

AN ASSESSMENT TOOL TO IDENTIFY ASSISTIVE TECHNOLOGIES USED TO SUPPORT COMMUNITY-DWELLING OLDER ADULTS WITH DEMENTIA

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INTRODUCTION

Dementia is a prevalent condition amongst older adults, affecting one in eight people over the age of 65 and one in three over the age of 85 [1]. Cognitive and physical impairments usually result in the person with dementia requiring help from a caregiver to complete activities that are required in daily life. Much of this support is provided by informal caregivers, who are usually family members. The 70 percent of older adults with dementia who were living at home in 2009 resulted in an estimated 10.9 million informal caregivers providing approximately 12.5 billion hours of unpaid care (an average of 21.9 hours per caregiver per week) in the United States alone [1]. In 2010, the cost of caring for people with dementia was estimated at US\$604 billion, a figure that is equivalent to 1% of global GDP [2]. As the world's population is aging, it is of great social and financial interest to enable people with dementia to remain in the community for as long as possible.

Supporting someone who has dementia is a complex and challenging undertaking. People with dementia and their carers employ a multitude of assistive technologies (ATs) to promote independence and to ease the burden of care [3]. Use of AT in community-based care has been shown to promote independence, safety, and autonomy of people with dementia, support the quality of life of affected people and their family caregivers, and postpone admittance to long-term care [4, 5]. While ATs are considered to be beneficial, and indeed perhaps imperative, to supporting community-dwelling people with dementia, it is still not clear exactly what types of AT are in use, how they are being used, or what the perceived

gaps in support for use are. This information would be invaluable to clinicians, such as occupational therapists (OTs), who are central to the identification of the need and recommendation of appropriate ATs. AT designers would also benefit from a deeper understanding of AT use in the home as this would allow for the development of devices that are more targeted, effective, and appropriate.

Supporting a person with dementia involves many different people and professions, therefore it follows that understanding AT's role should capture the viewpoints of the various stakeholders. In addition to the person with dementia, informal caregivers and OTs play a significant role in the selection and implementation of AT. Informal caregivers and OTs are not only familiar with the abilities of people with dementia, but also tend to have an interest and understanding regarding whether or not the AT was useful post-implementation. As such, informal caregivers and occupational therapists have the potential to provide expert knowledge regarding AT use.

This research developed and piloted semi-structured interviews intended to collect information regarding AT use in the community to support older adults with dementia from the perspectives of occupational therapists and informal caregivers.

METHOD

A mixed-methods, one-on-one semi-structured interview was selected for this research as it allows for the collection of rich and targeted information. This format also allows interviewers to expand on ideas and allows participants to demonstrate ATs should they wish to do so. Additionally, as many of the respondents are older adult caregivers, it was

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felt that benefits such as the personal nature of an interview and increased response rate would be maximised over other methods that would likely result in increased burden (e.g., telephone or internet surveys) [6]. While the definition of AT can be quite broad, this research considered only AT that supported activities clearly impacted by dementia (e.g., memory impairments, wandering, confusion). Questions in the interview guides were formulated based on a review of both peer-reviewed and gray literature (e.g. [7]), the authors' experience, and the Canadian Model of Occupational Performance and Engagement (CMOP-E) [8].

Two surveys were developed: one for caregivers of older adults with dementia and one for occupational therapists. While the surveys differed in some aspects so as to be appropriate for the targeted respondent group, the content was kept as uniform as possible to enable the potential comparison of points of interest from the two groups. Family caregivers responded about the person they were caring for while OT participants were asked at the beginning of the interview to select a specific client with dementia and answer all questions with that person in mind. The surveys were divided into sections: 1) Demographics, 2) Identification of ATs in Use, 3) Activity Performance and AT Use, 4) Identifying Unmet Needs, and 5) (OT survey only) Most Commonly Prescribed ATs. For Section 2, a literature review was used to identify ten categories of ATs, which are presented in Figure 1 and are discussed in greater detail in the Results and Discussion sections. Section 3 asked participants to identify one to two activities the person with dementia was able to do well and one to two activities they had difficulty with and to identify AT (if any) that were used in either case. Section 4 aimed at identifying currently unmet needs and perceived gaps in support. In Section 4, participants were asked to imagine that they had something that could help complete an activity the person with dementia was having difficulty with; what would this item be able to do and how would it provide support? The OT participants were also asked to list the top three categories of devices they most often prescribe or recommend to clients with

dementia living in the community and provide reasons why they most commonly recommend these types of AT.

The interview guides were reviewed and refined after trialing them with two informal caregivers and one OT who had experience with older adults with dementia. Family caregiver and OT participants were recruited from the greater Toronto area. To be included in the pilot study, family caregivers had to live with a family member who had a diagnosis of dementia, be the primary caregiver, and report a dependence of the person with dementia for at least two activities of daily living. OT participants had to have greater than three months of experience working with older adults with dementia living at home in the community, previously recommended or prescribed AT to clients with dementia, and be able to observe and recognize the use of ATs. Copies of the guides that were used for the interviews can be viewed at http://www.ot.utoronto.ca/iatsl/projects/community_at.htm.

RESULTS

Interviews were conducted in the homes of caregivers for people with dementia and in a place of choice for OTs. Interviews took approximately one and a half hours for caregivers and one hour for OTs. Due to time constraints of the project, only three family caregivers were recruited. All caregiver participants were female and provided care for either their spouse (n=2) or parent (n=1). Ten female OTs participated in this study and had between 1-5 years (60%) or greater than five years (40%) of experience working with older adults with dementia living in the community. Participants each discussed one client with dementia (males=6, females=4), with five clients living at home alone and five living with a family member. All participants reported that they enjoyed participating in the study and did not consider the interview to be too long or repetitive.

Figure 1 presents the percentage of respondents who reported use of different categories of ATs of the survey and (in the case of OTs) the categories of ATs that were most commonly recommended. Details regarding the specific devices used by the older adults with dementia, including descriptions of how devices

were used and what they were used for (purpose), were also captured. A visual analysis of qualitative data resulted in the identification of perceived enablers and barriers to AT use, which are presented in Figure 2.

DISCUSSION

Even with the small sample size of the pilot trial, several trends appeared to emerge. For instance, the ATs reported by caregiver participants in this study were almost all devices that had been owned prior to the onset of dementia or were affordable, easily obtained devices that were not necessarily targeted at supporting dementia (e.g., automatic kettle, post-it notes, pill boxes, TV remote controls), which has been documented in other research (e.g., [4, 9, 10]). Only a few ATs (e.g., contrasting colours on stairs, brightly coloured dishes) were acquired after the onset of dementia.

Alarm and monitoring units, environmental detectors and modifiers, fall detectors, and wandering technologies were not reported to be in use by caregivers of people with dementia. One reason for the lack of use of these categories of ATs could be that none of the caregiver participants reported wandering or other unsafe behaviours to be a problem, thus they were less likely to use these types of ATs. Caregiver participants mentioned more than once that they felt a lack of awareness regarding available AT to address cognitive impairments and that AT cost would impact future AT acquisition. Occupational therapist participants also cited awareness of available AT as a problem. Indeed, many of the OT participants were unaware of some of the ATs that were used by the interviewer, particularly in the memo minder category. A visual inspection of the qualitative data allowed predominant themes regarding enablers and barriers to the acquisition and use of ATs to be easily extracted (Figure 2). These findings are in line with those found in others' research (e.g., [10-12]).

While the results from this pilot must be interpreted cautiously, they do provide a tantalising example of the depth and breadth of data that can be captured through the interview guides and some of the possible comparisons of stakeholders' perspectives. Importantly,

participants felt the questions were clear and that it was easy to share their thoughts. Moreover, the mixed-methods approach allows for the quantitative and qualitative analysis of data, enabling researchers to drill down and gain more clarification about results of interest. Finally, the interviews are structured in a way that gathers information from end-users that can be manipulated into formats that are of use to multiple disciplines, including AT designers, clinicians, policy makers, caregivers, and potentially, people with dementia themselves.

CONCLUSIONS AND FUTURE WORK

The pilot data collected using the interview guides developed through this research appears to be able to provide insight into the types of ATs are in use in the community and how they are being used. Feedback from participants indicated that they enjoyed the interview procedure and were willing, and in many cases eager, to share their experiences. Future work includes refinement of the interview guides, development of a guide for use with older adults with early to middle stage dementia, and the piloting of the surveys in different geographical areas. The broad administration of interviewing multiple stakeholders seems to be a promising approach to providing diverse and concrete evidence regarding AT use in the community. This information could significantly impact how assistive technologies for people with dementia are designed and prescribed, potentially ranging from end-user procurement to impact at a policy level, ideally resulting in more appropriate and useful interventions.

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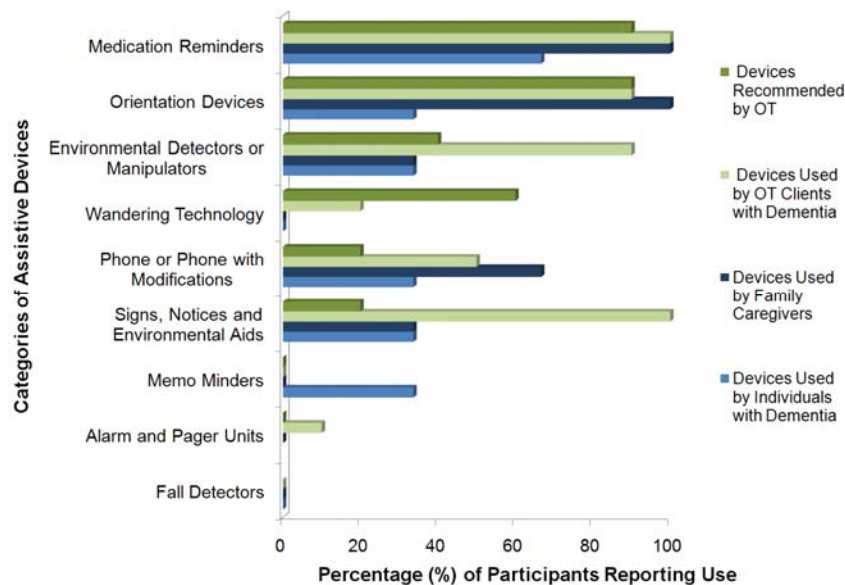


Figure 1. Data captured through *Section 2: Comparison of AT Categories* of the piloted interview guides with occupational therapists (green; n =10) and family caregivers of older adults with dementia (blue; n =3).

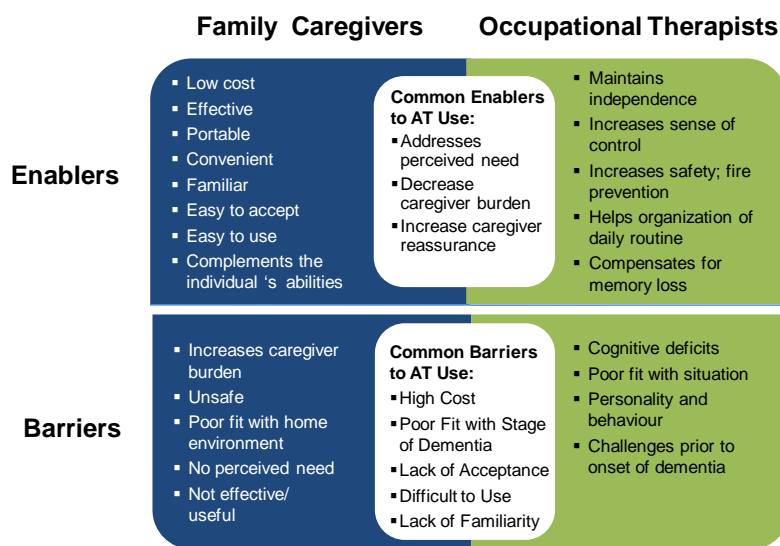


Figure 2. Enablers and barriers to the acquisition and use of assistive technologies to support older adults with dementia that were identified by family caregivers (n=3) and occupational therapists (n=10).