing), anxiety, irritability, depression (crying), apathy, repetitive verbalizations, delusions and hallucinations [29, 30]. Agitated and aggressive behaviours have been noted as the most prevalent of symptoms [31]. Up to 90% of individuals with dementia exhibit some form of responsive behaviours, which are commonly treated with antipsychotic medication or ignoring behaviour, and compromise quality of life for residents, as well as their caregivers and long-term care staff [15, 29, 30, 32-34]. Interestingly, vocally disruptive behaviours (e.g., screaming, repetitive verbalizations) have been shown to be more likely to occur when residents are depressed, anxious, socially isolated (participate in less activities), or have communication difficulties [24]. This suggests that unmet needs (e.g., loneliness, sadness), which often cannot effectively be expressed by the resident, are not being adequately addressed by caregivers or long-term care

staff. Of note, residents exhibiting vocally disruptive behaviours were given antipsychotic medications at a significantly higher rate than controls [24].

3.2 Antipsychotic Medications

Treatment to address responsive behaviours in older adults with dementia often involves the use of antipsychotic medications. In 2014, almost 40% of residents living in long-term care had at least one claim for antipsychotic medication, and 22.4% were chronic users. Of those 22.4% who use antipsychotic medications regularly, 64.3% of them were also chronic users of antidepressants [35]. In Canadian nursing homes, 37.7% of seniors in 2006-7 were prescribed antipsychotic medications [36].

A recent study collected data from 14,504 long-term care facilities across five countries: Canada, Finland, Hong Kong (China), Switzerland, and the United States. Globally, the use of antipsychotic medications in long-term care facilities was found to be lowest in Hong Kong (11%) and highest in Finland (38%) and Switzerland (34%), with Canada (26%) and United States (27%) falling somewhere in between [37].

Of particular concern are the severe adverse health effects associated with the use of antipsychotic medications. Review studies consistently demonstrate links between these medications and Parkinsonism, abnormal gait, and increased cerebrovascular events – e.g., stroke [38, 39]. Furthermore, individuals who take antipsychotic medications demonstrated more rapid declines in cognitive performance, and cardiac effects – such as tachycardia (faster than normal heartbeat) or increased risk of myocardial infarction in community-dwelling individuals treated with cholinesterase inhibitors [for a review see 40]. Antipsychotic medication is also associated with movement difficulties [see review by 41] – but not falls risk, after adjusting for confounding variables [see a recent meta-analysis, 42]. A randomized control trial has even linked the use of antipsychotic medication to an increased risk of death (odds ratios 1.54-1.7) in the treatment group, as compared to those given a placebo [43-45]. In spite of their prevalence, and the health risks associated with their use, there is little evidence that these medications are an effective treatment strategy for responsive behaviours [33].

To address the issue of over-prescription, the Ontario Ministry of Health and Long Term Care hired approximately 700 additional healthcare workers across the province to better manage responsive behaviours without the use of antipsychotic medications [46]. Furthermore, regulatory warnings were put in place by Health Canada [47] and the U.S. Food and Drug Administration (FDA; [48]). Health Canada advised antipsychotic drug manufacturers to include a risk warning on the safety information sheet for each drug [47], and the Committee on Safety of Medicines (CSM) in the UK recommended that risperidone (a particular antipsychotic medication) not be used in the treatment of responsive behaviours exhibited by individuals with dementia [49].

It appears that some of the efforts by health authorities to reduce the use of antipsychotic medications in long-term care have worked. In the province of Manitoba (Canada) there was a 6.7% reduction in rate of usage of antipsychotic medications in long-term care patients, from 38.2% in 2006 to 31.5% in 2014 [35]. An alternative non-pharmacological approach to the management of responsive behaviours includes addressing the underlying, root

cause of the agitation or aggression. Uncovering the unmet need that is driving the behaviour (e.g., boredom due to under stimulation) may be a safer approach to care for individuals with dementia.

3.3 Unmet Needs Model

How residents living in long-term care environments spend their days offers some insight into the lack of engaging activities available for use at any time. In a recent study [50], residents at seven publicly funded, not-for-profit nursing homes were observed during the day time (7am-3pm; Monday to Thursday) and evening (3-11pm; Monday to Thursday). The data (averaged across the seven sites and times of day) suggest that residents spend the majority of their time sleeping – both during the day (26%), as well as in the evenings (32.4%). Notably, residents were spending a large proportion of their day in passive activities such as sitting/watching others (25.1%) or watching TV (14.3%). Even though the seven sites under study had well-established recreational programming and staff, of residents' time only "2.1% {was} observed in scheduled activities (days 2.9%, evenings 1.2%)" (p.14), and a large proportion (67%) of the day was spent in their room. As noted by the study authors [50], the low percentage of residents' time spent in planned activities (ranging from 0% to 5.9%) may reflect a lack of enjoyment of group programming.

Antipsychotic medications only treat the surface issue – the responsive behaviour – but do not address the underlying, root cause of the behaviour. According to Cohen-Mansfield [30], there are unmet needs driving the expression of responsive behaviours in individuals with dementia. Unmet needs may be biological (pain, discomfort, needing to go to the bathroom), social (loneliness, boredom, lack of engagement) or psychological (depression, confusion) in nature.

Boredom and lack of meaningful, engaging activities in dementia care environments may be associated with increases in responsive behaviours, such as wandering [5, 51]. Conversely, creating programming and engaging people with dementia in meaningful activities in their care environments has been shown to calm agitated behaviours [52, 53].

Unmet needs can be used as an important indicator of quality of life [54]. Unfortunately, individuals with dementia have increasing difficulty adequately expressing their unmet needs (due to communication challenges) and, instead, may exhibit a responsive behaviour [e.g., screaming out of frustration; 55]. For example, Ahn and Horgas [56] found that pain severity was related to heightened levels of aggression and more frequent agitated behaviour in residents. In this case, a reduction in agitation would suggest that the needs of the individual (e.g., pain management) are being adequately understood and addressed [57]. Agitated behaviours (e.g., screaming, hitting) are also very distressing to caregivers and long-term care staff, leading to heightened frustration, anger and distress [24, 28, 31]; in this way, reducing responsive behaviours in residents through addressing unmet needs may also lead to better outcomes in those who care for them. Of note, the unmet needs of people with dementia living in long-term care are varied and unique to the individual; therefore, appropriately uncovering and addressing these needs requires the use of a person-centered approach to care.

4. PERSON-CENTERED CARE AND MONTESSORI FOR DEMENTIA

Person-centered care (PCC) is an approach to treatment that considers the needs of an individual across multiple domains, including biological, physical, social and psychological. PCC adopts a holistic approach to caring that values the whole person and their social as well as cognitive needs regardless of functional capacity [58]. PCC is a resident-focused, value-driven approach to providing care for individuals with dementia that is counter to the biomedical view (task-focused). It empowers people by encouraging autonomy and honouring well-being with respect to providing care. Furthermore, this approach respects individuals rights to make decisions by offering them and their families choices regarding services provided and care given [59, 60]. PCC considers the whole person, including cognitive, emotional, as well as spiritual needs, abilities, values and goals. The focus is on what remains – not the losses associated with their disease [58-61].

A randomized-controlled trial [62] evaluated the impact of using a PCC approach during bathing. This approach required staff to shift their focus away from completing the task and towards the preferences and needs of the individual by offering choices, using preferred toiletries (recommended by families or staff), and modifying the environment to enhance comfort levels. Those exposed to the PCC approach to care demonstrated significantly reduced agitation and aggression, as compared to controls, without compromising hygiene. Furthermore, staff who were trained using PCC techniques administered significantly fewer antipsychotic medications to the intervention group, as compared to controls – a change which was sustained for 12-months, and did not yield any difference in the expression of responsive behaviours between the two groups [63]. However, in one study PCC approaches did not lead to a reduction in the use of antipsychotic drugs [64].

Another example of a person-centered approach to dementia care utilizes Montessori principles to create meaningful and engaging sensory-motor experiences. Montessori-based activities were originally developed in the early 1900s and were implemented with children in an educational setting. More recently, these principles have been applied to dementia care [58], because, as people with dementia lose cognitive function, they return to a more sensor-motor stage of functioning. Thus, Montessori may be thought of as a special kind of PCC that caters to the sensory-motor capabilities that remain after other abilities, such as explicit memory and executive functioning, have been largely lost.

Montessori principles include:

- promoting self-confidence and independence
- focusing on the person’s functional capacity and interests
- clearly defining task expectations using cues and priming (e.g., “match the shapes”)
- providing constructive and corrective feedback on performance that promotes self-correcting behaviour (e.g., if the shape does not fit into the hole, try another hole)
- breaking tasks down into simple steps that progress from simple to complex [concrete to abstract; 51, 58, 65]

In dementia care, Montessori-based activities often encourage the use of skills and abilities based on an individual’s past hobbies (e.g., putting flowers in a vase or using a screwdriver to insert screws into wood). The focus is not on completing the task

perfectly, but on the act of “working” and on promoting a sense of accomplishment [66]. A study by Judge et al. [51] evaluated the use of Montessori-based activities to enhance engagement in 19 adults with dementia in an adult day care setting. They found that persons with dementia who used Montessori-based programming showed increased levels of constructive engagement (defined as any motor or verbal behaviour in response to an activity) and decreased passive engagement (looking and/or listening behaviour in response to an activity), as compared to those who were exposed to regular programming.

5. AMBIENT ACTIVITY TECHNOLOGIES

Utilizing Montessori principles, Ambient Activity Technologies (AATs, Figure 1) are designed to provide anytime engaging interactions for people with dementia – catering to a wide range of ages, mental abilities, and physical limitations. These technologies have been designed to have an easy to access, use and understand interface. The intent of AAT use is to increase quality of life among individuals with dementia, their families, and long-term care staff.

The development and design of AAT integrates a PCC approach with various technological interventions involving the integration of tablets, sensors, and hardware input devices such as wheels and switches (“tangibles”). To facilitate personalized activities, body-mounted IDs (e.g., radio-frequency identification – RFID, or Bluetooth) are used to recognize a nearby resident. Once identified, the individual will be presented with personalized content, such as a sing-along interactive game customized to the resident’s musical interests, which plays when the person turns the wheel on the unit (see Figure 1). The personalized playlist will have been created by the resident and/or family member and/or long-term care staff and uploaded to the AAT. Games are also personalized and have been created using flexible and adaptable difficulty levels to meet the ever-changing needs of individuals living with dementia.



Figure 1. Ambient Activity Unit installed on a wall in a long-term care facility in Ontario, Canada.

AATs can be used in two modes: independently by individuals with dementia or as a tool used by staff and family members to help alleviate responsive behaviours. The goal of the AAT is to:

- encourage meaningful engagement through access to appropriate and personalized experiences, memories, and activities
- reinforce familiarity and personal identity

- promote physical activity
- enhance confidence and promote independence
- offer a flexible product that can adapt to the mental and physical challenges of individuals living with dementia

6. REWARD-BASED LEARNING

Another engaging ambient technology designed for people with dementia is the Centivizer (Figure 2) – a computer-controlled hardware device that rewards targeted activities with nickels, applause, favourite music etc. After reviewing the scientific literature, Spira and Edelstein [67] concluded that there is evidence “that warrants optimism regarding the application of behavioural principles to the management of agitation among older adults with dementia” (p. 195). Token economies are a type of behavioural management that has been used in schizophrenia [e.g., 68] and dementia [e.g., 69]. However, one barrier to the use of reward-based learning in dementia care is the effort involved in running these types of programs. Since caregiver burden is already high, it is hard to justify the introduction of a technique that requires caregivers to continuously monitor behaviours.

The Centivizer is a reward-based wall-mounted activity for the efficient management of behaviour in dementia. Sensors and software control dispensing of nickels or other rewards (e.g., applause, or favourite music) based on the performance of desired behaviours. In an early prototype (Figure 2), rewards were given based on cognitive performance in a Whack-a-Mole game that measures executive functions, and based on performance in two low complexity games (a painting game and a slot machine game). An arm strengthening lever was also provided for physical exercise. Using Centivizers, family members and staff are also able to track behaviour over time using a web interface, where caregivers are able to set individual goals based on targeted behaviours, and measure progress of different residents.



Figure 2. The Centivizer System (first prototype) with Whack-a-Mole cognitive game displayed (left side, left image) and nickel dispenser (right side, left image). An arm strengthening lever is also shown (right image).

7. CONCLUSIONS AND IMPLICATIONS

Innovative methods are needed to help manage the behaviour of people with dementia and to improve their quality of life. While continuous, one-on-one interactions with well-trained caregivers might be desirable, high levels of personalized engagement is not a viable long-term solution, given resource constraints. Technologies offer a practical solution that enables the implementation of engaging interactions at any time without significantly increasing caregiver burden. In this paper, we briefly described two classes of technology for managing responsive behaviour and for possibly improving or maintaining physical

and/or cognitive functions in people with dementia. AATs are based on Montessori principles and provide sensori-motor interactions, as well as personalized content. Centivizers use a reinforcement learning approach, where targeted behaviours are rewarded (using rewards of different types depending on the preferences of the user). While current Centivizer prototypes focus on cognitive games and muscle strengthening, we envision future Centivizers that could be targeted at goals such as maintaining the ability to perform ADLs. In pilot testing, AATs have provided engaging interactions for some residents and we are currently carrying out a trial of their effectiveness in several long-term care facilities across Ontario, Canada. We are also exploring the design space of automated reinforcement learning activities using iterative design of Centivizer prototypes.

In the past, there have been few treatments for dementia other than behavioural management and antipsychotic drugs. The ambient and reward-based technologies described herein have the potential to improve not only the mental, but also the physical well-being of individuals with dementia. These technologies can provide anytime access to engaging interactions (currently largely missing from dementia care), thereby reducing caregiver burden, and the responsive behaviours that cause stress for family and staff who act as caregivers.

By reducing the impact of responsive behaviours, through appropriately designed ambient technologies, we can improve the quality of life and health of individuals living with AD and related dementias. As the design of technological interventions for dementia improve, we hope that AATs and Centivizers will not only re-establish engagement in people with dementia, but might also slow declines in their cognitive and functional status.

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