A framework to describe the levels of risk associated with dementia-related wandering

by

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Abstract

Introduction: Critical dementia-related wandering has been of significant concern in recent years, in part due to the rising prevalence of lost and missing persons involving older adults with dementia. Few resources exist to help guide families and persons with dementia to select and adopt proactive strategies to manage the risks associated with persons who are getting lost. The purpose of this thesis was to develop and validate a conceptual framework and series of guidelines that will help stakeholders, such as families and persons with dementia, choose specific high and low tech strategies to manage challenging behaviours associated with critical dementia-related wandering.

Methods: A scoping review was first conducted to identify the range and extent of wander-management, product readiness and associated outcomes within the scholarly and grey literature. Following this, semi-structured individual phone interviews containing 12 questions were conducted with family and formal caregivers, persons with mild dementia, health practitioners, police, social workers, industry and staff from community organizations that work with people affected by dementia. The purpose of the interviews was to determine what strategies were used or suggested by participants and what factors influenced their adoption of the specific strategy. A secondary study involved family and paid caregivers identifying antecedent behaviours indicative of "critical" wandering, or wandering associated with getting lost through recording daily observations for two to four weeks. Responses from the scoping review, interviews and observations were used to develop the conceptual framework and guidelines for strategy adoption of wander-management strategies. Face and content validity of the guideline was then assessed using eight focus groups and six interviews across participants, and were subsequently disseminated for use by community organizations and health professionals.

Results: A total of 96 participants participated in the development of the conceptual framework and guidelines, 34 assessed their face and content validity and 73 provided final feedback through an online and paper survey. Responses from the interviews produced four contextual factors that influenced the adoption of specific high and low tech wander-management strategies: (1) Risk associated with wandering; (2) Culture; (3) Geography; (4) Stigma. Common antecedent behaviours of critical wandering events included packing of belongings, preparing to go outside, and door lingering or tampering within continuing care facilities. The relationships of these four factors and antecedent behaviours were used in the development of the conceptual framework and guidelines. Overall impression of the conceptual framework and guidelines was positive according to users. Participants used the guidelines to choose proactive wander-management strategies. They suggested changes in some of the terminology and additional factors and strategies be added to the framework and guidelines.

Conclusion: This is the first study to describe and validate factors that influence strategy adoption for critical dementia-related wandering. The guideline for strategy selection and use was made available nationally for use by caregivers, health and community service providers to identify strategies to mitigate the risks associated with critical wandering. The findings from this thesis reinforce the importance of proactive strategies to mitigate the risks associated with getting lost and illuminate the need to balance between safety and independence when trying to mitigate this issue. It also highlights the significance of knowledge translation practices in critical wandering

research that transcends beyond traditional academic settings to ensure research evidence reaches policy and practice.

Preface

This thesis is the original work of Noelannah Neubauer. Dr. Lili Liu oversaw the conceptual design of the dissertation, writing process, technical aspects of equipment, equipment acquisition, and funding for the study. Noelannah Neubauer designed the study concept and experimental methods, undertook subject recruitment, data collection, analysis, and writing. The research studies, of which this thesis is a part, received ethics approval from the University of Alberta Research Ethics Board, Project Name “A framework to describe the levels of risk associated with dementia-related wandering”, Pro0076365, January 26, 2018.

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Table of Contents

List of Figures

Chapter 1: Introduction

Today, more than 47 million people worldwide are affected by dementia, with this number projected to increase to more than 131 million by 2050 as the world population ages (Alzheimer's Disease International, 2016). For many individuals, critical wandering, a form of wandering that leads a person with dementia to become lost due to wayfinding difficulties (Petonito et al. 2013), is among the most frequent, problematic, dangerous, and least manageable among dementia-related behaviours. It is estimated that more than 60 percent of those with dementia will wander (Alzheimer's Association, 2016). The adverse consequences of this behaviour vary from minor injuries (Douglas et al. 2011), falls and fractures (Buchner and Larson, 1987, Härlein et al. 2009), increases in caregiver stress (Etters et al. 2008, Longsdon et al. 1998), emotional distress, potential civil tort claims (Stevenson & Studdert, 2003), and death (Rowe & Bennett, 2003). In fact, if a person with dementia has exited a building and is not found within 24 hours, it is estimated that up to half of these individuals will suffer serious injury or death (Alzheimer's Association, 2016).

Due to the increasing prevalence of missing persons events involving older adults with dementia (Bowen, McKenzie, Steis, Rowe, 2011; Neubauer, Laquian, Conway, Liu, 2019), pressure has been placed on first responders, community organizations and governments to establish preventative initiatives (Neubauer et al. 2018a). In Canada for example, the case of Shin Noh from Coquitlam, British Columbia who has been missing since 2013 motivated the development of a community-based Silver Alert (Strandberg, 2018). In Scotland, the Herbert Protocol was developed following the case of George Herbert who died while he was missing trying to find his childhood home (Metropolitan Police, 2019). Similar lost person cases occur daily, with some police services receiving as high as five to seven calls per day involving a missing older adult with dementia (Neubauer et al. 2019a). This situation has raised questions as to how the adverse outcomes associated with critical wandering can be managed, and whether managing this behaviour can have an influence on improving the stressors that result from caring for a person with dementia who wanders (Nelson & Algase, 2007).

Traditionally, early interventions to manage critical wandering included physical barriers (e.g., locks), restraints (e.g., Posey restrains, or a Gerichair) (Hermans et al. 2009), and medications (e.g., trazodone, quetiapine, zaleplon, zolpidem) (Alexopoulos et al. 2005). The use of these strategies, however, is on a decline, in part due the significant ethical concerns over their use (Scheepmans, de Casterl , Paquay, Milisen, 2018), physical interventions producing negative consequences such as poor physical, psychological and social functioning (Hamers et al. 2004), medications causing unwanted side effects (Dewing, 2010) and the development of person centred approaches (Pazio, Pace, Flinner, Kallmyer, 2018). The shift away from these intervention has led to the development of a multitude of low tech management strategies that can be divided into the following categories: exercise (e.g., walking, exercise programs, music and distraction therapies), home modifications (e.g., door murals, signage, areas to walk indoors, patterns on floor or door, mirrors on the door, concealment of view through door window, personalization of bedrooms in long-term care), community based strategies (e.g., Silver Alert, Project Lifesaver) and personal identification information (e.g., ID card, bracelet or jewelry, Safe Return Program, embroidered clothes with name and address) (Neubauer, Azad-Khaneghah, Miguel-Cruz, Liu, 2018b). For behavioural changes, differential reinforcement (the delivery of reinforcement for the absence or omission of a target behaviour) has been found to be effective in reducing incidences of wandering (Heard & Watson, 1999). Exercise, music and distraction therapies have also provided promise for reducing wandering-related incidents (Robinson et al. 2007).

More recently, wander-management technologies, such as locator devices, offer options for management of wandering and may be a preferred strategy over chemical and physical restraints (Pot et al. 2012). In the coming decades, it is suggested that there will be more persons with dementia relying on fewer caregivers due to the decline in birth rates over the last 30 years, in addition to the increased number of adult children moving away from families. This has contributed to the promotion of remote monitoring and surveillance systems (Bowes et al. 2009). The promotion of such systems is also related to their ability to allow the individual a degree of autonomy at home and the raised potential to extend the time a person with dementia can live in their home and community (Pot et al. 2012; Welsh et al. 2003). High tech solutions can be separated into three categories: mobile locators (e.g., Global Positioning Systems (GPS), radio frequency and identification (RFID), Bluetooth, wireless internet (Wi-Fi), radio frequency (RF)), sensors and alarms (e.g., motion sensors with remote alarms), and way-finding technology (e.g., a wearable belt that has the capability to facilitate navigation) (Neubauer et al. 2018b).

While present wander-management strategies seem promising, there remain questions related to proactive versus reactive strategies to address wandering. If police are involved in the search and rescue of the missing person as a reactive strategy, the cost to public funds can be substantial (Sharples, 2009). Preventative strategies address potential behaviours that occur before the person with dementia has eloped from the home, while also addressing critical wandering when it is not at its most immediate level of risk. Generally, the primary preventative strategy is to avoid leaving the individual that wanders unattended as much as possible. It is suggested that leaving the home unsupervised was one of the two more frequent risks for injury in persons with dementia that wander (Nelson & Algase, 2007). Strategies such as respite care services have been suggested in the literature as an alternative strategy if the caregiver requires a break from caregiving (Nelson & Algase, 2007). Other proactive strategies are signage and alarms. The limitations however, are that other than locking the house with locks, a person with dementia still can leave the home. In addition, some caregivers may be reluctant to accept the need to implement change without first-hand experience of wandering or other risk behaviors taking the "it will never happen to us" perspective. Effective preventative strategies are not based on a person with dementia's past behaviours as a predictor of current or future events; any person with dementia is susceptible of getting lost regardless of whether there is a history of getting lost (Rowe & Glover, 2001).

Throughout the scholarly literature, strategies have solely focused on the "getting lost" aspect of critical wandering, resulting in a "one size fits all" intervention approach, such as the use of locator devices. While these technologies can be effective, they do not consider the spectrum of wandering-related behavior and circumstances. In addition, individual needs may fluctuate over the progression of dementia. Care practices and environmental demands can be modified over time to allow them to capitalize on their preserved abilities (Connell & McConnell, 2000). Overall, a blended approach that includes low and high tech technologies integrated into care appears to be an appropriate approach rather than a prescriptive application in all scenarios (Mulvenna & Nugent, 2010). Unfortunately, the type of information describing these strategies are diverse and difficult to find. This has led to challenges for caregivers and persons with dementia when trying to understand wander-management strategies and how to choose one that best suits their needs. A conceptual framework and guideline that simplifies and summarizes information on available strategies, such as low and high tech solutions, could help guide caregivers in this decision-making process. To enhance the usability and effectiveness of this guideline, information that would affect strategy adoption, such as perceived risk of wandering, should be incorporated.

Critical wandering in western cultural societies is typically viewed as a high risk which has resulted in locked doors and placement of individuals with dementia in facilities (Wigg, 2010). Wandering is generally medicalized within our society which has therefore turned it into a medical problem in need of a solution which legitimates social control efforts to “protect” persons with dementia that wander (Wigg, 2010). To allow persons with dementia to wander safely, risk as a sociocultural phenomenon has been proposed as an alternative to the biomedical view. As noted by Wigg (2010), the determination of risk (Douglas, 1990) of wandering related behaviours is different depending on the degree of exit-seeking behaviour or outdoor engagement. Care providers view persons with dementia who seek to be outdoors as a “higher risk” than those who walk aimlessly. In addition, those placed into continuing care because of wandering issues are also deemed as high risk by institution’s administration, due to the potential for litigation that derives from the negative outcomes associated with wandering (Robinson et al. 2007b). The challenge that derives from this is to seek a balance between protecting and respecting the rights of the individuals that wander (Wigg, 2010). This view of balance presents conflicting perspectives depending on the stakeholder that is involved. For example, professionals who are bound by duty as healthcare providers and the Hippocratic Oath, prioritize safety at the expense of personal rights. Family members of persons living in facilities may believe the opposite in that personal rights should be prioritized over personal safety (Wigg, 2010).

Instead of using wander management strategies to address what is perceived as "risky", we can investigate the meaning of risk to individuals in contemporary society (Lupton, 1999, 2005), and integrate differing, and at times competing knowledges of risk into a negotiated and effective system of risk management (Kemshall, 2000). According to cultural theory (Douglas & Wildavsky, 1982) what is considered as a risk, and how serious that risk is thought to be, is perceived differently depending upon the organization or group in which the person belongs (Wildavsky & Dake, 1990). There are a handful of papers that have evaluated the differing perceptions of risk in wandering and how it may influence wander management. For example, Brittain et al. (2010) evaluated how risk was perceived amongst formal caregivers and persons with dementia. What a person with dementia may see as an acceptable risk may not be viewed as such by caregivers. Persons with dementia for example were found to be more concerned with their rights and risk to their personal social identities, while caregivers were more concerned with physical risk. As described by the persons with dementia in this study, their caregiver's concern with physical risk was believed to curtail social activities rather than the actual risk itself, and further decreased this population's confidence in going places as they were not sure if they could remember how to get to their destination.

The information described above demonstrates the significant impact of perceived risk of wandering on the type of wander-management strategy a stakeholder is willing to adopt. To build on this concept of risk, a framework that aids choice of interventions to manage wandering in consideration of the associated risks and needs of persons who wander was developed. Moore, Algase, Powell-Cope, and Beattie (2009) identified varying levels of risk through a broad "perimeter transgression" criterion, which was based on the level of predictability the person with dementia would critically wander into the community. A low risk for example, would be defined when a person with dementia is wandering within their home excessively, however no attempts or threats have been made to leave the home. A high risk on the other hand, arises when the individual has exited the home unsupervised and is now wandering within their community. High tech solutions, such as global positioning systems, were then matched to these individual levels of risk. This framework was the first of its kind to simplify when high tech solutions should be incorporated, and presents implications on how caregivers can minimize the risks of harm associated with wandering.

Despite the benefits associated with the framework developed by Moore et al. (2009), it has its limitations. First, it does not encourage wandering in safe environments but focuses on the now more prevalent depiction of risk where the behaviour is regarded as entirely negative and dangerous (Lupton, 1999). This negates the positive aspects of risk taking, such as enhanced independence of persons with dementia, which could reframe activities that appear dangerous into strategies which may be life enhancing, such as exercise programs (Alaszewski & Manthorpe, 2000). In addition, the critical wandering framework of Moore et al. (2009) does not include descriptions of antecedent behaviours which may assist in timelier implementation of wander-management strategies, nor was it developed in a user-friendly format to enable its successful adoption.

To explore the applicability of Moore et al. (2009)'s framework, I developed an infographic based on the framework and presented it to more than 100 key stakeholders during a consultation session at the December 1, 2016 Locating Technology Forum in Toronto, Ontario (Neubauer et al. 2018a). Stakeholders in attendance included consumers (persons with dementia and family caregivers), representatives from the Alzheimer Society (public education coordinators, program coordinators, social workers and behavioural support staff), community organizations serving older adults, local and provincial first responders, technology industry, researchers, and government (Ministry of Seniors Affairs). This forum was hosted by the Alzheimer Society of Ontario's Finding your Way initiative and questions asked during this session included: (1) Can see yourself or someone you know using this? (2) What did you like best? (3) Does it help simplify and aid in your understanding of wandering? (4) Could you see this tool helping yourself or someone you know in determining which wander-management strategy may work best? (5) Is there anything you would like to add/change?

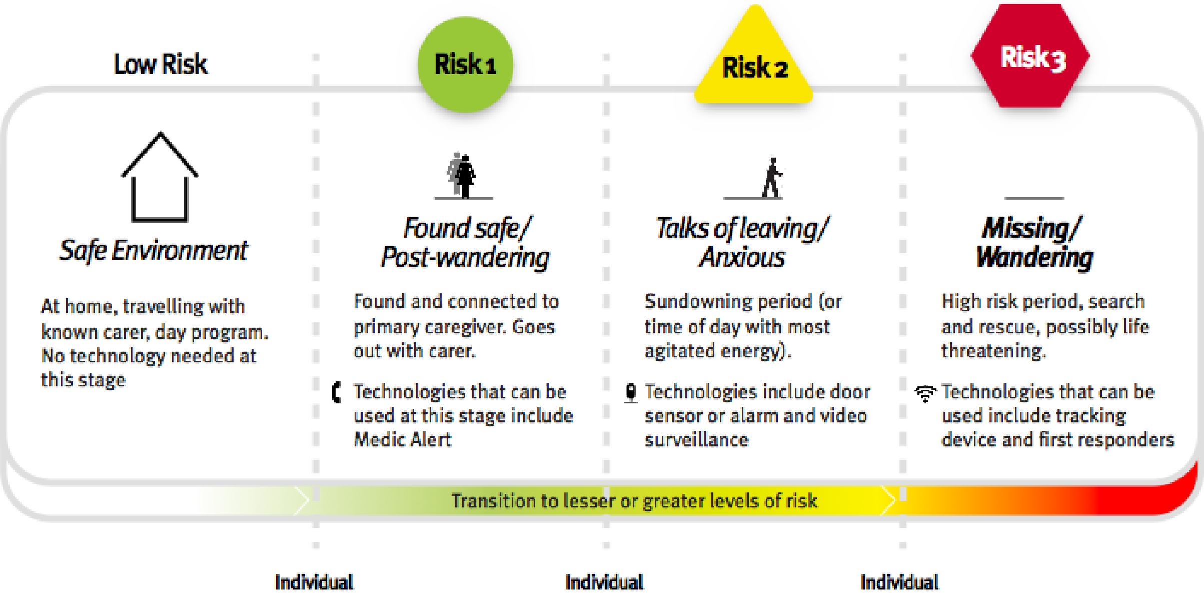

Figure 1. Preliminary guideline of wander-management strategies for the 2016 Finding Your Way Locating Technology Forum

Overall, participants felt the infographic would help to identify the risks associated with wandering and enable customized interventions based on individual situations. They liked that it was proactive and provided examples of high tech solutions, was simple for people to find information quickly and easy to understand. Suggestions to improve this infographic provided by participants included the need for incorporating low tech in addition to high tech solutions, that it needed to be available to those that do not have access to the internet, and needed to be customizable based on the stakeholder (e.g., police, family caregivers) (Neubauer et al. 2018a).

Input from forum participants demonstrates that a conceptual framework and series of guidelines on the implementation of strategies to address critical wandering is needed, however revisions to the framework by Moore et al. (2009), such as the incorporation of antecedent behaviours and perceived levels of risk, would enhance this framework. This approach would address the differing needs, values and perspectives of involved stakeholders, including persons with dementia, to enable effective implementation and successful adoption of such strategies. Finally, a framework would be comprehensive if takes into consideration the body of literature on wandering so that it is meaningful to family and professional caregivers, and to persons living with dementia. This approach has yet to be developed and could be applied across the spectrum of wandering-related behaviours, not just after a person with dementia gets lost.

Purpose

Few resources exist to help guide caregivers and persons with dementia to select and adopt proactive strategies to manage the risks associated critical dementia-related wandering. Given the aging population, increasing prevalence of persons living with dementia, and the subsequent rise in missing person events involving this population, the development of such tools could assist in tailoring a specialized program of care for persons with dementia at risk of getting lost, regardless of their place of residence. Developing these tools could have the potential to reduce the negative consequences associated with this issue. Therefore, I conducted a series of studies to meet the following overarching purpose: **to develop a conceptual**

framework and series of guidelines to help stakeholders choose specific strategies to manage challenging behaviours associated with critical dementia-related wandering.

To meet this primary objective, the following sub-objectives were set across the five key studies:

1) To identify the range and extent of wander-management strategies, their product readiness levels, and associated outcomes within the grey and scholarly published literature. To achieve this objective, the following questions were addressed:
    a. How many types of wandering strategies are available?
    b. How effective are they?
    c. Are they evaluated separately?
2) To determine the type of wander-management strategies used by stakeholder types and to identify the factors that influence their successful adoption. To achieve this objective, the following questions were addressed:
    a. What are the most common high and low tech solutions used among stakeholders to address critical dementia-related wandering?
    b. Does perceived risk differ depending on the stakeholder (i.e., persons with mild dementia, family caregivers that have a vested concern with wandering, paid caregivers (i.e., home care and long-term care), health professionals (e.g., occupational therapists, physicians), police, social workers and community organizations, cultural background, stigma or the location in which they live (e.g., family vs. formal caregiver; rural vs. urban)?
3) To describe the antecedent behaviours of critical wandering. To achieve this objective, the following questions were addressed:

    a. Is there one or more behaviours that a person with dementia exhibits immediately prior to critically wandering?
    b. Are these behaviours individualistic or are there similarities?
    c. Is there a relationship between these behaviours and baseline variables (e.g. personality, health status, functional disabilities)?

4) With this data, develop a conceptual framework and guidelines that to help stakeholders develop strategies to manage challenging behaviours associated with critical dementia-related wandering.
5) To evaluate the face and content validity of the developed conceptual framework and guidelines with key stakeholders. To achieve this objective the following questions were addressed:
    a. Does the framework need multiple versions depending on the stakeholder or location of residence?
    b. What is the potential of the implementation of this framework within the community, i.e., is this something that stakeholders are interested in using?
    c. Does it assist stakeholders in determining an effective course of action when trying to mitigate critical wandering and promote non-critical wandering?
    d. Is the use of Alzheimer Societies the best way to disseminate this framework to the lay public, or are there other avenues that need to be added?
6) To evaluate the knowledge translation of the developed guidelines and conceptual framework, if applicable, and to subsequently disseminate these guidelines to organizations across Canada. To achieve this objective the following questions were addressed:

a. What are the necessary steps to successfully disseminate the developed resources nationally?
b. What is the preliminary feedback from the participants actively using the disseminated work?

Organization of the Thesis

In this chapter, I introduced the research topic and purpose.

Chapter 2 Methods provides a general overview of the research approaches used for the five manuscripts, each describing a separate study.

Chapter 3 Manuscripts presents the published and submitted manuscripts for publication related to this thesis.

Chapter 4 Discussion and Conclusions summarizes the key findings, contributions, strength and limitations of the included manuscripts. Directions for future research and implications for practice are proposed.

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Chapter 2: Methods

In this chapter, I describe the methods used to address the research purpose to develop a conceptual framework and guidelines for adoption of strategies to manage dementia-related critical wandering. I begin by describing the theoretical positions that inform how five studies were conceptualized, designed, and carried out. Next, I describe the overarching methods of the studies that make up this thesis, the analyses performed, and the steps to ensure criteria for rigour were met.

Theoretical positions

This thesis used a multi-method design, with the primary work based on a qualitative descriptive approach. As noted by Thorne, Kirkham and O'Flynn-Magee (2004), traditional qualitative methods, such as grounded theory, phenomenology and ethnography are not always appropriate for health domains. This is due to health researchers, such as those within nursing, perceiving qualitative description as having the ability to provide a grounding for the conceptual linkages that become evident when one attempts to "locate the particular within the general, the state within the process, and the subjectivity of experience within the commonly understood and objectively recognized conventions that contemporary health care contexts represent as the temporal and symbolic location for health and illness" (Thorne et al. 2004, p. 3). Qualitative description therefore enables qualitative health researchers to work outside of the disciplinary confines of traditional methods and develop logic that is consistent with the aims of clinical health phenomena (Thorne et al. 2004).

Others, such as Caelli, Ray, and Mill (2003), and Sandelowski (2000), contend that many researchers claim methods they are not actually using. Instead of acknowledging the method, as described by Mayan (2009), they are using qualitative description. The theoretical perspective for qualitative description is based on general tenets of naturalistic inquiry and may take on characteristics of other methods, such as phenomenology, sampling is often purposeful, data collection is generally through interviews, and data analysis uses content analysis (Sandelowski, 2000). For this thesis, rather than focusing the associated studies through the lens of a well-known and traditional method (e.g., phenomenology, grounded theory or ethnography) (Caelli et al. 2003), I used qualitative description to understand the experiences of stakeholders when they try to manage the risks associated with critical dementia-related wandering. To support my understanding, I drew from concepts, models and theories developed in the field of dementia-related critical wandering that provided the overarching framework for the studies of this thesis.

The Ecological Theory on Aging (Nahemow, 2001) served as the hierarchical framework to this thesis whereby changes to the physical and social environment were implemented as a means of improving the fit between a person's competence (external and internal resources) and environmental demands (Wahl et al., 2012). Good fit must exist between a person and his or her environment to enable adaptive behaviour. When demands from social and physical environments are greater than the person's competence, because of changes within the environment or the individual, barriers arise within their environment, such as poor function or environmental stress, which as a result reduces the individual's ability to age in place (Lawton, Weisman, Sloane, & Calkins, 1997). As seen among persons with dementia, maladaptive behaviours, such as critical-wandering, can have a significant influence on whether these individuals are able to continue to age within their residence of choice (Bantry White & Montgomery, 2015). Changes to their physical and social environment, such as locator devices or alarms, can improve their personal competence, which may result in stress reduction among persons with dementia and their caregivers. The primary focus for this thesis was on proximal environments (e.g., home, neighbourhood, persons in direct contact with the individual with dementia) due to the need among persons with dementia and their caregivers for rapid targets for change (Greenfield, 2012). This need was reflected during consultations where proactive strategies were used by caregivers to mitigate the risks associated with critical wandering (Neubauer et al. 2018). It is with future intentions however, that distal environments (Greenfield, 2012), such as policy makers are engaged to further assist in this process.

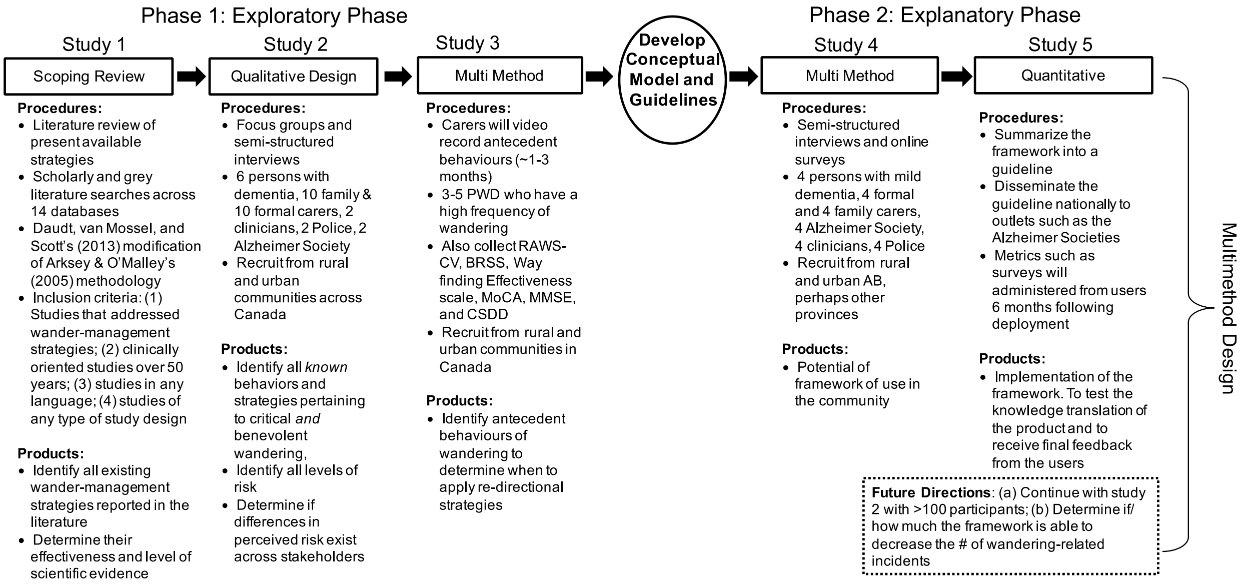
This thesis also drew on behavioural intervention research and implementation science. As indicated by Gitlin and Czaja (2016), behavioural intervention research is directed at creating evidence in the form of proven and tested interventions, strategies, and programs. The Social Ecological Systems Framework (Hinkel et al. 2015), one of the underlying frameworks of behavioural intervention research, was central in the design of the studies contained in this thesis. Like the Ecological Theory on Aging, it emphasizes that interventions must consider multiple levels of influence such as the individual, the community, social support systems, formal and informal networks, and the setting in which the intervention will be delivered (i.e., institution, home) (McGinnis & Ostrom, 2014). There are significant interactions among these levels, which in turn have the power to determine whether a developed intervention will be successful and sustainable. It is emphasized that such interventions must not be designed in isolation and focus solely on individual-level determinants of behaviours and health, which traditionally has been the practice. The final key piece to ensure the sustainability of interventions is their ability to remain adaptable to changes over time.

Regarding implementation science, it examines the best strategies for implementing proven evidence or programs into practice. It aims to identify pending roadblocks such as social, organizational or economic factors that prevent the implementation of strategies or turning evidence into practice. More specifically, implementation science represents a critical field of inquiry that determines how interventions can be implemented and sustained in real-world settings and conditions (Gitlin & Czaja, 2016). Implementation is often skipped in fields such as gerontechnology, where some products never leave the lab-based environment (Betwoski, 2018). Contextual fit, the match between the strategy and the resources, skills, cultural relevance, values and needs available in the setting (Horner & Blitz, 2014), is vital to the successful adoption of any strategy. In addition, dissemination of a proven strategy is more than "getting the word out", but includes support for end users, and evaluates the strategies to be disseminated, through five characteristics: relative advantage, compatibility, complexity, trialability, and observability (Beilenson, Gitlin & Czaja, 2016).

Finally, throughout this thesis, I used participatory research. Participatory research focuses on the co-construction of research through partnerships between researchers and participants that are affected by the issue under study (Jagosh et al. 2012). Key stakeholders for this thesis involved family caregivers who expressed concern in managing the wandering behaviour of a loved one, paid caregivers (i.e., home care workers and registered nurses from long-term care), police, health professionals, persons living with dementia, and community organizations. Participants were selected using a snowball sampling approach (Patton, 2002) where I recruited participants that were strong advocates for dementia, had lived experiences of critical wandering, or had close relationships with other members of the community that are affected by critical wandering. The inclusion of these stakeholders throughout the entire process of the thesis, as stated by Jagosh et al. (2012), is necessary to ensure the research is logistically and culturally appropriate, to enhance recruitment capacity, to enhance the quality of the outcomes, and to optimize the sustainability of this work beyond the time frame of this thesis. Since January 2016, I have worked directly with the Alzheimer Society of Ontario. During this time, I assisted in the development of an online consumer guideline for locator technologies (Neubauer et al. 2017a; Neubauer et al. 2017b), in addition to a best police practice resource to address the challenges police face when searching for missing persons with dementia (http://findingyourwayontario.ca/first-responders/). Because of the direct involvement, and their varying levels of expertise, the Alzheimer Society of Ontario was engaged throughout this thesis. In addition, Roger Marple and Paul Lea who are persons living with dementia and active advocates within their respective communities, provided support and guidance throughout the thesis. This was done through consultations to ensure the voices of persons living with dementia were included.

Overarching methods

The structure of this thesis included five studies and was organized into two phases: (1) Exploratory Phase, and (2) Explanatory Phase. Figure 1 and Figure 2 in this chapter describe the evolution of the methods used for this thesis from when it was initially proposed during the prospectus examination, to the final thesis document.



Procedures:

- Literature review of present available strategies
- Scholarly and grey literature searches across 14 databases
- Daudt, van Mossel, and Scott's (2013) modification of Arksey & O'Malley's (2005) methodology
- Inclusion criteria: (1) Studies that addressed wander-management strategies; (2) clinically oriented studies over 50 years; (3) studies in any language; (4) studies of any type of study design

Products:

- Identify all existing wander-management strategies reported in the literature
- Determine their effectiveness and level of scientific evidence

Procedures:

- Focus groups and semi-structured interviews
- 6 persons with dementia, 10 family & 10 formal carers, 2 clinicians, 2 Police, 2 Alzheimer Society
- Recruit from rural and urban communities across Canada

Products:

- Identify all *known* behaviors and strategies pertaining to critical *and* benevolent wandering,
- Identify all levels of risk
- Determine if differences in perceived risk exist across stakeholders

Procedures:

- Carers will video record antecedent behaviours (~1-3 months)
- 3-5 PWD who have a high frequency of wandering
- Also collect RAWS-CV, BRSS, Way finding Effectiveness scale, MoCA, MMSE, and CSDD
- Recruit from rural and urban communities in Canada

Products:

- Identify antecedent behaviours of wandering to determine when to apply re-directional strategies

Procedures:

- Semi-structured interviews and online surveys
- 4 persons with mild dementia, 4 formal and 4 family carers, 4 Alzheimer Society, 4 clinicians, 4 Police
- Recruit from rural and urban AB, perhaps other provinces

Products:

- Potential of framework of use in the community

Procedures:

- Summarize the framework into a guideline
- Disseminate the guideline nationally to outlets such as the Alzheimer Societies
- Metrics such as surveys will administered from users 6 months following deployment

Products:

- Implementation of the framework. To test the knowledge translation of the product and to receive final feedback from the users

Future Directions: (a) Continue with study 2 with >100 participants; (b) Determine if/ how much the framework is able to decrease the # of wandering-related incidents

Figure 2. Initial design of a conceptual framework to describe levels of risk associated with dementia-related wandering

Phase 1: Exploratory Phase

As mentioned in the previous chapter, the overarching purpose of this thesis was to develop a conceptual model and series of guidelines to help stakeholders choose specific strategies to manage the risks associated with critical dementia-related wandering. I intended to achieve this by advancing Moore et al. (2009)'s state of the art risk management framework. The overall objective of the first phase was to collect the data needed to advance Moore et al. (2009)'s framework. Such data included identifying wander-management strategies reported in the literature, and determining whether these strategies were being used by stakeholders in the real-world setting. I also identified factors that influence the adoption of wander-management strategies, and antecedent behaviours associated with critical wandering as essential elements to be included in the model and guidelines. Therefore, the specific objectives of this phase were: (1) to identify the range and extent of wander-management strategies used within the literature; (2) to determine the types of strategies used by stakeholder types; (3) to identify the factors that influence the adoption of wander-management strategies and (4) to describe the antecedent behaviours of critical wandering.

Objective 1 was addressed in Study One through a scoping review of the grey and scholarly literature. The scoping review was based on Daudt, van Mossel and Scott's (2013) modification of Arksey and O'Malley's (2005) methodology and involved six steps: (1) determine the research question, (2) identify the applicable studies, (3) study selection, (4) chart data, (5) collect, summarize and report the results and, 6) consultation exercise. Due to the diversity of the included studies, a qualitative approach was used (Onwuegbuzie, Leech, Collins, 2012), where content analysis was performed on the extracted data. Using a deductive approach, I assigned codes to the data for each extracted category, and the code frequencies were calculated to determine the most cited throughout the data (Leech & Onwuegbuzie, 2008). Descriptive statistics (i.e., averages and standard deviations (SD)) were also calculated for diversity of the technology specifications, strategy, cost, and Product Readiness Level (PRL) across the included wander-management strategies, in addition to participant age, number of participants from the included studies, and study length.

Objectives 2 and 3 were addressed in Study Two through semi-structured phone interviews with participants from across Canada (DiCicco-Bloom & Crabtree, 2006). I chose phone interviews as I was interested in gaining perspectives from participants across the country, and to ensure responses could be made in an environment most suitable for the participants. According to the literature, there are several benefits of conducting phone interviews. First, they enable researchers to include participants from any geographic location; no one is required to travel to the interviews; they may afford participants more anonymity, because they may use a pseudonym thereby not fully identifying themselves (Hill et al. 2005) as they sometimes describe very personal thoughts and experiences (Kvale, 1996). According to Brannen (1988), participants may also have less fear and be more forthcoming if they believe they will never cross paths with the interviewer after completing the research, with the detachment fostering greater disclosure.

For this study, I involved stakeholders such as persons with dementia, paid and family caregivers, health professionals, police, and Alzheimer societies. This study followed a qualitative descriptive approach (Caelli, Ray, Mill, 2003; Sandelowski, 2000), where I focused on understanding the experiences of stakeholders managing risks associated with critical dementia-related wandering. A qualitative descriptive approach was used over conventional methods because this study focused on basic description and the summary of the phenomenon of strategy use and critical wandering (Sandelowski, 2000). I worked and stayed close to the data to produce this summary and description. This approach was not highly interpretive, which enabled me to produce a rich summary of the participant's experiences (Mayan, 2009).

I drew from concepts, such as risk, (Douglas, 1990; Lupton, 1999) culture (Sewell, 1999), geography (Loon, 2002) and stigma (Link & Phelan, 2001), frameworks such as the one proposed by Moore et al. (2009), and the results from the scoping review in Study One to develop my interview guide. Questions during each interview therefore covered topics on strategies that have been used to manage dementia-related wandering, and how the perceptions of risk, culture, stigma, geographical location and other factors influenced strategy adoption. Probes were used to elicit more elaborate and richer information as well as clarifying meaning (Patton, 2002) (e.g., "Can you tell me more about that?", "What do you mean about ___?"). As data generation and analysis progressed, I made slight changes to the interview guide. For example, I added a question asking participants to discuss the role of stigma on adoption of wander-management strategies after the first interview participant brought up the topic of stigma. Because this additional factor was brought forward following the first interview, all participants could answer the additional question. I also took advantage of the flexibility inherent in semi-structured interviews, where participants were given as much time as needed to respond to questions. This sometimes resulted in conversations that were off topic (Gardner, 2008). While this initially appeared unproductive, it resulted in information relevant to this thesis. For example, after completing the questions within the interview guide, at times a participant and I would converse for another 10-15 minutes. In some cases, these off conversations resulted in the participant recommending other individuals for this project, or contacts and organizations for Studies Three, Four and Five of this thesis. Following each interview, I wrote a summary of my overall impressions to capture the 'whole' of the interview (Miles & Huberman, 1994). These summaries helped me determine where my data was 'thin' and to determine if additional questions were required for subsequent interviews with other participants.

All but five interviews were professionally transcribed verbatim to provide complete data of the content of interviews of the exact responses provided by participants regarding the topics of interest in this study. I transcribed the first five audio recordings to get a good sense of the data. Following this I hired a professional transcription service (Transcript Heroes Transcription Services Toronto) to transcribe the remaining interviews. To ensure confidentiality, all audio recordings were assigned a code. In addition, the transcription service was asked to alter any identifiable information in the audio recordings. All transcripts were first checked by listening to the audio recording while reading the transcript. If any discrepancies existed between the transcript and audio recording, changes were made. Following this, to enhance readability, 'uh-hms' and false starts were removed unless they contributed to meaning. To decipher inaudible words due to background noise and participants' accents, I reviewed the recording and interview notes again. I clarified those discrepancies by contacting the participant. In these cases, participants were not given their transcript to review but rather I summarized the section and inquired about the sentence, phrase or work under question. Transcripts were further cleaned to reduce the potential for participant identification. This included removing or changing the names and specific locations that were noted during the interview (Tilley & Woodthorpe, 2011). Transcripts and field notes were finally read and reviewed two additional times to ensure accuracy (Poland, 1995). Transcripts were stored in NVIVO 12.

Directed content analysis was used (Hsieh & Shannon, 2005; Mayan 2009) and was conducted through an iterative process of data collection-analysis-collection-analysis (Mayan, 2009). According to Hickey & Kipping (1996), content analysis uses a directed approach that is guided by a structured process and focuses on identifying, coding, and categorizing the primary patterns in the data (Mayan, 2009). Using existing theories and prior research, such as Moore et al. (2009)'s framework and the scoping review in Study One, I developed the interview guide, which in turn was used to identify key concepts and variables as initial coding categories. I first read the transcripts from the interviews and highlighted all text that on first impression appeared to represent used wander-management strategies and factors that influenced the adoption of these strategies. The next step of the analysis involved me coding all highlighted passages using the predetermined codes (Hsieh & Shannon, 2005). In this case, the predetermined codes included strategies used among participants to reduce the risk of persons with dementia getting lost, factors that influence strategy adoption such as perceptions of risk, culture, stigma, geographical location, stakeholder type, and existing gaps experienced by participants when trying to manage critical wandering. Any text that was not categorized with the initial coding scheme were given a new code. In this case, the new generated codes included existing gaps experienced by participants when trying to manage critical wandering. A code-recode strategy was followed with same data twice, giving one to two-week gestation period between each coding. This was done to compare the two codings to see if the results were the same or different (Chilsia & Preece, 2005). A constant comparative approach (Boeije, 2006) was applied following the coding of the data. As my study involved participants from multiple stakeholder groups, I followed three steps: (1) Comparison within a single interview; (2) Comparison between interviews within the same group; and (3) Comparison of interviews from different groups. The summaries I collected during and following each interview were also cross compared with the analyzed transcript data to determine whether the information from these notes could be used to further strengthen the final results. Role-ordered matrix was used to assist in the comparison and contrast of varying perceptions and responses by the included participants. The data regarding each semi-structured interview was summarized in a table and cross referenced.

Objective 4 was addressed in Study Three through a complete observer approach where family and paid caregivers were asked to write down the type and number of antecedent behaviours they observed of persons with dementia that were about to exit seek and leave over a period of 2 to 4 weeks. The frequency, range, mean, and standard deviations were calculated for observed critical wandering events. Frequencies were recorded for antecedent behaviours observed, and level of cognitive impairment. Descriptive statistics, and chi-square tests of independence were used to examine the relationship between wandering prevalence, antecedent behaviours, location of observation and level of cognitive impairment. A three-way analysis of variance (ANOVA) was conducted to compare the effect of antecedent behaviour, cognitive impairment and location of observation on wandering prevalence.

Phase 2: Explanatory Phase

The purpose of the explanatory phase was to incorporate the results from Studies One, Two, and Three into a conceptual framework and guidelines stemming from Moore et al. (2009)'s framework; to evaluate their content and face validity (objective 5); to evaluate the knowledge translation of the developed guidelines; and to subsequently disseminate these guidelines to organizations across Canada (objective 6). The development of the conceptual framework involved two steps: (1) Reduction, and (2) Organization. The purpose of reduction was to cull salient information from the data collected in Study Two without altering it to decrease the amount of data presented. I selected transcript data that discussed the factors that were indicated among participants as having an influence on the adoption of wander-management strategies. Any data that discussed the relationships between these factors, such as the effect of geography on perceived risk were also included. Organization involved the structuring of the data that was included in the reduction phase (i.e., the highlighted factors that affected the strategy adoption of wander-management strategies among participants were added to the conceptual framework, and the relationships of each factor, as described by the participants in this study were also included), in addition to determining where this data fit within the framework of Moore et al. (2009).

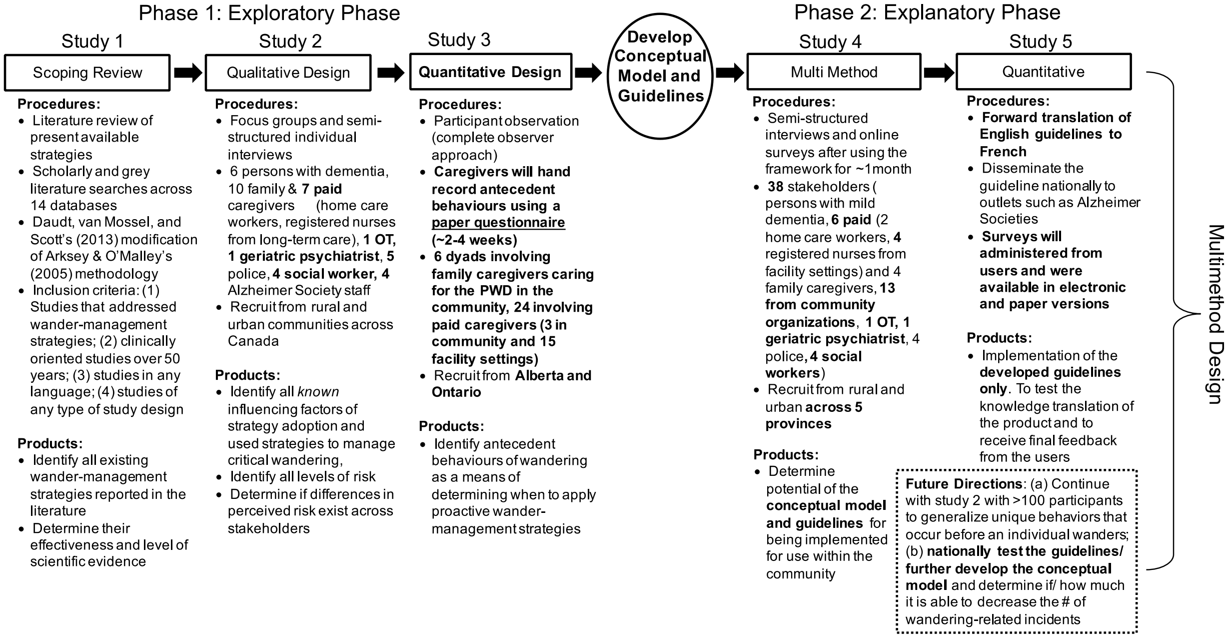
The development of the guidelines involved the following five steps: (1) It was determined from phase 1 that persons living with dementia, care home, and community versions were necessary to apply the guidelines to as many involved stakeholders as possible; (2) the guidelines were broken down into low, medium, high risk and adverse event as indicated by the perimeter transgression criterion as described by Moore et al. (2009); (3) the wandering behaviours indicated by Moore et al. (2009) and the highlighted antecedent behaviours from study 2 were added below each risk level; (4) general categories were generated from the risk management strategies identified in Studies One and Two and placed below each risk based from the elopement prevention and patient-specific goals indicated in Moore et al.'s framework (2009); and (5) key messages from study 2 were added to the guidelines as a means of indicating how the guideline should be interpreted, and messages to help generate discussions as to how we should address dementia-related wandering behaviour moving forward.

To further ensure the design of the conceptual framework and guidelines were effective, the following recommendations from Hoffmann and Worrall (2004) were followed during their development: (1) All key stakeholders, including patients, should be involved in the development and testing stages of designing written patient education materials; (2) The written material needs to be comprehensible to people across a range of literacy skills; (3) Provide understandable examples and present the information in a way that allows the target audience to see its relevance to their situation; (4) The text of written materials should be framed with white space and sections should be well spaced as it makes the material more appealing to the reader; (5) Illustrations should only be used if they improve the understanding of essential information; (6) Once a written health education material has been designed, it's effectiveness would be enhanced if it is pretested with a sample target audience where the reader's comprehension of the content as assessed and are given the opportunity to provide feedback about features such as content, layout and colour.

Following the development of the conceptual framework and guidelines, objective 5 was addressed in Study Four through an online/paper survey, semi-structured individual phone interviews with persons with dementia (DiCicco-Bloom & Crabtree, 2006), and focus groups with each stakeholder type (e.g., family caregivers). The qualitative and quantitative data was simultaneously collected and data from both were triangulated in the results, interpretation and conclusion phase. Both forms of data were collected to attain a complete understanding of the participants' views regarding the developed framework and guideline. Questions derived during each interview and focus group assessed the participant's thoughts and opinions on the conceptual framework and guidelines, whether they addressed their concerns, and whether additional changes needed to be made.

Changes were made to the guidelines and framework following each focus group and interview following an iterative process (Connell et al. 2018), where suggested changes from each interview and guideline were immediately applied to the conceptual framework and guidelines. Reasons for following this process include ensuring the same comments and suggestions were not made to avoid the potential for early saturation (Rudmik & Smith, 2011). The same approach used in Study Two was also used relating to the steps taken for the transcription of the interviews and focus groups, and directed content analysis (Hsieh & Shannon, 2005). The coding scheme was developed based on the interview and focus group guide. Results from the Likert scales within on the online survey underwent descriptive analysis and a one-way ANOVA was conducted for the survey data to determine if differences arose across stakeholder types.

Finally, objective 6 was addressed in Study Five where it involved the dissemination of the developed guidelines to various community organizations across Canada using multiple approaches such as websites, paper handouts, education sessions, and webinars (Grimshaw et al. 2001). In addition to the dissemination of the guidelines, knowledge translation of the guidelines was evaluated and final feedback was received from users using a paper or online survey. Electronic and paper versions were included to ensure as many users had access to the guidelines as possible (McDonald & Goergen, 2017). In addition to the above approaches, a forward-translation method was performed to convert the guidelines from English to French. Descriptive analysis was used to provide a general summary of the feedback provided from the paper and online surveys and was used to determine if future directions pertaining to the framework were required. One-way ANOVA was conducted for each feedback question to determine if differences arose across stakeholder types.



Procedures:
- Literature review of present available strategies
- Scholarly and grey literature searches across 14 databases
- Daudt, van Mossel, and Scott's (2013) modification of Arksey & O'Malley's (2005) methodology
- Inclusion criteria: (1) Studies that addressed wander-management strategies; (2) clinically oriented studies over 50 years; (3) studies in any language; (4) studies of any type of study design

Products:
- Identify all existing wander-management strategies reported in the literature
- Determine their effectiveness and level of scientific evidence

Procedures:
- Focus groups and semi-structured individual interviews
- 6 persons with dementia, 10 family & **7 paid** caregivers (home care workers, registered nurses from long-term care), **1 OT, 1 geriatric psychiatrist**, **5** police, **4 social worker, 4** Alzheimer Society staff
- Recruit from rural and urban communities across Canada

Products:
- Identify all *known* influencing factors of strategy adoption and used strategies to manage critical wandering,
- Identify all levels of risk
- Determine if differences in perceived risk exist across stakeholders

Procedures:
- Participant observation (complete observer approach)
- **Caregivers will hand record antecedent behaviours using a paper questionnaire (~2-4 weeks)**
- **6 dyads involving family caregivers caring for the PWD in the community, 24 involving paid caregivers (3 in community and 15 facility settings)**
- Recruit from **Alberta and Ontario**

Products:
- Identify antecedent behaviours of wandering as a means of determining when to apply proactive wander-management strategies

Procedures:
- Semi-structured interviews and online surveys after using the framework for ~1month
- **38** stakeholders (persons with mild dementia, **6 paid** (2 home care workers, **4** registered nurses from facility settings) and 4 family caregivers, **13 from community organizations**, **1 OT, 1 geriatric psychiatrist**, 4 police, **4 social workers**)
- Recruit from rural and urban **across 5 provinces**

Products:
- Determine potential of the **conceptual model and guidelines** for being implemented for use within the community

Procedures:
- **Forward translation of English guidelines to French**
- Disseminate the guideline nationally to outlets such as Alzheimer Societies
- **Surveys will administered from users and were available in electronic and paper versions**

Products:
- Implementation of the **developed guidelines only**. To test the knowledge translation of the product and to receive final feedback from the users

Future Directions: (a) Continue with study 2 with >100 participants to generalize unique behaviors that occur before an individual wanders; (b) **nationally test the guidelines/ further develop the conceptual model** and determine if/ how much it is able to decrease the # of wandering-related incidents

Figure 3 . Final design of a conceptual framework to describe levels of risk associated with dementia-related wandering

Achieving credibility in qualitative descriptive research

As this thesis focused on a qualitative descriptive approach, I followed Caelli, Ray & Mill (2003)'s credibility criteria: (1) theoretical positioning of the researcher; (2) the congruence between methodology and methods; (3) the strategies to establish rigour; and (4) the analytic lens through which the data are examined.

Theoretical positioning

To ensure my motives, presuppositions and personal history did not influence my subjectivity within this thesis, I chose this field of research where I do not have personal experiences with someone with dementia whom has critically wandered and has been lost or missing. My past experiences leading up to this thesis revolved around the field of neuromuscular physiology and frailty among older adults. Because of this, I saw myself as an instrument where all information flowed through me because of my involvement in each step of the research process, and was privileged to the whole data pool in comparison to the involved participants whom were only involved in their own personal experiences. As my knowledge in this area increased as I became more immersed with this research, I bracketed my subjectivity to reduce the risk of bias of the collected and analyzed data.

Congruence between methodology and methods

As highlighted by Caelli et al. (2003), methodological clarity is among the most common problems identified in qualitative descriptive studies. To address this key area in my thesis, I ensured the tools used to collect and analyze the data were congruent with the epistemological and ontological inferences of the approach taken (van Manen, 1998). In this case, my ontological and epistemological positioning, as described later in this chapter, matched my approach of using participatory research following a qualitative descriptive approach (Bradshaw, Atkinson, Doody, 2017).

Strategies to establish rigour

Credibility. As noted by Finlay (2006), credibility replaces internal validity used in quantitative research and is defined as the confidence that the data accurately represents the truthfulness of the data. Three strategies were used to enhance credibility.

First, member checking of the synthesized data (Harvey, 2015) was incorporated within these studies. The methodological purpose of member checking was to validate results by seeking contradicting voices, while also providing opportunities to add data (Charmaz, 2008). To achieve this, 65 percent of the participants in Study Four were recruited from Study Two. This was done to ensure the responses and interpretations from Study Two were accurately reflected. To avoid the risk of participants being less inclined to criticize or contradict their own recommendations from Study Two, the remaining 35 percent of participants recruited had no previous connection with this thesis.

Second, to ensure member checking was incorporated in Study Four, triangulation through online and paper surveys (Kitto et al. 2008) was implemented following the completion of the focus groups and semi-structured interviews and after the suggestions were incorporated in the framework and guideline. Within this survey, an open-ended question was included to allow participants to provide additional feedback and to note if any of their responses during the focus groups and interviews were indicated in the final version of this work.

Finally, I adopted Morse et al.'s (2002) approach to verification in that I constantly checked and re-checked the data, codes and categories through the process of moving back and forth between data generation and data analysis as well as between raw data and abstractions. Part of my verification process also included negative case analysis, which is a common method for addressing credibility (Onwuegbuzie & Leech, 2007).

Transferability. As defined by Lincoln and Guba (1985), transferability replaces external validity and refers to the degree in which study results can be transferred to other settings. I achieved this through thick description and maximum variation and snowball sampling (Bitsch, 2005). In Study Two, I provided subject characteristics of the included participants, as well as wove in excerpts from the interviews and focus groups so that readers could judge how the studies and their findings may apply to their settings. I also followed a snowball and maximum variation sampling method (Patton, 2002) where I recruited participants that were strong advocates for dementia, had lived experiences of critical wandering, and had close relationships with other members of the community that are affected by critical wandering. Therefore, during the interviews and focus groups, in addition to sharing their own thoughts, perspectives and experiences, they shared responses from others whom they have been in contact with, including populations I may have not been able to include if I tried to recruit them on my own.

Dependability. Dependability in qualitative research is defined by Lincoln and Guba (1985) as replacing the criterion of reliability in quantitative research and is achieved by providing sufficient information about decisions made during the data collection process and the rationale for these decisions so that the logic is transparent. According to Bitsch (2005) it also refers to “the stability of findings over time” (p.86). To ensure dependability within this thesis, I kept a detailed record of the processes through I generated, analyzed and produced findings. For example, I recorded and justified changes to the interview guide in Study Two, the methodological approach in Study Three, and decisions about merging categories. In addition, I followed a code-recode strategy where I coded the same data twice, giving one to two-week gestation period between each coding. This enabled me to compare the two coding to see if the results are the same or different (Chilsia & Preece, 2005).

Confirmability. As defined by Lincoln and Guba, (1985), confirmability replaces objectivity in quantitative methods and refers to the degree to which findings can be verified by others. Confirmability refers to findings representing the phenomenon being studied rather than the beliefs and assumptions of the research. Strategies to enhance confirmability included triangulation of the data in Study Four, the incorporation of participatory research (see next section), and member checking of the synthesized data.

The analytic lens

The term ‘analytic lens’ is used to refer to the methodologic and interpretive presuppositions the researcher brings when they engage with their data (Caelli et al. 2003). Because qualitative description and participatory research were the primary research approaches, this work embodied a subjectivist epistemology. This position places researchers in a position where they cannot understand the data from a purely objective stance, and that the researcher and the participant co-create knowledge and recognizes the dependent relationship between the knower and the known. Reality is expressed in a range of systems, and is stretched to fit the purposes of the individuals such that individuals impose meaning on the world and interpret it in a way that makes sense to them (Denzin & Lincoln, 2005). The value of positioning myself using this epistemology allowed me to understand how participant’s experience of critical wandering shaped their perception of the world and helped to explain why given strategies were implemented based from their individual circumstance.

Relating to my ontological positioning, I followed a relativist ontology. Relativist ontology is based is based on the philosophy that reality is constructed within the human mind, such that no one 'true' reality exists. Instead, reality is 'relative' according to how individuals experience it to any given time and place. I acknowledge each participant has his or her own point of view so the focus of the research is on the identification of contextualized meaning of these multiple points of view (Green, 2000) with the goal of creating a joint, collaborative reconstruction of the multiple realities that exist (Guba & Lincoln, 1989).

Reflexivity

I practiced reflexivity using three strategies. First, this thesis was designed to elicit contributions from a wide range of stakeholders in open disclosure. During the analytic process, constant comparisons between accounts of each group of participants was performed to uncover differences and similarities, which were subsequently highlighted within the included manuscripts. This approach ensured no group of participants was 'privileged' over others. This technique is also referred to as 'fair dealing' (Dingwall, 1992). Second, I incorporated participatory research principles throughout this thesis. Throughout multiple stages of the research process, I recruited and included participants who were actively engaged in this field.

Finally, to engage in explicit, self-aware analysis of my own role, I followed the advice of Finlay (2002) and described my experience working in areas that contain disadvantages. I maintained a reflexive journal in which I reflected upon how I influenced the study. I used notebooks filled with records and notes (reflecting peer debriefs, feedback from my supervisor, to-dos and activities), reflections and analysis (e.g., brain storms, memos and mind maps) and decisions. These journals were multipurpose, organizational and analytic tools as a means of enhancing the transparency of process and interpretations, and enabled me to go back and determine how I as the researcher affected the data that were created, affected the analysis, which affected the findings.

Ethical considerations

Ethical approval was obtained from the University of Albert Research Ethics Board. Informed consent was acquired at the beginning of Studies Two to Five. I maintained confidentiality by: separating participant's personal information from their data, limiting access to participants' personal information to me and my supervisor, and not discussing specific participants and issues that arose with other individuals that might know them (e.g., other participants, organizations they are associated with).

According to Tilley and Woodthorpe (2011), it is difficult to guarantee complete participant anonymity in qualitative research as the inclusion of interview and focus group excerpts in publications and reports increases the risk of participant identification. To manage this risk, I presented demographic information as a group rather than individual data. I also removed or altered other identifiers such as place of origin, use of words and distinctive occupations. Finally, I de-identified the transcripts from Studies Two and Four by using subject codes.

Summary of Chapter

In Chapter Two, I introduced the research approach that guided this thesis. I described the overarching methods of the five studies, in addition to the steps taken to ensure the thesis's quality and ethical considerations. Using a multi-method approach, I addressed the purpose of the research which sought to develop a conceptual framework and series of guidelines to mitigate the risks associated with critical dementia-related wandering. These findings and the in-depth methods are presented in the manuscripts located in the next chapter.

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Chapter 3: Manuscripts

In this chapter, I provide the completed manuscripts of the studies included in this thesis. There is a total of five manuscripts, each contains methods, results, discussion and conclusions. To date, the manuscript for study 1 was published in *Alzheimer's & Dementia Diagnosis: Assessment & Disease Monitoring*, study 2 has been submitted to *Dementia*, study 3 has been submitted to *Dementia and Geriatric Cognitive Disorders*, study 4 has been submitted to *Dementia*, and study 5 has been submitted to *The Gerontologist*.

Study One Manuscript

Neubauer, N., Azad-Khaneghah, P., Miguel-Cruz, A., Liu, L. (2018). What do we know about strategies to manage dementia-related wandering? A scoping review. Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring, 10: 615-628.

What do we know about strategies to manage dementia-related wandering? A scoping review

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Abstract

Three out of five persons with dementia will wander, raising concern as to how it can be managed effectively. Wander-management strategies comprise a range of interventions for different environments. While technological interventions may help in the management of wandering, no review has exhaustively searched what types of high and low technological solutions are being used to reduce the risks of wandering. In this article, we perform a review of grey and scholarly literature that examines the range and extent of high and low tech strategies used to manage wandering behaviour in persons with dementia. We conclude that while effectiveness of 49 interventions and usability of 13 interventions were clinically tested, most were evaluated in institutional or laboratory settings, few addressed ethical issues, and the overall level of scientific evidence from these outcomes was low. Based on this review, we provide guidelines and recommendations for future research in this field.

Keywords: Dementia; Wandering; Interventions; Aging in Place; Review

1. Introduction

The rates of cognitive impairment are on the rise worldwide as our world population ages. In 2016, 46.6 million people globally were living with dementia and this number is projected to increase to 75 million by 2030 [1]. As a result, the already high economic burden of $818 billion in 2015 has been estimated to have increased to $1 trillion by 2018. These staggering numbers have led to the establishment of more than 30 national dementia strategies worldwide as nations begin to work together to transform dementia care and support [2].

One significant concern for persons with dementia and their family caregivers is becoming lost when alone or are in unfamiliar environments [3,4]. This behaviour is often indicative of wandering. Wandering has been defined as "a syndrome of dementia-related locomotion behaviour having repetitive, frequent, temporally-disoriented nature that is manifested in lapping, random, and/or pacing patterns some of which are associated with eloping, eloping attempts, or getting lost unless accompanied" [5]. It can be either an aimless or purposeful behavior [5] and its severity can be affected by rhythm disturbances [6], spatial disorientation and visual-perceptual deficits [7], physical [8] and social [9] environments or changes in personality and behavior patterns [10]. A more recent definition of wandering also includes critical wandering, the type of wandering that results in older adults going missing. Indeed, critical wandering is what exposes persons with dementia to the potential dangers that concern caregivers [11].

More than 60% of persons with dementia will wander. The consequences of wandering vary from minor injuries [12], to high search and rescue costs and death [13]. If not found within 24 hours, up to half of those who wander and get lost will suffer serious injury or death [14]. Wandering behaviour also significantly impacts the care and economic burden of family caregivers. For example, caregivers have been found to experience increases in emotional distress and potential civil tort claims and regulatory penalties [15]. The severity of these outcomes has gained attention from caregivers and first responders alike [16], and raises questions about how the adverse outcomes associated with wandering can be managed, and whether managing this behaviour can have an influence on improving the stressors that result from caring for a person with dementia [17].

Early interventions to manage wandering included physical restraints and medications [18], however, use of such strategies have been in decline due to unwanted side effects [19] and negative consequences such as poor physical and social functioning [20]. High tech strategies, such as wearable global positioning system (GPS)-enabled devices [21] and low tech strategies such as visual barriers [22], offer options for mitigating risks while allowing a person with dementia with a degree of autonomy. These strategies may therefore be a preferred approach over restraints and medications [23]. Wander-management technologies may extend the time a person with dementia can live in a community, and provide peace of mind to caregivers [21, 22, 24]. While such strategies are more available to consumers, only one review [25] has been conducted to examine what existing interventions for wandering are being used, and whether their effectiveness has been tested in lab or community settings. This review, however, only included high tech solutions, excluding several key strategies, such as door murals and distractions, that may also help with managing this behaviour. While that review presents state of the evidence to support these interventions, it excluded potential vital reviews and studies that fall outside of this focus, limiting the scope of all available solutions within the scholarly and grey literature.

The current review serves as an extension from Neubauer et al. [25] where only high tech solutions used to manage dementia-related wandering behaviour, and only studies evaluating their usability or effectiveness were included. Therefore, the purpose of this review was to identify the range and extent of all wander-management strategies, their product readiness level, and all associated outcomes. This information provides evidence for caregivers and clinicians when they select strategies to manage wandering in persons living with dementia.

2. Methodology

2.1. Design

This is a scoping literature review based on Daudt, van Mossel and Scott's (2013) [26] modification of Arksey and O'Malley's (2005) [27] methodology. The original Arksey and

O'Malley's methodology [27] includes six steps: (1) determine the research question, (2) identify the applicable studies, (3) study selection, (4) chart data, (5) collect, summarize and report the results and, 6) consultation exercise (optional). Daudt, van Mossel and Scott's (2013) [26] modification of this methodology involves an inter-professional team in step two, and in step three uses a three-tiered approach to cross-check and select the papers.

2.2. Data sources and search strategy

We examined peer-reviewed and grey literature published between January 1990 and November 2017. Peer-reviewed literature were searched in six databases: EMBASE, CINAHL, Ovid Medline, PsychINFO, Web of Science, and Scopus. These databases were searched using the following terms identified in the title, abstract, or key words: (physical barrier* OR barrier* OR lock* OR low tech* OR nonpharmacological OR therap* OR exercise OR distraction OR pet therap* OR home modification* OR door mural* or signage OR identification information OR ID card* OR bracelet* OR jewelry OR technolog* OR gerontechnology OR telemonitoring OR telesurveillance OR telehealth OR assistive technology OR GPS OR sensor* OR mobile device OR application OR apps OR radio frequency telemetry OR radio frequency identification OR tracking OR surveillance OR alarms OR tagging OR electronic OR restraints) AND (wander* OR walk* OR sundowning OR escape OR restlessness OR pacing OR exit* OR missing OR stay OR benevolent wandering OR critical wandering OR non-critical wandering) AND (dementia OR Alzheimer's Disease OR cognitive disorders). Grey literature was searched in eight databases: Google, CADTH grey matters, Institute of Health Economics, Clinicaltrials.gov, The University of Alberta Grey Literature Collection, ProQuest Dissertations & Theses Global, National Guidelines Clearinghouse, and Health on the NET Foundation were searched for strategies developed to address wandering in persons with dementia. (dementia) AND (wander* OR elope OR sundowning OR critical wandering OR benevolent wandering OR non-critical wandering) (nonpharmacological OR therap* OR exercise OR distraction OR low tech* OR home modification OR technology OR tech* OR GPS OR RFID OR mobile applications OR iOS OR android OR wifi) (Appendix A).

2.3. Studies selection process

Articles were exported to a reference manager where duplicate articles were excluded. Two authors (NN, PA) first screened the titles and abstracts, reviewed the full text of all potential articles and extracted the data (Figure 1). Disagreements were resolved by consensus. Where disagreements were unresolved, the third reviewer (AMC) provided input. To determine agreement between raters, 20% of the selected articles were extracted and compared. The level of agreement between the raters was high, i.e., average agreement for abstracts 96% (298/310) (average kappa (κ) score of 0.87, $p< 0.000$), and 97% (198/204) average agreement for full papers (overall kappa (κ) score of 0.91, $p<0.000$). For included articles, reviewers first extracted: author initials, citation, and whether the study was eligible for review. If a study was considered ineligible for data extraction, the reason for exclusion was reported (Figure 1).

2.3.1. Inclusion criteria

1. Studies that:
    a. Address wander-management strategies in the home or supportive care environments for persons with dementia or cognitive decline regardless of

    whether it was embedded in an environment, was worn, or was implemented as a form of therapy.
    b. Address critical or non-critical wandering in older adults with dementia.
    c. Include strategies that support independence and address outcomes associated with wandering, regardless of level of development.
2. Clinically-oriented studies that included only persons with dementia over age 50 years.
3. Studies published in any language and available in full text in peer-reviewed journals or conference proceedings from electronic abstract systems.
4. Studies that used any type of study design or methodology, with positive or negative results.
5. Studies that used lower and higher complexity technologies for wander-management such as global positioning systems and door murals.
6. Studies published in books or book chapters and conference proceedings.
7. For grey literature: were websites suggesting or selling strategies to address dementia-related wandering

2.3.2. Exclusion criteria

1. Abstracts or studies that were not available.
2. Publications that did not provide adequate information for categorizing the study (e.g., participant characteristics).

2.4. Bias control

The procedure of Neubauer et al. [25] was followed to address bias. By including any language, multiple databases and data types, we conducted a thorough search, to achieve a high level of sensitivity [29]. Inclusion of studies with positive and negative results addressed publication bias [30]. Inclusion of studies registered in electronic abstract systems served as the first *'quality filter'*, and ensured a degree of scientific level of conceptual methodological rigor [31]. Studies published before 1990 were not included because most development of wander-management strategies occurred later [17, 32]. The use of two pairs of raters during the selection for relevant articles, and a third and fourth rater when there was disagreement, minimized rater-bias that may have arisen from the subjective nature of applying the inclusion and exclusion criteria.

2.5. Publications review and data abstraction

Peer-reviewed articles were examined for the following attributes: features of wander-management strategies (i.e., strategy type, specifications, cost, product readiness level), and characteristics of research (i.e., clinical implications, sample size, participant characteristics, level of clinical evidence of outcomes). Grey literature was reviewed for features of wander-management strategies (i.e., strategy type, specifications, cost, device features). Two raters individually extracted data from articles.

2.5.1. Features of wander-management strategies

(a) **Strategy type.** Refers to the name and strategy used to manage wandering. Primary categories identified include high tech [33] and low tech [33]. Solutions were indicated as high tech if the technology incorporated advanced features. Examples include locating devices, alarms/surveillance, wandering detection, wayfinding belt, distraction/ redirection strategies such as robotic pets, and locks/ barriers that include features beyond basic systems such as RFID-enabled locks. Solutions were indicated as low tech if the technology incorporated simple features. Examples include exercise, distraction/ redirection such as music therapy, locks/ barriers such as padlocks and deadbolts, physical restraints, community, signage, wayfinding, supervision, and education.

(b) **Product readiness level (PRL).** Assesses the maturity of evolving products during their development. We used the Product Readiness Level (PRL) [34] in which 9 levels are used and ranged from PRL1 (basic principles observed) to PRL9 (actual system proven in operational environment).

2.5.2. Characteristics of research conducted in wander-management strategies

(a) **Type of study, design of the study, level of clinical evidence and outcomes in the studies regarding wander-management strategies.** Studies were classified into four types, including strategy-oriented and clinical-oriented studies, usability, program-oriented, review or a combination of them. Study design was categorized using the McMaster assessment of study appraisal [35, 36]. An adaptation of the modified Sackett criteria proposed by Teasell et al. (2013) [37] was used to determine the level of evidence provided by the clinical oriented studies. Using this criterion, raters assigned a level of evidence for a given technological intervention based on a 7-level scale. Quality of the Randomized Controlled Trials (RCTs) was measured by the Physiotherapy Evidence

Database (*PEDro*) scale [38]. The PEDro scale has 11 criteria, 10 being the maximum score that a trial can achieve. Scores of 9-10 are considered “excellent” quality; 6-8 indicates “good” quality; 4-5 are “fair” quality; and below 4 is “poor” quality [28]. As the field of wander-management technologies is diverse, we assessed the levels of evidence across three device categories: mobile locator, sensor and alarm, and wayfinding. Data on sample size, experiment length, study strategy (i.e., clinical, usability, combined), study design (i.e., qualitative or quantitative research method), main outcomes of the study, and data collection location (i.e., home, community, facility) were collected.

(b) **Ethical concern associated with the implementation of the wander-management strategy.** Refers to the ethical concerns that were addressed regarding the implementation or use of the wander-management strategy. Examples of concerns include but not limited to protecting privacy, dignity, and autonomy of the person with dementia.

2.6. Data analysis

Data analysis was conducted by one person (NN). Due to the diversity of the included articles, a qualitative approach was used, where content analysis was performed on the extracted data highlighted above. Descriptive statistics (i.e., averages and standard deviations (SD)) were calculated for diversity of the technology specifications, strategy cost, and Product Readiness Level (PRL) across the included wander-management strategies, in addition to participant age, number of participants from the included studies, and study length.

3. Results

The initial search identified 4096 peer-reviewed studies; 118 studies were included in the data-abstraction phase and final analysis (2.9%, 118/4096) (Figure 1). Most studies (68.6%, 59/86) were excluded because they did not meet inclusion criteria 1a, 1b, 1c, or all three. Other reasons for exclusion from the final data-abstraction phase were that studies were not available (31.4%, 27/86).

For the grey literature, 130 strategies from 44 commercial websites, 1 dissertation website, 5 self-help websites, 8 Alzheimer specific websites, and 1 online magazine were included in the data-abstraction phase and final analysis. All met inclusion criteria 7, i.e., were websites suggesting or selling strategies to address dementia-related wandering.

Studies containing high tech only strategies were characterized by low journal impact factor (i.e., Source Normalized Impact per Paper (SNIP) mean 0.94, SD 0.59; 95% CI [0.79, 1.08]), and were published in journals located in Q1 (13 studies), Q2 (16 studies), Q3 (5 studies), and Q4 (6 studies) journal quartile per SCImago Journal Rank classification [39]. Studies containing low tech only strategies were characterized by low journal impact factor (i.e., Source Normalized Impact per Paper (SNIP) mean 0.99, SD 0.51; 95% CI [0.84, 1.14]), and were published in journals located in Q1 (19 studies), Q2 (16 studies), Q3 (6 studies), and Q4 (2 studies) journal quartile per SCImago Journal Rank classification [39]. Studies containing both high and low tech strategies were characterized by low journal impact factor (i.e., Source Normalized Impact per Paper (SNIP) mean 0.99, SD 0.82; 95% CI [0.58, 1.40]), and were published in journals located in Q1 (4 studies), Q2 (7 studies), and Q3 (1 studies) journal quartile per SCImago Journal Rank classification [39].

Regarding design [35, 36], seven high tech studies were of qualitative design (phenomenology (4), grounded theory (3)), 21 were of quantitative design (cross-sectional design (10), single-case design (4), case-study (3), before-after design (1), randomized controlled trial (1), randomized pre-post (1), and descriptive (1)), and 9 were reviews (systematic review (4), other review (5)). Low tech strategies included 2 which were of qualitative design (grounded theory (2)), 14 were of quantitative design (cross-sectional design (4), case-study (4), single-case design (2), retrospective (1), pretest-post test (1), ABA descriptive design (1), and randomized controlled trail (1)), and 17 were reviews (systematic review (10), Cochrane review (1), other review (6)). Publications containing high and low strategies included 2 which were of qualitative design (phenomenology (2)), 4 were of quantitative design (cross-sectional design (1), single-case design (1), randomized controlled trail (1), and case-study (1)), and 4 were reviews (systematic review (2), Cochrane review (1), other review (1)) (Table 1).

Included peer-reviewed literature came from 20 countries, with over half of the studies being conducted in the USA (58%, 47/118), and the UK (16%, 19/118). Similarly, for the grey literature, strategies were found to originate from 7 countries, with almost 80% of the technologies being from the USA and UK (75% USA, 12% Canada, 7% UK). Publication year of the included peer-reviewed literature varied, with wander-management strategy publications appearing in the early 1990s, and the total number of publications increasing over the last 27 years. A trend was evident pertaining to the type of strategy being published, where there has been a predominant focus on high tech vs. low tech strategies over the last decade.

3.1. Features of wander-management technologies

3.1.1. Wander-management strategy – type used and strategy specifications. A total of 183 high tech strategies (109 from peer-reviewed and 74 from grey literature), and 143 low tech strategies (85 from peer-reviewed and 58 from grey literature) were included in this scoping review, and included 6 subcategories of high tech strategies, and 14 subcategories of low tech strategies. The most commonly-used high tech subcategories from the scholarly literature were locating strategies (i.e. GPS, Radio frequency, Bluetooth, and Wi-Fi) (71.6%, 78/109) and alarm and sensors (i.e. motion and occupancy sensors, monitors and optical systems) (19.3%, 21/109). The most commonly-used high tech subcategories from the grey literature were also locating technologies (i.e. GPS, and Radio Frequency) (63.5%, 47/74), and alarm and sensors (i.e. motion sensors) (35.1%, 26/74) (Figure 2). The most commonly-used low tech subcategories from the scholarly literature were distraction/ redirection strategies (i.e., doll therapy, music therapy, mirrors in front of exit doors, visual barriers such as cloth on exit doors or door murals, and the integration of purposeful activities such as chores and crafts) (35.3%, 30/85), exercise groups (i.e. walking) (12.9%, 11/85), and identification strategies (i.e. ID cards, labels, and the Safe Return Program) (8.2%, 7/85) (Figure 2). The most commonly-used low tech subcategories from the grey literature was distraction/ redirection strategies (i.e. visual barriers, planning meaningful activities, animal therapy) (25.9%, 15/58), locks/ barriers (i.e. door locks) (15.5%, 9/58) and identification strategies (i.e. Safe Return and Medic Alert) (12.1%, 7/58) (Figure 2).

3.1.2. Product Readiness Level (PRL). For the peer-reviewed articles, 2 were in the analytical and experimental critical functions phase (PRL3), and 21 were either in development and testing phases in laboratory, or validated in relevant environments (PRL 4 and 5), or the technologies were in demonstration or pilot phase (PRL6). The remaining 31 articles contained strategies either prototypes near or planned in an operational system or were mature strategies in which actual systems operated over the full range of expected conditions (PRL9) (Table 1). A total of

19 high tech articles, 34 low tech articles, and 11 articles containing both high and low tech strategies could not be classified using the PRL scale. Primary reasons were due to the high number of review articles included in this study, in addition to many strategies that were proposed but not evaluated. Articles containing both high and low tech solutions was found to have the highest technology readiness level (PRL9), in comparison to high tech only articles with an average PRL7, and low-tech only strategies with an average PRL7.

3.2. Descriptive analysis of studies

3.2.1. Characteristics of the research conducted in wander-management technologies.

(a) ***Participant characteristics, sample size, length and location of included studies.***

Participants of the included studies had a mean age of 75 years (SD 9.7). The age ranged from 23 to 90 years for caregivers and 60 to 103 years for persons with dementia, with a high dispersion in the number of participants (i.e., mean of n = 217 and SD = 77.2). While all peer-reviewed articles included persons with dementia, only nineteen (16%, 19/118) specified their underlying degree of dementia and level of cognitive decline. Almost forty-three percent (38/88) of the included clinically-oriented studies were small trials with a total number of participants less than 50 (i.e., mean of n= 10.8; SD 10.0), whereas the remaining trials can be described as medium-large (i.e., >50) with a mean of n = 200.5 (SD 338.0). No mean differences were found across low and high tech strategy studies for small and medium-large trials ($p > 0.05$). Of the 88 included clinical studies, 29 did not report sample size, therefore, were not included in the above calculations. Fourteen studies involved caregivers, however, only seven reported the relationship between the individual with dementia and caregiver. The most common type of family caregiver was a combination of children and spouse (18.6%), followed by spouse only (17.7%), and children (16.7%). Professional caregivers, search and rescue workers, and nurses were also included, making up nearly half of the reported involved stakeholders (40.3%). Forty-three of the studies reported the ratio of male to female dementia clients and caregivers. The average total number of females included in this review was 60 (SD 27 whereas the average total number of males included in this review was 39 (SD 36). Only 11 of the 118 studies reported ethnicity of participants. Of these, two were 100% Caucasian, five were more than 70% Caucasian, four were 100% Asian, and five contained <25% for Latino, African American, and African Caribbean decent. The lengths of the included studies varied (mean 4.8 months SD 11.5). Only fifty-seven of the one hundred and eighteen studies (48%) reported the location of the study. The setting of tests for the included studies ranged from long term care (43.9%), community (26.3%), laboratory (10.5%), home (7.0%), hospital (5.3%), assisted living (3.5%), and outdoor environments (3.5%).

(b) ***Wander-management strategy outcomes.*** Effectiveness of wander-management strategies was measured using 96 outcome variables across the 118 studies. Of these, 76.0% (73/96) of the outcome variables were different. When breaking down the studies by technology complexity, high tech only studies used 60 outcome variables across 61 included studies, with 71.7% (43/60) of the outcome variables being different; low tech only studies used 20 outcome variables across 42 included studies, with 75.0% (15/20) being different; and studies containing high and low tech strategies included 16 outcome variables across 15 studies, with 93.8% (15/16) being different. The outcome variables for high tech strategies included perceived effect of the technology on the well-being of the user (e.g., level of caregiver burden, satisfaction, depression, mood, daytime fatigue), perceived usability of the device by the user (e.g., ease of use, comfort, confidence in the use of the device, perceived usefulness, concerns/problems), and the reliability, functionality and accuracy of the device (e.g., number of errors, alarm frequency, time to find wanderer, number of unattended exits, and number of nighttime injuries) (Table 2). For the measures used to assess the proposed outcome variables, 50 measures were reported, and of these, 74% (37/50) were different. The most commonly used approaches were Likert scales (3/50), interviews (5/50), observations (3/5) and true positive/negative rate (5/50).

The outcome variables for low tech strategies included wandering prevalence/ frequency, attempted door testing/exiting/entries, total time seated, number of aggressive events, restlessness, and success facilitating return of the missing person (Table 3). For the measures used to assess the proposed outcome variables, 17 measures were reported, and of these, 76% (13/17) were different. The most commonly used approaches were time between door testing/exiting (4/17), and observations (3/17). Finally, the outcome variables for studies that included low and high tech strategies included effectiveness of the intervention, experience and advise using the different strategies, acceptability related to the intervention, distance of wandering, and agitation and irritability (Tables 2 and 3). For the measures used to assess the proposed outcome variables, 16 measures were reported, and of these, 88% (14/16) were different. The most commonly used approaches were interviews (2/16) and observation (2/16).

For the overall outcomes, 48.3% (57/118) of the included peer-reviewed literature showed advantages of wander-management strategies in terms of managing wandering in persons with dementia. Forty-eight of the one hundred and eighteen studies reported negative or non-significant differences, but positive versus negative outcomes were not significantly different ($p > 0.05$). When separating the number of positive and negative or mixed outcomes by technology complexity, 52% (32/61) of the high tech strategies, 50% (21/42) of the low tech strategies, and 27% (4/15) of the studies that included low and high tech strategies demonstrated positive results. Thirteen studies did not include results that evaluated wander-management strategies, therefore, they were not included in calculations. The above indicates that while the implementation of strategies to manage the adverse outcomes associated with wandering is promising, there is significant room for improvement and requires further investigation. Table 1 shows the number of studies classifying the positive and negative outcomes per device type, in addition to details on the total number of participant and study design types.

(c) ***Evidence of the clinical outcomes.*** The level of scientific evidence of the clinical oriented studies that evaluated wander-management strategies using quantitative methods was low. Regarding the level of scientific evidence for the studies that evaluated high tech strategies, only one article incorporated an RCT design [13], however details were not explained. Ten papers used a cross-sectional design. All studies were at a level of evidence 5, and results indicated that high tech strategies have great potential for locating the wanderer quickly, however many devices do not follow to their claims, which could in part be due to the low quality of effectiveness testing. GPS locating devices consistently demonstrated superior accuracy to RF devices. Family caregivers were perceived significantly more important in the decision-making process than figures outside of the family. Four studies used a single case study design without baseline phase, also at a level of evidence 5, indicating that individuals with mild dementia are capable of following vibrotactile signals, that wandering detection devices can contribute toward improved safety by identifying attempts to elope by setting up alarms and sensors, and locating devices demonstrate promise as a novel and competent health care approach in the case of dementia scenarios. Seven studies used qualitative approaches, which cannot be assessed using Sackett's criteria [37].

Regarding low tech strategies, only one study incorporated an RCT design. This RCT [40] achieved a PeDRO score of 5, with a level of evidence 2, where adapted exercise games (i.e., active activities with a softball) significantly decreased agitated behaviours, such as searching or wandering behaviours (54%, $p < 0.05$), whereas escaping restraints had no significant change (40%, $p = 0.07$). Four papers used a cross-sectional design with a level of evidence 5, and results indicated that lighting conditions had no effect on disruptive behaviours such as door testing/exiting, and few persons with dementia who exercises in ways other than walking may influence sundown syndrome and sleep quality. Four studies used a single case study design with a baseline phase and had a level of evidence 4, indicating that cloth barriers reduced entry into restricted areas with a high treatment acceptability, music therapy can increase the amount of time seated by the persons with dementia, and highlighted the need to educate caregivers that all persons with dementia are at risk of getting lost, regardless of whether they have exhibited the risky behaviour in the past. Early education would allow caregivers to adopt preventative measures to reduce these impending risks. One study used a pretest posttest design, with a level of evidence of 4. Results demonstrated the effectiveness of integrating a wall mural painted on the entrance of doorways, through the reduction of door testing behaviours exhibited by the participants. Two papers used qualitative methods, which cannot be assessed using Sackett's criteria [37].

Regarding studies that included high and low tech solutions, one study included an RCT design [41], however the details were not explained. Results from this study highlighted that most devices presently used by family caregivers do not comprise of new technology but rather, use established items such as baby monitors, and home modifications that are recommended by an occupational or physical therapist. There was level 5 evidence from two case studies [42, 43] design indicating that no evidence of benefit from exercise or walking therapies were found, that tracking devices and home alarms and sensors both effectively detected wandering and locating lost patients in uncontrolled, non-randomized studies, and that IC tag monitoring system need further improvement for clinical use.

(d) ***Usability and strategy acceptance.*** Of the peer-reviewed studies, 12% (13 studies) aimed to study the usability and acceptance of wander-management strategies. Of these, 9 (69%, 9/13) examined acceptance of high tech solutions, and 4 (31%, 4/13) examined acceptance of low tech solutions. Overall acceptability and usability of these strategies were high among participants. For example, one study found that most respondents agreed that the use of locator devices was superior to existing search methods and would improve quality of life of caregivers and persons with dementia, that they were appropriate devices, and that they could operate the device successfully [24]. Those who were more inclined to use wander-management technologies, were older adults who had been lost once or more (89%) or who had been diagnosed with mild dementia and had a history of being lost (73%) [44]. For low tech solutions, cloth barriers for example, were found to have high treatment acceptability [22]. Low tech solutions were also seen as strategies that have already been implemented within a person's home, in part due to their affordable nature, and as established strategies that result from professional recommendations from occupational and physical therapists [41].

(e) While the acceptability of certain strategies was high, others did not have the same result. Locator devices in Yung-Ching & Leung (2012) [44] for example were met with resistance. Barriers towards the implementation of wander-management strategies are suggested to be partly related to caregivers' acceptance of the suggestions, which they often perceive as not necessary or that they wouldn't work in their situation. In addition to acceptance of wander-management strategies, barriers on the use of high tech strategies include concerns about damaging the device, cost of equipment, difficulties in using the strategy, false alarms caused by the device, uncomfortable wear of the device, inaccuracy of the coordinates for locator devices, forgetting to wear the device, and concerns about privacy and stigmatization. Device aesthetics were also considered important in purchase consideration [44]. Barriers on the use of low tech strategies include participants not being aware of the strategy (e.g., mirrors and grids on doors), not enough staff to implement the strategy (e.g. exercise programs), poor product design, unavailability or lack of cooperation, issues with building codes (i.e. locked door strategies), and the implementation of the strategy being challenging due to raised ethical concerns (i.e., doll therapy being seen as demeaning and patronizing).

Ethical concerns associated with the implementation of the wander-management strategy. Of the 118 articles, 36 reported using an approach or policy to guarantee privacy of the individuals that used wander-management technologies. High tech strategies comprised of the greatest percentage of concerns (92%) with low tech strategies only including 8% of the highlighted ethical issues (Table 4). This in part may be due high tech solutions involving devices that track or monitor persons with dementia, instilling concerns over privacy and security [45].

4. Discussion

This review examined the range and extent of all possible strategies used to manage wandering behavior in persons with dementia. We included 118 studies (out of 4096) and 130 strategies from the grey literature. Overall, 183 high tech strategies and 143 low tech strategies were included, with the majority (59.5%) of the strategies being derived from the scholarly literature. The percentage of strategies derived from scholarly and grey literature differs from that of Neubauer et al. [25] where most strategies were from the grey literature. This is in part due to the addition of low tech solutions and studies that do not evaluate the usability or effectiveness of the wander-management strategies to the current review. Out of the 296 strategies, there were 183 high and 143 low tech solutions. Of these, there were 6 different subcategories of high tech, and 14 different subcategories of low tech strategies, with locating strategies, alarms and sensors, and distraction/ redirection strategies were the most common. Of the 118 included studies, less than half (48.3%) evaluated the usability or effectiveness of the strategies.

Only 16% were clinically tested in home or community settings and 25% were tested in formal care settings. The small percentage of home location studies may have a significant impact on the generalizability of the findings, in part due to the significant proportion of persons with dementia that live at home [46]. In addition, all testing locations took place in urban settings. The lack of real world evaluation, raises question about the degree of effectiveness of the proposed wander-management strategies, and whether users are able and willing to adopt these solutions. In addition, rural regions were significantly underrepresented, leaving out a significant cohort which may have presented different and necessary views by caregivers on the use and integration of these interventions in their communities [47]. An increased focus on usability testing in home-based rural and urban settings and the use of user-centred and participatory design approaches, would enable real users to identify problems with existing strategy designs, which could enhance adoption and acceptance of wander-management strategies [48].

Aside from a lack of usability testing and user-centred approaches of wander-management strategies, available solutions were difficult to find and were vastly scattered across the grey literature. Most high tech solutions were available through an array of commercial websites selling the technology. Two websites, tech.findingyourwayontario.ca and alzstore.com were the only websites containing strategies from multiple companies. Low tech solutions, were primarily suggested in Alzheimer specific websites such as through the Alzheimer Association, however little information was provided on where or how to access these strategies. In addition, no website provided an in-depth description of all available low and high tech wander-management strategies. These findings help to support difficulties caregivers and persons with dementia may face when trying to choose a strategy that works best for their individual needs. A guideline available through different mediums and locations is therefore necessary to simplify this information for a population that is often time constrained due to their caregiving responsibilities [49].

While the mass diversity of wander-management strategies may be promising in terms of having multiple options to help serve the unique needs of persons with dementia and their caregivers, only 13% of studies (15/118) in this review included high and low tech strategies together. Even fewer (2%; 2/118) compared their effectiveness. This raises the question whether certain high and low tech strategies are more effective than others, and if various combination of wander-management strategies are necessary to meet the unique needs of persons with dementia and their family caregivers. Some persons with dementia for example wander inside and outside of their homes [50] while some may only wander in one of these settings. In terms of living arrangements there is a growing number of persons with dementia that are living at home alone in the community, changing the scope of how one might care for these individuals [46]. When looking at the diverse context of those affected by dementia, income levels, perceptions of risk associated with wandering behaviour, culture, and beliefs may all play key roles in the successful adoption of wander-management strategies [51]. These factors however have yet to be evaluated within the present literature.

In addition to examining the range and scope of high and low tech wander-management strategies in this review, we wanted to identify their level of product readiness, and to characterize the present evidence on the implementation of such interventions. Overall, most included peer-reviewed articles that described strategies in which they were prototypes that were near or planned in an operational setting. This signifies the positive state of wander-management strategies in that most have been tested in a relevant environment and are in the process of being deployed in operational environments. Despite the potential advantages of using high and low tech strategies to manage wandering, only 52% (61/118) of the included studies could be evaluated using the PRL scale, due to many studies only proposing the strategy. With 194 different high and low tech strategies being included in the scholarly literature alone, this highlights the sheer infancy of present strategies that are being used to manage wandering. Further research in this area is therefore required due to the low percentage of strategies that could be evaluated using the PRL scale.

Mixed outcomes were found for both high and low tech strategies, where positive outcomes were found for 52% of the included high tech strategies and 50% for the low tech strategies. Overall, the use of non-constraining strategies provided promise to facilitate persons with dementia to support independence and enable them to engage in meaningful activities, such as walking and remaining engaged within their community [51]. For high tech strategies, locating technologies such as GPS and RFID devices, were suggested to have great potential for locating wandering persons with dementia quickly, provides increased confidence and peace of mind of caregivers, and was found to be a preferred option by users. The implementation of alarms and surveillance strategies, were also promising. Issues however such as cost, over sensitivity, appearance, privacy, stigma, and the need to combine multiple products to meet the variable needs of users is required. For low tech interventions, strategies such as door murals, methods of distraction, visual barriers, exercise programs, and therapies (i.e., doll and music therapy) all demonstrated reductions in wandering and exit seeking behaviours. Conflicting evidence however was found across all strategies, and scientific rigor was repeatedly mentioned as being poor quality [52]. This raises to question the feasibility and effectiveness of the adoption of these strategies in formal and community based settings. Aside from the outcomes that measured caregivers' perceptions on strategies to manage wandering, like the findings of Neubauer et al. [25], none of the included studies addressed the needs and opinions of persons with dementia, more specifically those with mild dementia. While addressing the concerns of family caregivers is important, the end outcome of these strategies is to ensure the safety of persons with dementia at risk of getting lost. The involvement of both caregivers and persons with dementia in the design and implementation of wander-management strategies is therefore critical to enable enhanced user satisfaction, adherence, and inevitably improved safety and quality of life of persons with dementia.

The significant variation of included outcomes, participants type, assessment tools, study duration, testing settings and study design may have influenced the mixed outcomes of the high and low tech wander-management strategies. Intervention implementation for example ranged from 25 minutes to one year, with most (78%) being only applied for 3 months or less. The high variation and short study length indicates a need to determine a duration that is best suited for strategy development and evaluation. Longitudinal field studies are also required to identify the long-term impact of each wander-management strategy, and there remains a need for standardized outcomes to compare the effectiveness of strategies to manage wandering. Other measures based on models such as the Technology Acceptance Model [53] and the Unified Theory of Acceptance and Use of Technology [54], are necessary to ensure strategies are designed in a way that take into consideration factors that are essential to user adoption. The level of scientific evidence provided by clinical oriented studies that used quantitative methods is low as the highest level per Sackett criteria [37] was 2, with most studies containing at level of evidence of 4 or less for both high and low tech included studies. Thus, there is a need for more RCT studies to increase the level of evidence of wander-management strategies for persons with dementia.

Finally, there is a gap in the literature with respect to privacy and ethics of persons affected using wander-management strategies. There has been no approach or recommendations published to address ethical issues. Future studies on privacy vs. safety, the influence of stigma, and conflicts of interest between caregivers and persons with dementia need to be further explored.

4.1. Limitations of this review

We could only quantitatively assess the strength of studies that used RCT (using PeDRO scale); as far as we know there is no standardized scale that determines the quality of either quantitative or qualitative non-RCT studies. While there are tools and guidelines available for performing a critical appraisal of research literature, the result was a proxy measure of quality. Without a scale, comparison of the relative quality of the included studies was not possible.

5. Future research and conclusions

From this review, we can conclude that many high and low tech strategies exist to manage the negative outcomes associated with wandering in persons with dementia. There is a general agreement that wander-management strategies can reduce risks associated with wandering, while enabling persons with dementia with a sense of freedom and independence. Further research could determine the factors that may influence intervention adoption, and demonstrate the efficacy of high and low tech wander-management strategies.

Highlights

- We identified 6 categories of high tech and 14 subcategories of low tech strategies that can be used by caregivers and persons with dementia.
- While wander-management strategies are believed to mitigate the risks associated with wandering, most were evaluated in institutional or laboratory settings, few addressed ethical issues, and the overall level of scientific evidence from these outcomes was low.
- Research is required to demonstrate the efficacy of high and low tech wander-management strategies and their feasibility in urban and rural community-dwelling environments.

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Conflict of interest

The authors have no conflicts of interest to declare.

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Figures

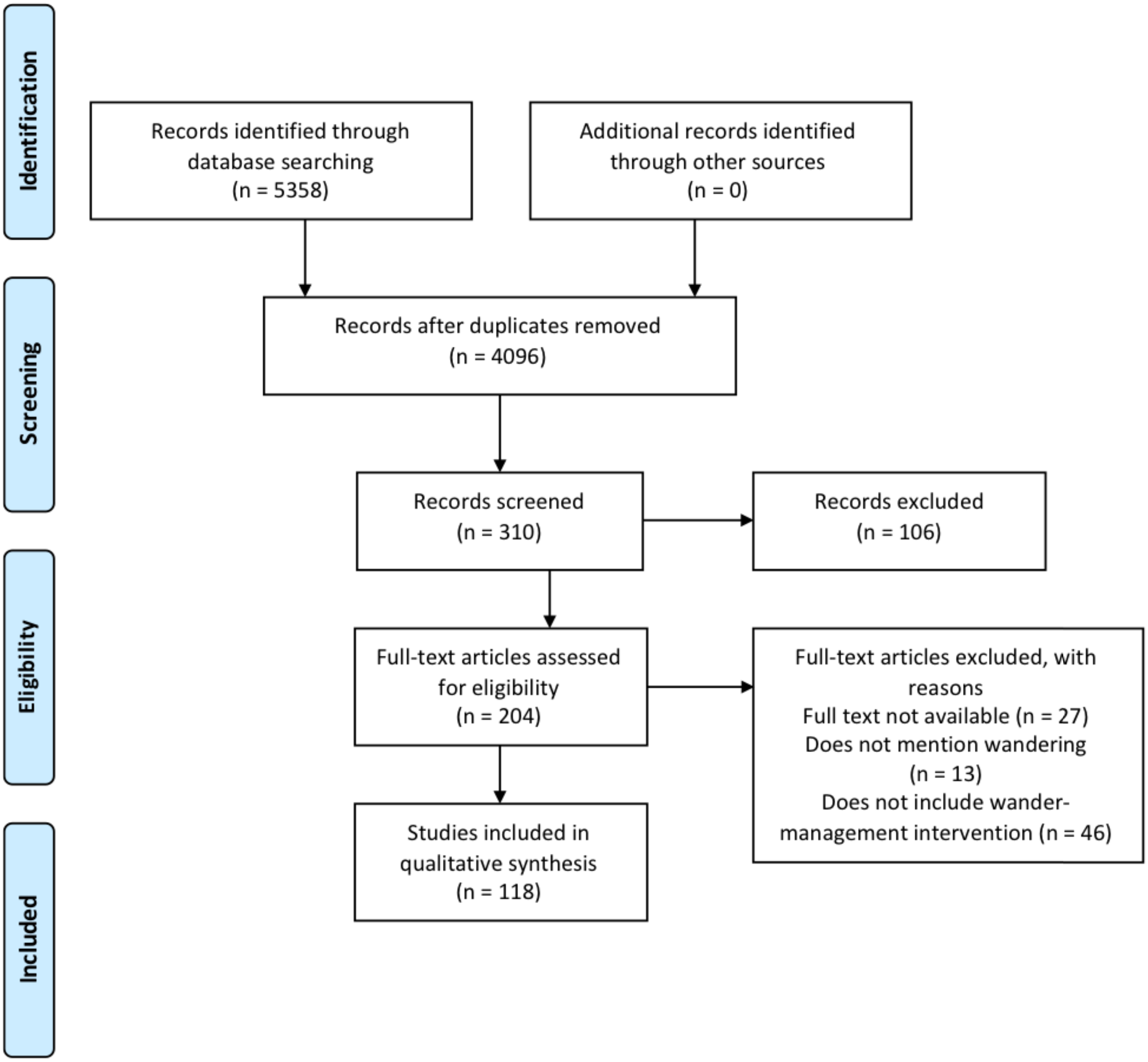

Figure 1. Scholarly reviewed literature article search results

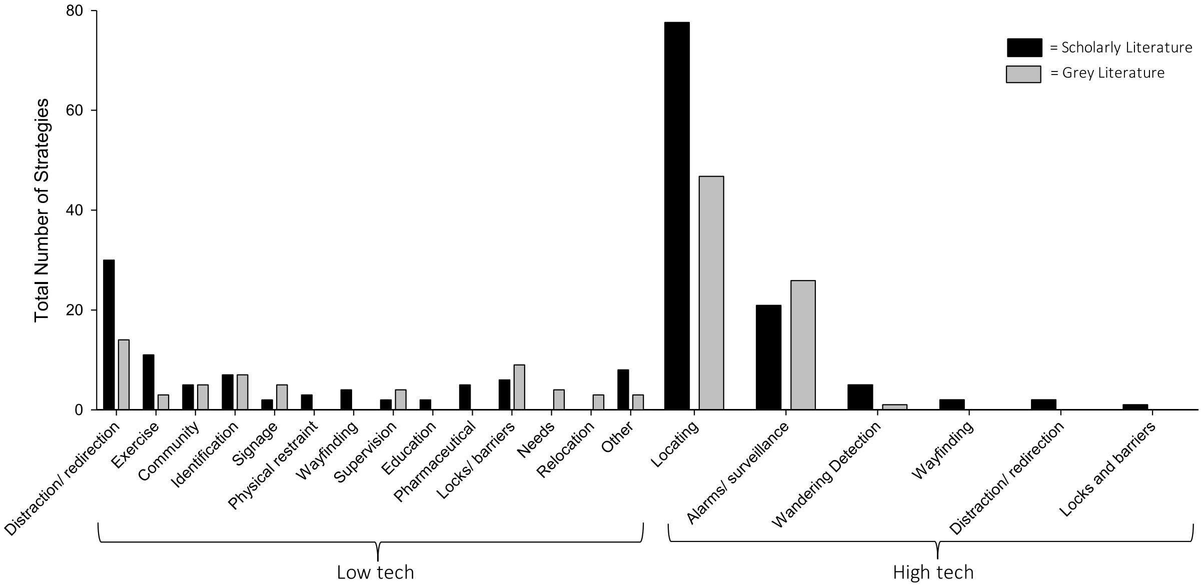

Figure 2 . Number of strategies that were high (n=183) and low (n=142) tech

Tables

Table 1. Positive and negative outcomes per type of strategy (high tech vs. low tech) (n = 118) of scholarly literature

Strategy Type	No. of studies (%)		Avg. no. of participants	Design of Study	Level of evidence	Type of study	Product Readiness Level (PRL)	PeDro Scale
	Negative or mixed outcomes	Positive outcomes						
High tech strategy	26 (43%)	32 (52%)	51 ± 77	Cross-sectional design (1), Single-case design (4), Case study (3), RTC (1), Randomized pre-pose (1), Descriptive (1), Before-after design (1), Phenomenology (4), Grounded theory (3), Systematic review (4), Other review (5), N/A (24)	Conflicting	Strategy-oriented (32), Usability (5), Clinical-oriented (15), Strategy and clinical-oriented (1), Review (8)	6.8 ± 1.9	N/A
Low tech strategy	13 (31%)	21 (50%)	110 ± 365	Cross-sectional design (4), Single-case design (2), Case study (4), Retrospective (1), Pretest-posttest (1), ABA descriptive design (1), RCT (1), Grounded theory (2), Systematic review (1), Cochrane review (1), Other review (6), N/A (9)	Conflicting	Strategy-oriented (1), Technology-oriented & Clinical-oriented (22), Program-oriented (1), Review (17), N/A (1)	6.8 ± 2.1	5 (1 study)
Contains both high and low tech strategies	9 (60%)	4 (27%)	113 ± 195	Single-case design (2), Case study (1), RCT (1), Phenomenology (2), Systematic review (2), Cochrane review (1), Other review (1), N/A (2)	Conflicting	Clinically-oriented (9), Review (4), N/A (2)	9 ± 0	N/A

Note. 3/61 high tech, 8/42 low tech, and 2/15 articles that contained both high and low tech strategies did not evaluate the effectiveness of wander-management strategies and only proposed potential strategies. Therefore outcomes of these included articles could not be provided. Level of evidence according to Sackett criteria proposed by Teasell et al., R. Teasell, S. Marshall, N. Cullen, M. Bayley, L. Rees, M. Weiser, P. Welch-West, C. Ferri and J.-A. Aubut, "Evidence-based review of moderate to severe acquired brain injury. Executive summary," December 2013. [Online]. Available: http://www.abiebr.com. [Accessed 29 7 2014].

Table 2. High tech main outcomes of scholarly literature

Strategy subtype	Main outcome(s)
Locating	RFID device had great potential for locating the wanderer quickly with localization ranging from 5 – 60 meters (3). Locating devices increased confidence and peace of mind of caregivers (3), and provided perceptions of reassurance and enhanced independence for the person with dementia. GPS was found to be more time effective in finding a missing person with dementia than RF. Overall, users were satisfied with locator devices and found them to be useful and acceptable. Electronic tagging was found to be a preferred option by users, however it was highlighted that there is a need to tailor the device to the user's needs and send better alerts (2). Ethical issues, such as coercing persons with dementia to use locating devices (2), concerns over the device conveying the user as frail as sick (2), removing the person with dementia of their dignity, and worries over privacy and security were conveyed.
Alarms/ surveillance	Wide variability amongst commercial alarm products such as alarm sound pressure levels, power consumption, frequency, and force measurement data for pressure activated systems and pull tab alarms. Most devices were too sensitive leading to false alarms. Results raise a need to link multiple products into one system to meet the variable needs of the users. Devices focused on ongoing surveillance at home for persons with dementia are needed so could be quickly adopted. Technologies that alter the appearance of the home or resemble medical devices will not be adopted by this population.
Wandering detection	Wandering detection devise had an excellent detection performance and low false alarm rate (smaller than 0.07). Wandering detection devices raise potential to contribute toward improved safety by identifying attempts to elope and successful exits and will facilitate the examination of trigger events for intensive wandering.
Way-finding	Results of study are promising and individuals with mild dementia are capable of following vibrotactile signals. Attention capture needs to be included. Device is not functionally relevant to those that have progressed to moderate stages.
Distraction/ redirection	Interactive wall was experienced positively by wandering elders and installation was an improvement in attracting persons with dementia than old empty environments.

Note. Abbreviations: RFID (Radio-frequency identification), GPS (Global positioning system), RF (Radio-frequency)

Table 3. Low tech main outcomes of scholarly literature

Strategy subtype	Main outcome(s)
Music therapy	Shows as a promising alternative to decrease the length of wandering. Music therapy was found to increase the amount of time seating more than reading therapy (2x the time seated) (4)
Doll therapy	Caregivers felt that there were clear benefits of using doll therapy in reducing wandering however some studies were subjective and anecdotal in nature, questioning the true effectiveness of this strategy.
Exercise programs	Was found to reduce wandering behaviours (2) however no evidence was found in randomized trails. Demonstrated less aggressive incidents (30%), and nighttime wandering decreased.
Mirror in front of exit door	Mirror was found to reduce exit attempts by 50% (1), and 40% (1), and saw general decreases in successful exiting.
Blind/cloth barriers	Barriers on an exit door (i.e. covering the door knob or using black tape/cloth to alter the exit door) was found to be more effective (96%) than horizontal mini blinds on the window panels on exit doors (44%). Combined methods reduced attempts by 88%. Changing floor patterns were least effective. Cloth barriers were also found to be more effective than staff redirected entries without the visual barrier present and demonstrated a high treatment acceptability.
Door mural	Door testing behaviours were reduced by 42%.
Signage	Studies were found to be underpowered and not convincing where no evidence was generally found. Those implementing signage need to take into consideration the downward gaze of the person with dementia.
Differential reinforcement	Results indicated a significant decrease in wandering with reductions ranging from 65-80%. Differential reinforcement techniques ranged from lack of attention for two participants, availability of sweet food for one, and sensor stimulation for another.
Distraction	Methods of distraction included providing activities for the person with dementia after meals (i.e. chores, crafts, watching videos, singing songs, etc.), and to encourage pottering. Self-stimulator products however are needed when staff are unavailable to direct the activities. Strategies however were only proposed, but its effectiveness was never evaluated.
SilverAlert	Massive variation from one state to the next on procedures. There is a limitation on available knowledge about the program (costs, effectiveness, etc.)
Safe Return Program	Proposed but effectiveness was not evaluated
Aromatherapy	Rubbing lotion with lavender, geranium, rosemary, and mandarin oils into the person with dementia's skin decreased anxiety and wandering.
Reality orientation	Strategy was suggested in the literature but its effectiveness was not evaluated.
Lighting conditions/ noise level/ temperature	No effects of temperature on wandering prevalence were found. Higher noise in rooms indicated increased levels of wandering. Lighting conditions influenced wandering prevalence, where micro-slated glazed windows with bronze micro-slats coated in black were found to decrease wandering incidents, while brighter lighting was found to cause more wandering
Pharmaceutical strategies	Risperidone demonstrated reductions in wandering but did not specify by how much. Alprazolam and Fasudil also indicated decreases in wandering behaviour.
Locked units and physical restraints	Perceived as effective however is not used by a majority of facilities (only used by 28% of facilities)

Table 4. Ethical concerns associated with wander-management strategies

Strategy type	Ethical concern to the use of the wander-management strategy
High tech	There are concerns over control and restraint (i.e. tagging like a criminal).
	Electronic tagging can be viewed as stigmatizing, demeaning, an invasion of privacy and removes one's dignity.
	There are concerns of data leakage for locator devices
	It is suggested that locator devices do not increase autonomy but just assists in finding the person with dementia sooner.
	Locating devices raise issues as to who benefits and there is a conflict of interest between the caregiver and the person with dementia, need formal agreements from all involved.
	Little attention has been placed on the perspective of the person with dementia on locator devices.
Low tech	Doll therapy was demeaning and patronizing
	There is a need for procedural safeguards of SilverAlert to protect privacy
	The role of mental health providers in activation of SilverAlerts should be more thoroughly explored

Appendix

Table s1. Peer-reviewed Literature Search Strategy

Database	Keywords	Results
Ovid MEDLINE	1. Dementia/pc, rh [Prevention & Control, Rehabilitation] 2. (Alzheimer's Disease or Cognitive Disorders or Mild Cognitive Impairment).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3. exp Wandering Behavior/ 4. (Walk* or sundowning or escape or restlessness or pacing or exit* or missing or "benevolent wandering" or "critical wandering" or "non-critical wandering").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5. Wireless Technology/ 6. (gerontechnology or telemonitoring or telesurveillance or "assistive technology" or GPS or "global positioning system" or "mobile device" or application or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitor*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 7. telemedicine/ or telerehabilitation/ 8. (Safetracks or WanderGuard or "Project Lifesaver" or "GPS Smartsole" or "ConnectMe Medical Alarm" or WanderTrack or "Find-me Carers Watch" or MedicAlert or iTraq or "Keruve Family Direct Locator" or "Silvercloud Sync" or "Mindme locate" or "PocketFinder GPS Tracker" or "Clevercare Smartwatch" or "Stray Star GPS Tracker" or "Mini Merlin" or "Safemate Personal Alarm" or "The Companion Anti-Wandering System" or "WalkAbout" or "Accutech ResidentGuard" or "Alimed Wireless Wander System").mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 9. ("low tech" or "physical barrier" or barrier or lock* or "door mural*" or sign or signage or "identification information" or ID or "ID card*" or bracelet* or jewelry or "management strategy" or "alternative strategy" or "wander management strategy" or "strategy" or non-pharmalogical or therap* or exercise or distraction or "pet therapy").mp. [mp=title, abstract, original title, name of substance word, subject heading word,	574

	keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 10. 1 or 2 11. 3 or 4 12. exp Technology/ 13. 5 or 6 or 7 or 8 or 9 or 12 14. 10 and 11 and 13	

Ovid PsychINFO	1. exp DEMENTIA/ 2. (alzheimer's Disease or Cognitive Disorders or Mild Cognitive Impairment).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 3. exp WANDERING BEHAVIOR/ 4. (walk* or sundowning or escape or restlessness or pacing or exit* or missing or "benevolent wandering" or "critical wandering" or "non-critical wandering").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 5. exp INFORMATION TECHNOLOGY/ or exp TECHNOLOGY/ or exp ASSISTIVE TECHNOLOGY/ 6. exp Telemedicine/ 7. (gerontechnology or telemonitoring or telesurveillance or "assistive technology" or GPS or "global positioning system" or "mobile device" or application or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitor* or telemonitoring or telesurveillance or "assistive technology" or GPS or "global positioning system" or "mobile device" or application or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitor*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 8. ("low tech" or "physical barrier" or barrier* or "door mural" or signage or sign* or "identification information" or ID or "ID card" or bracelet or jewelry or non-pharmalogical or therapy or exercise or distraction or "pet therapy" or strategy or "management strategy" or "alternative strategy").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 9. (Safetracks or WanderGuard or "Project Lifesaver" or "GPS Smartsole" or "ConnectMe Medical Alarm" or WanderTrack or "Find-me Carers Watch" or MedicAlert or iTraq or "Keruve Family Direct Locator" or "Silvercloud Sync" or "Mindme locate" or "PocketFinder GPS Tracker" or "Clevercare Smartwatch" or "Stray Star GPS Tracker" or "Mini Merlin" or "Safemate Personal Alarm" or "The Companion Anti-Wandering System" or "WalkAbout").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 10. 1 or 2 11. 3 or 4 12. 5 or 6 or 7 or 8 or 9 13. 10 and 11 and 12	889

EBSCO CINAHL	((MH"Wandering Behaviour") or sundowning or escape or restlessness or pacing or exit* or missing or stay or "benevolent wandering" or "critical wandering" or "non-critical wandering")) AND (MH "Dementia+") OR (alzheimer disease or cognitive impairment)) AND ((MH "Assistive Technology") OR (gerontology or tele monitoring or telesurveillance or telehealth or GPS or "mobile device" or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitoring or Safetracks or WanderGudard or "Project Lifesaver" or "GPS Smartsole" or "ConnectMe Medical Alarm" or WanderTrack or "Find-me Carers Watch" or MedicAlert or iTraq or "Keruve Family Direct Locator" or "Silvercloud Sync" or "Mindme locate" or "PocketFinder GPS Tracker" or "Clevercare Smartwatch" or "Stray Star GPS Tracker" or "Mini Merlin" or "Safemate Personal Alarm" or "The Companion Anti-Wandering System" or WalkAbout or "Accutech ResidentGuard" or "Alimed Wireless Wander System") OR ("Physical barrier" or barrier or lock or "low tech" or "door mural" or signage or "identification information" or "ID card" or bracelet or jewelry or non-pharmacological or therapy or exercise or distraction or "pet therapy" or therapy))	554
Ovid Embase	1. dementia/rh [Rehabilitation] 2. (Alzheimer's Disease or Cognitive Disorders or Mild Cognitive Impairment).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 3. exp wandering behavior/ 4. (sundowning or escape or restlessness or pacing or exit* or missing or "benevolent wandering" or "critical wandering" or "non-critical wandering").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 5. exp technology/ or exp assistive technology/ or exp appropriate technology/ or exp assistive technology device/ or exp information technology device/ 6. assistive technology/ or assistive technology device/ 7. exp telehealth/ 8. (gerontechnology or telemonitoring or telesurveillance or "assistive technology" or GPS or "global positioning system" or "mobile device" or application or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitor* or telemonitoring or telesurveillance or "assistive technology" or GPS or "global positioning system" or "mobile device" or application or applications or apps or "radio frequency telemetry" or RF or "radio frequency identification" or RFID or tracking or surveillance or alarms or tagging or electronic or restraints or sensor* or monitor*).mp. [mp=title, abstract, heading word, drug trade name, original title, device	

	manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 9. (Safetracks or WanderGuard or "Project Lifesaver" or "GPS Smartsole" or "ConnectMe Medical Alarm" or WanderTrack or "Find-me Carers Watch" or MedicAlert or iTraq or "Keruve Family Direct Locator" or "Silvercloud Sync" or "Mindme locate" or "PocketFinder GPS Tracker" or "Clevercare Smartwatch" or "Stray Star GPS Tracker" or "Mini Merlin" or "Safemate Personal Alarm" or "The Companion Anti-Wandering System" or "WalkAbouts").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 10. ("low tech" or physical barrier* or barrier* or lock* or "low technology" or "door mural" or signage or sign* or "identification information" or ID or "ID card*" or bracelet* or jewelry or non-pharmalogical or therapy or exercise or distraction or "pet therapy").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word] 11. 1 or 2 12. 3 or 4 13. 5 or 6 or 7 or 8 or 9 or 10 14. 11 and 12 and 13	
Web of Science	#3 AND #2 AND #1 (TS=(“Assistive Technology” OR gerontology OR “tele monitoring” OR tele-surveillance OR tele-health OR GPS OR “mobile device” OR applications OR apps OR “radio frequency telemetry” OR RF OR “radio frequency identification” OR RFID or tracking OR surveillance OR alarms OR tagging OR electronic OR restraints OR sensor* OR monitoring OR Safetracks OR WanderGuard OR “Project Lifesaver” OR “GPS Smartsole” OR “ConnectMe Medical Alarm” OR WanderTrack OR “Find-me Carers Watch” OR MedicAlert or iTraq OR “Keruve Family Direct Locator” OR “Silvercloud Sync” OR “Mindme locate” OR “PocketFinder GPS Tracker” OR “Clevercare Smartwatch” OR “Stray Star GPS Tracker” OR “Mini Merlin” OR “Safemate Personal Alarm” OR “The Companion Anti-Wandering System” OR WalkAbout OR “Accutech ResidentGuard” OR “Alimed Wireless Wander System” OR “Physical barrier” OR barrier OR lock OR “low tech” OR “door mural” OR signage OR “identification information” OR “ID card” OR bracelet OR jewelry OR non-pharmacological OR therapy or exercise OR distraction OR “pet therapy” OR therapy)) (TS=(dementia OR “alzheimer’s disease” OR “cognitive impairment”)) (TS=(“wandering behaviour” OR sundowning OR escape OR restlessness OR pacing OR exit* OR missing OR stay OR “benevolent wandering” OR “critical wandering” OR “non-critical wandering”))	

Elsevier B.V. Scopus	TITLE-ABS (dementia OR “alzheimer’s disease” OR “cognitive impairment” AND (“wandering behavior” OR sundowning OR “benevolent wandering” OR “critical wandering” OR “non-critical wandering”) AND (“Assistive Technology” OR gerontology OR “tele monitoring” OR tele-surveillance OR tele-health OR gps OR “mobile device” or applications OR apps OR “radio frequency telemetry” OR rf OR “radio frequency identification” or rfid OR tracking OR surveillance OR alarms OR tagging OR electronic OR restraints OR sensor* OR monitoring OR safetracks OR wanderguard OR “project lifesaver” OR “gps smartsole” OR “connectme medical alarm” OR wandertrack OR “find-me carers watch” OR medicalert or itraq OR “keruve family direct locator” OR “silvercloud sync” OR “mindme locate” OR “pocketfinder gps tracker” OR “clevercare smartwatch” OR “stray star gps tracker” OR “mini merlin” OR “safemate personal alarm” OR “the companion anti-wandering system” OR walkabout OR “accutech residentguard” OR “alimed wireless wander system” OR “physical barrier” OR barrier OR lock OR “low tech” OR “door mural” OR signage OR “identification information” OR “ID card” OR bracelet OR jewelry OR non-pharmacological OR therapy or exercise OR distraction OR “pet therapy” OR therapy))	
INCLUDING REPEATED ARTICLES		5358
REPEATED ARTICLES REMOVED		1262
TOTAL		4096

Table s2. Grey Literature Search Strategy

Source Searched	Date searched	Search terms	Results
Google	Nov 30, 2017	dementia and wander* and solutions	207,000 results (58 relevant)
Google	Dec 5, 2017	dementia and wander* and (solutions or “low tech” or “high tech”)	46,400 results (10 relevant)
Google	Dec 5, 2017	dementia and wander* and (solution* or strategy)	376,000 results (2 relevant)
Google	Dec 5, 2017	dementia and wander* and medications	393,000 results (1 relevant)

Google	Dec 5, 2017	Dementia and wander* and distraction	38,000 results (2 relevant)
Google	Dec 5, 2017	Dementia and wander* and camouflage	694,000 results (1 relevant)
CADTH grey matters	Dec 5, 2017	wandering	16 results (9 relevant)
Clinicaltrials.gov	Dec 5, 2017	Dementia and wandering	5 results (1 relevant)
The University of Alberta Grey Literature Collection	Dec 6, 2017	dementia and wander* and solutions	11 results (2 relevant)
ProQuest Dissertations & Theses Global	Dec. 6, 2017	all(Dementia OR "Alzheimer Disease" OR "mild cognitive impairment") AND all(wander* OR sundowning OR "critical wandering" or "benevolent wandering" OR "non-critical wandering" or "missing") AND all(technolog* OR gerontechnology or tele monitoring OR "assistive technology" or GPS OR "mobile device" OR apps OR RFID OR tracking OR surveillance OR restraints OR sensor* OR "physical barrier" OR barrier* OR lock* OR "low tech*" OR door mural* OR sign* OR "identification information" OR ID card* OR bracelet* OR non-pharmalogical OR therapy OR distraction OR exercise OR "pet therapy")	34 results (5 relevant)
ProQuest Dissertations & Theses Global	Dec. 6, 2017	all(Dementia) AND all(wander* OR sundowning) AND all(solution OR intervention OR strategy)	23 results (6 relevant)
ProQuest Dissertations & Theses Global	Dec. 6, 2017	all(Dementia) AND all(wander* OR sundowning)	52 results (3 relevant)
National Guidelines Clearinghouse	Dec. 6, 2017	Dementia and wandering	3 results (1 relevant)
Google	Dec 7, 2017	dementia and wander* and technology	161,000 results (10 relevant)
Google	Dec 7, 2017	dementia and wander* and tech*	1,050,000 results (14 relevant)

Google	Dec 7, 2017	dementia and wander* and tech* and company*	5,860,000 results (2 relevant)
Google	Dec 7, 2017	dementia and wander* and GPS	147,000 results (15 relevant)
Google	Dec 7, 2017	Dementia and wander* and RFID	38,000 results (4 relevant)
Google	Dec 7, 2017	dementia and wander* and wifi	694,000 results (4 relevant)
Google	Dec 7, 2017	dementia and wander* and mobile applications or iOS or android	90,900 results (0 relevant)
Google	Dec 7, 2017	dementia and elope* and technology	48,500 results (0 relevant)
Google	Dec 7, 2017	dementia and sundowning and technology	136,000 results (0 relevant)
Institute of Health Economics	Dec 7, 2017	dementia	0 results
Institute of Health Economics	Dec 7, 2017	Dementia and wandering	0 results
CADTH grey matters	Dec 7, 2017	Dementia and wandering	3 results (2 relevant)
The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and wander* and technology	6 results (0 relevant)
The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and eloping and technology	0 results
The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and wander* and GPS	2 results (0 relevant)
The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and wander* and RFID	2 results (0 relevant)

The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and wander* and wifi	0 results
The University of Alberta Grey Literature Collection	Dec 7, 2017	Dementia and wander* and mobile applications	0 results
Health on the Net Foundation	Dec 7, 2017	Dementia and wander* and technology	21,900 results (0 relevant)

Study Two Manuscript

Influence of stakeholder perspectives on user adoption of wander-management strategies

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ABSTRACT

Sixty-percent of Canadians with dementia will wander and become lost. Strategies, such as wall murals that camouflage doors, and locator devices, offer proactive options for keeping persons with dementia who wander safer. Information that describes available strategies to mitigate this issue is diverse and inconsistent, creating challenges for caregivers and persons living with dementia when choosing helpful strategies. This project aimed to describe the spectrum of risks and wander-management strategies associated with dementia-related wandering. Thirty-six phone interviews from across Canada were conducted with stakeholders including persons with dementia, paid and family caregivers, health professionals, police, and Alzheimer societies. Interviewees were asked about strategies that they have used to manage dementia-related wandering, and how their perceptions of risk, culture, stigma, and geographical location may influence strategy adoption. Overall, a wide range of high and low tech solutions were used or suggested by participants, and factors such as risk, culture, geography and stigma were considered essential elements to successful adoption of these strategies. Results from this study highlight the need for unique combinations of strategies based on the type of stakeholder and influencing factors involved.

Keywords: Wandering; Dementia; Missing Persons, Risk-management; Strategies; Technologies

INTRODUCTION

Critical wandering, or wandering that leads a person with dementia to become lost due to difficulties in wayfinding (Petonito, et al. 2012), is a significant concern among health practitioners, police and caregivers (Bantry White & Montgomery, 2015; Neubauer et al. 2018a). This is due to the increased risk of negative adverse outcomes associated with missing person events, such injury, death, and for some, placement in a care facility (Bantry White & Montgomery, 2015). The determination of risk (Douglas, 1990) of wandering-related behaviours is associated with the degree of exit-seeking behaviour or outdoor engagement (Wigg, 2010). Care providers typically view persons with dementia who seek to be outdoors as a 'higher risk' than those who walk aimlessly. Further, individuals placed into continuing care because of wander issues are also deemed as high risk by an institution's administration, due to the potential for litigation that derives from the negative outcomes associated with wandering (Robinson et al. 2007).

Few studies however, have evaluated whether the perception of risk associated with wandering varies across all involved stakeholders. Stakeholders include first responders, Alzheimer societies, health practitioners, persons living with dementia, paid and family caregivers. Only one study (Houston et al. 2011a) has evaluated how family caregivers perceive the risk of wandering. In this study, family caregivers were asked to identify how they perceived wandering, and to describe what risks were associated with this behaviour. In some cases, family caregivers did not perceive wandering as a risk, causing most to not make physical changes to their home for persons with dementia that frequently wandered, despite the fact that 66.5% of these individuals had spent time alone, unsupervised during the week. In fact, many did not identify wandering and getting lost as a problem and assumed it only occurred during late stages of dementia. It is not known however how other stakeholders view the risks associated with wandering. As this perception is associated with strategies implemented to mitigate the risks, it would be important to understand the views of other stakeholders whom are also responsible for the integration of these strategies, such as paid caregivers, persons with dementia. While often not direct recipients of wander management strategies, the perception of risk among police and community organizations may also be vital due to their involvement in the education and prevention of critical wandering.

As well as perception of risk, other factors that may impact the adoption of wander-management strategies among persons with dementia could include cultural and geographical influences. Connel and Gibson (1997), for example, found that cultural differences and caregivers' perception of wandering behaviour work as a mediating factor on stress and burden. There was evidence to suggest community involvement and views may differ between urban and rural settings. Residents in rural communities have been found to be less likely to choose continuing care as such a move may require them to relocate a long distance away from family, friends, and familiar environments. This population may be more inclined to adopt to home-based services and strategies (Alzheimer Society, 2016). No study to date however, has evaluated the influence of geographical location, i.e., rural versus urban, on the adoption of strategies to mitigate critical wandering.

Finally, with the increasing prevalence of missing person events involving lost persons with dementia (Lissemore et al. 2019), there has been a significant increase in the number of available strategies focused on managing critical wandering (Neubauer et al. 2018a). From low tech strategies such as wall murals to camouflage doors, and vulnerable persons registries, to higher tech solutions such as locator devices, the options are numerous. It was indicated through the findings by Neubauer et al. (2018) however, that the evidence of effectiveness of these strategies is inconclusive. In addition, a guideline to assist caregivers and persons with dementia in the adoption of these strategies however, does not exist making it difficult for users to choose a strategy that best suits their needs (Neubauer, Azad-Khaneghah, Miguel-Cruz, Liu, 2018b). As highlighted by Neubauer et al. (2018b) the types of strategies used by all involved stakeholders has not been determined. Therefore, the purposes of this study were to: (a) to determine the types of strategies used by certain stakeholder types; (b) describe the spectrum of risks and wander-management strategies associated with dementia-related wandering; and (c) identify the factors that may influence adoption of wander-management strategies.

METHOD

Participants and sample size

A maximum variation sampling method was used (Patton, 2002) to identify essential and variable features of wander-management strategy adoption experienced by diverse stakeholders (Suri, 2011). To further ensure the quality and richness of information collected, a snowball sampling method (Patton, 2002) was also used through recommendations of potential participants from key informants such as Alzheimer Societies. Persons with mild dementia, family caregivers who have expressed concern in managing dementia-related wandering, paid caregivers (i.e., home care and continuing care), health professionals (e.g., occupational therapists, geriatric psychiatrists, social workers), police, industry and Alzheimer societies were recruited. Five of the recruited family caregivers were required to have minimal or no outside help from paid caregivers. The reasons for this, is only one third of older adults are engaged with paid services (Reinhard, Given, Petlick, Bemis, 2008), with most families providing care for the person with dementia on their own.

Inclusion criteria

1) At least 18 years of age
2) English speaking
3) Must be a person with a diagnosis of dementia, be family or paid caregiver of someone with a diagnosis of dementia or must have worked with someone living with dementia
4) Must have personally experienced one or more critical wandering incidents

Exclusion criteria

1) Individuals with severe hearing and vision impairments that cannot be corrected with aids as it would limit their ability to participate in the interviews
2) For persons with dementia: individuals with severe cognitive impairment who cannot communicate in a conversation. This was determined through preliminary consultation with the primary caregiver of the person with dementia.

Procedure

Participants were recruited from rural and urban communities, and from across Canada. Rather than focusing through the lens of a known methodology (e.g., phenomenology, grounded theory or ethnography) (Caelli et al. 2003), this study followed descriptive qualitative method (Sandelowski, 2000), due to the basic description and summary of the lived experiences of managing the risks associated with critical dementia-related wandering being desired. We drew from concepts, models and theories, such as the framework developed by Moore et al. (2009)

that manages the risks associated with dementia related wandering, to serve as the overarching framework for this study.

Due to the sensitive nature of this topic and to ensure responses among participants were in-depth and not influenced by others, semi-structured individual interviews were conducted (Gill, Stewart, Treasure, Chadwick, 2008). Ten family caregivers, seven paid caregivers, 6 persons with mild dementia, 1 occupational therapist, 1 geriatric psychiatrist, 5 police, 4 social workers, 1 industry and 4 staff members from community organizations participated in the interviews.

All semi-structured interviews took place via. telephone or videoconference to ensure responses could be made in an environment most suitable for the participants, to enable the recruitment of participants nationally, and to yield the potential for more honest and rich discussions because of the anonymity involved (Trier-Bieniek, 2012). The interview schedule was developed from the findings in Neubauer et al. (2018b) and included 8 questions. Questions that were asked included participants identifying what strategies they are using or have suggested to reduce the risks associated with critical dementia-related wandering. Other questions included asking participants to determine whether perceived risk, culture (Baldwin, Faulkner, Hecht, 2006), location (i.e., urban vs. rural), stigma or other factors influenced why they adopted or suggested the indicated wander-management strategy. Participants were given as much time as needed to answer the questions. Participants were recruited through local Alzheimer Societies, dementia care networks, gerontology associations, established connections, and word of mouth. Semi-structured interviews were audio recorded and notes were made following each interview that focused on key messages from the participants' responses.

Data Analysis

To enable the identification of existing strategies and factors that influence strategy adoption, a qualitative description (Sandelowski, 2000) approach was chosen. All interviews were professionally transcribed verbatim. Transcripts and field notes were read and reviewed multiple times to ensure accuracy (Poland, 1995). Directed content analysis was used (Hsieh & Shannon, 2005), and an initial coding scheme (Strauss & Corbin, 1998) was developed based on the interview guide. Codes were assigned to short segments of text related to the strategies used among participants to reduce the risk of persons with dementia getting lost; factors that influence strategy adoption such as perceptions of risk, culture, stigma, geographical location, stakeholder type; and existing gaps experienced by participants when trying to manage critical wandering. A code-recode strategy was followed with same data twice, giving a one to two-week gestation period between each coding. This was done to compare the two coding to see if the results were the same or different (Chilsia & Preece, 2005). A constant comparative method (Boeije, 2006) was applied following the coding of the data. As our study involved participants from multiple stakeholder groups, we followed three steps: (1) Comparison within a single interview; (2) Comparison between interviews within the same group; and (3) Comparison of interviews from different groups. Role-ordered matrix was used to assist in the comparison and contrast of varying perceptions and responses by the included participants. The data regarding each semi-structured interview was summarized in a table and cross referenced.

RESULTS

The sample comprised of persons with mild dementia (n = 6), family caregivers (n = 10), paid caregivers (n = 7), social workers (n = 4), police and search and rescue (n = 5), community organizations (n = 4), an occupational therapist (n = 1), and geriatric psychiatrist (n = 1). The semi-structured interviews took approximately 60 minutes each. Overall, participants were from 5 provinces (British Columbia (5/36, 13.9%), Alberta (20/36, 55.6%), Ontario (7/36, 19.4%), Nova Scotia (3/36, 8.3%), Newfoundland (1/36, 2.8%), across 16 cities or communities. Twenty-nine participants (80.5%) were from urban communities (i.e., communities with a population 1,000 or greater) (Statistics Canada, 2011a) and 7 (19.4%) were from rural communities (Statistics Canada, 2016). These numbers were representative of the present urban-rural proportions in Canada, where fewer than one in five (18.9%) lived in rural areas in 2011 (Statistics Canada, 2011b). Participant demographics can be found in Table 1.

The results from the analysis of the interviews can be broken down into two main categories: (1) strategies used; and (2) factors that influence adoption of wander-management strategies.

Strategies used

A total of 17 different types of high tech and 28 different types of low tech wander-management strategies were used among participants. For high tech solutions, commercial locating devices (i.e., Global Positioning Systems), phone locating devices, alarms, and locks were the most common (Figure 1) and for low tech strategies, MedicAlert, door murals, distraction therapies, identification kits and involving the local community was the most common (Figure 2). Each individual stakeholder group was found to use variations of these strategies. Paid caregivers, health practitioners and social workers for example shared similarities in which they focused on strategies that prevent or notify whether a person with dementia was about to transgress away from the home into outdoor settings. They were therefore more inclined to integrate different variations of alarms and sensors such as door alarms, as well as floor or bed mats. Lower tech solutions often included distraction approaches, door murals to camouflage the exits, curtains over doors to hide exits, and wayfinding aids, such as signage within facilities.

Police, family caregivers, and community organizations however were focused on strategies that would be used when the person with dementia is already out in the community. Commercial and existing GPS devices (programs available using the GPS on a person's phone), RFID (Project Lifesaver), vulnerable persons registries, identification tools and notifying the neighbours were therefore suggested to be the most common strategies used.

Persons living with dementia used strategies that assisted them in wayfinding in times when they were away from home. Persons with dementia sought strategies that included mainstream technologies that they already use on a regular basis, such as their smartphone. Therefore, programs such as Google Maps, Life360, and Find My Friends were adopted. Lower tech solutions included in MedicAlert, using the memory card through the Alzheimer Society, walking for a reason, leaving paper reminders of their intended destination in their hand, and calling the bus helpline.

Factors that influence adoption of wander-management strategies

Four factors were discussed among participants that influence the adoption of wander-management strategies: risk perception, geography, culture, and sigma.

Risk perception

The influence of risk perception on the adoption of wander-management strategies was highlighted by interviewees in four ways: (1) education of severity of risks; (2) lived experience;

(3) location of the missing person with dementia; and (4) balance between safety and risk (Table 2). It was highlighted by other study participants that in many circumstances, persons with dementia and their family caregivers do not realize the risk associated with getting lost among this population and are unaware that the risk level can change quickly due to the unpredictability of dementia. As discussed by one of the family caregivers, this unawareness was in part due to limited education available around this issue.

"There was absolutely no discussion over the risk of my dad getting lost, any of the professions that we were in contact with. Not even the physician - there was absolutely no discussion on wandering." – family caregiver

Low risk perception among persons with dementia and family caregivers can also be influenced by where they live. In small towns for example, as noted by one of the family caregivers, everyone knows one another, therefore leading to a sense of security knowing that if the person with dementia is lost, members of the community would redirect them home.

"Not so much [in seeing her father being at risk of getting lost]. In the small town - everybody knows everybody else and if we were to get lost, he would be able to find somebody who knew him in a heartbeat, that would be able to connect him to again." – family caregiver

The familiarity of the land, available resources such as supervision, and geographical hazards such as roadways and extreme weather were also described by some interviewees as having an influence on perceived risk. They linked the limited understanding of these risks, specifically that the perceived risk of getting lost is often low until a missing incident occurs, to family caregivers overreacting to the risk, resulting in the implementation of reactive versus preventative strategies. Unfortunately, with this reactive way of thinking, persons with dementia were seen as potentially experiencing negative associated outcomes, such as serious injury or death, and while causing fear and negative perceptions among caregivers about wandering behaviour.

"They will not see the risk of getting lost until it happens to them, I don't think. You know, again, unless you've walked in their shoes so to speak." – person with dementia

"If we don't have enough in the toolkit then I think it sort of opens the doors to this negative impact about wandering, about risks, and people are going to be more frightened – and if they have a bad situation… there's a certain number of hours that after that time it becomes riskier as time goes on. You know, thinking of managing risk is so – it's a way that you deal with that risk versus reacting to the risk." – paid caregiver

The developed fears and negative perceptions of wandering following missing person incidents, in many circumstances were found to cause restrictions in independence of the person with dementia with the hope of increasing their safety. Such views were prevalent not only among family caregivers but with paid caregivers and persons with dementia as well. Strategies included home seclusion and locked dementia units. In fact, this extreme form of reactive strategy adoption, was the most common concern among those with dementia that have been lost, raising concern that it will cause separation among the family unit.

"I'm thinking of a family that have experienced their person with dementia going out at night in the winter with their pajamas on. It's almost to the point where it's a crisis and sometimes they think oh god, this is it, this is the end, we can't do anything about this, we have to lock them away." – family caregiver

"For six years I never left the house because I got panicked… I freaked out. I guess that's because I was scared [after the first time I got lost]." – person with dementia

Participants, such as one of the interviewed stakeholders, expressed that care facilities are risk adverse and implement precautions for residents, whom may impose not risk at all to critically wander.

"She hadn't shown any signs of wandering but they were really adamant about her having the Wanderguard on and the family was offended by it… it felt like they were too risk adverse. It doesn't make any sense for us to strap on a number of alarms onto anybody if they're not indicating any risk." – social worker

Interviewees noted that persons with dementia should have the opportunity to live with some level of risk to ensure their quality of life is not sacrificed. As indicated by one of the paid caregivers, balance between risk and safety deserves further exploration.

"You cannot afford to just be willy-nilly about the level of risk. But I don't believe that people should not have the opportunity to have some kind of risk." – paid caregiver

It is key to note however that finding a means of achieving this balance among all stakeholders will not be an easy feat. The social workers interviewed for example feel level of experience significantly influences the level of risk they are willing to let clients live in. In many circumstances, it was felt among interviewees that the more experienced social workers and home care nurses allow persons with dementia to live at home with some risk, while those that are newer to the practice, strategies such as locked units are often their primary choice.

"Their perspective can really depend on whether that patient gets placed or not. And often the more experienced home care nurses or social workers are more likely to let someone live at risk, whereas the ones that are new get really nervous and they want to just protect them and not let anything bad happen." – social worker

Geography

The influence of geography on the adoption of wander-management strategies was highlighted by interviewees in five ways: (1) influence of geographical location on risk perception; (2) influence of geographical location on type of risk; (3) rural and urban life; (4) availability of resources; (5) differences in type of help seeking services (Table 3). There was a 50/50 split between stakeholder groups when it came down to determining which type of environment (i.e., rural vs. urban communities) placed persons with dementia that critically wander at higher risk when a person goes missing. Social workers, family caregivers, and paid caregivers perceived rural settings as being safer for this population. This was due to participants' perception of big cities placing persons with dementia at a greater risk of being taken advantage of and of an accident resulting in injury. One of the interviewed police officers for example stated:

"When you're in the city, it's really the hazard is now people. Now you're worried about what can happen to you because of the people that are out there - - that are being taken advantage of." – police officer

In contrast, health professionals, police, and community organizations thought rural communities put the person with dementia at greater risk of harm due them being closer to large bodies of water and wooded areas, isolation and a greater chance of not being found in time.

How participants interacted in rural and urban communities was also seen as having an influence on what strategy was implemented among families and persons living with dementia. In rural environments, one of the participants described rural life as living in a community where everyone knows each other. Because of this, family caregivers are more inclined to follow a community approach by having local neighbours keep a look out for the person who have dementia:

"In town people knew her…people knew who she was - so, unless she went really far, everyone knew who she was, she could've gone to the next town and everyone would've still known who she was. But that was kind of a pro being a small town and people would sort of help each other out and that kind of thing." – family caregiver

In urban communities, people may be less inclined to become involved in the lives of neighbours, strategies to account for this such as technologies would therefore be considered. One of the paid caregivers whom lives in a large urban community for example noted:

"Yeah, well I would even suggest that in a big city the elements can also be a huge factor because people just don't want to – you know, get involved in other people's business sometimes." – paid caregiver

Putting these perspectives together, it is evident that interviewees identified different types of risk exist based on where the person with dementia lives. Urban environments pose more of a community risk of other people whereas in rural communities, the risks are focused on the elements. Because of this, stakeholders in rural communities are more prone to rely on the community to find a missing person with dementia, whereas urban communities are more likely to reach out to the police for assistance. In addition, the type of strategy adopted is largely influenced by geography. For example, locator devices such as global positioning systems (GPS) may be more useful for those in remote areas as it would assist families and police in finding them out in the woods and in areas you are not otherwise going to see them. Whereas in cities, there's more places for them to wind up so alert systems, such as a Silver Alert system would activate more resources to look for them.

Culture

The influence of culture on the adoption of wander-management strategies was highlighted by interviewees in four ways: (1) individualistic and collectivist cultures; (2) personal factors; (3) personal experiences; and (4) language barriers (Table 4). In terms of individualistic and collectivist cultures, this category was found across all involved stakeholder groups. Some of the interviewees felt that those who came from individualistic cultures were more inclined to keep things private and would rely on more technical resources. Collectivist cultures on the other hand often include multi-generational housing and decisions were made collectively by a family. It was suggested by one of the family caregivers for example that strategy adoption and technology acceptance would need consider these roles in that depending whether they come from a collectivist of individualistic culture, would determine whether the entire family would need to be on board for successful adoption of wander-management strategies to occur, or whether just the person living with dementia and/or primary caregiver need to be involved.

"People who come from more collectivist culture might rely more heavily on those low-tech like community groups, and people they know in their neighbourhood that might look out for each other, more so than people who come from individualistic cultures might be more inclined to keep things a little more private." – family caregiver

Personal factors were suggested among most participants to involve upbringing and trust among family caregivers and the person living with dementia, personality and values. The importance of independence and having a meaning in life for persons with dementia for example was an essential part of some of the person with dementia's identity. Strategies were chosen to respect this key value.

"Her independence was really important to her. She grew up in a, I'll use the word ableist environment. It was really question of how could you contribute; how could you accomplish something..." – family caregiver

As highlighted among social workers, police and community organizations, personal experiences, such as negative experiences with police were also believed to have a significant influence on the strategies families and persons with dementia are willing to adopt. For families that value privacy and have had poor experiences with police are less inclined to contact the police if a person with dementia is missing. Therefore, strategies such as utilizing local distress centres may be an appropriate alternative.

"There's also then the fear of the police that some cultures have or if they've emigrated from a different country where the police were maybe not as trusted or were corrupt, they're not going to turn to the police first for sure." – police officer

In addition, the level of experience with strategies that are higher tech was also described by Alzheimer Society staff as having a significant influence on the adoption of such strategies. The present older adult population in comparison to the baby boomer generation is generally known to have lower comfort levels with technology. Therefore, such comfort levels would be considered.

"The comfort level with technology amongst the people I work with is probably on average much greater than it is in a similar group of 80 year olds. And that is going to influence what they might select as a solution." - Alzheimer Society staff member

It is key to note however, some of the interviewees, specifically some of the paid caregivers did not believe that culture would have an influence on strategy adoption.

Stigma

The stigma that surrounds dementia was expressed among interviewees and was identified as being societal or culturally based. This quote by a person living with dementia refers to the feared consequence of being locked up if family perceive the person to be "crazy".

"[There are] family members who think you're crazy now and should be locked up - When I was first diagnosed I did believe I was going to be locked up by in a month or so. And that was 5 years ago." – person with dementia

Among all participants, stigma, was believed to be associated with denial that someone has dementia, and this would lead family or the person with dementia to not seek help in determining what strategies can be put in place to keep the person with dementia safe from getting lost. For example, *“That will keep people home, that will stop them from going out in the community, that will impede their asking for help. - whether it’s talking to somebody in the family, or talking to the intermediary. Stigma will often be the overriding problem.” – person with dementia*

Stigma was also noted as having an influence on what strategies families were willing to use. For example, some families were observed among Alzheimer Society staff as turning down strategies that draw attention that the person living with dementia. One such strategy that brought concern of stigma was the MedicAlert bracelet.

“People don't like wearing the MedicAlert bracelet cause it's a signifier or something that's perceived to bring stigma - they don't want to be out there clearly marked in some way, that there's something wrong with them. Nor does the family.” – Alzheimer Society staff member

Participants explained that one source of stigma was little or no knowledge about dementia. If the public had a better understanding of what dementia is and that it is a disease that should not be pitied, families would be more inclined to share their experiences with others and would have a greater chance of seeking help when they need it. From the media standpoint, public also does not hear any of the good stories of a person living well with dementia and we are not hearing any of them because good stories are not catchy and sensational for media outlets. Therefore, this negative connotation only further encourages development of stigmas associated with dementia.

"We will only ever hear the sensational stories, which is a person lived horribly, they got lost, they have been house-bound and they didn't even know how to feed themselves. Those are the stories that you're going to hear." – police officer

DISCUSSION

The purpose of this study was to describe the types of dementia-related wander-management strategies used by participants, and to identify the factors that may influence the adoption of these approaches. To our knowledge, this is the first study to identify real world strategies that are being used among caregivers and persons with dementia, and to explore what factors led to the adoption of these strategies among all involved stakeholders (i.e., police, health practitioners, paid and family caregivers, etc.). Overall, factors such as risk, culture, geography and stigma were considered essential elements to successful adoption of these strategies.

In terms of risk perception, most participants expressed that family caregivers do not see the risk of the person with dementia getting lost until a serious lost event has occurred, leading to the use of reactive rather than proactive strategies. The low level of perceived risk among family caregivers is consistent with Houston et al. (2011a). There were also concerns about a caregiver's risk perception moving from perceived low risk to perceived high risk, at the opposite end of the risk continuum after serious adverse event. This can result in the removal of all levels of independence for the person living with dementia, such as home confinement and locked dementia units. Such changes in perception could be due to critical wandering being associated with harm following a missing incident (Manthorpe, 2003). As suggested by Slovic and Peters (2006), strong visceral emotions elicited from adverse outcomes, such as fear, play a key role in risk as feelings, and are known to amplify risk estimates. This is known as "affect heuristic” where such feelings become a way of coping and guide judgement and decision making (Slovic & Peters, 2006).

To avoid this sudden shift in risk perception, a balance between risk and safety is emphasized by Robinson et al. (2007) and the interviewees within this study. Balance of risk and safety, as a concept, needs to be emphasized further to ensure that quality of life of this population remains intact. To build on this phenomenon described by the involved participants in this study, we propose the “Goldilocks Principle on Dementia and Wayfinding” (Figure 3). This principle highlights the need for the perception of risk of critical dementia-related wandering being “just right” among caregivers, persons with dementia and health professionals. Within this principle, the different levels of risk perception are proposed, shedding light on the limitations that come with each end of the spectrum (i.e., no risk perception ensures independence while sacrificing the safety of the person with dementia, while high risk perception, ensures safety while sacrificing their independence). This principle proposes that future strategies and education directed to involved stakeholders must strive towards addressing an “optimal risk perception” where all parties involved see the risk of persons with dementia getting lost, resulting in adoption of proactive strategies that enable some level of independence for the person with dementia while still ensuring that they remain safe within their home of choice (i.e., early adoption of monitoring devices). This principle was developed with the intention of including it in a conceptual framework that would encompass proactive strategies to mitigate the risks associated with getting lost. It is anticipated that an understanding of the concept of “optimal risk” captured within the Goldilocks Principle, would result in adoption and use of wander-management strategy guidelines available strategies.

There was a consensus among study participants that geography plays a significant role in the types of strategies that are integrated to keep persons with dementia safe from getting lost. The familiarity of the land, available resources, and geographical hazards such as roadways and extreme weather are also believed to have a significant influence on perceived risk. These findings are supported from those of Aud, (2004), where environmental risks associated with lost persons with dementia were reported, such as outdoor temperatures and acquired physical injuries. Individualistic views among urban and collective cultures in rural communities were also highlighted as key factors. For example, rural communities were suggested to be more inclined to follow a community approach through involving strategies that involved their community whereas in urban environments caregivers were more private and would tend to rely on professional services for assistance. Among rural and urban communities, stakeholders differed in their views on which setting poses greater risk for people living with dementia to get lost and to be exposed to the elements. Such views could be attributed to lived experiences of the participants. According to Gilmour, Gibson and Campbell (2003), persons with dementia living in rural environments and known by businesses and neighbours for an extended length of time, are less vulnerable to harm in part due to informal surveillance provided by members of their community. However, one participant who was a police officer, commented that, due to the vastness of rural communities, their search radius can be larger than urban searches. In situations such as missing persons with dementia when time is of the essence, rural searches pose the risk of taking longer to find the missing person.

Among the influence of culture on adoption of wander-management strategies, individualistic and collectivist cultures, and personal factors and experiences were brought up. Individualistic cultures, such as those emulated in North America, have compelling emphasis placed on personal control, whereas collectivist cultures, such as those from Asia, integrate coping strategies that focus on the involvement of the immediate family and community (Kue, 2010). As indicated by Kue (2010), an understanding of these approaches to coping and strategy are critical in the development of conceptual models and theories in this field. Personal factors and experiences, such as values of independence, experiences with police and technology are also important. Personality (Honda & Jacobson, 2005), negative connotations with police (Schafer et al. 2003) and technologies (Mitzner et al. 2010) for example, were described by interviewees as being a deterrent for adopting either strategy when seeking help when a person with dementia is lost. Such experiences therefore need to be recognized and a plan needs to be in place in terms of the appropriate steps to ensure some form of wander-management strategy can be adopted. It is key to note that not all participants recognized that culture affected strategy adoption. Both health professionals however worked in an institutional based setting where more standard operating procedures are found.

Results from this study also indicate the influence of stigma on persons living with dementia and families seeking help during lost and missing incidences. As highlighted by interviewees, stigma in many circumstances needs to be addressed first before exploring the other factors of strategy adoption. The internalization of negative views of dementia can result in self-stigma, which in term can lead to low self-esteem and a tendency to avoid seeking help (Mukadam & Livingston, 2012). One’s resistance to seek help may prevent families from learning about the existing strategies to reduce the risk of the person with dementia getting lost, which in turn would result in no proactive strategies being adopted.

From our interviews, 17 different types of high tech and 28 types of low tech strategies were described as being used among stakeholder in this study. Unlicensed and licensed health services used similar strategies that focused largely on the preventative side of critical wandering. These similarities as highlighted by interviewees could be due to them being made aware of the potential risks of getting lost within their schooling and work settings, and due to the potential fear of litigation (Landau et al. 2010). As noted by one of the interviewed social workers, this high perception of risk suggests the potential gap for them wanting to incorporate approaches that reduce the independence of the person living with dementia, such the prevalent use of institutionalization to address the issue of critical wandering. In terms of these specific stakeholders, education perhaps would be less on ensuring these groups are aware of the risks of getting lost, and more so need to highlight the other end of the spectrum of the Goldilocks Principle on Dementia and Wayfinding, where they need to allow these populations to still live with a degree of risk to ensure levels of independence are maintained.

The similarities in strategies among police, family caregivers and community organizations however may reflect their value of preserving autonomy of the person with living with dementia (Clarke, 2000), as well as a reflection of limited education on the use of proactive strategies. Tailored educational approaches based on each stakeholder group could be explored in future research. In addition, the diverse range of wander-management strategies among interviewees demonstrates how so many factors, such as perceived risk, culture, geography and stigma influenced what strategies they are using. This therefore highlights the need for unique combinations of strategies based on the type of stakeholder involved.

CONCLUSION

This study revealed the different approaches of stakeholders to manage dementia-related wandering. These findings were further supported by the various factors that are believed to impact their decision in adopting these strategies such as the influence of perceived risk, geography, culture and stigma. To build on the words from the involved participants in this study, the we propose a principle of balancing risk with safe among persons living with dementia at risk for getting lost termed “The Goldilocks Principle on Dementia and Wayfinding”. This principle highlights the need for ensuring independence and quality of life of this population remains intact when determining appropriate wander-management strategies. The findings from this study highlight the need to develop a conceptual framework and guideline that reflects the different approaches of adopted strategies used among participants. Data from this study will be used to contribute to the development of a conceptual framework that would be used to identify what strategies may be used to mediate the risks associated with critical wandering.

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Figures

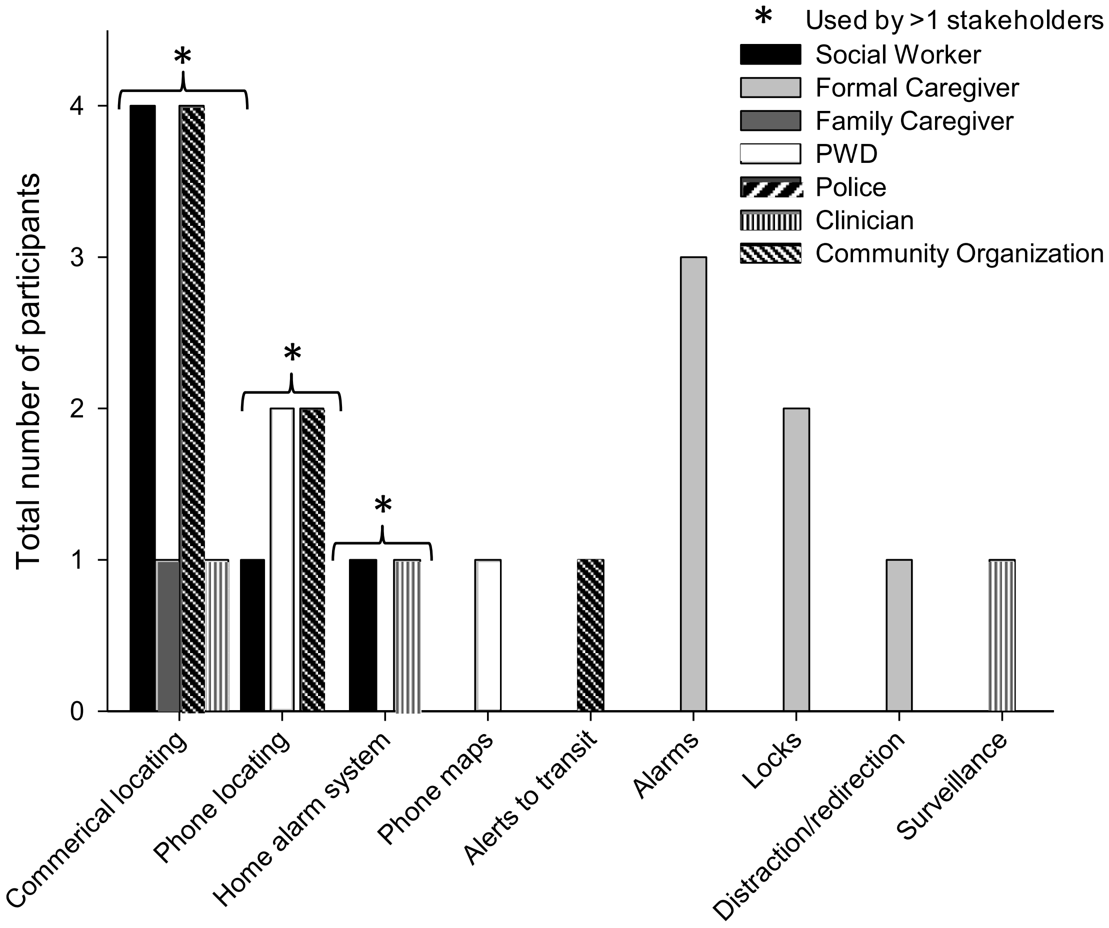

Figure 1. Wander-management high tech strategies used among stakeholders.

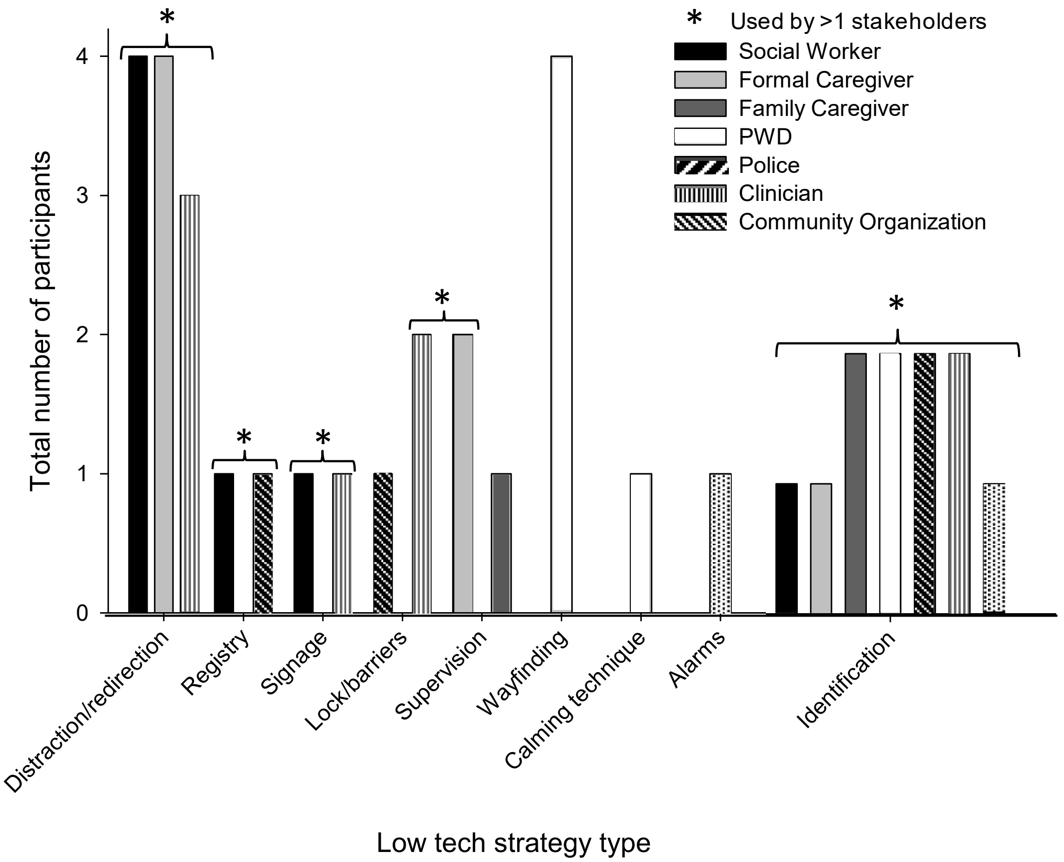

Figure 2. Wander-management low tech strategies used among stakeholders.

★ ***Goldilocks Principle***

- *Extremely high risk perception*: Fears the risk of getting lost to the point that all levels of independence are removed (e.g. home confinement, locked dementia units) — ☐ **Independence** ☑ **Safety**
- *Optimal risk perception*: Sees the risk of getting lost that causes proactive strategy adoption, however enables some level of independence for the person with dementia (e.g. early adoption of GPS devices) — ☑ **Independence** ☑ **Safety**
- *No risk perception*: Doesn't see the risk of the person with dementia getting lost. Results in no strategy adoption until a serious lost event has occurred. Leads to reactive strategies and the potential for risk perception to move to the opposite end of the spectrum (i.e. extremely high risk) — ☑ **Independence** ☐ **Safety**

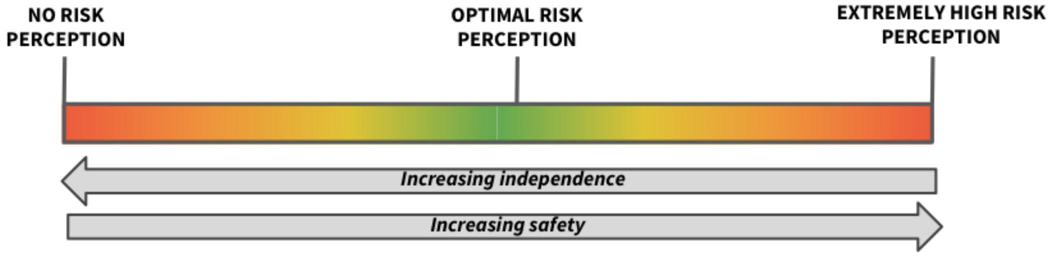

Figure 3. Goldilocks Principle on Dementia and Wayfinding

Tables

Table 1. Participant characteristics

Stakeholder	Age	Gender	Ethnicity	Education	Previous/current occupation, role or occupation setting	Experience working with PWD	Dementia characteristics of PWD	Living arrangement of PWD
Person with dementia	65 ± 4.6 years	Male (3); Female (2)	Caucasian (5); Asian (1)	College or higher (6)	Commercial pilot; accountant; supply chain management; assistant manage; data analyst		Alzheimer's Disease (3); Vascular dementia (2); Lewy body dementia (1)	Live alone (5); live in an assisted living facility (1)
Family caregiver	44 ± 11.3	Male (5); Female (5)	Caucasian (9); Asian (1)	College or higher (10)	Post office worker; consulting firm; gym owner; music or technological industry; full-time caregiver	7.3 ± 3.1 years	Alzheimer's disease (5); Vascular dementia (3); Dementia (2); 7.7 ± 4.8 years since diagnosis	Live with the PWD (5); live within close proximity (2); provide care from a distance (3)
Paid caregiver	51 ± 11.9	Female (7)	Caucasian (3); Jamaican (3); Asian (1)	College or higher (7)	Care facility settings were license practical nurses (4); community setting: nursing assistant (1), registered nurse (1)	14 ± 11 years	N/A	N/A
Police & SAR	53 ± 13	Male (4); Female (1)	Caucasian (4); Asian (1)	College or higher (5)	Staff Sergeant; media relations; road constable; search and rescue manager; adult safety educator	25 ± 7.3 years	N/A	N/A
Social work	38 ± 7.3	Male (1); Female (3)	Caucasian (4)	College or higher (4)	Transition care centres; long-term care; coordinator for an age-friendly initiative	14 ± 14 years	N/A	N/A
Community organizations	50 ± 6.8	Male (1); Female (3)	Caucasian (4)	College or higher (4)	Education and support coordinator for an Alzheimer Society; program manager for a community program; service coordinator; elder abuse support team worker	16.5 ± 11 years	N/A	N/A
Occupational therapist	58	Female (1)	Caucasian (1)	College or higher (1)	Works with clients in the community	15	N/A	N/A
Geriatric psychiatrist	64	Male (1)	Caucasian (1)	College or higher (1)	Works with patients in the community	35	N/A	N/A

Note. Abbreviations: PWD (Persons with Dementia)

Table 2. Influence of risk perception on wander-management strategy adoption across stakeholders

Stakeholder	Category	Risk Perception
Family Caregiver; PWD; Police; Formal Caregiver; Community Organization	Education of severity of risks	Not educated on the severity of the risk of missing PWD. Need to use real words to hit home the true risks of wandering. Needs to be done as early as possible.
Community Organization; Police	Education of severity of risks	People need to be aware that risk level can change quickly because dementia changes so quickly
Police	Education of severity of risks	Risk perception is influenced by the consequence of getting lost and the chance of the person getting lost; no perceived risk results in the family not prepared and no preventions are made
Police; PWD	Resources	Education and resources key to strategy adoption and risk perception. Need to implement preventative measures to reduce the risks of wandering. Sometimes people know there is a risk but don't know what to do.
Formal Caregiver; Community Organization	Misconceptions	Safety is key however fear if they admit the risk it will result in long term care, separating couples.
Police	Awareness	Unless stakeholders see the risk, they will not perceive the behaviour as a risk themselves
Family Caregiver; Social Worker; Community Organization	Supervision	Constant supervision reduces perceived risk. More eyes, less concern over risk of the person getting lost. PWD that live alone are at the highest risk. Many fail to realize the lack of supervision at night.
Social Worker; PWD; Police; Family Caregiver	Location	Familiarity of where the PWD lives reduces the risk. In small towns, everyone knows the PWD so perceived risk is reduced. Risk can also be based on location (e.g. highway, lakes, forests); homeless in the area. Need to be aware that urban environments are dangerous.
Formal Caregiver; Police; PWD	Weather and time of day	Hot and cold temperatures, getting lost at night, high precipitation and wind conditions influence risk of harm.
Social Worker	Experience of the clinician	Experience of social worker influences how much risk they let PWD live with. More experienced clinicians are more inclined to live at home with some risk.
Family Caregiver; Social Worker; Clinician; Police; Industry; Community Organization	Lived experience	Perception of risk is low until it happens to someone. Experiencing the PWD being lost increases perception of risk, resulting in strategy adoption.
Family Caregiver; Social Worker, Police, PWD, Community Organization	Balance between risk and safety	Balance between risk and safety. Some risk is necessary for independence and health of PWD. In the end safety trumps privacy (i.e. reduced privacy = increased independence). Perceived high risk = use strategies that reduces independence.
Formal Caregiver; Social Worker	Perceived risk will influence what strategies are used	Sees risk as being so high that locked doors are the only option. Risk perception influences what someone would be willing to use for safety. Families feel facilities are too afraid of risk and media coverage causing implementation of too many precautions for residents that may impose no risk at all.

Note. Abbreviations: PWD (Persons with Dementia)

Table 3. Influence of geography on wander-management strategies across stakeholders

Stakeholder	Category	Geography
Family Caregiver; Formal Caregiver; Social Workers	Location	Perceived that smaller communities are safer. In big cities, more likely to be taken advantage of and more risk for an accident to happen.
Clinician; Police; Community Organization	Location	Rural communities have a higher risk as are closer to water and wooded areas, have more risk due to isolation and greater risk to become lost and not found.
Police; Community Organization	Location	Different types of risks exist. Urban more on community risk and risk of other people. Rural the risks are focused on the environment. Urban rely on police rural rely on the community.
Family Caregiver; Formal Caregiver; Social Worker; Clinician; Police	Rural & urban life	Big cities have more individualistic culture; small towns more collectivist culture so would use a community approach.
Family Caregiver	Availability of resources dependent on geography	Lack of available resources for those that live in rural communities.
PWD	Differences in types of help seeking services	Urban and rural use different modes of help (i.e. urban relies on police or social workers and rural relies on community or church groups).
PWD	Lack of training	Social workers in rural communities less equipped to deal with dementia.
Community Organization	Lack of cell service	Types of technologies may be different as GPS may not work as well in rural.
Police	Influence of politics	Urban more bureaucracy longer to implement changes. Urban could be a lot faster.
Formal Caregiver; Social Worker, PWD, Industry	Disagrees geography should not be considered	Feels it shouldn't matter upon their geography on how they implement their safety.

Note. Abbreviations: GPS (Global Positioning System), PWD (Persons with Dementia)

Table 4. Influence of culture on wander-management strategy adoption across stakeholders

Stakeholder	Category	Culture Perception
Family Caregiver; Formal Caregiver; Police; PWD; Community Organization	Individualistic & collectivist	Individualistic vs. collectivist culture. Some less inclined to reach out for help and keep it as family business. Some are individualistic so do not want to interfere with lives of family members; Some collectivist includes multi-generational housing, influencing technology acceptance.
Formal Caregiver; Social Worker; Police; PWD; Community Organization	Understanding of dementia & wandering	Culture affects perception of dementia which will influence strategy adoption if they don't see it as an issue (i.e. some don't call dementia just say they are confused). Some cultures view dementia negatively limiting their chance of seeking help.
Formal Caregiver; Social Worker	Language barrier	Agrees it adds to the complexities. Need to be aware of language barriers; Need to consider the language spoken as it may influence the effectiveness of education.
Social Worker; Police; Community Organization	Personal experiences	Past experiences of individual influence strategy adoption (i.e. negative experience with police, technology, etc.).
Family Caregiver; PWD	Less on culture and more on personality	Need to focus on the personality of the person and what factors make up their identity (independent, etc.).
Family Caregiver; Social Worker	Family values	Need to evaluate the family's values prior to implementing strategies (i.e. keeping parents at home, privacy, etc.)
Police; PWD; Clinician	Heritage degree on dementia understanding	Degree of cultural heritage and how long the family has been in their new country of residence will influence strategy adoption.
Clinician; PWD	Geographic culture	Some provinces have a culture of institutionalization; while some multicultural countries have a bias of dementia.
Formal Caregiver; Industry	Disagrees culture should not be considered	Feels it shouldn't matter upon their culture on how they implement their safety.

Note. Abbreviations: PWD (Persons with Dementia)

Study Three Manuscript

Evaluation of antecedent behaviours of dementia-related wandering in community and facility settings

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ABSTRACT

Objective: The primary aim of this study was to identify the antecedent behaviours to critical wandering episodes among persons living with dementia in or outside of a facility. **Methods:** This prospective study followed a complete observer approach where family and paid caregivers were asked to write down the type and number of antecedent behaviours they observed of persons with dementia that were about to exit seek and leave over a period of 2 to 4 weeks. Observations were made through a developed questionnaire that prompted the necessary responses. **Results:** The average observation period was 18 ± 4.9 days. Overall, six different types of antecedent behaviours indicative of critical wandering were observed in persons living with dementia: (1) the person stating his or her intent to go outside or leave; (2) pushing, pacing and waiting near exit doors; (3) preparing to go outside (i.e., carrying a purse or putting on a jacket); (4) packing up belongings; (5) calling friends or family to be picked up; (6) draw to outside stimuli. **Conclusion:** The highlighted antecedent behaviours from this study can be used in the education of wander-management strategy adoption among family and paid caregivers of persons with dementia at risk of getting list. Information collected from this study was used to develop a series of three guidelines to assist persons with dementia and their caregivers choose appropriate wander-management strategies.

INTRODUCTION

The occurrence of missing persons incidents involving older adults living with dementia has been on a rapid incline in recent years [1]. Critical wandering, a form of wandering that leads persons living with dementia to lose their way due to wayfinding difficulties [2], is an issue in community and facility settings. In long term care, for example, some persons with dementia that "wander away" or "critically wander" [2] have a goal of finding a way out of the facility to which they devote total concentration [3]. Among community dwelling persons with dementia, many have been reported to leave their home unattended and at times have required third parties, such as first responders, to help them return home safely [4]. The risks of critical wandering include heightened caregiver stress [5], injury, death [6], and legal litigation against care facilities, staff, and family caregivers (7, 8).

While the consequences of critical wandering have been extensively explored (9, 10, 11), the antecedent behaviours indicative of critical wandering have yet to be examined within community and facility settings using a concurrent approach. For example, Heard (1997) [12] evaluated antecedent behaviours of persons with dementia that wander in a long-term care setting. Wandering behaviour however was not observed for any of the included participants, limiting the author's ability to identify such antecedent behaviours. In addition, wandering behaviour in this study was defined as "seemingly aimless or disoriented movement" [13] (p. 699) and not the critical wandering behaviours that specifically lead to exit seeking and eloping [2].

An understanding of antecedent behaviours in community settings can help family caregivers recognize and prevent critical wandering [14]. The identification of these behaviours can also contribute to the development of guidelines for adoption of strategies to mitigate critical wandering. According to Michie and Johnson (2004) [15], specific behaviours that are precisely described in guidelines enhances the likelihood of implementation as there is clarity about what behaviours to look for. Health professionals' ability to implement strategies when antecedent behaviours are present are also suggested to be a powerful way of changing behaviour [15]. For example, antecedent behaviours are assessed by physicians to determine a patient's level of risk of self-harm, such as suicide intent, which in turn influences what and when specific interventions can to be implemented [16]. A similar approach may be appropriate among persons living with dementia and their families when managing critical wandering. While antecedent behaviours related to critical wandering and getting lost may vary between individuals, caregivers can observe and recognize patters of behaviours specific to an individual. The process of recognizing patterns of antecedent behaviours can be captured in a guideline to help caregivers be proactive.

The purpose of this study was to identify patterns of behaviours that precede critical wandering episodes among community and facility dwelling persons with dementia and to determine whether these behaviours can be used to assist in the implementation of proactive wander-management strategies.

METHODS

Design

Participants

A non-probability convenience sampling method was used. We recruited 30 dyads of caregivers and older adults with dementia who critically wandered, i.e., wandered and got lost at least once a month.

Inclusion criteria of caregivers

1) Able to communicate in written and verbal English
2) Must be a family or paid caregiver to someone with a clinical diagnosis of dementia

Exclusion criteria

1) Individuals with severe vision and hearing impairments that cannot be corrected with vision or hearing aids as this would limit the caregiver's ability to provide detailed observations of antecedent behaviours exhibited by the person with dementia

Inclusion criteria of persons with dementia

1) Must have a history of critically wandering (i.e., usually or always wanders and gets lost or demonstrates exit seeking behaviour) [17]
2) Can reside in a community or facility setting

Procedure

A complete observer approach ("outsider") was followed to ensure the presence of the researcher did not influence the pre-wandering behaviours that were anticipated [18]. This approach was completed by having a caregiver write down the type and number of antecedent behaviours they observed of persons with dementia that were about to exit seek. Recordings were made through a questionnaire developed by the investigator. Questions within the questionnaire included the location of the observed behaviours (e.g., assisted living, home) and the number of times during the day a person with dementia were observed to exit seek from the home or facility. If exist seeking behaviours were seen, participants were asked to indicate what behaviours they saw that led up to this exit seeking event, whether there was one behaviour that occurred more than others, what strategies the caregiver used to try and decrease the exit-seeking behaviour, and the general level of cognitive impairment of the person with dementia that portrayed these seeking behaviours (i.e., mild cognitive impairment, moderate dementia). Should no behaviours be observed during a specific day the person with dementia tried to critically wander, participants were asked to indicate this in the questionnaire. These recordings took place for 2 to 4 weeks (or until more than one crucial wandering episode occurred).

The primary aims for this method of data collection were: (1) To determine what behaviours precede wandering episodes; (2) to determine if these behaviours were unique to each participant or if there were any similarities between participants; and (3) what strategies are used to address the observed exit seeking behaviours. Participants were recruited either individually from the community through recommendations from local Alzheimer Societies, gerontology associations, or from word of mouth in professional networks.

Data Analysis

The frequency, range, mean, and standard deviations were calculated for wandering events. Frequencies were recorded for antecedent behaviours observed, strategies used, and level of cognitive impairment. Descriptive statistics, and chi-square tests of independence were used to examine the relationship between wandering prevalence, antecedent behaviours, location of observation and level of cognitive impairment. A three-way analysis of variance (ANOVA) was conducted to compare the effect of antecedent behaviour, cognitive impairment and location of observation on wandering prevalence. SPSS 24.0 (IBM Corp, Armonk, NY, USA, 2016) was used to organize and analyze the data.

RESULTS

The sample comprised of 30 dyads of persons with dementia and caregivers. Of these caregivers, 6 were family, and 24 were nurses or care aids. Overall, participating dyads were from 2 provinces (Alberta (19/30, 63%), and Ontario (11/30, 37%). Six persons with dementia were reported to live in the community with care received from family caregivers, 9 lived in the community but frequently used a local day facility, while the remaining 15 resided in a care facility. Of the participants who received care only from family caregivers, 1 was reported to have mild dementia while the remaining 5 had moderate dementia. Of the participants who regularly attended a day facility, 3 were reported to have mild dementia and 6 had moderate dementia. Among residents observed at care facilities, 4 were reported by the caregivers to have mild dementia and 11 had moderate dementia.

The average observation period was 18 ± 4.9 days. During this time frame, 63 critical wandering attempts were observed across the 30 dyads, with a range of 1 to 3 attempts among those who only received care from family caregivers (1.8 ± 1.0), a range of 1 to 3 attempts for those at the day facility (1.9 ± 0.8), and a range 1 to 6 attempts for those living in a care facility (2.6 ± 1.4). Within those living in the community critical wandering episodes occurred during various activities, such as during a bike ride, walking, and going out for errands. Some had the intention to “go to work” or their previous residence and their caregiver could catch them in time before they left home. One was found stopped at a train station heading to Montreal from Toronto. Others within the day program attempted to leave as they thought their spouse was going to be there soon to pick them up. In care facilities, most of the persons with dementia were found trying to leave the facility, with one managing to go through the locked door and was brought back by police (Table 1).

Wander-management strategies used

Four subcategories of high and low tech strategies were used by family and paid caregivers to address the observed exit seeking behaviours: (1) distraction/redirection, (2) reassurance, (3) locator devices, and (4) signs (Figure 1). Locator devices and the use of signs were used by family caregivers only.

Among paid caregivers in facilities, common distraction/redirection strategies included removing seating from the main exit doors, playing games with the persons with dementia, singing, taking them out for a walk, talking about different topics, or engaging in chores. Reassurance strategies involved validation by showing that they are willing to help them and reassuring them that their family would come to visit them or take them for their doctor's appointment.

For family caregivers, common distraction/redirection strategies included keeping the person with dementia on a set schedule, always making sure a friend or member of the family was with the person with dementia so they were always kept busy, blocking out windows in the home to prevent the person with dementia from being drawn to going outside, and taking them out for regular walks to ensure they remained as active as possible. Family caregivers also noted validating the person's story as one of their strategies, and 4 of the 6 dyads used locator devices. Locating technologies included commercial devices such as a GPS lanyard, insole or

WanderGuard system, and downloadable mobile phone applications such as the Find My Friends app.

Antecedent behaviours observed

Overall, six different types of antecedent behaviours indicative of critical wandering were observed: (1) the person with dementia stating their intent to go outside or to a particular destination; (2) pushing, pacing and waiting near exit doors; (3) preparing to go outside; (4) packing up belongings; (5) calling and asking friends/family to pick them up; (6) drawing stimulus (i.e., drawn to the events occurring outside that they want to investigate, such as members of the community walking outside past the house, animals being seen from the window, etc.) (Figure 2).

Paid caregivers in facilities reported the following as the most common antecedent behaviours in persons with dementia: stating their intent of going outside, and pushing, pacing and waiting near exit doors. Prior to critical wandering episodes, persons with dementia were often found to ask for directions on how they could leave the facility, or expressed a need to find their way home as they did not identify the facility as their place of residence. Other common behaviours were preparing to go outside (i.e., carrying or holding their jacket, putting on extra clothes, carrying a bag/purse, pulling out their wallet, looking for their car), packing up their belongings (i.e., in bags, pillow cases and grocery bags), contacting someone from outside of the facility to pick them up, frequently looking at their watch and drawing stimuli often caused by seeing something outside that they want to investigate (Figure 2).

For family caregivers, common antecedent behaviours also included persons with dementia stating their intention of going outside, preparing to go outside such as putting on their coat and shoes and grabbing their keys, as well as being drawn to something they saw outside. What differed from this population in comparison to those in facility environments, was none of them expressed the need to pack up their belongings, nor pushing, pacing or waiting near exit doors. One family caregiver did not observe any antecedent behaviours. He noted this was because he already had a proactive strategy by having his wife wear a locator device, causing him to see no need to observe or look for any indicators of such behaviours (Figure 3).

Chi-square tests of independence were performed to examine the relation between observation location of the person with dementia, level of cognitive impairment, and antecedent behaviour type with critical wandering frequency. The relationship between these variables was not significant (observation location X^2 (10) = 7.58, $p>0.05$; level of cognitive impairment X^2 (5) = 8.12, $p>0.05$; antecedent behaviour type X^2 (40) = 53.66, $p>0.05$). There was also no significant effect of observation location, level of cognitive impairment and antecedent behaviour type on critical wandering prevalence [F (2,30) = 1.63, $p > 0.05$).

DISCUSSION

This prospective study identified the antecedent behaviours to critical wandering episodes among community and facility dwelling persons with dementia. To our knowledge, this is the first study to examine these behaviours in facility and community settings. This study found a pattern of commonly occurring behaviours that precede critical wandering which include the person with dementia stating their intent to leave the home/facility; pushing, pacing and waiting near exit doors; preparing to go outside; packing up belongings; calling family/friends to be picked up; and drawing stimuli. Of these behaviours, packing of one’s belongings and pacing, pushing and waiting near exit doors were only present in facility dwelling persons with dementia. Reasons for these minor differences in antecedent behaviours could be due to the interior design typical in care facilities. Within long term care facilities, corridors are regularly built in a way where they directly lead to the exit door and are within the wandering path of the resident. Consequently, residents are drawn to the door and can exit easily [19]. Other reasons could include the person with dementia's desire to go home, confusion as to why they are at the facility, desire to leave the environment and its stresses [20], as well as due to unmet needs of the resident often stemming from their impaired communication skills [21]. However, it is unclear how much each contributed to the critical wandering behaviour.

The findings from this study were interpreted in relation to the commonly known "ABC" approach to behavioural analysis in that it is based on the observation that behaviour is intertwined with environmental events which precede and follow the occurrence of the behaviour [22, 23]. Like Rapp et al. (1992) [24], in this model the "A" (antecedent) is the environmental event(s) or situation(s) occurring immediately before the targeted behaviour. The "B" is the behaviour targeted for modification and "C" (consequence) is the observable environmental event(s) or situation(s) occurring immediately after the targeted behaviour. What differs from Rapp et al. (1992) [24] however is that while critical wandering is a behaviour that is of concern due to the risk of getting lost and its associated outcomes, it should not be discouraged entirely due to the benefits that also arise with wandering, such coping with stressful conditions, ability to exercise [25], and providing the person with dementia with a sense of identity and independence [26]. Therefore, the approaches to managing "B" should be a balance between risk and safety.

Strategies implemented by family and paid caregivers to address observed exit seeking included distraction/redirection strategies, reassurance strategies, locator devices, and the use of signs to assist in wayfinding. These strategies were highlighted as being integrated among paid caregivers following the "ABC" approach to behavioural analysis where interventions were applied following the observation of antecedent behaviours. The type of intervention used however was largely dependent on what facility or setting the caregiver and persons with dementia were in. One of the participating sites for example, followed the Butterfly Approach [27] where differential reinforcement such as distraction/redirection strategies were the most commonly used. Therefore, the wander-management strategies used were largely determined through this policy. This is consistent with Noguchi et al. (2013) [28] where staff were trained to implement differential reinforcement following the identification of antecedent behaviours that were indicative of behavioural and psychological symptoms of dementia. This promising effect in terms of highlighting such antecedent behaviours demonstrates the importance of including these indicators in the education of wander-management strategy adoption among caregivers across community and facility settings.

The observations from this study indicate that there were behaviours that were specific or unique to each person with dementia, and there were behaviours that only occurred in facility versus community living. This suggests that personal histories, disease progression, and the physical living environments are related to the observed antecedent behaviours. Chi-square tests and three-way ANOVA in this study however found no significant relation nor effect between observation location of the person with dementia, level of cognitive impairment, and antecedent behaviour type with critical wandering frequency. This may in part be due to the small sample sizes for each category (i.e., number of community dwelling persons with dementia, cognitive impairment, type of observed antecedent behaviour, etc.). Personality characteristics may have also had an influence however such information was not collected in this study. From these results, it was identified that once a pattern of antecedent behaviours is recognized for an individual, caregivers can identify the best strategies to mitigate or prevent the incidents of exit seeking and getting lost. These antecedent behaviours however are unique to each individual and may change when the person's condition progresses, or changes living environments. These results can be further supported from Heard (1997) [12] where individualized assessment for wandering behaviour can have a significant influence on the implementation of individualized treatment conditions.

While the highlighted antecedent behaviours in this study has the potential to assist in the implementation of proactive wander-management strategies, as described by Bowen et al. (2011) [29], persons with dementia were last seen by the caregiver in sometimes as short as a few minutes before they were missing. The unpredictability and rapid occurrence could explain why these behaviours are so difficult to identify and stop. Catching these antecedent behaviours and integrating a timely intervention to prevent the person with dementia from eloping and getting lost, while useful in terms of education around the behaviour, is a challenging task especially due to the already existing time constraints and burden experienced by family and paid caregivers [30, 31]. One participant in this study implemented proactive strategies, such as getting his wife to wear a locator device long before she exhibited signs of critical wandering. Because of this, he felt there was no need to be aware of antecedent behaviours and noted that the early implementation of the locator device brought him peace of mind knowing that she was safe. This demonstrates that while antecedent behaviours can help caregivers to identify the most appropriate strategies to prevent a person with dementia from getting lost, due to these behaviours' unpredictability and rapid occurrence, early implementation of proactive strategies is recommended.

Limitations of this study

There are limitations to consider in interpreting the included results. Due to some of the participants' request for themselves and the persons with dementia they were observing to remain anonymized for the data collection of this study, baseline data such as personality, wandering characteristics, cognitive impairment using assessment tool such as MoCA, gait and balance [32] could not be collected. Future studies should therefore incorporate this information to understand why certain participants critically wander more than others and to help explain why certain behaviours are exhibited prior to a wandering episode. Despite this limitation, this study's findings may be used to design education tools to further assist in the awareness of critical wandering behaviours and the implementation of proactive interventions.

Conclusion

From this study, we identified six antecedent behaviours of critical dementia-related wandering. In many circumstances, these behaviours were unique to each person with dementia, and there were behaviours that only occurred in facility versus community living. Individualized assessment of expressed antecedent behaviours is needed in community and facility settings. Findings from this study can be used in the education of wander-management strategy adoption among family and paid caregivers. strategies.

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Conflict of interest

The authors have no conflicts of interest to declare.

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Figures

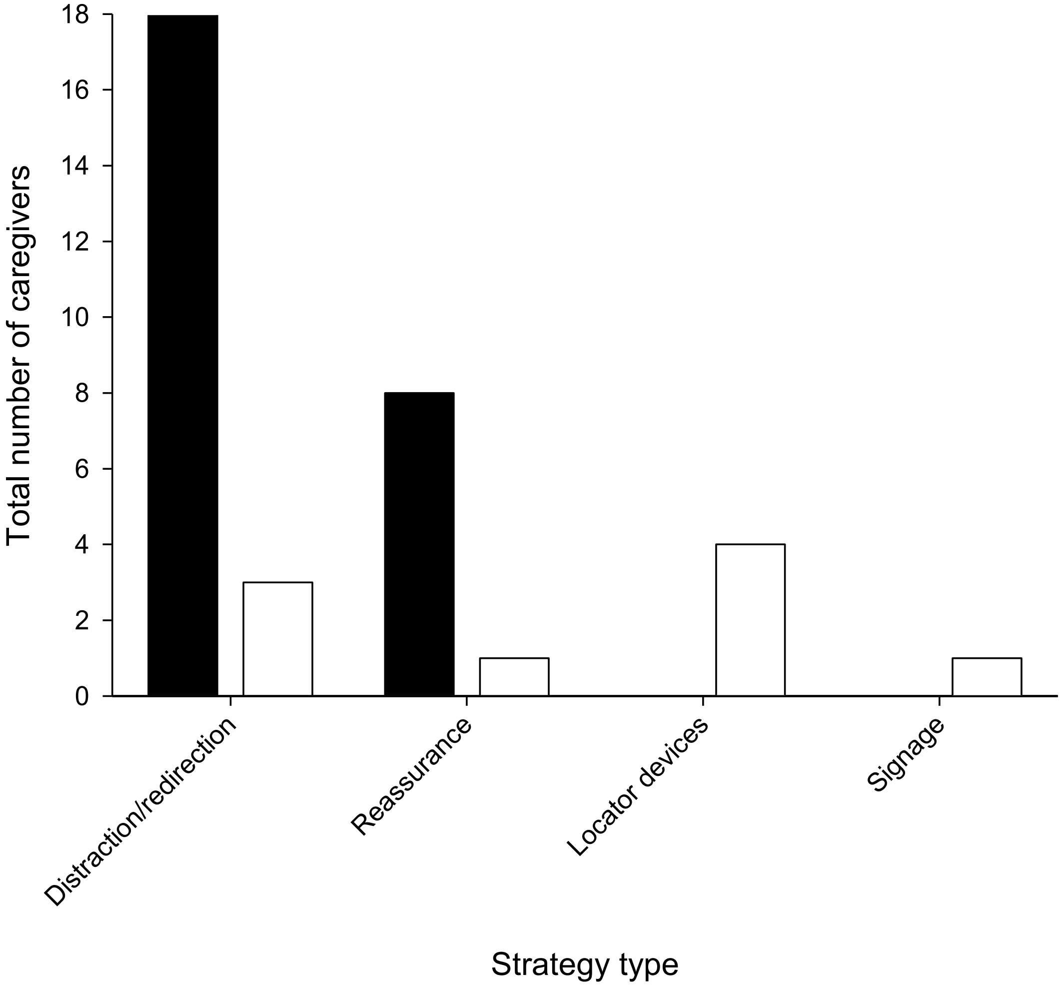

Figure 1. Wander-management strategies used among community and facility dwelling persons with dementia. Facility setting (black bar) and community setting (white bar) (n=36)

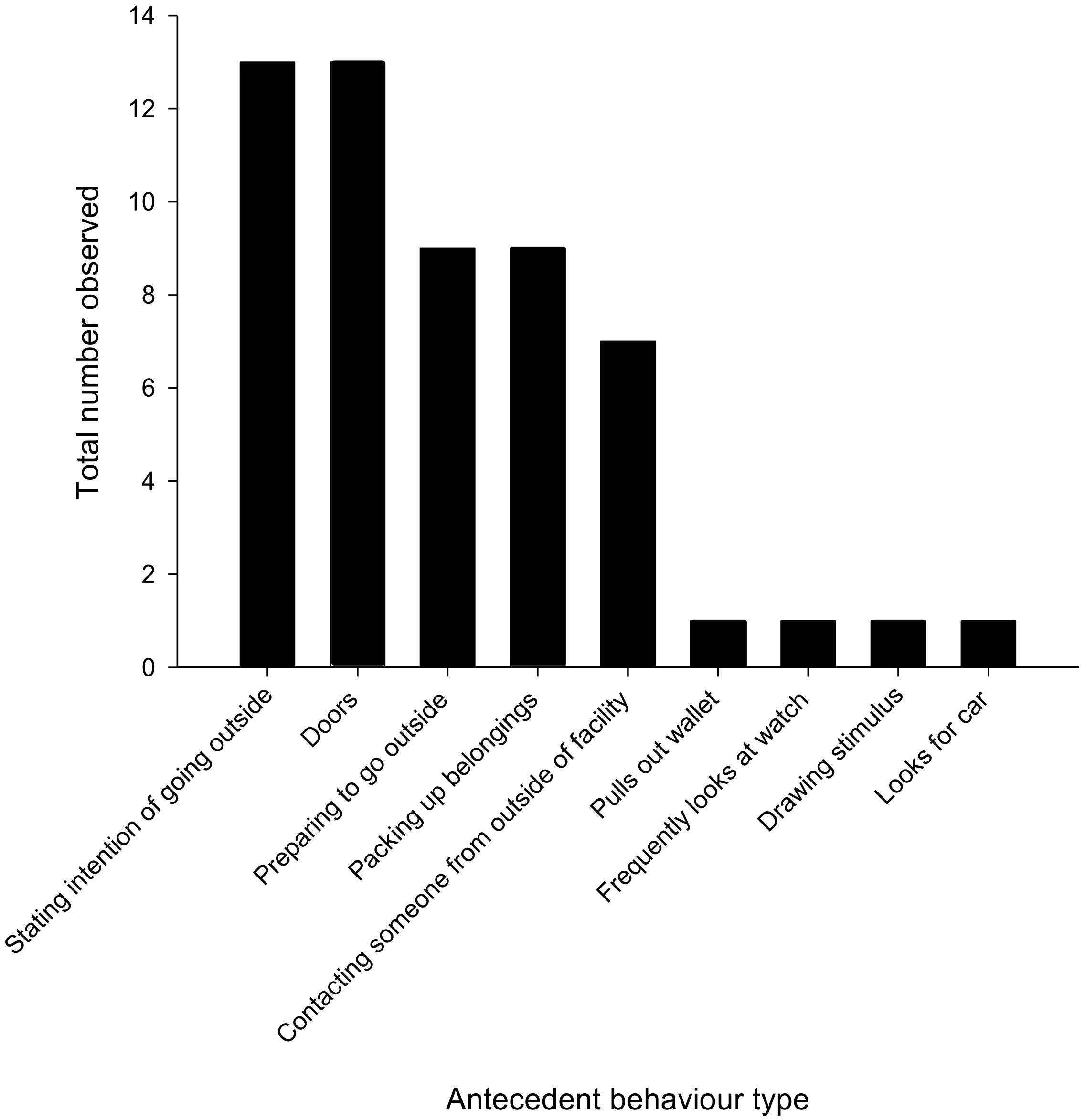

Figure 2. Observed antecedent behaviours among facility dwelling persons with dementia (n=24).

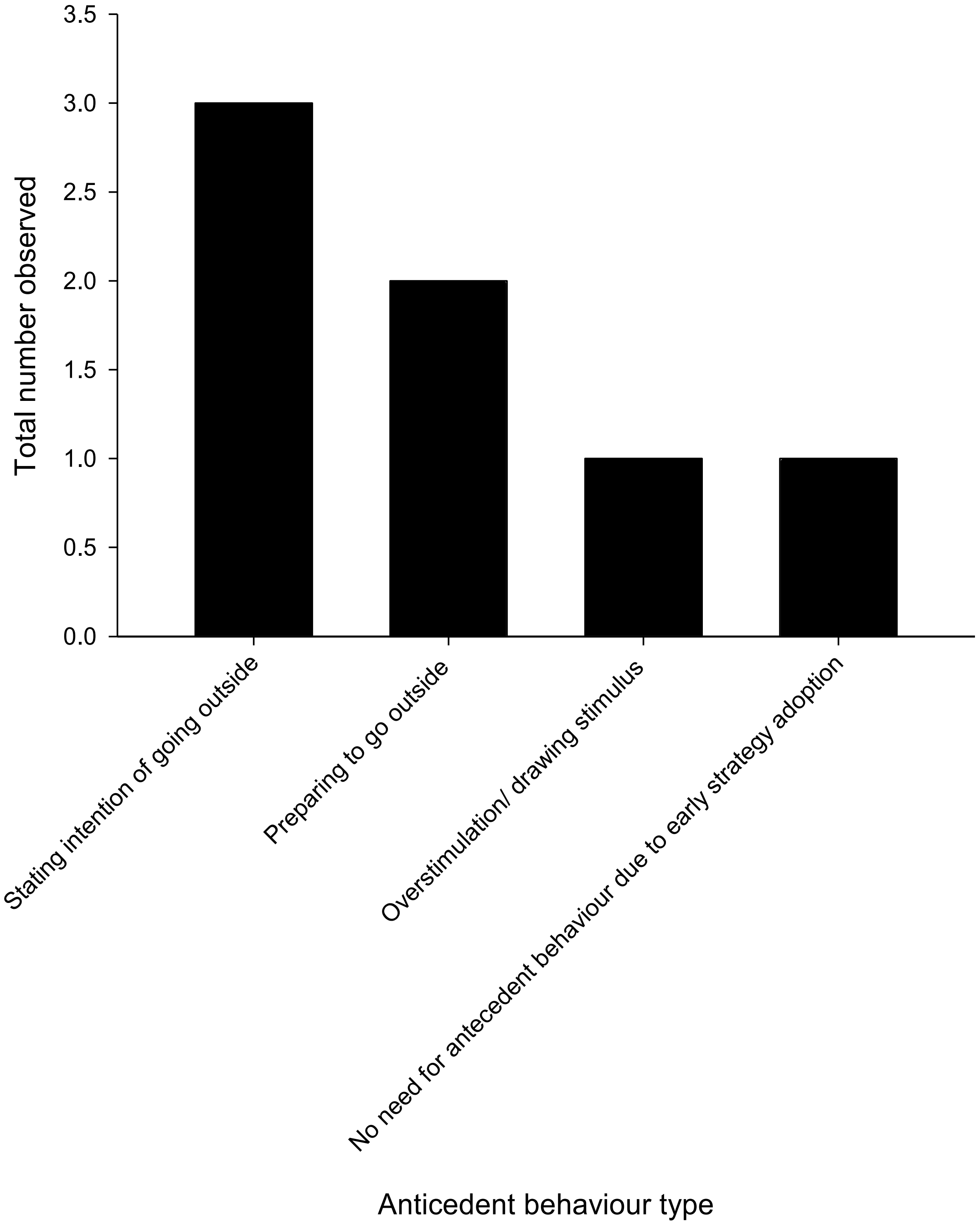

Figure 3. Observed antecedent behaviours among community dwelling persons with dementia (n=6).

Table 1. Critical wandering and exit seeking incidents among community and facility dwelling persons with dementia

Living situation of the person with dementia	Caregiver type	Description of Incident	Total number of times the incident took place
Community	Family	Went out on bike and got lost overnight	1
Community	Family	Went out for a walk without wife and got lost	1
Community	Family	Went for a walk and was brought back by the police	1
Community	Family	Went to get groceries with spouse and got lost while in the store	1
Community	Family	Went outside without notifying his wife to try and find his "home"	1
Community	Family	Went to the bank then tried to take the train from Stouffville to Montreal but was stopped by staff at Toronto Union station	1
Community	Family	Was found trying to go to work	1
Community	Family	Went out on her routine walk and husband was notified by her wearable GPS that she surpassed the created geo-fence	2
Day program	Family	Tried to leave room of day program at 1:30pm because person with dementia knew wife was coming to get him	3
Facility	Family	Went out through the locked door and was brought back by police	1
Facility	Paid	Walked out door adjacent to room or the main front entrance	6
Facility	Paid	Was trying to figure out how to open the door of the locked facility to go outside	44

Study Four Manuscript

Development and validation of a conceptual model and strategy adoption guidelines for persons with dementia at risk of getting lost

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Abstract

Various solutions are available to address critical wandering however no guideline exists to allow for the successful adoption of these strategies. This study developed and validated a conceptual framework and series of guidelines to facilitate choice of wander-management strategies. Face and content validity of the framework and guidelines were assessed through an online/paper survey, individual interviews and focus groups across stakeholders. Directed content analysis was performed. Overall impression of the conceptual framework and guidelines was positive. Valued features included the guidelines' ability to help users in choosing proactive wander-management strategies. Suggested changes included changes in terminology and additional factors and strategies to be added to the model and guidelines. This work will be disseminated and used by persons with dementia, caregivers, health practitioners, and community service providers to identify strategies to mitigate the risks associated with critical wandering.

Keywords: Wandering, dementia, strategies, guideline, conceptual framework

Introduction

The prevalence of missing persons involving older adults with dementia is on the rise (Bowen, McKenzie, Steis, Rowe, 2011; Neubauer & Liu, 2019a) and is pushing community organizations, police and policy to establish initiatives that protect persons with dementia at risk of getting lost (Neubauer et al. 2018a). The risks associated with getting lost vary from minor injuries (Douglas, Letts, Richardson, 2011), high research and rescue costs and death (Rowe & Bennett, 2003). To meet this growing need, an increasing number of high and low technological strategies have become available to consumers (Neubauer, Azad-Khaneghah, Miguel-Cruz, Liu, 2018b). Despite the promise this creates for caregivers in managing wandering at home and in long-term care, information describing these strategies remain diverse and difficult to find (Neubauer et al. 2018a). This has led to challenges that caregivers face when trying to understand how these wander-management strategies work and how to choose one that best suits their needs. A conceptual framework and series of guidelines that simplify and summarize this information on present available strategies could help simplify this information and guide caregivers and persons with dementia in this decision-making process (Landau & Werner, 2012).

Moore, Algase, Powell-Cope, and Beattie (2009) identified varying “levels” of risk through a perimeter transgression criterion, which was based off the level of predictability the person with dementia would critically wander into the community. Critical wandering, as noted by Petonito et al. (2013), occurs when an older adult leaves their home or institution and are unaware of their situation in terms of time and/or place. A low risk, for example, would be described as a person with dementia who wanders excessively within the home, makes no attempts or threats to leave the home. A high risk on the other hand, is when the individual has transgressed away from the home unsupervised and are now wandering within the community.

High tech solutions, such as alarms and sensors were then matched to these individual levels of risk. This framework was the first of its kind to simplify when high tech solutions should be incorporated, and raises implications on how caregivers can minimize the risks of harm associated with wandering.

Despite the benefits associated with Moore et al. (2009)'s model and its promises for changing how we conceptualize and manage wandering, it has its limitations. Primarily, it does not acknowledge the benefits of walking in safe surroundings, such as it serving as a means of providing exercise and is a way to cope with stressful conditions (Brittain et al., 2017), but rather focuses on the now more prevalent depiction of "risk" as negative and dangerous, instead of a neutral term that be 'good' or 'bad' and involve loss or gain (Lupton, 1999). As suggested by Douglas (1990) this neutral vocabulary of risk is necessary to ensure connection between the known facts of existence and the construction of a moral community. There are positive aspects of risk taking (i.e., important expression of individuality and independence) which could reframe activities that appear hazardous into actions which may be positive and life enhancing (e.g., exercise) (Alaszewski & Manthorpe, 2000). This approach enables persons with dementia who wander to experience a sense of independence, freedom and control. In addition, Moore et al. (2009)'s framework of wandering does not include behaviours that occur prior to critical wandering which may be used as the best opportunity to implement wander-management strategies, nor is it specific to persons with dementia living in community or facility settings.

Due to the narrow view of wandering, revisions to the framework by Moore et al. (2009) are required, from a focus on disease progression, to a view of wandering from a perspective of risk. It could be updated with the vast body of literature on wandering, and translated into something that stakeholders can use to help this population. This approach has yet to be developed and could be applied across the spectrum of wandering-related behaviours, not only when a person with dementia gets lost, but *before* such incidents occur. In this article, we propose a new model and series of guidelines that assist in successful adoption of wander-management strategies. The guidelines were developed in multiple versions based on community and facility settings, and to enhance in the usability and effectiveness of this work, a study to evaluate face and content validity was conducted.

Methods

Participants

A maximum variation sampling method was used (Patton, 2002) to reflect the lived experienced of diverse stakeholders among those who are a part of cases involving persons with dementia at risk of getting lost (Suri, 2011). A snowball sampling method (Patton, 2002) was also used to enhance the quality and richness of the information collected. This was done through recommendations of potential participants from key informants such as Alzheimer societies. Sixty-five percent of the participants were recruited from a study that preceded the development of the guideline (Neubauer & Liu, 2019a) and which described the spectrum of risks and wander-management strategies associated with dementia-related wandering and identified factors that may influence adoption of wander-management strategies. Participation of the previous study's participants was essential to ensure that responses from the first study were further reflected in the developed conceptual model and guidelines (Kitto et al. 2008). Key stakeholders (i.e., registered nurses in long-term care, home care workers, family caregivers, persons with mild to moderate dementia, clinicians, first responders, and community organizations such as Alzheimer Societies) were recruited. Ethics approval was obtained from the University of Alberta Research

Ethics Board and in accordance with the Declaration of Helsinki. Written consent was obtained prior to participation in this study.

Inclusion criteria

1) English speaking
2) For persons with dementia:
    a. Must have a clinical diagnosis of dementia
    b. Must be community dwelling
    c. Must have mild or moderate cognitive impairment (MMSE score > 10)
    d. Must express a vested interest and concern in dementia-related wandering
3) For family caregivers:
    a. Must express a vested interest and concern in managing dementia-related wandering
    b. Must be a caregiver to family member with dementia who wanders
4) For formal caregivers:
    a. Must be a caregiver for a person with a clinical diagnosis of dementia
    b. Can include a home care worker in the community or a registered nurse in long-term care
5) For other stakeholders:
    a. Must have directly worked with an individual with dementia that wanders, whether through search and rescue, heath care (i.e. clinicians), education, or caregiving

b. Must have a vested interest in assisting in the management of wandering behaviour and lost person incidences

Development of the conceptual model and guidelines

The conceptual model (Figure 1) was developed following the framework developed by Moore et al. (2009) while also incorporating the four key factors that influence the adoption of wander-management strategies from our previous work (Neubauer & Liu, 2019a): risk perception, geography, culture (Baldwin, Faulkner, Hecht, 2006) and stigma. Relationships discussed between these factors were also indicated within the model. The primary purpose of the conceptual model was to highlight the complexity of successful adoption of wander-management strategies, and to demonstrate the need for an individualized versus one-size fits all approach when choosing proactive interventions to manage the risk of persons with dementia getting lost.

The development of the guidelines involved five steps: (1) the guidelines were created as three versions, one for community settings which can include family and paid caregivers (Figure 2), one specifically addressing persons living with dementia (Appendix) and one specifically addressed for paid caregivers working in care home settings (Appendix); (2) the guidelines were broken down into low, medium, high risk and adverse event as indicated by the perimeter transgression criterion as described by Moore et al. (2009); (3) wandering behaviours indicated by Moore et al. (2009) and the highlighted antecedent behaviours from Neubauer & Liu (2019b) were added below each risk level; (4) general categories were generated from the risk management strategies identified in Neubauer & Liu (2019a) and (5) key messages from Neubauer & Liu (2019a) were added to the guidelines as a means of indicating how the guideline should be interpreted, and messages to help generate discussions as to how we should address dementia-related wandering behaviour moving forward.

To further ensure the design of the conceptual model and guidelines were effective, the following recommendations from Hoffmann and Worrall (2004) were followed during their development: (1) All key stakeholders, including patients, should be involved in the development and testing stages of designing written patient education materials; (2) The written material needs to be comprehensible to people across a range of literacy skills; (3) Provide understandable examples and present the information in a way that allows the target audience to see its relevance to their situation; (4) The text of written materials should be framed with white space and sections should be well spaced as it makes the material more appealing to the reader; (5) Illustrations should only be used if they improve the understanding of essential information; (6) Once a written health education material has been designed, it's effectiveness would be enhanced if it is pretested with a sample target audience where the reader's comprehension of the content as assessed and are given the opportunity to provide feedback about features such as content, layout and colour.

Design and data collection

The conceptual model and guidelines were developed referencing the findings of Moore et al. (2009), Neubauer et al. (2018b), and Neubauer and Liu, (2019a, 2019b). Following the creation of these tools, the face and content validity study followed a multi method design (Hussein, 2015). Qualitative and quantitative data was simultaneously collected and data from these two forms of data were triangulated in the results, interpretation and conclusion phase. Both forms of data were collected to attain an adequate understanding of the participants views regarding the developed model and guideline, and to ensure the internal validity of our findings (Bush et al., 1999). All semi-structured interviews and focus groups were conducted via telephone or through videoconferencing software to ensure responses could be made in an environment most suitable for participants to enhance their participation, and were necessary to enable to recruitment of participants across Canada (Trier-Bieniek, 2012). As noted by Morgan (1988), focus groups are essential to elicit rich experiential data and are key when providing feedback (Kitzinger & Farquhar, 1999; Powell, Single, Lloyd, 1996). Persons with dementia however, often have a harder time in larger groups and domination by one or two vocal participants is particularly problematic in research involving persons with dementia (Bamford & Bruce, 2002). To ensure all included persons with dementia could provide meaningful feedback on the developed conceptual model and guidelines, semi-structured interviews were conducted via telephone or via videoconferencing software in the comfort of their home (Nyård, 2006). All interviews were conducted individually however persons with dementia were also provided the option of participating in the presence of a family member.

Participants were provided the guidelines and conceptual model via email or mail one week prior to the scheduled interview/focus group and were asked to spend this time brainstorming their preliminary thoughts, questions and suggested changes related to this work. To assist in the participant's understanding of the guidelines and conceptual model, a detailed summary explaining the handouts were provided, and this summary was iterated by a member of the research team at the beginning of each interview/ focus group, and points of clarification were provided prior to commencing the guiding questions. The purpose of including individual semi-structured interviews and focus groups was to determine the potential of using the generated conceptual model and guidelines for being implemented for use within the community and to ensure the conceptual model and associated guidelines assist stakeholders in determining a proper course of action when trying to mitigate critical wandering and promote non-critical wandering. All participants were asked the same questions in the same order. A guide was used during the interview and included questions such as the whether the conceptual model and guidelines made sense to the participant, their potential of being implemented for use, and whether changes needed to be made to improve the usability of the model and guidelines. Interviews and focus groups were audiotaped and transcribed verbatim.

Changes were made to the guidelines and models following each focus group and interview following an iterative process (Connell et al., 2018; Luo et al., 2016). Reasons for this include ensuring the same comments and suggestions were not made to avoid the potential for early saturation (Rudmik & Smith, 2011). Due to the community organizations being responsible for the future dissemination of this work, two of the focus groups which involved community organizations were scheduled as the last focus groups to ensure the potential of this working being in its final form after the discussion with these groups.

A survey containing the latest version of the conceptual model and guidelines was also administered to all included participants immediately after each interview and focus group through paper and online versions based on their specific preference. Follow-up emails were sent to participants to complete the survey to ensure there was a high response rate. The purpose of the survey was to determine the perceived usefulness and ease of use of the conceptual model and guidelines, and to serve as a member check of the qualitative data. Factors that were evaluated included the overall rating and developed subsections such as visual features, ease of use, and applicability of the conceptual model and guidelines for the targeted population (Davis, 1989). Participants were asked to respond to each item using a five-point Likert scale from 1 – 5 (i.e., 1 as strongly disagree/strongly dissatisfied and 5 as strongly agree/strongly satisfied).

Data analysis

All interviews and focus groups were professionally transcribed verbatim. Field notes and transcripts were read and reviewed multiple times to ensure accuracy (Poland, 1995). Directed content analysis was used (Hsieh & Shannon, 2005), and a coding scheme was developed based on the interview and focus group guide. Results from the Likert scales within the online survey underwent descriptive analysis. Due to the small sample size, Kruskal-Wallis H Tests were conducted for the survey data to determine if differences arose across stakeholder types. The qualitative and quantitative data were combined at the level of analysis (Hussein, 2015), where survey data was used to support the findings from the interviews and focus groups. Excel, IBM SPSS and NVivo were used to assist in the analysis of the collected qualitative and quantitative data.

Results

Face and content validity

The sample for the face and content validity of the conceptual model and associated guidelines (n=37) comprised of persons with mild dementia (n = 5), formal caregivers (home care (n = 2) and registered nurses (n = 4) from long-term care), family caregivers (n = 4) whom have expressed concern in managing dementia-related wandering, community organizations (i.e., Alzheimer Society) (n= 13), first responders (n = 4), clinicians (n = 2) and social workers (n = 4). The semi-structured interviews among persons with dementia took approximately 40 minutes each, and focus groups took between 60 – 90 minutes. All thirty-seven participants completed the subsequent survey. Overall, participants were from 5 provinces (British Columbia (6/37, 16.2%), Alberta (20/37, 54.1%), Ontario (6/37, 24.3%), Nova Scotia (1/37, 2.7%), Newfoundland (1/37, 2.7%), across 14 cities/communities.

Analysis of the interview transcripts and online surveys resulted in four main categories: (1) overall perception of the conceptual model and guidelines; (2) changes that need to be made; (3) potential of the model and guidelines for uptake; (4) and ways of seeing the model and guidelines used.

Overall perception of the conceptual model and guidelines

The overall impression of the conceptual model and guidelines was positive. Participants were very satisfied with the initial presentation of this work with an average Likert score of 4.00 (± 0.71) for the conceptual model and an average Likert score of 4.41 (± 0.70) for the associated guidelines. Such results were consistent across all participants (conceptual model $x^2(6) = 8.900$, $p = 0.18$; guidelines $x^2(6) = 2.233$, $p = 0.90$) (Figure 3). Enjoyed features that were discussed in most of the focus groups and interviews included the visuals involved (Likert score conceptual model 4.31 ± 0.76, $x^2(6) = 10.052$, $p = 0.12$; guidelines 4.71 ± 0.49, $x^2(6) = 3.615$, $p = 0.73$) such as the use of bright colours and infographics. Participants felt the information was presented coherently, and particularly liked the strategies that were included. Perceived benefits included their proactive approach and ability to guide health professionals, social workers and community organizations through conversation to help them decide what strategies families can use to keep the person with dementia safe. As noted by one social worker:

"I thought this is what we need- we needed sort of a way of guiding people through a conversation to help them decide what they need and so I was really excited about it."

Among interviewed persons with dementia, many demonstrated excitement about a tool that will help them maintain their independence and to be proactive in their own care.

"When someone's first diagnosed it gives them something to take home and look at and read and process - and it helps us be proactive in our own care. I was so afraid because they were talking about me going into a facility so that created a lot of stress for me."

It was also affirmed by the involved persons with dementia the points discussed in Neubauer & Liu (2019a) were reflected in the model and guidelines.

"I think you've hit the real chief points. I really like these - I think again I was at a higher risk not that long ago when I lived alone; now that I'm no longer living alone, my risk is a little less, although because I do naturally explore it puts me at that higher risk level again. I think you've done an amazing job, I really am happy with what I see here."

Relating specifically to the developed guidelines, participants, noted the layout was easy to understand and has the potential to help stakeholders determine the risk level and understand what is coming next for the person with dementia critically wandering. Day to day words, bullets for the different risk factors and looking at the issue from risk rather than disease progression attributed to this. The high levels of perceived ease of use among all involved stakeholders was further supported by the surveys (Likert scale 4.5 ± 0.64, $x^2(6) = 2.456$, $p = 0.87$) (Figure 3). It was also indicated that participants, such as health professionals, liked the statement that risk levels can change at any time. This message included in the guidelines helps to underscore the unpredictability of critical wandering. A registered nurse for example stated:

"I really think at the very end you had the one sentence that said, the risk levels can change at any time, and that underscores the unpredictability of it; don't get confident that what you need to do, you don't need to do anymore. It changes all the time."

One police officer also noted:

"What I like is, under Risk, it seems to be, like, a very clear criteria. We're familiar with this from search and rescue, because we have a risk management framework developed here in British Columbia that handles this kind of thing."

Participants, specifically the community organizations, social workers, and health professionals liked that the guidelines are trying to shift the language around wandering, specifically that we want to encourage the behaviour rather than restrict it. As noted by one of the health professionals:

"The other thing I do really like about this, is that it's trying to shift the language around wandering. This is a start about talking about that, because wandering does have a negative

connotation. And to be able to let people live with risk and have some behaviours that might be risky, but still let them do that a little bit, right?"

The conceptual model in its present state was consistently emphasized across all participants as being complicated and overwhelming due to the higher-level framework (Likert scale 3.6 ± 1.02, $x^2(6) = 10.840$, $p = 0.09$). While it took time for many participants to understand it, interviewees, such as social workers noted it as being compelling and was necessary to demonstrate the complexity in terms of successful adoption of wander-management strategies. Among social workers and community organizations, many felt it captured their experiences when working with persons living with dementia, highlighting that there are many factors that come into play.

"I was overwhelmed by the first page but I had some time to kind of digest it. I found it really compelling… I think the complexity of this issue is properly demonstrated in this image, like it is complex and I think avoiding some of the complexity might develop some problems later on, so I think it's a really good framework right now… yeah I'm excited for it."

Social workers, clinicians and Alzheimer societies noted they would like to see the conceptual model eventually turn into a series of questions they could ask regarding each factor, such as geography, and link them directly to the developed guidelines. Including different weights to each of the included factors would also be useful to assist in determining which factors to emphasize among persons with dementia and their families.

"And you have questions and maybe some idea of the different weights of these different factors. Work when you translate it for more of a general audience, because I think it would be really nice to have something theoretical. And simplified."

Pertaining to the Goldilocks principle on Dementia and Wayfinding, participants liked the concept and felt that the balance between safety and independence is a crucial part of the discussion when looking at potential strategies to mitigate dementia-related wandering. An Alzheimer Society staff for example stated:

"I think is a really crucial part of the discussion and its part of the reason why - if the person living with dementia is still able to be part of the conversation they definitely should be because often that kind of swing to the high end of risk management could be the thing that actually really impacts quality of life."

Changes that need to be made

Suggested changes provided by participants within the interviews and focus groups were broken into five categories for the developed guidelines: (1) listed strategies, (2) terminology, (3) layout, (4) risk, and (5) ease of use. Three categories were revealed for the conceptual model: (1) terminology, (2) additional factors, (3) additional visuals (Table 1). In general, most edits discussed were related to listed strategies within the guidelines. This ranged from including vulnerable persons registries in all four risk levels and adding strategies what were missed in Neubauer et al. (2018b) and Neubauer & Liu, (2019a) such as including a list of where the person with dementia used to live and work, and having someone regularly checking in on those with dementia that live alone. Terminology for the conceptual model and guidelines, involved the need to be aware of the negative connotation that could arise with the chosen wording as well as ensuring the terms used are specific, understandable, and consistent to all audiences. Finally, funding, literacy and isolation were recommended to be added to the conceptual model as additional influencing factors to strategy adoption.

Potential for and application of the model and guidelines for uptake

The potential for uptake of the conceptual model and associated guidelines was well received among all involved stakeholders (4.27 ± 0.88) and several avenues as to where this work could be used was expressed (Table 2). Social workers, family caregivers, and persons with dementia for example explicitly stated their intention of using them when they are disseminated. This in part is due to the desperation that exists for information and due to the limited available guidelines of strategies to manage critical wandering. One family caregiver stated:

"People are desperate for information. I think it is even powerful for the person with the diagnosis to be given information about what might be coming their way because that is often lacking too. Just as you said, that they're not really given the tools, this is a tool that can be used for everybody in the situation."

Overall, the most important piece of the conceptual model that will assist in the implementation of such management strategies is their ability to serve as a discussion piece with family caregivers and persons with dementia. Community organizations for example felt the conceptual model could be implemented within their existing dementia friendly initiatives. Just knowing that this work comes from a reputable source of in-depth information can help in training those at local Alzheimer Societies. For social workers, they could see themselves using it during their meeting with patients and caregivers who struggle to balance the risks between independence and safety. Specifically related to the guidelines, this work was suggested to be a good substitute to rough draft notes from health professionals due to it being professionally developed and from evidence based practice, and could serve as a handout for doctors, police and community organizations. Alzheimer Societies from across the country could also see potential for including this work within their education programming due to the hunger for practical tools that are easy to use. Within British Columbia for example it was stated:

"I can certainly see it being incorporated into our education programming as well. I feel like we've got the sort of channels to distribute it out there, so I think there's definitely lots of possibility and I think there's also that hunger for the information and for some really practical kind of tools. I'm sort of excited about the strategies, like having that as a supplement to this."

Across stakeholders it was felt the conceptual model (Likert scale 4.3 ± 0.89, $x^2(6) = 8.155$, $p = 0.23$) and guidelines (Likert scale 4.4 ± 0.78, $x^2(6) = 10.972$, $p = 0.09$) have the strong applicability of getting help by helping families to identify the risks of getting lost, being able to provide the options for managing critical wandering all in one place and increase awareness to the families that more help is available to them. Family caregivers for example unanimously understood and appreciated the ability of the conceptual model and guidelines to assist them in determining a strategy that is tailored for each person living with dementia regardless of where their loved one is residing. It was viewed that the antecedent behaviours would acts as a clue for the caregiver to determine what is causing the wandering behaviour such as unmet needs, etc.

While the implementation of the model and guidelines were promising across all interviews and focus groups, it was mentioned among police, persons living with dementia and paid caregivers that their success will largely depend on the timeframe the guidelines get introduced to the family and person with dementia, and the frequency of when the risk assessment needs to take place. Within search and rescue for example, risk assessment occurs whenever conditions such as weather changes. This same approach may therefore be required to ensure the right strategies are in place to reduce the risks associated with the person with dementia getting lost.

"It's one of those things that needs to be brought forward over and over again to remind people to – because that's one of the things we talk about in search and rescue, risk assessment isn't something you do once and then stop."

Health professionals on the other hand would likely use the guidelines in a follow-up appointment and during a time when they are more open to accepting new information. The first initial appointment is often overwhelming. It is key to note however that this caution was not expressed among interviewed persons with dementia where many were reading everything they could after their initial diagnosis and considering every angle.

Discussion

The purpose of this study was to develop and provide face and content validity for a conceptual model and series of guidelines to assist in the adoption of high and low tech wander-management strategies for persons with dementia at risk of getting lost. Through interviews, focus groups, and surveys, key stakeholders provided their views and concerns relating to the content, structure, ease of use, and applicability of the developed conceptual model and guidelines. In summary, they expressed concerns over terminology that was sensitive and could potentially deter caregivers and persons with dementia from using them; confirmed and suggested additional factors, strategies, and messages missed within the model and guidelines; and provided guidance in terms of their final layout and future directions. Suggestions provided resulted in a total of fourteen iterations to the guidelines, and four iterations to the conceptual model.

While the reliability of instruments and guidelines are important, the key stage of development of any tool is that of content and face validity (Connell et al., 2018). Like the findings from Connell et al., (2018) this paper demonstrates the importance of considering the views of end users who will ultimately adopt and disseminate this work. Including participants from all involved stakeholder groups (i.e., police, community organizations, persons living with dementia, caregivers, health professionals) ensured aspects such as readability, and stigma were addressed to further improve the usability and opportunity of adoption of the developed model and guidelines. By including such a diverse group of key stakeholders with vast experiences in the field of dementia-related wandering, multiple perspectives could be included. This as a result may avoid false objectivity (Thomas, Hathaway, Arheart, 1992), and significantly improve the capabilities of successfully mobilizing the knowledge of this work to the public (Abma et al., 2017).

In terms of the developed conceptual model, while factors that influence behavioural intervention research has been extensively explored in other areas of dementia (Gitlin & Czaja 2016), this model is the first to involve the perspectives from an array of stakeholders whom are in contact with people with dementia that critically wander, and examine the relationships of all factors that may influence specifically the adoption of wander-management strategies. The model highlights the complexity in terms of choosing strategies that will be successfully integrated among caregivers and persons with dementia and showcases that it is not as simple as users understanding the risks associated with dementia-related wandering. Factors such as geography and culture for example were suggested among stakeholders as having a significant influence on how families and persons with dementia perceive the risk of getting lost. If one factor is not taken into consideration, this may have a significant influence on the type of strategy that should be suggested to the user. Therefore, as suggested by participants in this study, the model could be used by health professionals and community organizations to guide discussions with family caregivers and persons with dementia. To improve its ability for successful integration however, the conceptual model will need to be developed into a series of questions regarding each factor, such as geography, and link them directly to the developed guidelines. The weighting of each factor and quantifying it into a predictor model will also be useful to assist in determining which factors to emphasize among persons with dementia and their families. Subsequent studies can address these suggestions.

Pertaining to the developed guidelines, recommendations in guidelines are rarely specified in precise behavioural terms such as who, what, where, when and how (Michie &

Johnston, 2004). An example of this is the National Institute for Clinical Excellence which has been widely circulated throughout the NHS (National Institute for Clinical Excellence, 2002). Despite the high-quality review of evidences of the guideline, the recommendations were not behaviorally specific, it is long and the recommendations in short form exceed 20 pages, making it difficult for users to find the recommendations. The same could be said for the framework developed by Moore et al., (2009) where the non-pharmacological wandering management strategies were listed in table format across 3 pages, strategies were not matched based on the type of stakeholder involved, and the specific behaviours rather than being matched to each specific strategy, were listed in a separate table. Therefore, for the developed guidelines in this study for wander-management strategies, three versions were created for: (1) persons living with dementia, (2) care homes, and (3) community. This is unique because to our knowledge, few materials have been developed in such a matter that provides guidelines on strategies for different settings, and includes a tool specifically for those living with dementia. There is a tendency for educational tools to target only caregivers. In this study, participants living with dementia want to become active agents in their own care, however lack the resources to do so. This is particularly of relevance for persons with dementia that live alone, a population that is on the rise and is becoming a greater concern (Eichler et al., 2016).

The guidelines were also minimized so all information was condensed into a one page hand-out, and they provide a wide array of potential strategies to address the distinct factors addressed in the conceptual model that may impact strategy adoption (Gitlin & Czaja, 2016). Aside from highlighting available strategies for persons with dementia and caregivers to implement, the guideline organized these interventions by risk level, noting specific behaviours that would indicate *who* and *when* the individual would fall under each level. These behaviours were collected in a previous study by Neubauer & Liu, (2019b) where observations of antecedent behaviours that indicate critical wandering were made by formal and family caregivers in community and facility settings. By having such antecedent behaviours included, proactive strategies may be able to be implemented in a timelier fashion to prevent the behaviour from becoming an incident (Stockley, 2015; Wheeler, Carter, Mayton, Chitiyo, 2006). As indicated by Neubauer & Liu, (2019b) and Bowen et al. (2011) however, these behaviours at times are unpredictable and can occur just seconds prior to critically wandering. Therefore, while useful in terms of education around the behaviour, it is recommended that proactive and preventative strategies within the guideline are implemented as early as possible and are cautioned from waiting until the indicated antecedent behaviours become present.

While a wide range of wander-management strategies have been integrated within the developed guidelines, it is important to note the limited evidence for many of the suggested strategies. As noted by Neubauer et al. (2018b), few studies have evaluated the effectiveness of high and low tech wander-management strategies, raising question whether certain strategies are more effective than others and if certain combinations of strategies are necessary to meet the unique needs of persons with dementia and their caregivers. To further increase the potential impact of these guidelines on users, future studies are therefore required on the included strategies. Rigorous research using methodologies such a single case design (Law et al. 1998) on the suggested strategies would also be useful to indicate the effectiveness of the developed guidelines.

Aside from the specific evaluation of implemented wander-management strategies, it was indicated among participants that there is a driving need to understand when is the opportune time to discuss with families the risk of getting lost. It was expressed that caution needs to be placed on beginning these discussions too early such as when families receive the initial diagnosis of dementia due to the fears of overloading them with too much information. This may however depend on the background of the person with dementia. One of the participants living with dementia for example was a retired nurse that worked in long-term care. Due to her extensive experiences working with dementia populations, she was proactive after receiving her initial diagnosis, reading everything she could get her hands on and considering every angle. The conceptual model therefore may also play a role in timing, where it may differ depending on the background of the person with dementia and their family (Flemming, Closs, Foy, Bennett, 2012). Unfortunately, there is limited evidence as to when to begin these conversations. Therefore, future research needs to be done to evaluate this among other dementia education tools to ensure successful adoption of the suggested strategies.

Limitations of this study

The authors did not conduct an audit trail of the analyzed qualitative data, which may have had an influence on the data's credibility (Finlay, 2006). To account for this limitation, member checking of the conceptual model and guidelines was performed by having all participants complete an online or paper survey that contained the suggested changes from the interviews and focus groups. Changes missed following the interview and focus groups could be further reflected in the model and guidelines following the administration of the survey.

Conclusion

Critical wandering is becoming a more prevalent public health concern as our population ages and as more persons are living with dementia. To minimize the risks associated with this behaviour and to encourage the use of proactive strategies, we have provided a conceptual model and series of guidelines to facilitate choice of wander-management strategies. Our work extends from the framework developed by Moore et al., (2009), where it includes antecedent behaviours indicative of critical wandering, have developed guidelines specifically tailored for the community, care homes, and persons with dementia, and have developed a conceptual model that identifies the factors that may influence the adoption of the suggested strategies. This work serves as a starting point for tailoring a specialized program of care for persons with dementia at risk of getting lost, regardless of their place of residence. Future directions include the development of a quantitative predictor to assist in determining which factors from the conceptual model to emphasize among persons with dementia and their families, and the dissemination of the guidelines to community and health organizations internationally.

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The authors have no conflicts of interest to declare.

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Figures

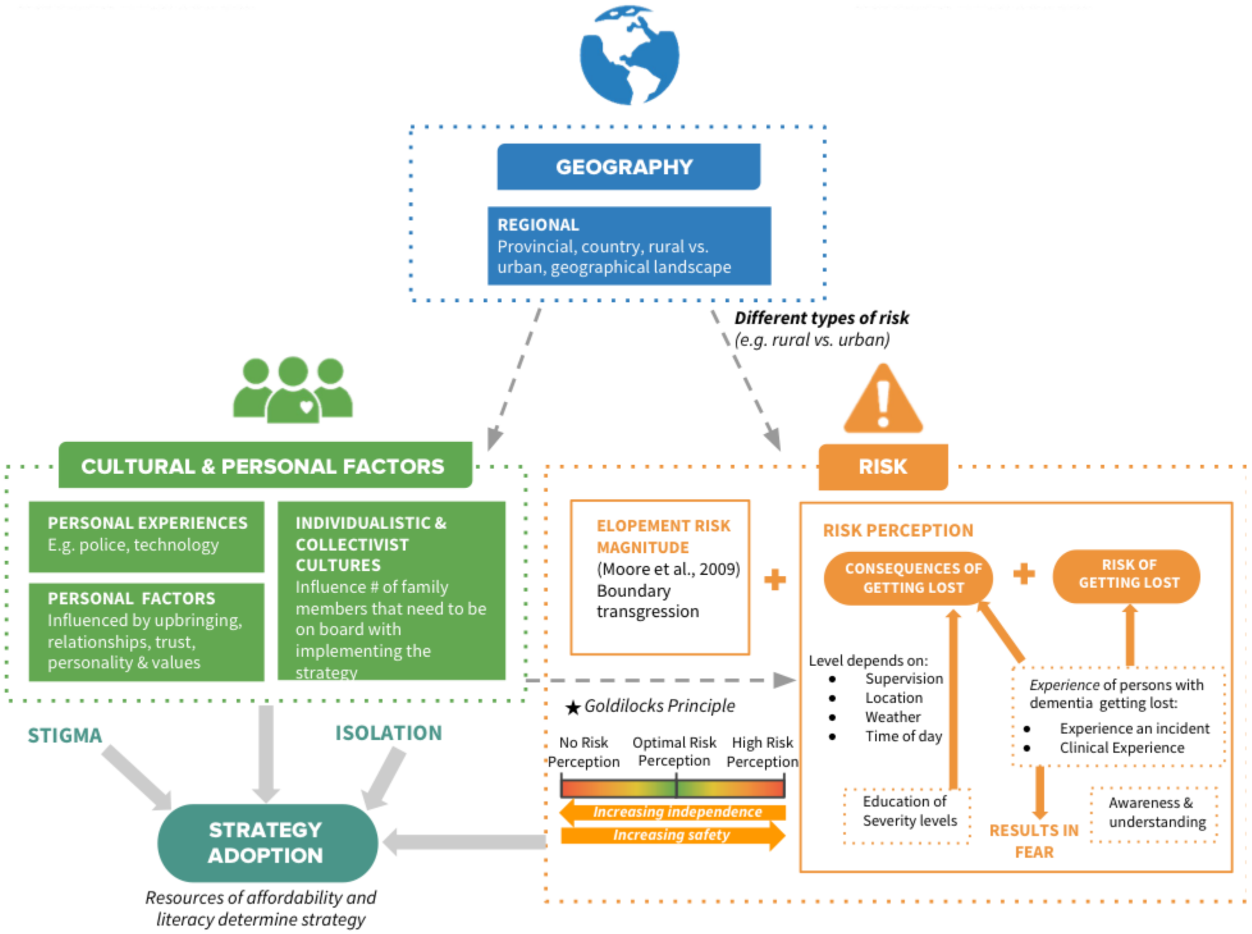
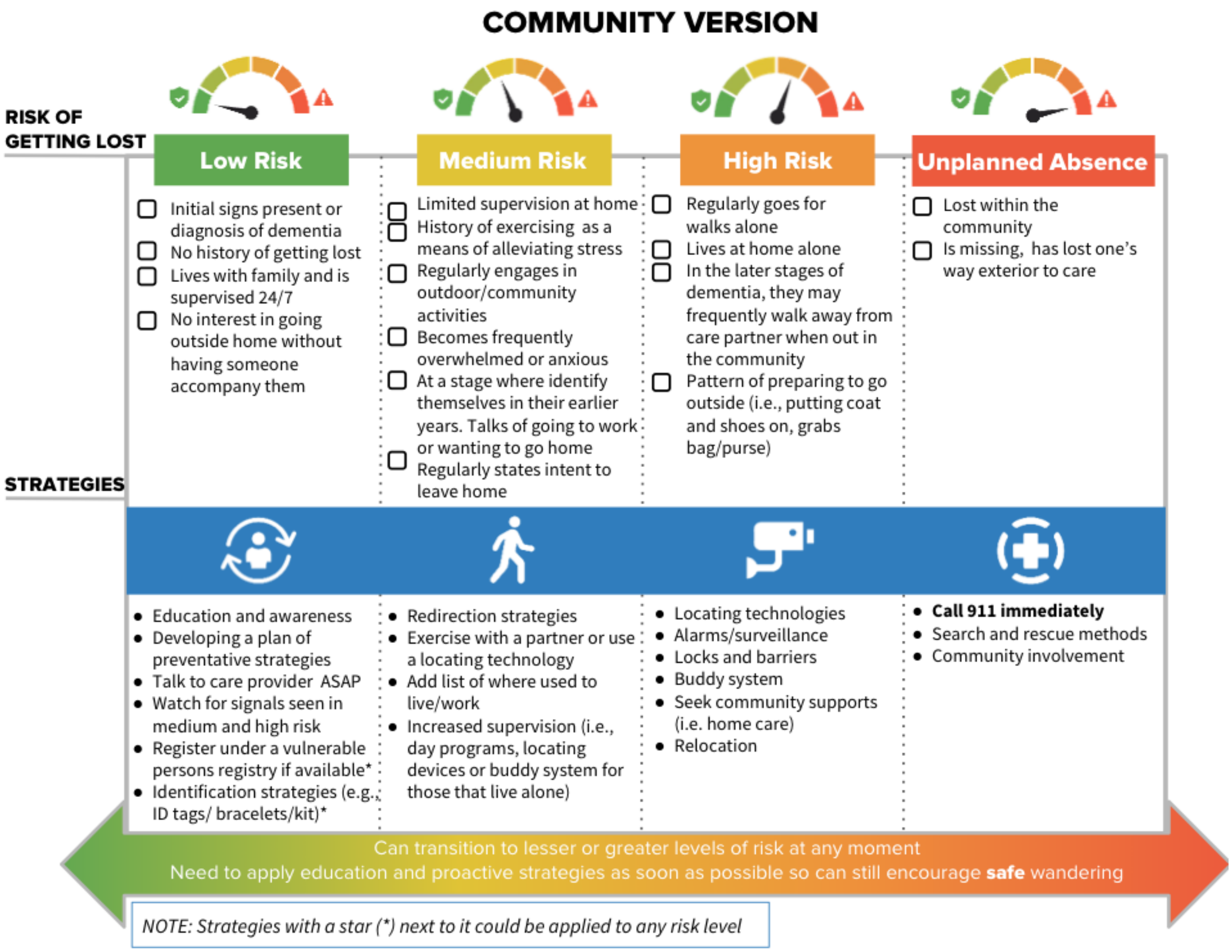


Figure 1. Conceptual Framework on Strategy Adoption for Dementia and Wayfinding.

COMMUNITY VERSION



RISK OF GETTING LOST	Low Risk	Medium Risk	High Risk	Unplanned Absence
	☐ Initial signs present or diagnosis of dementia ☐ No history of getting lost ☐ Lives with family and is supervised 24/7 ☐ No interest in going outside home without having someone accompany them	☐ Limited supervision at home ☐ History of exercising as a means of alleviating stress ☐ Regularly engages in outdoor/community activities ☐ Becomes frequently overwhelmed or anxious ☐ At a stage where identify themselves in their earlier years. Talks of going to work or wanting to go home ☐ Regularly states intent to leave home	☐ Regularly goes for walks alone ☐ Lives at home alone ☐ In the later stages of dementia, they may frequently walk away from care partner when out in the community ☐ Pattern of preparing to go outside (i.e., putting coat and shoes on, grabs bag/purse)	☐ Lost within the community ☐ Is missing, has lost one's way exterior to care
STRATEGIES	● Education and awareness ● Developing a plan of preventative strategies ● Talk to care provider ASAP ● Watch for signals seen in medium and high risk ● Register under a vulnerable persons registry if available* ● Identification strategies (e.g., ID tags/ bracelets/kit)*	● Redirection strategies ● Exercise with a partner or use a locating technology ● Add list of where used to live/work ● Increased supervision (i.e., day programs, locating devices or buddy system for those that live alone)	● Locating technologies ● Alarms/surveillance ● Locks and barriers ● Buddy system ● Seek community supports (i.e. home care) ● Relocation	● **Call 911 immediately** ● Search and rescue methods ● Community involvement

Can transition to lesser or greater levels of risk at any moment

Need to apply education and proactive strategies as soon as possible so can still encourage **safe** wandering

NOTE: Strategies with a star (*) next to it could be applied to any risk level

Figure 2. Community Version Guideline for the management of dementia-related wandering. ID = identification.

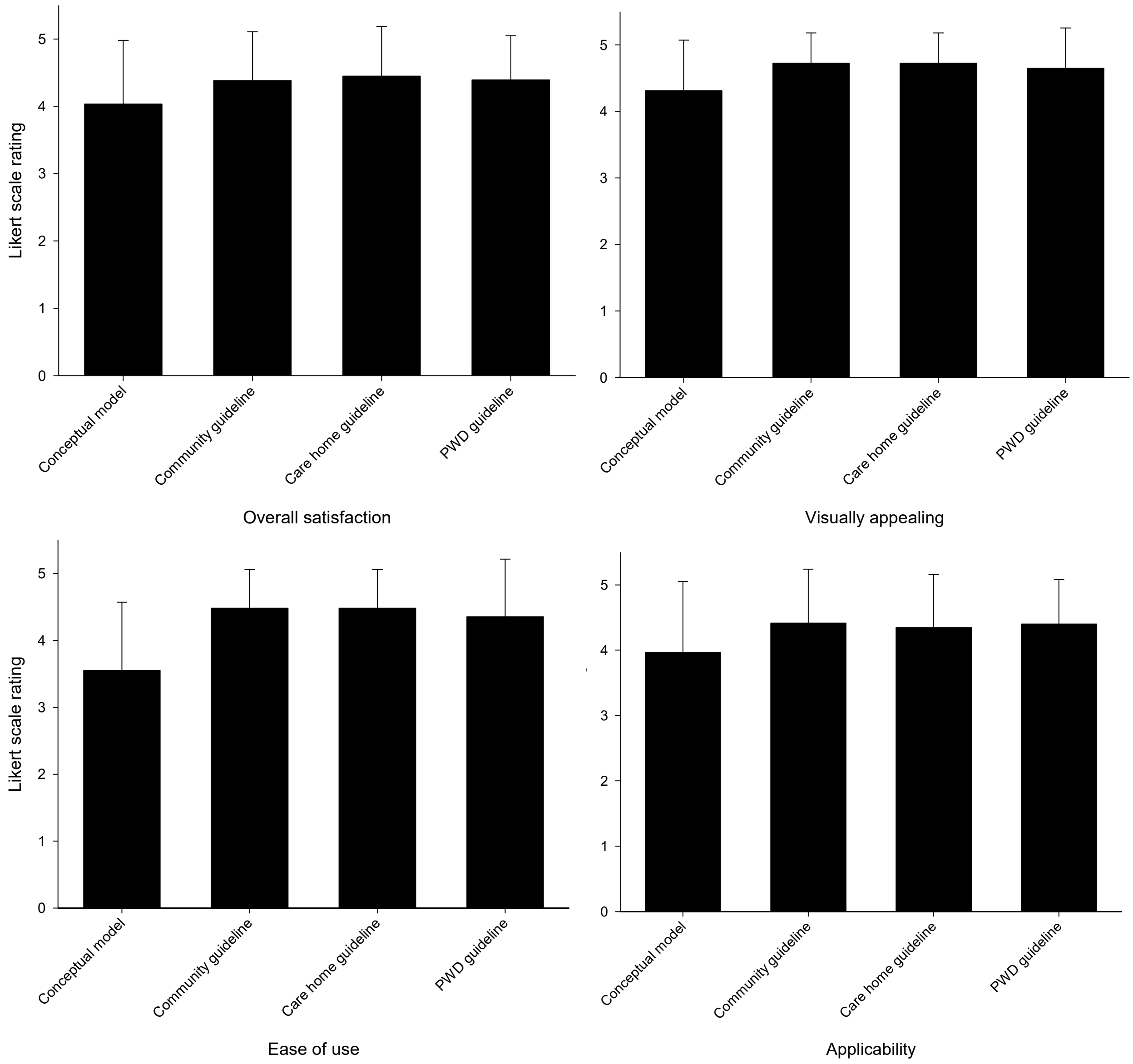


Figure 3. Perceived usefulness and ease of use of the conceptual model and guidelines. Likert scale 1-5 (1 = strongly agree, 5 = strongly disagree) (n=37). PWD = persons with dementia.

Tables

Table 1. Proposed changes to the guidelines per stakeholder type

Note: Abbreviations: PWD (Persons with dementia)

Change Type	Suggested Change	Stakeholder Type
Terminology	Eloped and exterior to care are not familiar terms. Need to remove or reword them.	Family caregiver, community organization
	Drawing stimulus is not a familiar term. May require rewording or further examples/ explanation	Community organization
Education	Would like to see the guidelines incorporated in education sessions	Community organization
	Need to be sure that high risk people are not intimidated by newer technology. Should teach them these things prior to their dementia becoming more severe.	Health professional
Availability in other languages	Need the guidelines in multiple languages so they can be used with non-English speaking families and/or persons with dementia	Family caregiver, community organization
Links	Would like to see more links for strategies such as the Vulnerable Persons Registry, and identification strategies	Family caregiver
Too much information	Need to ensure the guidelines are for those with a lower education and have the option to be provided in a larger font	Social worker, clinician
Change in layout		
Additional strategy	Add a spectrum to the Goldilocks principle to assist in its messaging	Community organization

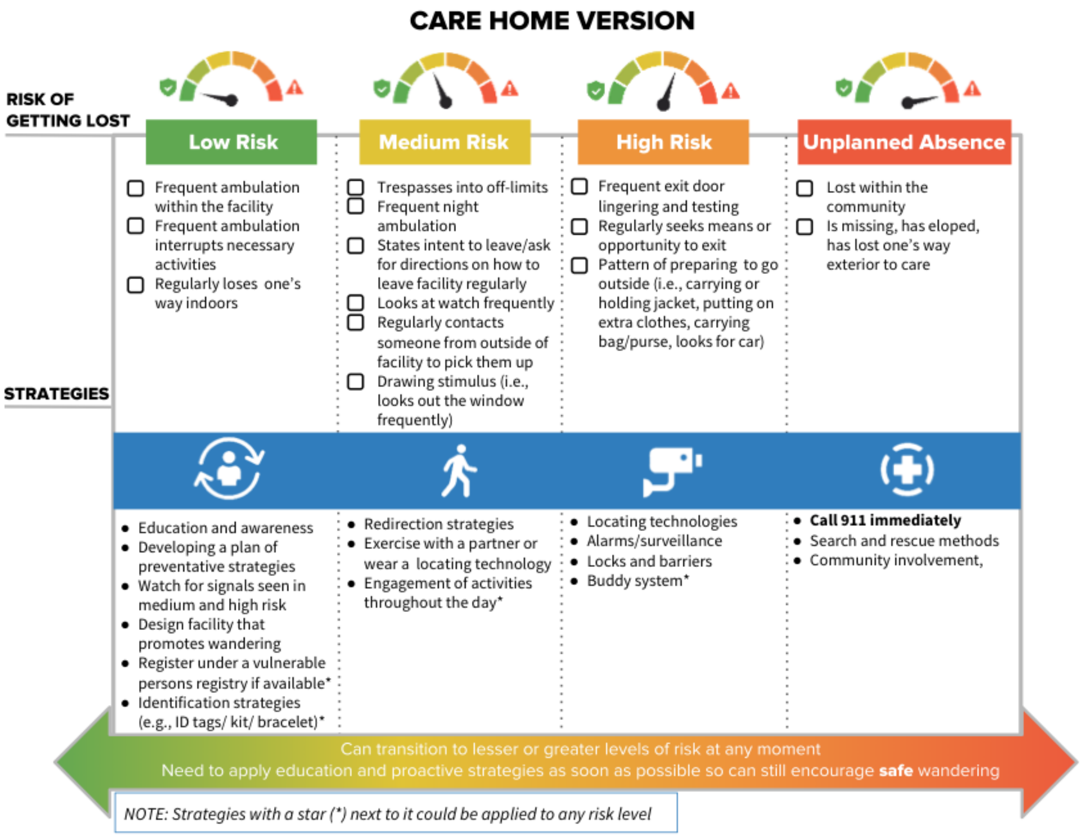
Table 2. Suggested avenues for the conceptual framework and guidelines by stakeholder type

Stakeholder type	Suggested avenues for the conceptual framework and guidelines
Community organization	Support groups
Family caregiver, social worker, PWD, police	Alzheimer Societies
Paid caregiver, PWD, community organization	Medical channels such as the Primary Care and Local Health Integration Networks, physicians, dementia health lines, first link navigators and memory clinics
Paid caregiver	Senior Centres
Social worker, health professional	Advocate groups who work alongside policy makers such as the Seniors United Now, Seniors Advocate, Seniors Newfoundland
Police	Industry such as Project Lifesaver; police and SAR to hand out when they return someone that was missing

NOTE: PWD (persons with dementia)

Appendix

Care Home Version Guideline



CARE HOME VERSION

RISK OF GETTING LOST	Low Risk	Medium Risk	High Risk	Unplanned Absence
	☐ Frequent ambulation within the facility ☐ Frequent ambulation interrupts necessary activities ☐ Regularly loses one's way indoors	☐ Trespasses into off-limits ☐ Frequent night ambulation ☐ States intent to leave/ask for directions on how to leave facility regularly ☐ Looks at watch frequently ☐ Regularly contacts someone from outside of facility to pick them up ☐ Drawing stimulus (i.e., looks out the window frequently)	☐ Frequent exit door lingering and testing ☐ Regularly seeks means or opportunity to exit ☐ Pattern of preparing to go outside (i.e., carrying or holding jacket, putting on extra clothes, carrying bag/purse, looks for car)	☐ Lost within the community ☐ Is missing, has eloped, has lost one's way exterior to care
STRATEGIES	• Education and awareness • Developing a plan of preventative strategies • Watch for signals seen in medium and high risk • Design facility that promotes wandering • Register under a vulnerable persons registry if available* • Identification strategies (e.g., ID tags/ kit/ bracelet)*	• Redirection strategies • Exercise with a partner or wear a locating technology • Engagement of activities throughout the day*	• Locating technologies • Alarms/surveillance • Locks and barriers • Buddy system*	• **Call 911 immediately** • Search and rescue methods • Community involvement,

Can transition to lesser or greater levels of risk at any moment

Need to apply education and proactive strategies as soon as possible so can still encourage **safe** wandering

NOTE: Strategies with a star (*) next to it could be applied to any risk level

LIST OF AVAILABLE STRATEGIES

Low Risk

- Keep a list of people to call on for help
- Education and awareness
  - Finding Your Way Program (http://findingyourwayontario.ca)
  - Alzheimer Society (http://alzheimer.ca/en/on)
- Design facility that promotes wandering (i.e., secured gardens outside and/or inside, lots of room to walk indoors)
- Register participant with the Vulnerable Person Registry (if available) or with an identification program
  - MedicAlert (https://www.medicalert.ca)
- Place identification information on items of clothing, or objects they regularly use (i.e., walker, wallet)

Medium Risk

- Distraction/redirection strategies
  - Providing meaningful activities (i.e. chores, tasks, etc.) or play music that they grew up to
  - Increase staff/resident interactions
  - Install signs to assist in way-finding
  - Provide areas that allow the person to wander (i.e. enclosed gardens, larger areas to walk, etc.)
- Try to understand the underlying causes of wandering and exit seeking behaviour among the resident. Many times, these behaviours are due to certain needs not being met such as them being hungry, lonely, or do not identify the care home as where they live.
- Integrate exercise programs or classes into their everyday routine
- Engagement of simulating activities throughout the day to keep the resident busy

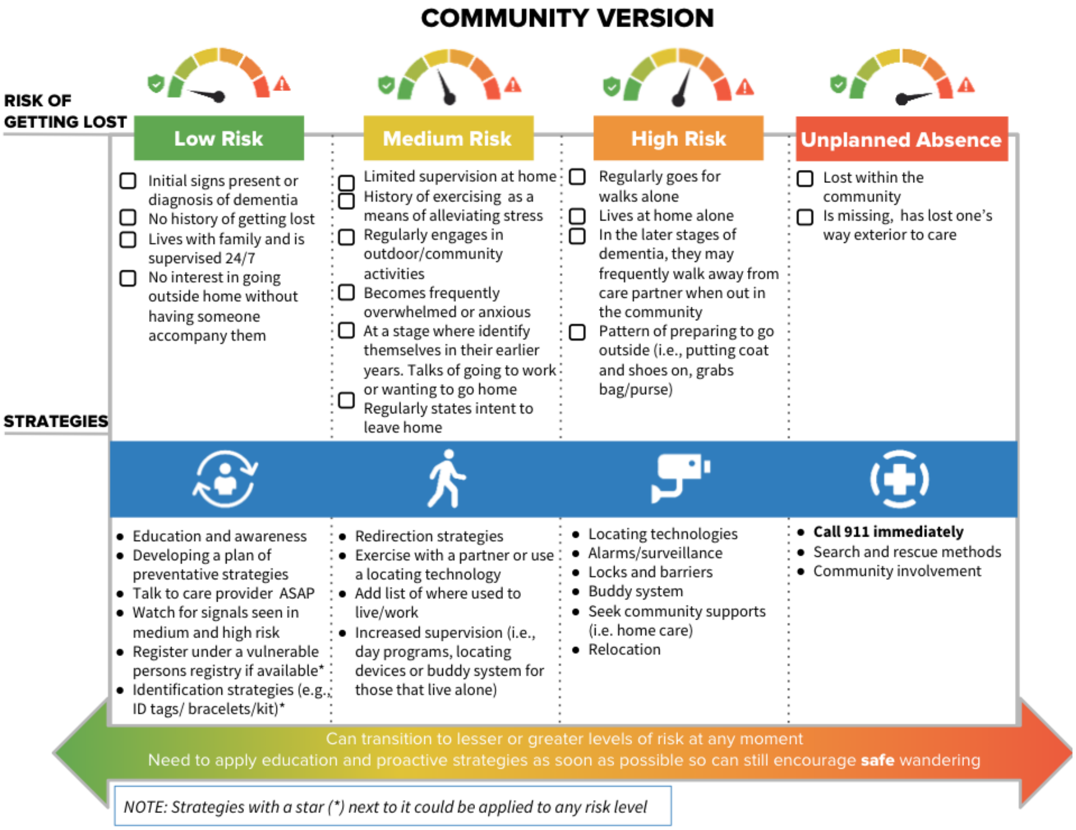
High Risk

- Use devices that signal when a door or window is opened
- Avoid busy places that are confusing and can cause disorientation
- Install door murals (camouflaged exit doors), place mirrors or curtains in front of the exit door
- Increase supervision (i.e., locating devices or a buddy system)
- Consider locating technologies:
  - GPS (https://tech.findingyourwayontario.ca)
  - RFID (https://projectlifesaver.org)

Unplanned Absence

- Call 911 immediately DO NOT wait 24-48 hours to alert the police. The police want to know right away about the missing person even if you find them soon after.
- Keep up to date information relating to each resident on hand such as a photo, name, height, weight, physical description and emergency contact information in a safe place such as a binder or computer file. In the event the resident has gone missing this information can be quickly forwarded to the police.
- Notify the community to keep a look out for the missing person

Community Version Guideline



COMMUNITY VERSION

	Low Risk	Medium Risk	High Risk	Unplanned Absence
RISK OF GETTING LOST	☐ Initial signs present or diagnosis of dementia ☐ No history of getting lost ☐ Lives with family and is supervised 24/7 ☐ No interest in going outside home without having someone accompany them	☐ Limited supervision at home ☐ History of exercising as a means of alleviating stress ☐ Regularly engages in outdoor/community activities ☐ Becomes frequently overwhelmed or anxious ☐ At a stage where identify themselves in their earlier years. Talks of going to work or wanting to go home ☐ Regularly states intent to leave home	☐ Regularly goes for walks alone ☐ Lives at home alone ☐ In the later stages of dementia, they may frequently walk away from care partner when out in the community ☐ Pattern of preparing to go outside (i.e., putting coat and shoes on, grabs bag/purse)	☐ Lost within the community ☐ Is missing, has lost one's way exterior to care
STRATEGIES	• Education and awareness • Developing a plan of preventative strategies • Talk to care provider ASAP • Watch for signals seen in medium and high risk • Register under a vulnerable persons registry if available* • Identification strategies (e.g., ID tags/ bracelets/kit)*	• Redirection strategies • Exercise with a partner or use a locating technology • Add list of where used to live/work • Increased supervision (i.e., day programs, locating devices or buddy system for those that live alone)	• Locating technologies • Alarms/surveillance • Locks and barriers • Buddy system • Seek community supports (i.e. home care) • Relocation	• **Call 911 immediately** • Search and rescue methods • Community involvement

Can transition to lesser or greater levels of risk at any moment
Need to apply education and proactive strategies as soon as possible so can still encourage **safe** wandering

NOTE: Strategies with a star (*) next to it could be applied to any risk level

LIST OF AVAILABLE STRATEGIES

Low Risk

- Keep a list of people to call on for help
- Education and awareness
  - Finding Your Way Program (http://findingyourwayontario.ca)
  - Alzheimer Society (http://alzheimer.ca/en/on)[
- Register participant with the Vulnerable Person Registry (if available)) or with an identification program
  - MedicAlert (https://www.medicalert.ca)

Medium Risk

- Redirection strategies:
  - Providing meaningful activities (i.e. chores, tasks, etc.) or play music that they grew up to
  - Install signs to assist in way-finding
- Have person with dementia exercise with a partner or use a locating technology (https://tech.findingyourwayontario.ca)
- Keep a list at home of the places the person with dementia used to live and work
- Increase supervision (i.e., day programs, locating devices or a buddy system for those with dementia that live alone)

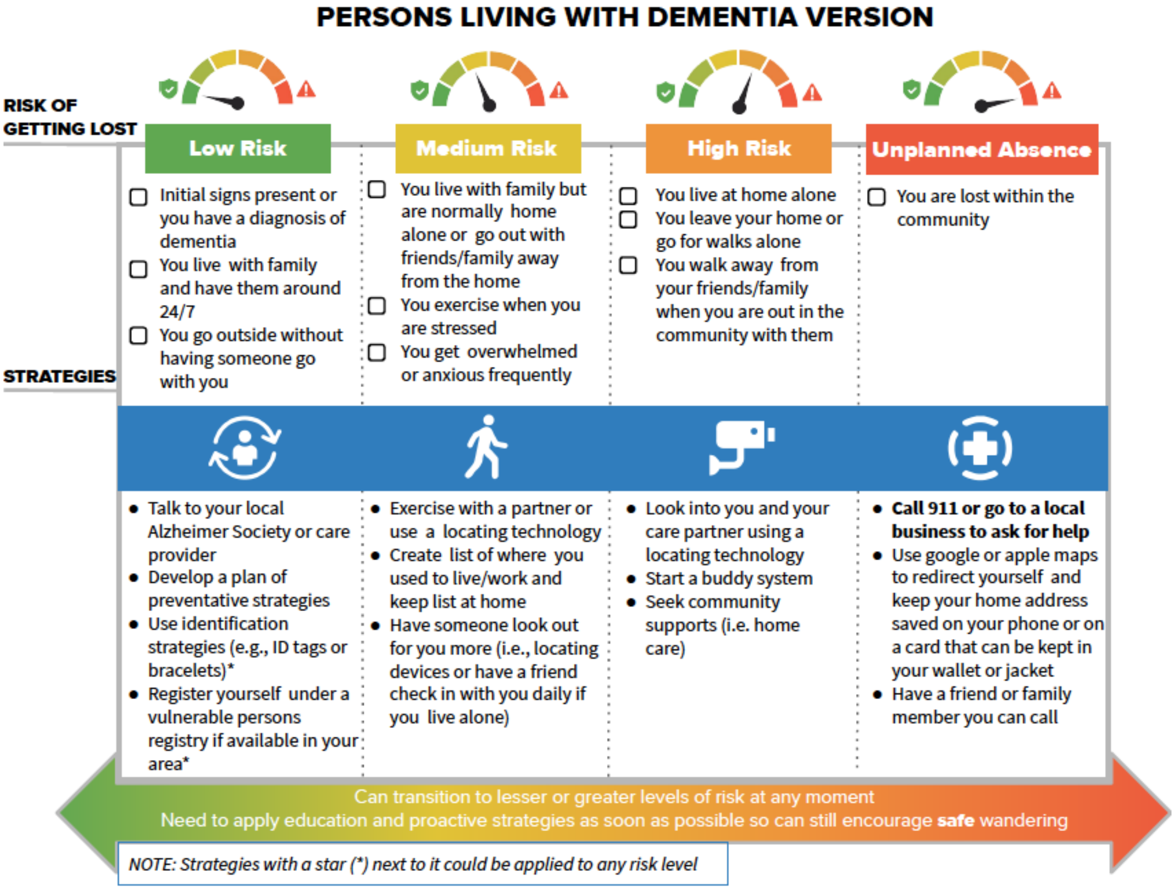
High Risk

- Keep car keys out of sight
- Avoid busy places that are confusing and can cause disorientation
- Increase supervision (i.e., day programs, tracking devices or being connected to a care worker for those that live alone)
- Install locks or alarm systems on the exit door or window to know when it is opened *Disclaimer: locks should ONLY be implemented when the care partner is at home for safety reasons such as fire risk, etc.*
- Consider locating technologies such as Commercial GPS (https://tech.findingyourwayontario.ca) or GPS devices available on your phone (e.g. Find My Friend App or Google maps)
- Install door murals (painted camouflaged exit doors), place mirrors or curtains in front of the exit door
- Ensure someone has descriptors readily accessible of the person with dementia (i.e. photo, locations they like to go to, etc.)
- Place identification information on items of clothing, or objects they regularly use (i.e., walker, wallet)
- Discuss long term care options

Unplanned Absence

- Call 911 immediately DO NOT wait 24-48 hours to alert the police. The police want to know right away about the missing person even if you find them soon after. The longer you wait to call the greater the risk they are at for being found seriously injured or deceased
- Notify the community to keep a look out for the missing person

Persons Living with Dementia Version Guideline



PERSONS LIVING WITH DEMENTIA VERSION

	Low Risk	Medium Risk	High Risk	Unplanned Absence
RISK OF GETTING LOST	☐ Initial signs present or you have a diagnosis of dementia ☐ You live with family and have them around 24/7 ☐ You go outside without having someone go with you	☐ You live with family but are normally home alone or go out with friends/family away from the home ☐ You exercise when you are stressed ☐ You get overwhelmed or anxious frequently	☐ You live at home alone ☐ You leave your home or go for walks alone ☐ You walk away from your friends/family when you are out in the community with them	☐ You are lost within the community
STRATEGIES	• Talk to your local Alzheimer Society or care provider • Develop a plan of preventative strategies • Use identification strategies (e.g., ID tags or bracelets)* • Register yourself under a vulnerable persons registry if available in your area*	• Exercise with a partner or use a locating technology • Create list of where you used to live/work and keep list at home • Have someone look out for you more (i.e., locating devices or have a friend check in with you daily if you live alone)	• Look into you and your care partner using a locating technology • Start a buddy system • Seek community supports (i.e. home care)	• **Call 911 or go to a local business to ask for help** • Use google or apple maps to redirect yourself and keep your home address saved on your phone or on a card that can be kept in your wallet or jacket • Have a friend or family member you can call

Can transition to lesser or greater levels of risk at any moment
Need to apply education and proactive strategies as soon as possible so can still encourage **safe** wandering

NOTE: Strategies with a star (*) next to it could be applied to any risk level

LIST OF AVAILABLE STRATEGIES

Low Risk

- Education and awareness
  - Finding Your Way Program (http://findingyourwayontario.ca)
  - Alzheimer Society (http://alzheimer.ca/en/ab)
- Register yourself with the Vulnerable Person Registry (ask local police or Alzheimer Society to determine if your community has one in place) or with an identification program
  - MedicAlert (https://www.medicalert.ca)

Medium Risk

- Exercise with a partner or wear a locating device. These devices can be purchased (https://tech.findingyourwayontario.ca) or you can use the ones already on your phone (e.g. Find My Friend App or Google maps)
- Create a list to keep with a close friend or your care partner of where you used to live and work so in the event you get lost this information can be used to help find you
- Have someone keep tabs as to where you are (i.e., locating devices or a buddy system)

High Risk

- Consider locating technologies that you and your care partner can use:
  - Commercial GPS (https://tech.findingyourwayontario.ca)
  - GPS devices available on your phone (e.g. Find My Friend App or Google maps)
- Seek community supports (i.e., home care, social workers, etc.)
- Register yourself with the Vulnerable Person Registry (ask local police or Alzheimer Society to determine if your community has one in place) or with an identification program
  - MedicAlert (https://www.medicalert.ca)

Unplanned Absence

- Use google or apple maps on your phone to help you find your way back home and keep your home address saved on your phone or on a card that you can keep in your wallet or jacket
- Have a friend or family member you can call in case you are lost
- Go to a local business to ask for assistance
- Identification strategies (i.e., wear an identification bracelet, or put your care partner's phone number in your jacket or wallet)

Study Five Manuscript

Dissemination and implementation of strategy adoption guidelines for persons with dementia at risk of getting lost

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Abstract

Background and Objectives: To address the concerns associated with critical dementia-related wandering, a series of guidelines were developed to guide families in choosing proactive wander-management strategies. While research findings are generally shared via conference presentations and publications in academic journals, few focus on knowledge mobilization methods that work directly with organizations to disseminate this work to the public. The purpose of this project was to evaluate the knowledge translation of the developed guidelines on wander-management strategies and to subsequently disseminate these guidelines to organizations across Canada.

Research Design and Methods: Steering committees across Canada were established for consultation. An online and paper survey was also developed and collected from participants nationally to gain final feedback on the guidelines. A forward-translation method was also performed to convert the guidelines from English to French.

Results: The guidelines were successfully integrated across ten organizations covering four provincial regions across Canada. It took 22 months from the development of the guidelines to the dissemination and launch of the guidelines to the public. Overall participants were very satisfied with the developed guidelines and felt they were easy to navigate, easy to understand, the information provided was useful, and are likely to recommend this work to a friend or relative.

Discussion and Implications: Using google slides, establishing partnerships with multiple organizations, and following a stakeholder-driven approach to guideline development and dissemination were successful methods for reducing the time for this work to become practice. This can replace conventional methods where guidelines can quickly become outdated.

Keywords: Translational research, dementia, wandering, guidelines

Introduction

The conversations behind the significant time lag in translational research has been on the rise in recent years (Atkins, Rush, Mehta, Lakind, 2016). It is frequently stated that it takes an average of 17 years for research evidence to reach policy and practice (Green, Ottoson, Garcia, Hiatt, 2009; Trochim, 2010). This is of concern in part due to its negative effect on internal rate of return and is often seen as a sacrifice of potential patient benefit (Ward, House, Hamer, 2009; Health Economics Research Group, 2008). In addition, there is a lack of resources and education among researchers to disseminate research findings beyond conference presentations and academic journal publications (Wilson, Petticrew, Calnan, Nazareth, 2010).

Research in critical wandering, a behaviour that enhances the person with dementia's risk of getting lost (Petonito et al. 2013) holds true to the above statement. While there has been an increase in the number of strategies to mitigate wandering, the level of scientific evidence from these outcomes remain low (Neubauer et al. 2018a) and few involve the integration of proactive strategies (Neubauer et al. 2018b). As suggested by Landau & Werner (2012), practical guidelines for family and paid caregivers are needed when making decisions on using assistive technologies for persons with dementia at risk of getting lost, particularly locator technologies. Such suggestion was also noted during consultations with local Canadian Alzheimer Societies (Neubauer et al. 2018b), where most do not know what direction to point caregivers in terms of the integration of wander-management strategies. To respond to this need, Neubauer & Liu (2019a) developed a series of guidelines that offer proactive strategies to reduce the risk of getting lost among persons with dementia. Since their creation, the guidelines have undergone face and content validity through multiple focus groups and consultations with stakeholders including persons with dementia, family and paid caregivers, health professional, police, social workers and community organizations.

Due to the increasing number of lost and missing persons with dementia (Neubauer, Laquian, Conway, Liu 2019b), there is a significant need to accelerate the time it takes for research in this area to become practice and to have involved stakeholders feel included by having the opportunity to provide final feedback prior to the dissemination and implementation of research findings. As stated by Rosenfeld & Wyer (2018), stakeholder-driven guidelines are more likely to address quality improvement needs and concerns of patients and clinicians, including populations that are understudied and have multiple chronic conditions. Traditional topic-driven approaches however which are driven by evidence rigor and epidemiologic purity, often address “typical” patients and are based on research that may not reflect high risk groups, such as persons living with dementia that are excluded from studies due to the desire for a pure research design.

Unfortunately, while stakeholder-driven approaches are becoming a preferred method within areas such as rehabilitation (Xia et al. 2016), few involve the voices of persons with dementia. This is in part due to concerns whether their responses are viable due to their level of cognitive impairment (Hubbard, Downs, Tester, 2003). Recent evidence however has led to suggest that the inclusion of persons with dementia in research are vital to ensure interventions deviate from the traditional medicalized view to include the social context and personhood of the individual (Bond & Corner, 2001). The purpose of this project was therefore to test the knowledge translation strategy? and successfully disseminate a series of developed guidelines on wander-management strategies that were co-developed alongside stakeholders including persons with dementia.

Design and Methods

Design:

Participants

A purposive sampling method was used (Etikan, Musa and Alkassim, 2016). Community organizations, dementia advocates who were living with dementia or were caring for someone with dementia, and health professionals were sought to assist in disseminating the developed guidelines. Individuals seeking wandering related services from the Alzheimer Society of Alberta, Ontario, and Calgary were recruited to complete the surveys. Notices of the guidelines and available survey were also distributed through the Alberta Association on Gerontology (AAG), Bowmont Seniors Assistance Association, the Alberta Seniors Communities & Housing Association (ASCHA) and the Institute for Continuing Care Education and Research (ICCER). Multiple consultations with representatives from the Continuing Care Branch within Alberta Health Services, and key stakeholders part of Alberta's dementia strategy were also conducted to ensure the guidelines reflected the needs of the intended audience, and to explore avenues of dissemination above and beyond the research team's existing network.

Inclusion criteria

1) English speaking
2) Must have a vested interest in managing wandering behaviour and dementia-related lost/missing persons events

3) Have internet access or access to the partnering community organization that is disseminating the guidelines

Exclusion criteria

2) Individuals with severe vision and hearing impairments that cannot be corrected with vision or hearing aids

Study procedure

The developed guidelines from Neubauer & Liu (2019a) were converted into electronic and paper versions and the six principles of knowledge translation noted by Phillipson, Goodenough, Reis & Fleming (2016) were applied. The electronic version was developed using the Google Slides platform. A master copy was held in Google Drive and additional copies were created and held in individual folders for partnering organizations. Organizations interested in disseminating the guidelines were granted permission to their own file by the principle investigator. The reason for doing the initial launch with the *findingyourwayontario.ca* website was due to the direct contributions provided by the Alzheimer Society of Ontario (Neubauer et al. 2018; Neubauer et al. 2019), in addition to previous work being linked to this website during the beginning phases of the guidelines' implementation. The guidelines were initially disseminated to this website by developing multiple infographics based from the findings of Neubauer et al. (2018a, 2018b). These guidelines were also included in the Alberta Association on Gerontology website. Finally, paper versions were distributed by the Alzheimer Society of Alberta, Ontario and Calgary to ensure users without internet access also had access to the framework.

For paper versions, Alzheimer Societies were encouraged to have dialogue with family caregivers prior to distributing the infographic. Online and paper surveys were administered from users within the Alzheimer Society network. Paper versions of the survey were collected by the local Alzheimer Societies and community organizations. The survey was provided using a Likert Scale (i.e., strongly agree, disagree, neutral, agree, strongly disagree) and a general comments section enabled users to provide more specific feedback. Questions were based off the USE Questionnaire (Lund, 2001) and included: participant's demographic data, overall impression of the developed guidelines, visual features, ease of navigation, whether the information was easy to understand, whether the information provided was useful, that the participant found what they were looking for, and whether they were likely to recommend the guidelines to a friend or relative

In addition to the evaluation of the framework, a forward translation method (de Courval et al. 2006) was applied to create French versions of the guidelines developed in Neubauer & Liu (2019a) that further aided in the guideline's dissemination. A French translator whom translates documents on behalf of the Alzheimer Society of Canada and the Alzheimer Society of Ontario was recruited to complete this translation. Due to his extensive experience of doing such translation work in this field, he had significant knowledge in terms of the terminologies the Alzheimer Societies often look for. Therefore, because the guidelines were developed in partnership with the Alzheimer Societies and underwent face validity with these organizations, a forward translation rather than a forward-backward translation was warranted.

Data analysis

Descriptive analysis was used to provide a general summary of the feedback provided from the users and was used to determine if future directions pertaining to the framework were required. One-way ANOVA was conducted for each feedback question to determine if differences arose across stakeholder types. Excel and IBM SPSS was used to assist in the analysis of the collected survey data.

Results

Survey responses

A total of 73 participants completed the online or paper version of the survey. The Respondents comprised of family caregivers (n = 36), staff from community organizations (n = 17), persons living with dementia (n = 7), health professionals (n = 8), and paid caregivers (n = 5). Most participants were female (n= 63) and had an average age of 53 ± 14 years. Average age, gender, and the family caregiver's relationship to the person with dementia they were caring for can be found in Table 1.

The overall impression of the disseminated guidelines was positive. Participants were very satisfied regarding their overall impression of the three guidelines with an average Likert score of 4.27 (± 0.73) (Figure 1). Such results were consistent across all stakeholder types (F (4,67) = 1.82, $p = 0.14$). Positive comments that were noted at the end of the survey included respondents liking the consistency, colours, flexibility of being able to update the guideline as strategies become available, links available on the back page of each guideline, that they were well organized with needed information, was easy to read, that the respondents value the inclusion of their feedback in this work, and in general the guidelines were very helpful and useful. Several community organizations noted the successes of using the guidelines with their clients and many health professionals first introduced to the guidelines indicated their desire of having access to the guidelines to give to patients in their families. One of the staff members of a local Alzheimer Society for example noted:

"I used the guide with people living with dementia and they felt it was useful as a guide if they found themselves in the positon of being lost and had a better idea as to what strategies they can use."

Other specific comments worth highlighting include one of the family caregivers liking the sliding scale of risk:

"I thought the sliding scale of risk was valuable especially if the person you are dealing with was at a low risk level"

Another family caregiver stated the included antecedent behaviours being one of the key features of the guideline that stood out the most for them:

"The opportunity to see what behaviours indicate increased risk would allow for more proactive preventative strategies"

Overall participants felt that the visual features of the guidelines were pleasing to the eye (average 4.19 ± SD 0.76); that they were easy to navigate (average 4.01 ± SD 0.86); easy to understand (average 4.03 ± SD 0.87); the information provided was useful (average 4.34 ± SD 0.69); they found what they were looking for (average 3.93 ± SD 0.77); and were likely to recommend the guidelines to a friend or relative (average 4.14 ± SD 0.89) (Figure 2). No differences were observed for the above responses across stakeholder groups for visual features (F (4,68) = 0.55, $p = 0.70$), ease of navigation (F (4,68) = 0.73, $p = 0.57$), ease of use (F (4,68) = 1.34, $p = 0.26$), usefulness (F (4,68) = 1.23, $p = 0.30$), finding what they were looking for (F (4,68) = 0.85, $p = 0.50$), nor whether they would recommend the guidelines (F (4,68) = 1.71, $p = 0.16$).

Suggested changes provided by respondents within the completed surveys were broken into seven categories: (1) terminology, (2) education, (3) availability in other languages, (4) links, (5) amount of information provided, (6) change in layout, and (7) additional strategy (Table 2). Most edits indicated were related to terminology that were not familiar terms to various family caregivers and community organizations, such as “eloped”, “exterior to care” and “drawing stimulus”. The need for using the guidelines in education sessions and on higher tech solutions among persons with dementia were also noted as being a priority. Finally, additional changes, such as including dementia dogs as a solution, condensing the content in the guidelines, providing links to more of the strategies, and ensuring the guidelines in multiple languages were also suggested by respondents. Upon incorporating the above suggested changes, a total of 17 iterations (14 from Neubauer & Liu, (2019a) and 3 from the present study) make up the final form of the developed guidelines.

Dissemination of the guidelines

It took 22 months from the conceptualization and development of the guidelines to the dissemination and launch of the guidelines to the public. A total of ten different community and health organizations assisted in the preliminary dissemination of the developed guidelines. Partner organizations ranged across four provinces (British Columbia, Alberta, Saskatchewan, and Ontario), and involved local and provincial Alzheimer Societies, provincial gerontology associations, dementia-friendly community initiatives, as well as local and provincial health authorities specifically with a home care focus. Multiple methods and mediums were used as a means of getting the information out about the guidelines to as many audiences as possible. Webinars and in person presentations were a vital component of sharing and generating interest on the developed guidelines. Presentations within the first three months of deploying the guidelines included dementia advocacy groups, geriatric grand rounds, provincial and regional health authorities, health professional associations, and provincial dementia strategies. Other strategies, such a regular consultation sessions, involvement of identified champions within the conceptualization, development and dissemination phases of the guidelines, and inclusion of this work on websites such as *findingyourwayontario.ca* and *albertaaging.ca* were also integrated.

Discussion

This study was designed to attain final feedback on a series of developed guidelines on wander-management strategies and to determine whether they can be successfully disseminated through community organizations across Canada. More than 70 participants from four Canadian provinces completed the survey, and respondents ranged from persons living with dementia, caregivers, health professionals and community organizations. Final feedback from the surveys on the developed guidelines were promising. Participants were very satisfied with the developed guidelines and felt that they were easy to navigate and understand, the information provided was useful, and were likely to recommend them to a friend or relative. Additional changes were also indicated to further improve the final version of the guidelines. As noted, the primary means of dissemination of the guidelines were through multiple community organizations and health authorities, where the guidelines were made available through electronic and paper copies, and were provided in English and French. The intention of disseminating the guidelines was to explore methods necessary to speed up the process it takes for research to translate into practice; to inform the broader dementia and health community of the guideline's existence; and to encourage discussion of their content and applicability to real lives in terms of adopting proactive strategies to mitigate the risks associated with getting lost.

The comments from the respondents in the survey provided further validation from Neubauer and Liu (2019a) on the layout and content of the developed guidelines. Participants for example noted the value of including the sliding scale of risk (Neubauer & Liu, 2019a) and antecedent behaviours (Neubauer & Liu, 2019c) in the guidelines, and felt that these features would assist in the promotion and incorporation of proactive strategies among families and persons living with dementia. Respondents also confirmed the importance of having the guidelines available in different languages; having available links to the suggested strategies; the value of including their feedback in the finalization of the guidelines; and the flexibility of the guidelines in terms of having them regularly updated using google slides. Such feedback provided confidence in terms of knowing that the developed guidelines were on the right track, and further emphasizes the importance following a stakeholder-driven approach in their development and continual validation (Jull, Giles, Graham, 2017).

Developing and housing the guidelines as live versions for partnering organizations is an innovative solution for addressing the downfalls that often underlie traditional guidelines. As noted by Brown et al. (2013), traditional guideline development and dissemination generally occurs through written publications, which face the risk of being out of date before they are published and hit main stream. This is a result of the time lag between data collection and publication date. Like the wikis used in Brown et al. (2013), Google Slides can be directly edited via a web browser by anyone with access to it. Google Slides can also support hyperlinks which are essential to direct persons with dementia and caregivers to additional websites to further assist them in choosing and adopting specific wander-management strategies such as locator devices. This also enables the guidelines to be custom tailored to each region and organization that distributes them. The Alzheimer Societies in Canada for example, have their own contact information from province to province and have varying partner organizations, such as the Distress Centre in Calgary which they use as a mode for helping clients during off hours. Traditional modes of disseminating guidelines via publications therefore would not be able to provide such flexibility. In addition, the guidelines can be updated from the back-end from the involved research team as the guidelines continue to undergo iterations following their initial launch. This enables the guidelines to be up to date as the research in this field evolves.

As previously noted, it took 22 months from conceptualization to dissemination of the developed guidelines. This is significant as the online approach used in this study is likely to take much less than 17 years for research evidence to reach everyday practice (Morris, Wooding, Grant, 2011). Specifically pertaining to the area of dementia and caregiving, there are over 200 proven behavioural interventions for family caregivers, yet less than 2% of these interventions have been submitted for translation into real world settings and only 4,566 caregivers have participated in a translational effort. This represents less than 0.001% of the more than 15 million caregivers affected by dementia in the United States (Gitlin, Marx, Stanley, & Hodgson, 2015).

The successes of the speed in which it took for the guidelines in this study to be developed and disseminated is largely attributed to the knowledge translation process being imbedded within the proposal of the project, in addition to the involvement of key stakeholders throughout the research process. In fact, the guidelines were developed in part due to an expressed need from caregivers, Alzheimer Societies and police during consultation sessions (Neubauer et al. 2018a). Engaging end users, such as persons living with dementia can enhance the adoption of resources and technologies due to their ability of providing lived experience behind the highlighted issue at hand. As noted by Mader et al. (2018), there is a clear mismatch between research ideas that patients prioritize and those that are investigated. The involvement of such stakeholders in the conceptualization and follow through of research ideas therefore become essential to enhance the knowledge mobilization and integration in this field.

Networking and establishing relationships with all involved stakeholders also became key when disseminating the developed guidelines. As highlighted by Jull, Giles, Boyer, Stacey, 2016), to do so often requires investments in effort and time to develop opportunities for relationships, and to find common points of interest that are not typical in traditional research settings. Therefore, for this study, many involved participants were derived from pre-existing relationships with the authors months, and sometimes years prior to the development and dissemination of the guidelines. These relationships were fostered from countless in-person and teleconference meetings, and joint collaborations in past projects which enabled a closer degree of understanding and trust among all key players. Embedding the teachings from the Social Ecological Systems Framework (Hinkel et al. 2015) and placing an emphasis on involving multiple levels of influence was also critical to the successful dissemination of the guidelines. Therefore, the guidelines were not designed and integrated in isolation, but rather involved stakeholders ranging from policy, community organizations, health professionals, first responders, families, and persons living with dementia.

The final key component that was necessary for widespread knowledge integration of the guidelines, was involving multiple organizations and modalities of this work. As indicated during past consultations with participants in Neubauer and Liu (2019), many residents in rural communities do not have access to a local Alzheimer's society. Therefore, by disseminating the guidelines only through the national Alzheimer Society would potentially raise the risk of excluding countless caregivers and persons with dementia that need access to them. Understanding these local community organizations, and having support from underlying provincial and national governments that have connections to these groups, becomes a dire component to truly making this work inclusive. Providing the guidelines in multiple mediums, such as through education sessions, webinars, handouts and websites are also suggested to be methods of improving inclusivity (Grimshaw et al. 2001).

Limitations of this study

Feedback was sought when the guidelines were initially released. Due to the inability of the guidelines to be used for an extended period by end users, such feedback was reliant on initial reactions to the guidelines. A longitudinal study is therefore warranted to determine the guidelines' usefulness and effectiveness after they have been used and integrated into daily practice.

Implications

This study collected final feedback and highlighted the successful dissemination of a series of wander-management strategy guidelines for persons with dementia at risk of getting lost. Using google slides to ensure the guidelines' ability to remain up to date, establishing partnerships with multiple organizations, and following a stakeholder-driven approach to guideline development and dissemination were successful methods for reducing the time it took for this work to transition from research to practice. This work served as a starting point to replace conventional methods where the development of guidelines is timely and can quickly become outdated. It is our hope that the guidelines can provide a focal point for continuing attention to and discussion of the risks associated with getting lost among those living with dementia, and to provide a means for this population to adopt proactive strategies that focus on the balance between safety and independence. Future directions include dissemination of the guidelines across all eleven provinces in Canada, with eventual plans of having the guidelines available internationally using the International Consortium on Dementia and Wayfinding as a preliminary platform.

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Conflict of interest

The authors have no conflicts of interest to declare.

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Figures

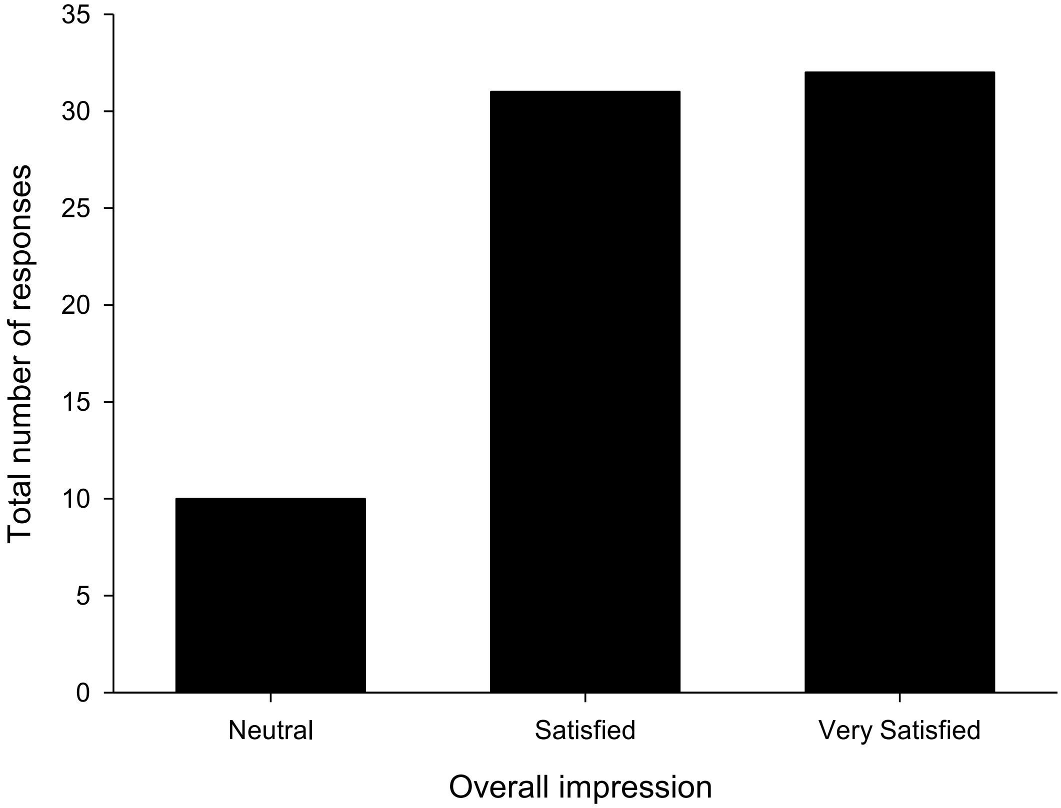

Figure 1. Overall impression of the disseminated guidelines. Likert scale (1 = strongly agree, 5 = strongly disagree) (n=73).

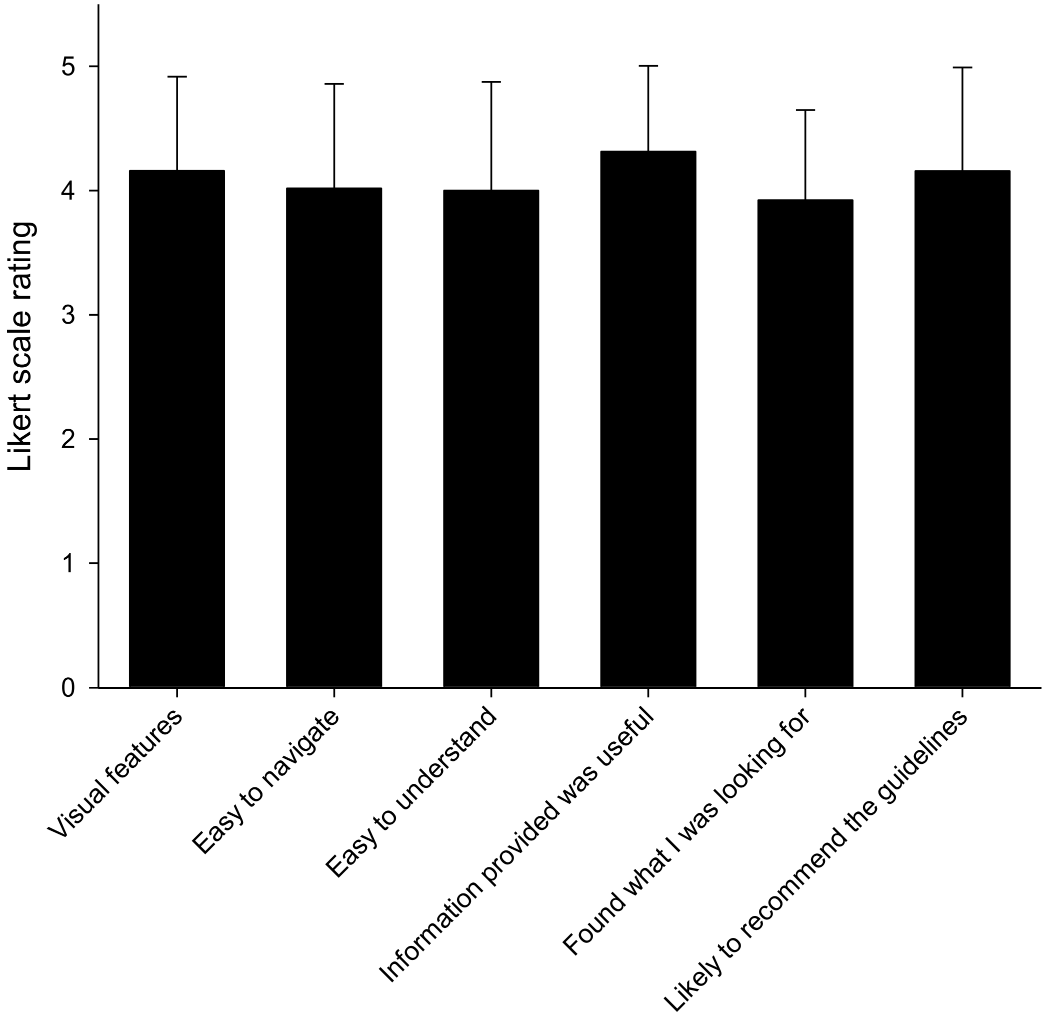

Figure 2. Perceived usefulness and ease of use of the guidelines. Likert scale 1-5 (1 = strongly agree, 5 = strongly disagree) (n=73).

Tables

Table 1. Survey Respondent Characteristics (*n* = 73)

Stakeholder type	Relationship to the person living with Dementia (n)	Sex (Female/Male)	Age (mean years ± SD)
Community organization	N/A	15/2	49 ± 15
Family caregiver	Daughter (24); Spouse (8); Son (1); Sibling (1); Parent (1); Friend (1)	33/3	56 ± 10
Paid caregiver	N/A	5/0	51 ± 17
Person living with dementia	N/A	2/5	65 ± 11
Health professional	N/A	8/0	39 ± 15

Table 2. Proposed changes to the guidelines per stakeholder type

Change Type	Suggested Change	Stakeholder Type
Terminology	Eloped and exterior to care are not familiar terms. Need to remove or reword them.	Family caregiver, community organization
	Drawing stimulus is not a familiar term. May require rewording or further examples/ explanation	Community organization
Education	Would like to see the guidelines incorporated in education sessions	Community organization
	Need to be sure that high risk people are not intimidated by newer technology. Should teach them these things prior to their dementia becoming more severe.	Health professional
Availability in other languages	Need the guidelines in multiple languages so they can be used with non-English speaking families and/or persons with dementia	Family caregiver, community organization
Links	Would like to see more links for strategies such as the Vulnerable Persons Registry, and identification strategies	Family caregiver
Too much information	Need to ensure the guidelines are for those with a lower education and have the option to be provided in a larger font	Social worker, clinician
Change in layout		
Additional strategy	Add a spectrum to the Goldilocks principle to assist in its messaging	Community organization

Summary of Chapter

In this chapter, I provided the five manuscripts of this thesis that have either been published or submitted to an academic journal. Throughout these manuscripts, I described the background, methods, results, discussion and conclusions of each study and organized it in a way that they can flow from one paper to the next. An overview of the main findings, implications, strength and limitations of the thesis, and the general conclusion, recommendations and directions for future research are included in the next chapter.

Chapter 4: Discussion and Conclusions

This final chapter of my thesis is organized into three sections. I begin by providing the main findings and implications of the manuscripts within the broader context of the literature, linking the findings of each manuscript back to the literature. Next, I review the overall strengths and limitations of this thesis. Finally, I provide the conclusion and discuss recommendations and directions for future research to move the field of critical dementia-related wandering forward.

Main findings and implications of the manuscripts

The purpose of this thesis was to develop and validate a conceptual framework and series of guidelines that will help stakeholders choose strategies to manage challenging behaviours associated with dementia-related critical wandering. Through a scoping review, focus groups, semi-structured interviews, observations and surveys, existing high and low tech wander management strategies were highlighted, and antecedent behaviours and factors that influence strategy adoption were identified. In summary, 96 participants were involved in the development of the conceptual framework and guidelines, 34 participants assessed their face and content validity and 73 provided final feedback through online and paper surveys. Responses from the interviews highlighted four contextual factors that were considered among participants to influence the successful adoption of wander-management strategies: (1) Risk associated with wandering, (2) Culture and Personal Factors, (3) Geography, and (4) Stigma. Perceived risk, culture and personal factors, geography and stigma were conveyed as influential factors of strategy adoption across all stakeholder groups. Common antecedent behaviours of critical wandering events derived from the direct observations of family and paid caregivers ranged from packing of belongings, preparing to go outside, and door lingering or tampering within continuing care facilities. The relationships of the four factors influencing strategy adoption were used in the development of the conceptual framework. The strategies included from the interviews and scoping review, the antecedent behaviours from the observation study, and the existing framework from Moore et al. (2009) informed the creation of the guidelines. Overall impression of the conceptual framework and guidelines during the validity study and final feedback was positive. Valued features included this works ability to guide users in choosing proactive wander-management strategies, and to promote conversations among community organizations and health professionals with their clients. Suggested changes included adjustments in the terminology used and adding additional factors and strategies to the framework and guidelines. Due to the complexity of the existing version of the conceptual framework, only the developed guidelines were disseminated nationally to community organizations.

Pertaining to the wander-management strategies highlighted in studies one and two of this thesis, this work was the first to highlight all available wander-management strategies within the literature and to indicate which ones are specifically used by a wide range of stakeholders. While more than three-hundred strategies were indicated in the scoping review (Neubauer et al.

2018), few are being used by present day participants. Mobile phone applications such as Find My Friend and Life360 for example, while not indicated in the literature review were one of the most commonly used strategies among interviewees. This trend of using existing mainstream high and low tech strategies was in fact a common phenomenon among participants, with accessibility being a key feature to these solutions. Other strategies such as installed security alarm systems, guide dogs, and clothing labels were also found to be used among participants while not being included in the literature. Another crucial finding was there were no strategies included in Neubauer et al. (2018) that were designed specifically for persons with dementia but rather, were only targeted for family caregivers. Because of this, strategies listed within the guidelines came specifically from persons with dementia that participated in this thesis. As indicated by the participants in Study Two, persons living with dementia want to become active agents in their own care, however often lack the resources and strategies to allow them to do so effectively and in a safe manner. This issue needs to be addressed as the percentage of persons with dementia that live alone continue to increase (Eichler et al. 2016). The above findings demonstrate the significant gap that exists between research and practice in terms of what is being developed in academic settings and what is being used in the community. Such findings are not uncommon in dementia research (Draper et al. 2009) and give rise the importance of stakeholder engagement in strategy development and dissemination (McCarron, 2018).

Specifically related to the conceptual framework derived from studies two and four, while factors that influence the adoption of strategies has been extensively explored in other areas of dementia (Gitlin & Czaja, 2016), the work from this thesis is the first to develop a framework that specifically addresses the factors that influence wander-management strategies and puts it all together in a way that encompasses the underlying relationships for each of the included factors. As noted in the Study Four manuscript for example, factors such as culture, personal factors and geography were suggested among participants as having a significant influence on how caregivers and persons with dementia perceive the risks associated with getting lost. This knowledge can be used among community organizations and health professionals in understanding why perceived risk differs from person to person. This framework is also the first to signify the importance of understanding the influence of stigma on the adoption of wander-management strategies. Previous literature has focused solely on locating technologies and their risk of producing social stigma (Kearns, Algase, Moore, & Ahmed, 2008; Robinson et al. 2007). The ability to understand influencing factors of successful strategy adoption and stigma's ability to reduce help seeking behaviour, could as a result influence timelier implementation of education and strategies based on the individual needs of the person living with dementia and their family. It could also serve another mode to assist in reducing the general stigma that often comes with those living with dementia (Phillipson et al. 2015). Another critical element of the conceptual framework is the involvement of the perspectives from all involved stakeholders following the Social Ecological Systems Framework (Hinkel et al. 2015). As what will be noted in more detail towards the end of this section, this becomes an essential piece to sustainability of the implemented wander-management strategies.

As for the developed guidelines from all four studies and Moore et al. (2009) they are unique in that they are catered to three different audiences: (1) persons living with dementia, (2) community settings (i.e., home care workers and family caregivers); and (3) care home settings (i.e., health professionals). In fact, this is the first work of its kind that has wander-management strategies catered specifically for persons living with dementia. It was noted among participants in studies one and three that too often guidelines of this nature are only developed for family caregivers. Because of this, there are little resources available for persons with dementia to be active agents in their own care. It was suggested by many that if the work isn't catered specifically to the population of interest, necessary education and awareness strategies are often ignored. One of the persons living with dementia in Study Four stated "*When it's not addressed to me, I'm not going to pick it up. There needs to be something that attracts my attention.*" This finding relates to others within the literature where it is often key to ensure the sustainability and uptake of educational tools and resources (Beer et al. 2011; Nayton et al. 2014). With the rising prevalence of lost incidences (Neubauer et al. 2019), and the rate of persons with dementia living on their own increasing (Eichler et al. 2016), more approaches of this nature need to be made to ensure successful implementation strategies and education programs to manage the risk of getting lost.

In addition to the different versions of the guidelines, other novel features include the categorization of strategies associated with a risk level. As a continuation of Moore et al. (2009), the guidelines presented critical wandering behaviour from a perspective of risk, rather than disease progression or stage. This is significant because risks of challenging behaviours, such as wandering, do not necessarily progress with cognitive impairment (Thomas, Glogoski, & Johnson, 2006). To build on the proposed framework by Moore et al. (2009), levels of risk within the guidelines were developed to include community and care home settings. In addition, antecedent behaviours derived from Study Three of this thesis were used to highlight examples of what was necessary for the person with dementia to fall under each level of risk. Within the care home version of the guidelines for example, exit door testing and patterns of preparing to go outside observed in Study Three were reflected as a high risk. The placement of the antecedent behaviour under each level of risk was further confirmed in the content and validity phase of

Study Four. Within studies four and five, it was reflected among participants that the listed antecedent behaviours in the form of a checklist was a useful means for the person with dementia and their family to determine what level of risk they are at in terms of getting lost. This use of antecedent behaviours as highlighted by Michie & Johnston (2004) is one of the primary recommendations for guideline development, and can be seen in others within healthcare, such as the Clinical Practice Guidelines for Dementia in Australia (Laver et al. 2016) and the Clinical Practice Guidelines for Geriatric Anxiety Disorders (Subramanyam, Kedare, & Pinto, 2018).

The means of guiding strategy use based on risk is also common among first responders in Canada. One of the search and rescue managers in Study Four of this thesis highlighted that him and his team follow a risk management framework when they respond to missing person cases. The search urgency within their standard operating procedures is often based on the missing persons ability to care for themselves. Persons with dementia for example are classified as one of the highest search urgencies due to their risk of harm. Other factors such as weather and clothing worn by the missing person also factor within this search urgency (Missing Women Commission of Inquiry, 2012; OSARVA Senior Search and Rescue Trainers, 2016). Among participants across studies two, three, and four, it was indicated that the risk of a person with dementia to get lost can shift rapidly where the person with dementia was last seen by their caregiver in sometimes as short as a few minutes before they were discovered missing. Because of this, the line 'Can transition to lesser or greater levels of risk at any moment' was added at the bottom of each guideline to convey unpredictable nature that often comes with missing persons incidents involving persons with dementia (Bowen et al. 2011), and to encourage caregivers and persons with dementia to be prepared for all levels of risk by having multiple strategies integrated and readily accessible.

The statement ‘Need to apply education and proactive strategies as soon as possible so can still encourage safe wandering’ within the guidelines was also added as a means of encouraging the benefits of wandering in safe surroundings (Carlson et al. 1995; Linton et al. 1997). As noted by one of the persons living with dementia in Study Four of this thesis, *‘[in care facilities] they create a lot of people wanting to elope because they keep people too contained and this is because they misunderstand what wandering is. You need to put at the forefront that safe wandering is important’*. Referring missing incidents involving persons with dementia to wandering is not uncommon and was often referenced as the same entity up until the early 2000s. Through extensive work led by Dr. Meredeth Rowe and her team, a significant body of research has been conducted on both missing incidents and wandering suggesting that these are conceptually distinct behavioural symptoms associated with dementia (Rowe et al. 2015). Unfortunately, this knowledge has not made it to the public with most still generalizing wandering and missing incidents as the same thing. Compounded with the new stigmatization of the term ‘wandering’, it has become standard to eliminate a person with dementia’s ability to wander with the intention of reducing the chance of them getting lost and going missing (Goudie, 2017). As a result, this raises the risk of negatively impacting their independence, emotional well-being and overall quality of life (Dreyfus, Phillipson, & Fleming, 2018). Therefore, with the inclusion of the above message in the developed guidelines of this thesis, it can serve as a discussion piece to begin the shift in restricting wandering behaviour to one that should be promoted, providing proactive strategies, such as locator devices, are in place. The included message could also be framed usefully as an ethical tension between autonomy and safety and could be used to highlight that this tension is not fully resolvable but rather, is something persons with dementia and their families and other care partners live with. It could also be linked to shifts in person centeredness in dementia care.

Specifically, within dementia research there is a gap between the knowledge obtained in dementia research and their use in clinical practice and the community (Draper et al. 2009). This has in turn resulted in 30-45% of patients not receiving care supported by recent scientific evidence and 20-25% of care provided being unnecessary or even harmful (Gaddis, Greenwald, Huckson, 2007). To mediate this gap, knowledge translation represents a shift from the traditional practice of researchers disseminating their findings within academic settings to wide dissemination of findings through interacting with key stakeholders to provide momentum for the process and communication among groups (Draper et al. 2009). Due to dissemination of the work generated from this thesis being one of the primary objectives, knowledge translation became one of the focal points throughout the explanatory phase of this thesis. Opinion leaders, facilitators, champions, linking agents, and change agents, all key interpersonal roles indicated by Draper et al. (2009) for successful knowledge translation, were included in studies four and five. Phillipson, Goodenough, Reis, and Flemming (2016)'s six proposed principles for education in dementia were also applied within study 5. The integration of multimodal learning strategies, opportunities for multiple learning exposures and feedback, fostering meaningful partnerships with key stakeholders, and using simple compelling messages enabled participants to benefit from multiple exposures to different ideas. As a result, this also allowed opportunities for end users to try out the framework and guidelines and provide new conceptualizations to further improve the work generated from this thesis.

As indicated by Jull, Giles and Graham (2017) participatory research approaches throughout all stages of research become essential when involving participants in a meaningful manner. It represents otherwise silenced voices and creates a shift from participants being the object of research to a research partner (Abma, Nierse & Widdershoven, 2009). While conventional social science research paradigms challenge this work's validity in terms of the undermining authority and contribution of the researcher, recent arguments have gone on to show that participatory research enhances the researcher's understanding of the data, enabling improved quality of the data produced (Jagosh et al. 2016). It also has the potential to contribute to and advance implementation science and inevitably the sustainability of the research through its ability to provide value to the local community or organizations involved (Abma et al. 2019; Littlechild, Tanner, & Hall, 2014). Involving credible people and organizations is in fact seen as being highly valued among policy makers (Gollust et al. 2017). Therefore, for this thesis, research questions, process, validation, and dissemination were all done through the guidance of key stakeholders including family caregivers, persons with dementia, police, health professionals and community organizations. Having participants involved in varying levels of iterations throughout each stage of the conceptual framework and guidelines' development was also critical for successful dissemination and adoption of the guidelines due its ability to ensure the same comments and suggestions were not made to avoid the potential for early saturation (Rudmik & Smith, 2011). It is key to note however that while participants were involved throughout all stages of the research, I was the one that facilitated, analyzed, and independently developed the conceptual framework and guidelines outlined in this thesis.

To further build on the importance of partnerships and interdisciplinary collaborations within this thesis and future work involving critical dementia-related wandering, I initiated the creation of the International Consortium on Dementia and Wayfinding April 2018. This consortium is a global network of academics, policy-makers, practitioners, community organizations, caregivers and people living with dementia. The goal of the network is to help people living with dementia go out into the community safely without fear of stigma, getting lost, or going missing and plan to do this using research and sharing best practices from around the world. I co-founded the consortium with PhD Candidate, Katie Gambier-Ross from the University of Edinburgh. Since the consortium's inception, we have over 65 members from across 8 countries and this number continues to grow as we become more established. Calgary, Canada and Edinburgh, UK were the first locations to host symposiums which took place February and March of this year. One of the highlights from these symposiums related to this thesis, was the ability to enable sharing of the newly developed conceptual framework and guidelines and to gain further insight and feedback from an international audience. The conceptual framework, guidelines and Goldilocks Principle on Dementia and Wayfinding for example underwent consultations during a 'think slot' session at the Edinburgh Symposium. During this session, there was interest of looking at disseminating this work internationally. Using children stories such as Goldilocks and Three Bears is a unique way of getting the lay audience to understand various principles and terminologies in this field. While Goldilocks is well known in Canada, the United States and the UK however, such a story was not known by consortium members from Italy and Spain. Therefore, to make the Goldilocks principle an internationally relatable term, other children's stories that underlie the teachings of finding something that is 'just right' needs to be investigated further for international translations.

While the initial dissemination of the guidelines among community organizations has been successful, other avenues need to be explored to ensure their sustainability and ability to be integrated across Canada and in other countries. In addition to consultations with the International Consortium on Dementia and Wayfinding, plans, such as discussions with

Canada’s National Dementia Strategy, is therefore being arranged to assist in this initiative. This continued generation of feedback will help determine whether different versions need to be made based on the country, in addition to the feasibility of including this work in multiple languages.

Strengths and limitations of thesis

Strengths

Participatory research and successful mobilization of the developed conceptual framework and guidelines are one of the hallmark strengths of this thesis. Taking into consideration Gitlin & Czaja (2016)’s suggested effective behavioural intervention approaches, the studies within this thesis included the following necessary features to knowledge translation: (1) interventions and characteristics that are grounded in theory; (2) followed a participant-centered approach in that it integrated the client’s perspective; (3) used active engagement of participants throughout all four studies; (4) provided flexible delivery characteristics to accommodate differences in practice settings (i.e., care home and community settings); (5) outcomes are closely aligned with and reflected intervention intent; and (6) strategies are tailored to participant needs, characteristics, and cultural preferences.

Another strength of this thesis was its intention from the beginning of disseminating the final version of the guidelines to organizations nationally prior the final study’s completion. In fact, the design and purpose of Study Five was specifically to test the knowledge translation of the developed guidelines and to identify the process required to have this work actively used by its intended users less than two years following the initial conceptualization of this work. There are hopes that this will become one of many where knowledge translation and mobilization strategies are embedded within the doctoral student’s thesis. By incorporating such an approach, this could assist in the significant time lag in translational research that is too often observed in health research (Atkins, Rush, Mehta, Lakind, 2016).

Limitations

The overarching limitation of this thesis was the methodological rigor involved in three of the five studies. Little work of this nature has been done that focuses on critical dementia-related wandering. Due to the limited and often outdated resources in this field to draw from, and the research for this thesis taking place in real world settings, messy and nonlinear methods were at times required (Amidon & Simmons, 2016). This can be supported by Marshall and Rossman (1989) where real research is often fundamentally nonlinear, messy and often confusing. The concept of “messy research” was derived for circumstances where ill-defined core concepts and unknown relationships exist, and allow the complexity of the given research question to be broken down into essential components and linked to related variables in rigorous theory development (Parkhe, 1993). As what will be indicated in the future research section later in this chapter, there are intentions of further rigorously evaluating the work derived from this thesis now that a foundation has been developed in terms of the conceptual framework and associated guidelines.

Specifically, for Study Three of this thesis that focused on identifying antecedent behaviours indicative of critical wandering, the initial plan was to use a complete observer approach using video recordings of the home of the participant for ~ 1 month or until a critical wandering episode occurred. After 4 months of actively seeking individuals to take part in the study, no participants could be recruited due to the invasion of privacy felt during recruitment sessions. Given the time constraints of completing such a study as part of this thesis, the methods changed from one that required surveillance cameras, to one that involved paid and family caregivers providing direct observations over the span of 2-4 weeks and were asked to complete a questionnaire whenever an observation of a critical wandering episode was made. While patterns of antecedent behaviours were identified using this method, busy schedules led by these individuals (Marziali & Garcia, 2011) could have reduced the chance of observing other behaviours that otherwise would have been caught using a video camera.

In addition, there were initial intentions of using quantitative tools in addition to the observations, such as those reported in Ali et al. (2016) to determine if frequency, wayfinding capabilities, depression and agitation can help to explain the recorded antecedent behaviours. Three of the four participating care home facilities however felt such a request was too much to ask of their already overloaded staff and inquired to only do the direct observation of the antecedent behaviours. Due to the importance of including these facilities, these tools were removed from the methods of this study to ensure the protocol was consistent across all participants. Finally, only 24 persons with dementia were observed in this study. This number is considerably less in comparison to other observation studies that focus on dementia-related wandering behaviour (Martino-Saltzman, Blasch, Morris, McNeal, 1991; Algase et al. 2010). Therefore, to further strengthen the limitations of Study Three of this thesis, a follow-up study will need to involve video surveillance and the quantitative tools suggested in Ali et al., (2016) to further validate the antecedent behaviours recorded by the caregivers. An increased number of involved participants following the existing methods from this study could also be used to further validate the findings.

The primary limitation of studies two and four involved me being the only one that did the data collection and analysis of the associated interviews and focus groups. In addition, no audit trail was completed which may have an influence on the data's credibility (Finlay, 2006) and interpretative rigour (Kitto, Chesters, Grbich, 2008). As noted in the Study Four manuscript, member checking of the synthesized data (Harvey, 2015) was incorporated within these studies. The methodological purpose of member checking was to validate results by seeking contradicting voices, while also providing opportunities to add data (Charmaz, 2008). To achieve this, 65 percent of the participants in Study Four were recruited from Study Two. This was done to ensure the responses and interpretations from Study Two were accurately reflected.

To ensure member checking was incorporated in Study Four of this thesis, triangulation through online and paper surveys (Kitto et al. 2008) was implemented following the completion of the focus groups and semi-structured interviews and after the suggestions were incorporated in the framework and guideline. Within this survey, an open-ended question was included to allow participants to provide additional feedback and to note if any of their responses during the focus groups and interviews were indicated in the final version of this work. Finally, I adopted Morse et al.'s (2002) approach to verification in that I constantly checked and re-checked the data, codes and categories through the process of moving back and forth between data generation and data analysis as well as between raw data and abstractions. Part of my verification process also included negative case analysis, which is a common method for addressing credibility (Onwuegbuzie & Leech, 2007). For example, in Study Two some of the family caregivers indicated rural settings placed the person with dementia they were caring for at less risk of adverse outcomes if lost in the community. Yet a few participants (and sometimes the same participants who provided this statement) in fact reported the heightened risks of living in a rural environment causing various wander-management strategies to be implemented. Upon carefully reviewing and reconsidering all data related to risks associated with getting lost in rural communities, I discovered that elevated levels of risk exist within almost all participant accounts. However, it was the type of risk that had an influence on the participant's responses, where risks associated with the elements contributed to heightened risk in rural communities, whereas the risk of negative outcomes caused by human interaction was found in urban communities.

Conclusion and implications for research

In the final section of this last chapter, I provide the conclusion and outline key recommendations and implications for future research to improve the outcomes associated with critical dementia-related wandering.

Conclusion

Critical wandering is becoming a greater public health concern as our population ages and more Canadians are living with dementia. As more strategies and programs become available on the market, resources that have the capacity to guide caregivers and persons with dementia on how to choose a strategy that best meets their individual needs becomes vital. The developed conceptual framework and guidelines from this thesis will initially benefit family caregivers and persons with dementia who have an expressed concern of dementia-related critical wandering and whom have access to the current partnering organizations that are actively distributing and sharing this work within the community. A readily available conceptual framework and guidelines would allow this cohort to have access to this tool when they need it. Paid caregivers, health professionals and other stakeholders, such as police and other first responders will also be impacted by this research by introducing them to strategies that may enhance their ability to locate missing vulnerable older adults, and will assist in providing further education to their clients on the importance of proactive strategies to mitigate the risks associated with getting lost. Aside from this, continuing consultations with government officials and Alzheimer Societies from across the country, in addition to involvement of the International Consortium on Dementia and Wayfinding will enable this research to have a national and international impact. This work will also have an industry impact, where manufacturers will have a standard guideline for the development of new strategies that can be used to address one or more of the highlighted levels of risk of wandering, and further manage or prevent such risks.

Recommendations

Given the results presented in this thesis, the following recommendations can be made:

(1) To our knowledge, no critical wandering strategies to date have included an approach of indicating what strategies persons with dementia are using to assist themselves in wayfinding. The strategies included in the developed guidelines while indicated as useful among the persons with dementia interviewed in this thesis, have yet to be noted and evaluated in the scientific literature. Therefore, research needs to incorporate persons with dementia involving dementia-relating wandering, and subsequent research to evaluate the effectiveness of the strategies they used is warranted. In addition, as indicated from the scoping review in this thesis, more research pertaining to the effectiveness of all involved high and low tech strategies is needed.

(2) There is inadequate education on positive and negative experiences of critical wandering, which in turn may perpetuate stigma that is attached to the management of this issue. Awareness campaigns that emphasize the shared lived experiences of stakeholders could assist in combating this associated stigma by educating the greater public on understanding the risks associated with critical dementia-related and highlight how it is possible to be at risk but still able to live a safe and good quality of life if the appropriate strategies are incorporated.

(3) Perception of risk of critical wandering could be better balanced with "The Goldilocks Principle on Dementia and Wayfinding". This could be used as an education and discussion piece among stakeholders to assist in this way of thinking.

(4) A wide range of tailored wander-management strategies should be explored among caregivers and persons with dementia. Factors that influence strategy adoption, as indicated in the developed conceptual framework, should also be addressed.

(5) Knowledge translation practices that transcend beyond traditional academic settings should be made of priority among future research in critical dementia-relating wandering to ensure research evidence reaches policy and practice.

Implications for research

Looking ahead in terms of the results generated from the thesis, four subsequent studies are in development to continue moving this work forward. For the first study, initially there were plans to identify the perception of wandering among participants in Study Two of this thesis. While this information was collected, the rich information generated from this discussion warranted the need for this information to be conveyed in a manuscript on its own, rather than being included in the Study Two paper. Due to my involvement in the newly developed International Consortium on Dementia and Wayfinding, discussions were held during the Calgary and Edinburgh meetings to take this information, and conduct similar interviews with participants in other countries involved in the consortium to provide an international perspective on the term "wandering". In fact, one of the first primary objectives of the consortium is to provide an international term to wandering, and to propose recommendations on how we can separate this term from those with dementia that are missing. As indicated by Rowe et al. (2015), these two concepts are in fact separate entities however at times, wandering can lead to lost and missing person incidents. Unfortunately, this separation in terminology and language are often missed by the public. The initiation of these interviews is set to take place following ethics approval with an intended start date of September 2019.

Second, due to the limitations in Study Three where only the antecedent behaviours and no assessment measures to further explain these behaviours were recorded, future steps include collecting this information through our recent partnership with Home Care within Alberta Health Services (AHS). A care manager with AHS in Calgary has confirmed that data involving exit seeking behaviours are often recorded by home care workers using the Modified Dementia Observation System. This system exists across Alberta and we are presently seeking access to this data. Follow up surveys are also in the works with the International Consortium on Dementia and Wayfinding. The plan would be to have these antecedent behaviours recorded in countries around the world to determine if any differences across geographical locations exist.

Finally, the preliminary results from the face and content validity study of this thesis indicated promise that the conceptual framework and guidelines might be useful tools to help persons with dementia, their caregivers and other stakeholders understand the risk of the person with dementia getting lost, and to link them to personalized management strategies. The conceptual framework however has yet to determine the weighted percentage for each influencing factor to strategy adoption, nor has it indicated whether the framework is a helpful tool to estimate the risk of person with dementia to getting lost. As for the guidelines, the effectiveness of this work has yet to be evaluated.

Therefore, the next logical step for the conceptual framework is to test it quantitatively**.** To the best of our knowledge, however, there has been no work (neither at the research nor at the practice domains) that utilizes demographic, environmental, cultural, risk perception to wander, elopement risk, and medical condition factors of persons with dementia to predict the risk level of getting lost of persons with dementia. In addition, no work has linked such a predictive framework to appropriate strategies that are catered to the individual needs of caregivers and persons with dementia. The purpose of this project would be to estimate a multivariate quantitative predictor-indicator that quantifies the risk of getting lost among persons with dementia, to understand what are the most important factors that affects the risk of getting lost of this population, and to determine quantitatively how a calculated predictor-indicator can be linked with strategies to mitigate (or reduce) the risk of getting lost. As for the guidelines, an effectiveness study following a 6-month before and after design in urban and rural sites across Canada would be performed. Outcomes would include timing (i.e., before or after a lost incident) and type of proactive strategies adopted among caregivers and persons with dementia that resulted from using the guidelines, and the number of lost incidences following the implementation of the guidelines.

Summary of Chapter

As the prevalence of lost and missing persons incidences involving persons with dementia continues to rise, we will only continue to witness these harrowing cases, impacting more members of the community with each passing moment. If members of the community, families, health professionals, community organizations and police are committed to ending the loss of independence and hopelessness that too often comes with those with dementia that are at risk of getting lost, then they must look beyond their traditional scope of locks and barriers and consider the alternative proactive strategies that are waiting to be used and integrated.

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Appendices

Appendix A: Definition of terms

Critical wandering. In this thesis, critical wandering was defined as a form of wandering that leads a person with dementia to become lost due to wayfinding difficulties (Petonito et al. 2013).

Perimeter transgression. Based off the level of predictability the person with dementia would critically wander into the community (Moore et al. 2009).

Appendix B: Recruitment posters and emails

Thesis Study 2

Recruitment e-mail

We are conducting a study to evaluate different home-based solutions to keep persons with dementia that get lost safe. To volunteer you must be an adult 18 years or older and be a clinician, police officer, Alzheimer Society staff that regularly works with individuals with dementia that are prone to getting lost, person with mild or moderate dementia, or a formal or informal caregiver of an individual with dementia. You must also have an expressed interest in finding solutions to keep individuals with dementia that get lost in the community safe.

We invite you to participate in a 60-minute session in which you will talk about different ways of preventing someone with dementia from getting lost; and will discuss how you view the higher chance of a person with dementia getting lost and to see how dangerous and stressful it might make you feel. This will all be done in a small group of other participants. We will audio record these discussions and will transcribe them to summarize your point of views and suggestions. There will be a short break and we will provide refreshments and reimburse you for the parking costs should you acquire any.

Participation in this study is completely voluntary. If you are interested in participating in this study please contact Noelannah Neubauer via e-mail (noelanna@ualberta.ca) or phone (780-909-8625) for more information. Also please see the attached poster for more details.

Thank you very much.

PARTICIPANTS NEEDED FOR STUDY ON DEVELOPING A GUIDELINE FOR HOME-BASED SOLUTIONS FOR PERSONS WITH DEMENTIA THAT GET LOST

We are seeking volunteers to take part in a study to evaluate different home-based solutions to keep persons with dementia that get lost safe.

To volunteer you must be an adult 18 years or older and be a clinician, police officer, Alzheimer Society staff that regularly works with individuals with dementia that are prone to getting lost, person with mild dementia, or a formal or informal caregiver of an individual with dementia. You must also have an expressed interest in finding solutions to keep individuals with dementia that get lost in the community safe. As a participant in this study, you will be invited to:

- Talk about different ways of preventing someone with dementia from getting lost; will discuss how you view the risks that are associated with a person with dementia getting lost, and to see how dangerous and stressful a missing person event might make you feel. This will all be done online or via. telephone in a small group of other participants and this information will be used to create a guideline that will help stakeholders in choosing strategies that will help prevent persons with dementia from getting lost.
- Your responses will be recorded but will be stored in a locked room at the University of Alberta.
- Time commitment: 60-90 minutes
- Voluntary: You are free to withdraw from the research study at any time before May 31, 2018.

For more information or to volunteer for this study, please contact:
Noelannah Neubauer
PhD Student, Department of Occupational Therapy at
(780) 909-8625 or Email: noelanna@ualberta.ca

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of

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Thesis Study 3

Recruitment e-mail

We are conducting a study to determine if a pattern of behaviours exist immediately prior to persons with dementia attempting to leave the home unsupervised. Identifying these behaviours would allow for more timely use of management strategies that will allow the person with dementia to remain safe at home.

To volunteer you must be 50 years or older, have a clinical diagnosis of dementia, have left your home and been lost within your community at least once, and must reside in the community. Your caregiver will record any behaviours that may indicate you are about to exit seek using a questionnaire. These observations will be done daily for 2-4 weeks.

Your participation will help in making a guideline that could be used by caregivers and other stakeholders, in preventing persons with dementia from leaving the home unsupervised and getting lost. There will be no costs for your participation.

Participation in this study is completely voluntary. If you are interested in participating in this study please contact Noelannah Neubauer via e-mail (noelanna@ualberta.ca) or phone (780-909-8625) for more information. Also, please see the attached poster for more details.

Thank you very much.

PARTICIPANTS NEEDED FOR STUDY ON DEVELOPING A GUIDELINE FOR HOME-BASED SOLUTIONS FOR PERSONS WITH DEMENTIA THAT GET LOST

We are seeking volunteers to take part in a study to determine if a pattern of behaviours exist immediately prior to persons with dementia attempting to leave the home unsupervised. Behaviours could include grabbing their bag, talks of going home, etc. Identifying these behaviours would allow for more timely use of management strategies that will allow the person with dementia to remain safe at home.

To volunteer you must be a caregiver of someone with dementia and can be from anywhere in Canada. The person(s) you care for must have attempted to leave the home or facility unsupervised at least once. As a participant in this study, you will be invited to:

- Write down behaviours using a questionnaire that might indicate the person with dementia is about to leave the home unsupervised. These observations will be done for 2 weeks for those that are unaware of these behaviours or can be done without the need for an observation phase for those that are aware. The questionnaire will take approximately 5-10 minutes to complete.
- Completed questionnaires will only be viewed by the principal investigator (Noelannah Neubauer). Your responses will be kept confidential.
- Voluntary: You are free to withdraw from the research study at any time before July 31, 2018.

For more information about this study, or to volunteer for this study, please contact:

Noelannah Neubauer
PhD Candidate, Department of Occupational Therapy at
(780) 909-8625
Email: *noelanna@ualberta.ca*

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research conduct of research, contact the Research Ethics Office at (780) 492-2615.

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Thesis Study 4

Recruitment e-mail

We are conducting a study to evaluate the ease of use of a guideline that helps in the decision of choosing an appropriate home-based strategy to prevent persons with dementia from getting lost in the community.

To volunteer you must be an adult 18 years or older and be a clinician, police officer, Alzheimer Society staff that regularly works with individuals with dementia that are prone to getting lost, person with mild or moderate dementia, or a formal or informal caregiver of an individual with dementia. You must also have an expressed interest in finding solutions to keep individuals with dementia that get lost in the community safe.

We invite you to complete a 10-minute survey and a one-time online focus group that will take approximately 1 hour. During the survey and focus group you will be asked to provide feedback on the guideline and provide suggestions on how to make it better. Your responses will be kept confidential and you are free to withdraw from the study at any time before December 31st, 2018.

Participation in this study is completely voluntary. If you are interested in participating in this study please contact Noelannah Neubauer via e-mail (noelanna@ualberta.ca) or phone (780-909-8625) for more information. Also, please see the attached poster for more details.

Thank you very much.

PARTICIPANTS NEEDED FOR
STUDY ON DEVELOPING A GUIDELINE FOR HOME-BASED SOLUTIONS FOR PERSONS WITH DEMENTIA THAT GET LOST

We are seeking volunteers to take part in a study to evaluate the ease of use of a guideline that helps in the decision of choosing an appropriate home-based strategy to prevent persons with dementia from getting lost in the community.

To volunteer you must be an adult 18 years or older and be a clinician, police officer, Alzheimer Society staff that regularly works with individuals with dementia that are prone to getting lost, person with mild or moderate dementia, or a formal or informal caregiver of an individual with dementia. You must also have an expressed interest in finding solutions to keep individuals with dementia that get lost in the community safe. As a participant in this study, you will be invited to:

- Complete a 10-minute survey and a one-time online focus group that will take approximately 1 hour. During the survey and focus group you will be asked to provide feedback on the guideline and provide suggestions on how to make it better.
- Your responses will be kept confidential.
- Voluntary: You are free to withdraw from the research study at any time before December 31st, 2018

For more information about this study, or to volunteer for this study, please contact:

Noelannah Neubauer
PhD Candidate, Faculty of Rehabilitation Science at
(780) 909-8625
Email: *noelanna@ualberta.ca*

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

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Thesis Study 5

RECRUITMENT E-MAIL

We are conducting a study to attain feedback on a set of guidelines that helps in the decision-making process of choosing appropriate strategies to prevent persons with dementia from getting lost in the community. These guidelines have been validated and feedback generated from this study will assist in the finalized versions as they begin to be disseminated for use among organizations across the country.

To volunteer you must you must have a vested interest in helping people with dementia that are prone to getting lost.

We invite you to review the guidelines provided in this email and to complete a 10-minute survey where you will be asked to provide feedback on the guidelines. The survey can be completed using the attached document, or can be completed online using the following link: https://docs.google.com/forms/d/e/1FAIpQLSdsfspk0jbw6yPckBxe_7y8DsKgYN4L7P-G16ex3LqJpdsrBw/viewform?usp=sf_link . Within this survey, you will also be asked to provide comments and suggestions on how to improve the guideline

Participation in this study is completely voluntary. If you are interested in participating in this study please contact Noelannah Neubauer via e-mail (noelanna@ualberta.ca) or phone (780-909-8625) for more information. Also, please see the attached poster for more details.

Thank you very much,

Noelannah Neubauer
PhD Candidate
Faculty of Rehabilitation
University of Alberta

PARTICIPANTS NEEDED FOR
STUDY ON DEVELOPING A GUIDELINE FOR HOME-BASED SOLUTIONS FOR PERSONS WITH DEMENTIA THAT GET LOST

We are seeking volunteers to take part in a study to provide feedback on a series of guidelines that help in the decision-making process of choosing an appropriate strategies to prevent persons with dementia from getting lost in the community.

To volunteer you must have a vested interest in helping people with dementia that are prone to getting lost. As a participant in this study, you will be invited to:

- Review the guidelines provided and to complete a 10-minute survey where you will be asked to provide feedback on the guidelines. Within this survey, you will also be asked to provide comments and suggestions on how to improve the guideline
- Your participation will be anonymous; your identity cannot be linked to your responses. Your responses will be kept confidential.
- Time commitment: you can interact with the guideline as long as you want. The survey will take approximately 10 minutes.
- Voluntary: You are free to withdraw from the research study at any time before May 1, 2019.

For more information about this study, or to volunteer for this study, please contact:

Noelannah Neubauer
PhD Candidate, Department of Occupational Therapy at
(780) 909-8625
Email: *noelanna@ualberta.ca*

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

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Appendix C: Information letter and consent forms

Thesis Study 2

Person living with dementia form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:
Noelannah Neubauer
1-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
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stroulia@ualberta.ca
780 9098625

Research Co-Investigator:
Dr. Lili Liu
2-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
Edmonton, AB, T6G 2G4
lili.liu@ualberta.ca
780 4925108

Background

- People with dementia have a higher chance of getting lost and going missing.
- While more are being diagnosed with dementia, few want to live in nursing homes and a growing number want to live at home. Ways of preventing and managing the person with dementia from getting lost at home and in the community may differ. It can depend on the stakeholder involved and where you live.

Purpose

- To talk about different ways of preventing the chance of you getting lost

- To talk about how you view the risks that might come with getting lost, and to see how this many influence what prevention strategies you might be willing to try.

Study Procedures

- You will be interviewed by the principal investigator via. teleconference. You will be asked 9 questions on the strategies you use or have heard of to prevent the chance of you getting lost. You will also be asked what risks you think might occur if you get lost, and how this might influence what type of strategies you are willing to use to prevent these events from happening. The answers to these questions will be recorded with a tape recorder and notes will be written down by the researcher. The discussion of these 9 questions will take no longer than an hour.

Benefits

- You may not directly benefit from participating in this study.
- Your discussions will help to develop a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that would be interested in using this guideline.
- There will be no costs for your participation.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.

- You can withdraw from the study prior to the study, during the study, or until May 31, 2018. After May 31, we will transcribe the audio-recorded information and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be secured. We will guard your privacy as much as possible and use your information only for this project. We cannot guarantee that others in the study will maintain the confidentiality of what is said. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412
- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

______________________________________ _________________

Participant Providing Consent Date
Name (printed) and Signature

Caregiver form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:	**Research Co-Investigator:**
Noelannah Neubauer	Dr. Lili Liu
1-64 Corbett Hall	2-64 Corbett Hall
Department of Occupational Therapy	Department of Occupational Therapy
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G4	Edmonton, AB, T6G 2G4
stroulia@ualberta.ca	lili.liu@ualberta.ca
780 9098625	780 4925108

<u>Background</u>

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them. Ways of preventing and managing the person with dementia from getting lost at home and in the community may differ. It can depend on your involvement with the person with dementia and where you live.

<u>Purpose</u>

- To talk about different ways of preventing someone with dementia from getting lost
- To talk about how you view the higher chance of a person with dementia getting lost and to see how dangerous or stressful it might make you feel.

Study Procedures

- This study will consist of two sessions. The first session, you will do a 20-minute interview that contains 4-5 questions discussing your experiences of working with someone with dementia who has a risk of getting lost. Following this, you will be asked to monitor your family member with dementia for one month to see what kind of behaviours that might arise regarding their risk of getting lost, and to note what kind of strategies you used to keep them safe.
- After one month of doing the interview, you will join a group of other caregivers to discuss your experiences as a caregiver. You will be asked 8 questions on the strategies you use or have heard of to prevent someone with dementia from getting lost. You will also be asked what risks you think might occur if a person with dementia gets lost and goes missing, and how this might influence what type of strategies you are willing to use to prevent these events from happening. The answers to these questions will then be brainstormed by the participants at the table and will be recorded with a tape recorder and notes will be written down by the researcher. The discussion of these 8 questions will take no longer than an hour.

Benefits

- You may not directly benefit from participating in this study.
- You will be given the chance to share your experiences, thoughts and opinions on caregiving for someone with dementia that has a high chance of getting lost.

- Your discussions will help to develop a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that works with this population.
- There will be no costs for your participation. We will pay for parking or transportation should you require it.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until March 31, 2018. After March 31, we will transcribe the audio-recorded information and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence

of child abuse or neglect. As much as possible the information we keep will be secured. We will guard your privacy as much as possible and use your information only for this project. We cannot guarantee that others in the study will maintain the confidentiality of what is said. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412
- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
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Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

______________________________________ _________________

Participant Providing Consent Date
Name (printed) and Signature

______________________________________ _________________

Name (printed) and Signature of Person Date
Obtaining Consent

Other stakeholder form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:	**Research Co-Investigator:**
Noelannah Neubauer	Dr. Lili Liu
1-64 Corbett Hall	2-64 Corbett Hall
Department of Occupational Therapy	Department of Occupational Therapy
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G4	Edmonton, AB, T6G 2G4
stroulia@ualberta.ca	lili.liu@ualberta.ca
780 9098625	780 4925108

Background

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them. Ways of preventing and managing the person with dementia from getting lost at home and in the community may differ. It can depend on your involvement with the person with dementia and where you live.

Purpose

- To talk about different ways of preventing someone with dementia from getting lost.
- To use the information from this study to create a guideline of strategies to prevent a person with dementia from getting lost and going missing.

Study Procedures

- You will be asked 9 questions on the strategies you have suggested or have heard of someone using to prevent someone with dementia from getting lost, in addition to determining if perspectives on risk, culture, and living environment would have an influence when choosing these strategies. The answers to these questions will be recorded with a tape recorder and notes will be written down by the researcher. The discussion of these 9 questions will take no longer than an hour.

Benefits

- You may not directly benefit from participating in this study.
- You will be given the chance to share your experiences, thoughts and opinions on working with someone with dementia that has a high chance of getting lost.
- Your discussions will help to develop a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that works with this population.
- There will be no costs for your participation.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until May 31, 2018. After May 31, we will transcribe the audio-recorded information

and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be secured. We will guard your privacy as much as possible and use your information only for this project. We cannot guarantee that others in the study will maintain the confidentiality of what is said. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412

- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_______________________________________ _________________

Name of the Participant Providing Consent Date
Name (printed) and Signature

Thesis Study 3

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:	**Research Co-Investigator:**
Noelannah Neubauer	Dr. Lili Liu
1-64 Corbett Hall	2-64 Corbett Hall
Department of Occupational Therapy	Department of Occupational Therapy
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G4	Edmonton, AB, T6G 2G4
stroulia@ualberta.ca	lili.liu@ualberta.ca
780 9098625	780 4925108

Background

- People with dementia have a high chance of getting lost and going missing.
- Few people with dementia want to live in nursing homes and want to live at home. Their chance of getting lost can give stress to family, friends and communities that take care of them. Home based strategies like GPS may help to reduce this stress. Most home solutions are used when the person with dementia has already left the home. No one knows if there are behaviours a person with dementia may show right before attempting to leave the home unsupervised. If behaviours like these exist, home solutions could be used earlier which could further reduce care giving stress and decrease the chance of the person going missing.

Purpose

- To determine if a pattern of behaviours exist immediately prior to the person with dementia attempting to leave the home unsupervised.

Study Procedures

- Daily logs using a questionnaire developed by the research will be made the family or paid caregiver responsible for caring for the person with dementia's everyday tasks. These logs will include observations of exit seeking behaviours expressed by the person will dementia and will be gathered in a master log for inspection. Daily logs will take place for 2-4 weeks pending the frequency of these behaviours. Weekly check-ins by the researcher will take place to determine when to stop the daily logs.

Benefits

- You may not directly benefit from participating in this study.
- You will be able to learn more about the behaviours that may indicate a person with dementia is about to leave the home/ facility unsupervised.
- Your participation will help in making a guideline that could be used by caregivers such as yourself, in preventing your loved one with dementia from leaving the house unsupervised.
- There will be no costs for your participation.

Risk

- There are no risks in your participation of this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to participate if you feel uncomfortable and you can stop taking part at any time of the study.

- You can withdraw from the study prior to the study, during the study, or until July 31, 2018. After July 31, we will analyze the daily logs and pre-study tests and remove all information that identifies who you are. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the analyzed data.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be anonymous; it will not have your name on it. We will guard your privacy as much as possible and use your information only for this project.
- Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412

- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____ _________________

Participant Providing Consent Date
Name (printed) and Signature

Thesis Study 4

Caregiver consent form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:
Noelannah Neubauer
1-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
Edmonton, AB, T6G 2G4
stroulia@ualberta.ca
780 9098625

Research Co-Investigator:
Dr. Lili Liu
2-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
Edmonton, AB, T6G 2G4
lili.liu@ualberta.ca
780 4925108

<u>*Background*</u>

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them.
- Strategies such as GPS or door locks have been used as a way of keeping people with dementia safe at home instead of needing to send them to nursing homes. There are many strategies to choose from though making it hard to choose a strategy that works best for the individual.
- A guideline was created to help guide choosing these strategies.

Purpose

- To determine how easy this guideline is to use and to suggest any ways of making it better.
- To determine the best way to get this guideline to the people that want to use it
- To determine whether different versions of this guideline need to be created for people depending on what kind of stakeholder they are and based on language and cultural differences.

Study Procedures

- We will send you the current version of the guideline to try for one week.
- After trying the guideline for one week, you will be asked to complete a 10-minute online survey and an online or telephone interview will be scheduled with the researcher. This interview will be audio recorded. The purpose of this interview is to determine the potential of others using this guideline to help prevent those with dementia from getting lost. It will also allow us to determine if the guideline is easy to use and to see how we can distribute this guideline so anyone across Canada has access to using it. The interview will take approximately 30 minutes.

Benefits

- You may not directly benefit from participating in this study.
- You will be given the chance to help improve a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that also cares for someone with dementia.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until December 15, 2018. After December 15, we will transcribe the audio-recorded information and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be anonymous; it will not have your name on it. We will guard your privacy as much as possible and use your information only for this project. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the

research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412
- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_____________________________________ ________________

Participant Providing Consent Date
Name (printed) and Signature

______________________________________ ________________

Name (printed) and Signature of Person Date
Obtaining Consent

Person living with dementia form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:
Noelannah Neubauer
1-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
Edmonton, AB, T6G 2G4
stroulia@ualberta.ca
780 9098625

Research Co-Investigator:
Dr. Lili Liu
2-64 Corbett Hall
Department of Occupational Therapy
University of Alberta
Edmonton, AB, T6G 2G4
lili.liu@ualberta.ca
780 4925108

<u>Background</u>

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them.
- Strategies such as GPS or door locks have been used as a way of keeping people with dementia safe at home instead of needing to send them to nursing homes. There are many strategies to choose from though making it hard to choose a strategy that works best for the individual.
- A guideline was created to help guide choosing these strategies.

Purpose

- To determine how easy this guideline is to use and to suggest any ways of making it better.
- To determine the best way to get this guideline to the people that want to use it
- To determine whether different versions of this guideline need to be created for people depending on what kind of stakeholder they are and based on language and cultural differences.

Study Procedures

- We will send you the current version of the guideline to try for one week.
- After trying the guideline for one week, you will be asked to complete a 10-minute online survey and an online or telephone interview will be scheduled with the researcher. This interview will be audio recorded. The purpose of this interview is to determine the potential of others using this guideline to help prevent those with dementia from getting lost. It will also allow us to determine if the guideline is easy to use and to see how we can distribute this guideline so anyone across Canada has access to using it. The interview will take approximately 30 minutes.

Benefits

- You may not directly benefit from participating in this study.
- You will be given the chance to help improve a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that has dementia and is at risk of getting lost.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until December 15, 2018. After December 15, we will transcribe the audio-recorded information and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be anonymous; it will not have your name on it. We will guard your privacy as much as possible and use your information only for this project. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the

research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412
- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_______________________________________ _________________

Participant Providing Consent Date
Name (printed) and Signature

____ _________________

Name (printed) and Signature of Person Date
Obtaining Consent

Stakeholder form

INFORMATION LETTER and CONSENT FORM

Study Title: A framework to describe the levels of risk associated with dementia-related wandering

Research Investigator:	**Research Co-Investigator:**
Noelannah Neubauer	Dr. Lili Liu
1-64 Corbett Hall	2-64 Corbett Hall
Department of Occupational Therapy	Department of Occupational Therapy
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G4	Edmonton, AB, T6G 2G4
stroulia@ualberta.ca	lili.liu@ualberta.ca
780 9098625	780 4925108

Background

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them.
- Strategies such as GPS or door locks have been used as a way of keeping people with dementia safe at home instead of needing to send them to nursing homes. There are many strategies to choose from though making it hard to choose a strategy that works best for the individual.
- A guideline was created to help guide choosing these strategies.

Purpose

- To determine how easy this guideline is to use and to suggest any ways of making it better.
- To determine the best way to get this guideline to the people that want to use it
- To determine whether different versions of this guideline need to be created for people depending on what kind of stakeholder they are and based on language and cultural differences.

Study Procedures

- We will send you the current version of the guideline to try for at least one week.
- You will be asked to complete a 10-minute online survey and an online focus group or telephone interview will be scheduled with the researcher. This interview/ focus group will be audio recorded. The purpose of this interview/focus group is to determine the potential of others using this guideline to help prevent those with dementia from getting lost. It will also allow us to determine if the guideline is easy to use and to see how we can distribute this guideline so anyone across Canada has access to using it. If you are doing an interview, it will take approximately 30 minutes, and if you are doing a focus group it will take approximately 60 minutes.

Benefits

- You may not directly benefit from participating in this study.

- You will be given the chance to help improve a guideline of strategies to prevent someone with dementia from getting lost. In the future this will be accessible to you and anyone you know that also works with someone with dementia who is at risk of getting lost.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until December 15, 2018. After December 15, we will transcribe the audio-recorded information and remove all information that identifies who you are from the interview. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the transcript.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be

anonymous; it will not have your name on it. We will guard your privacy as much as possible and use your information only for this project. Any electronic information will be stored at secure University of Alberta locations. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Further Information

If you have any questions regarding this study, please do not hesitate to contact:

- John Misiaszek, Associate Dean, Graduate Studies and Research, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492-2412
- Lili Liu, Professor and Chair, Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta; Phone: (780) 492 - 0836
- A Research Ethics Board at the University of Alberta has reviewed the plan for this study for its adherence to ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Consent Statement

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_____________________________________ _______________

Participant Providing Consent Date
Name (printed) and Signature

______________________________________ _______________

Name (printed) and Signature of Person Date
Obtaining Consent

Thesis Study 5

Study Title: A framework to describe the levels of risk associated with dementia-related wandering: survey of newly developed guidelines

Research Investigator:	**Research Co-Investigator:**
Noelannah Neubauer	Dr. Lili Liu
1-64 Corbett Hall	2-64 Corbett Hall
Department of Occupational Therapy	Department of Occupational Therapy
University of Alberta	University of Alberta
Edmonton, AB, T6G 2G4	Edmonton, AB, T6G 2G4
noelanna@ualberta.ca	lili.liu@ualberta.ca
780 9098625	780 4925108

Background

- People with dementia have a higher chance of getting lost and going missing.
- While more older people are getting dementia, few want to live in nursing homes and a growing number want to live at home. This change in where people with dementia live gives stress to family, friends, and communities that take care of them.
- Strategies such as GPS or MedicAlert have been used as a way of keeping people with dementia safe at home instead of needing to send them to nursing homes. There are many strategies to choose from though making it hard to choose a strategy that works best for the individual.
- A guideline was created to help guide choosing these strategies. This paper versions of this guideline have been made available to the Alzheimer Society of Alberta and the Alzheimer Society of Ontario. Electronic versions have also been incorporated in the findingyourwayontario.ca and Alzheimer.ca websites.

Purpose

- To determine if the Alzheimer Society is the best way of getting the guideline on strategies to help those with dementia at risk of getting lost to the public
- To gain final feedback on changes or improvements that could be made to the guideline

Study Procedures

- On your own time, you are asked to provide feedback on the content and ease of use of the guideline using a rating scale. You will also be asked to provide comments and suggestions on how to improve the guideline and provide feedback on other ways of getting the guideline to the public that may not have access to the internet and/or local Alzheimer Society. The survey will take approximately 10 minutes.

Benefits

- You may not directly benefit from participating in this study.
- You will be given the chance to help improve a guideline of strategies to prevent someone with dementia from getting lost.
- There will be no costs for your participation.

Risk

- There are no risks for participating in this study.

Voluntary Participation

- Being involved in this study is voluntary.
- You do not have to answer questions or participate if you feel uncomfortable and you can stop taking part at any time of the study.
- You can withdraw from the study prior to the study, during the study, or until March 31, 2019. After March 31, we will analyze the information and remove all information that identifies who you are from the survey. After this, if you want to withdraw from the study, it is impossible for us to identify your comments to remove them from the analysis.

Confidentiality & Anonymity

- The researchers may preset the findings at a scientific conference or use them to write a paper for a scientific journal. We will not use any information that may result in identifying who you are in our presentations or publications.
- The research team will make every effort to keep your information private. All information you share follows University of Alberta policies as well as the laws of Alberta and Canada. The information collected will be kept confidential, unless we are requested by law to reveal the information. Example is evidence of child abuse or neglect. As much as possible the information we keep will be anonymous; it will not have your name on it. We will guard your privacy as much as possible and use your information only for this project. The information will be password protected. None of this electronic information will include your name or personal information. Only the members of the research team will have access to this data. All records will be destroyed after five years.

Consent form

1. Do you understand that you have been asked to be in a research study? (please circle)
    a) Yes
    b) No
2. Do you understand that you consent to participate by filling out this survey? (please circle)
    a) Yes
    b) No

3. Do you accept to participate in this study? (please circle)
    a) Yes
    b) No

Appendix D: Tools used for data collection

Thesis Study 2

Thesis Study 2 Interview demographic information

Date of data collection:

Name:

Participant code:

Age:

Gender:

Ethnicity:

Town/ city of residence:

Education:

General occupation:

Years with dementia/ working with someone with dementia (if applicable):

Dementia diagnosis (if applicable):

Present living situation for the PWD:

Study 2 interview guiding questions

Questions for family caregiver group

Semi-structured interview questions

Definition of wandering, experiences with wandering, and risk perception

1. Describe your experience in living with persons at risk for getting lost or wandering. Have there been any instances when they got lost? If so describe what you did to try to find them.
2. Do you see this behaviour as a risky behaviour? If so, how high do you see this risk to be? What kind of risks are associated with this?
3. How do you define *wandering*?

Strategies used to keep the person with dementia safe

1. Have you tried or thought of trying strategies to help manage this behaviour? If so describe what strategies you used, and what caused you to want to use these strategies (what was your tipping point that made you realize that something needed to be done)?
2. Putting the last two questions together, if you saw wandering as a higher or lesser risk than what you perceive now, would this change what strategy you are willing to use?
3. Do you think where you live (rural vs. urban) would have an influence on what strategies you are willing to use?
4. Would your cultural background also influence what strategies you are willing to use?
5. Do you think the *stigma* associated with dementia influences what strategies you are willing to use? If *stigma* were reduced or eliminated (like cancer) would you be more willing to involve your family, or ask for help?
6. Are there any other factors that would influence what strategies you are willing to use?

Thesis Study 3

Family caregiver version

Antecedent Behaviour Questionnaire

Observation period start date:

Observation period end date:

First name(s) of caregiver observing the behaviours:

Location of the observed behaviours (i.e. assisted living, home, etc.):

Purpose: The purpose of this study is to determine if a pattern of behaviours can be observed that would indicate a person with dementia is about to exit seek or wander (i.e. antecedent behaviours). The identification of these behaviours would be applied in the form of a guideline, that would assist caregivers in determining ways to reduce these seeking behaviours, and to apply appropriate strategies to reduce the risk of the individual getting lost.

Instructions: To assist in this study, the following questionnaire will be used over the next four weeks or until one or more exit seeking or critical wandering behaviours (i.e., has wandered outside and was lost) was observed. Each time you observe a person with dementia exit seeking or critically wandering, please complete this questionnaire.

PART 1: Please answer the following questions regarding exit seeking or wandering behaviour

1. During your day, did you observe the person with dementia exhibit exit seeking or wandering behaviour that resulted in them getting lost?

   ☐YES ☐NO

   Please describe the incident:

2. If you answered yes, approximately how many times? _______

PART 2: If you answered yes to the questions above, please answer the following questions regarding antecedent behaviours

1. From your observations, did the person with dementia show behaviours that might indicate that they were about to try and exit seek or wander and get lost (i.e. grabbing their purse, made calls during the day to be picked up, etc.)?

   ☐ YES ☐ NO

   If you answered yes, please describe these behaviours:

2. Was there one behaviour that occurred more than others?

   ☐ YES ☐ NO

   If you answered yes, please describe this behaviour:

3. What strategies did you use to try and decrease these exit-seeking behaviours?

4. Please check mark below the general level of cognitive impairment of the individual that portrayed the above exit-seeking behaviours:

☐ Mild cognitive impairment

☐ Moderate cognitive impairment

☐ Severe cognitive impairment

Other comments pertaining to their cognitive impairment:

Care facility version

Antecedent Behaviour Questionnaire

Observation period start date:

Observation period end date:

First name(s) of staff/ caregiver observing the behaviours:

Location of the observed behaviours (i.e. assisted living, home, etc.):

Purpose: The purpose of this study is to determine if a pattern of behaviours can be observed that would indicate a person with dementia is about to exit seek or wander (i.e. antecedent behaviours). The identification of these behaviours would be applied in the form of a guideline, that would assist caregivers in determining ways to reduce these seeking behaviours, and reduce the risk of the individual getting lost.

Instructions: To assist in this study, the following questionnaire will be used over the next four weeks or until one or more exit seeking or critical wandering behaviour (i.e., has wandered outside and was lost) was observed. During your shift, each time you observe a person with dementia exit seeking or critically wandering, please complete this questionnaire.

PART 1: Please answer the following questions regarding exit-seeking

1. During your day with your clients, did you observe the person with dementia exit seeking or wandering behaviour that resulted in them getting lost?

   ☐YES ☐NO

   Please describe the incident:

2. If you answered yes, approximately how many people? _______

3. Did you observe these behaviours multiple times throughout the day?

   ☐YES ☐NO

4. If you answered yes to question 4 how many times were these behaviours exhibited for each person with dementia?

   ____

PART 2: If you answered yes to the questions above, please answer the following questions regarding antecedent behaviours

5. From your observations, did any of your clients show behaviours that might indicate that they were about to try and exit seek or wander (i.e. grabbing their purse, made calls during the day to be picked up, etc.)?

   ☐YES ☐NO

   If you answered yes, please describe these behaviours:

6. Was there one behaviour that occurred more than others?

☐YES ☐NO

If you answered yes, please describe this behaviour:

7. What strategies did you use to try and decrease these exit-seeking behaviours?

8. Please check mark below the general level of cognitive impairment of the individual that portrayed the above exit-seeking behaviours:

☐ Mild cognitive impairment

☐ Moderate cognitive impairment

☐ Severe cognitive impairment

Other comments pertaining to their cognitive impairment:

Study 4 Interview guiding questions

Interview guiding questions

1. Does the conceptual framework and infographic make sense to you? Is there anything you think should be added/ changed/ removed?

2. Describe the potential of using this framework for being implemented for use within the community.

    a. Do you see it as something that will be quickly used for uptake by the community?

    b. Do you see it as being helpful? If so, please describe

    c. Is it something you could see yourself using?

    d. Can you see it as a tool that will help improve the quality of life and independence of persons with dementia whom are at risk or are concerned about getting lost?

    e. Do you see this framework as being something that will help the general population understand what wandering is and will be something that will change how they view wandering?

    f. Do you see it as something that will help promote non-critical wandering rather than restricting it?

3. What is the best way to get this framework to the hands of the user? We are collaborating with the Alzheimer Societies to help with paper and electronic copies. For those who have not gotten into contact with this organization however, what can we do to get this key information to them?

Thesis Study 5

Survey Questions

Section 1: Demographic Data

1. Age (years): ______

2. Gender (please circle):
    a. Female
    b. Male
    c. Other

3. Type of stakeholder (please circle):
    a. Formal care partner (i.e., you are paid to give care)
    b. Informal care partner (i.e., you are not paid to provide care e.g. family member)
    c. Clinician (i.e., nurse, occupational therapist, physician)
    d. Community organization
    e. Other: ______________

4. If you are an informal caregiver, what is your relationship to the person living with dementia? (please circle):
    a. Daughter
    b. Son
    c. Spouse
    d. Sibling
    e. Parent
    f. Friend

Section 2: Feedback on the guidelines

Section 2 examines the overall satisfaction, visual features and ease of use of the guidelines. Please circle the appropriate response for the following 7 questions (Note: circle only ONE response per question):

1. What is your overall impression of the developed guidelines?
    a. Very dissatisfied
    b. Dissatisfied
    c. Neutral
    d. Satisfied
    e. Very Satisfied

2. The visual features of the guidelines were pleasing to the eye
    a. Strongly disagree
    b. Disagree

    c. Neutral
    d. Agree
    e. Strongly agree

3. I think that the guidelines were easy to navigate
    a. Strongly disagree
    b. Disagree
    c. Neutral
    d. Agree
    e. Strongly agree

4. I think that the information was easy to understand
    a. Strongly disagree
    b. Disagree
    c. Neutral
    d. Agree
    e. Strongly agree

5. I think that the information provided was useful
    a. Strongly disagree
    b. Disagree
    c. Neutral
    d. Agree
    e. Strongly agree

6. I found what I was looking for
    a. Strongly disagree
    b. Disagree
    c. Neutral
    d. Agree
    e. Strongly agree

7. I am likely to recommend the guidelines to a friend or relative
    a. Strongly disagree
    b. Disagree
    c. Neutral
    d. Agree
    e. Strongly agree

Final Feedback

If possible, please provide comments or suggestions on how to further improve the guidelines shown today: