

Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate
Dementia in Long-Term Care Homes

by

Adebusola Adekoya

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF NURSING

College of Nursing

Rady Faculty of Health Sciences

University of Manitoba

Winnipeg

Copyright © 2018 by Adebusola Adekoya

Abstract

Wandering is often described as “aimless walking” and “disruptive”. Kitwood’s Enriched Model of Dementia challenges us to focus on the person, not the behaviour. This exploratory study addressed a gap in the literature on wandering behaviour by gaining the perspectives of older adults living with mild to moderate dementia in long-term care homes and their family members. Walking interviews were conducted with eight older adults. Family members provided additional information on their relatives’ walking history. Key themes were: *walking as enjoyable and good, walking for health benefits, walking as purposeful, walking as a lifelong habit, walking as a form of socialization, walking as a coping strategy, and walking to find and be with animals*. These results suggest a reconceptualization of wandering from aimless walking and a disruption to a purposeful and beneficial activity. The findings form the groundwork for future studies on promoting safe walking for older adults living with dementia.

Acknowledgments

I want to appreciate Dr. Lorna Guse, my academic advisor for her support and guidance throughout my graduate studies. Thank you for giving me the opportunity to learn from you. I also want to thank my thesis committee members, Dr. Elaine Mordoch, Dr. David Strang, and Dr. Lois Stewart-Archer for their contributions to the success of my research. Thank you for your encouragement and taking the time to examine my work.

I am grateful for the generous financial support of the University of Manitoba Graduate Studies for the University of Manitoba Graduate Fellowship, the Manitoba Centre for Nursing and Health Research, Fort Garry Legion Trust Fund Research Grant, Red River College, Foundation for Registered Nurses of Manitoba, Graduate Nursing Students Association Scholarship, Irene E. Nordwich Foundation Scholarship, Mona McLeod Award, Ann C. Beckingham Scholarship, Christine Michalchyshyn Memorial Bursary, and Peter and Dorothy Saydak Memorial Scholarship. I am also thankful to all my colleagues and faculty members who have encouraged me and asked about my study while it was in progress. I appreciate your support and interest in my study.

I also want to thank the residents and family members who participated in my study. Without you, there would be no study. I am grateful to the leadership team and staff of the long-term care homes who granted me access to their facilities and assisted in the screening process for my study.

My sincere appreciation goes to my family and friends for their support and encouragement throughout my studies. Adeniyi Adekoya, my love forever, I appreciate your unwavering support and for providing a shoulder to always lean on. Thanks to my parents, Mr. and Mrs. Adeyinka for your prayers and support. To my siblings, Oluwafemi Adedeji, Adeyemi Adeyinka, Adeola Abiola, Oluwaseyi Adeyinka, and Ayooluwa Abiodun-Alo, and my in-laws, thank you for your prayers and always being there for me. Olabisi and Akintayo Adegunju, thank you for your friendship all these years and for always being there to listen to my stories. Oyedele Ola, thanks for your support and for the “push”. Finally, I thank the Almighty God for His wisdom, strength and grace. Without you Lord, I am nothing.

Dedication

I dedicate my thesis to

Mr. and Mrs. Adeyinka

And

Adeniyi Adekoya.

Thank you Dad and Mom, for instilling in me at a tender age the value of education. Without you

Dad, I would not be the nurse that I am today, thank you.

Adeniyi, you believe so much in me and have been my greatest support, words cannot express

how much I appreciate you.

Table of Contents

Abstract.....	ii
Acknowledgments	iii
Dedication	v
Table of Contents	vi
List of Tables	x
List of Figures.....	xi
Chapter 1: Introduction	1
Purpose.....	4
Theoretical Framework.....	5
Research Questions	5
Significance of the Study	6
Self-Disclosure.....	8
Summary	9
Chapter 2: Literature Review.....	10
The Enriched Model of Dementia.....	10
The Need-driven Dementia-compromised Behaviour (NDB) Model	14
The Progressively Lowered Stress Threshold (PLST) Model	15
Wandering Behaviour	16
Summary	32
Chapter 3: Research Design and Methods	34

Interpretive Description	34
Recruitment, Site, and Sample	35
Data Collection Procedure	38
The Walking Interview	41
Data Analysis Process	45
Trustworthiness and Integrity of the Study	48
Ethical Considerations	52
Summary	54
Chapter 4: Results.....	56
Description of the Study Sample	57
Profile of Family Members	68
Walking as enjoyable.....	70
Walking for health benefits.....	72
Walking as purposeful.....	75
Walking as a lifelong habit.....	76
Walking as a form of socialization.....	78
Walking to be with animals.....	80
Resident Participants' Walking- and Not Walking-Related Concerns	82
Family Participants' Perspectives on Walking	83
Walking for health benefits.....	84
Walking as a coping strategy.....	85
Walking is good.....	86
Walking as purposeful.....	87

Walking as a form of socialization.	87
Walking to find animals.	88
Family Participants' Walking-Related Concerns.....	90
Family Participants' Not Walking-Related Concerns.....	95
Other Findings from Family Members	97
Participant Observation and Reflection Findings	100
Summary	107
Chapter 5: Discussion of the Findings	109
Research Question Number One.....	109
Research Question Number Two	120
A Visual Representation of the Key Themes.....	123
Residents' Concerns.....	124
Family Members' Concerns.....	126
Participant Observation and Reflection	135
Strengths	138
Limitations	140
Recommendations for Practice	141
Future Research	143
Conclusion	144
References	146
Appendices.....	168
Appendix A. Recruitment Process for Participants	168
Appendix B. Screening for Wandering (Dewing, 2005)	169

Appendix C. Letter of Permission to Use the Dewing’s Wandering Screening Tool	170
Appendix D. Letter to the Director of Care (DOC)	171
Appendix E. Research Project Information Sheet	173
Appendix F. Poster on Research Project.....	174
Appendix G.1. Information and Written Consent Form (Resident Participant)	175
Appendix G.2. Joint Consent Form (Resident and Family Participants).....	179
Appendix G.3. Information and Written Consent Form (Family Participant).....	183
Appendix H. Resident Participants Interview Items (including probes)	187
Appendix I. Family Participants Interview Questions (including probes)	188
Appendix J. Pledge of Confidentiality	190
Appendix K. Research Ethics Board Certificate of Approval	191

List of Tables

Table 1: Use of assistive devices.....	59
Table 2: Summary of key themes and sub-themes for resident participants' perspectives on walking.....	81
Table 3: Summary of key themes and sub-themes for family participants' perspectives on walking.....	89
Table 4: Family participants positive comments about LTC homes and staff.....	99

List of Figures

Figure 1: The Enriched Model of Dementia (Kitwood, 1993).....	5
Figure 2: Sociodemographics of the sample (n = 8).....	58
Figure 3: Walking history of participants (n = 8, P = participant).....	64
Figure 4: A visual representation of the key themes of the study	123

Chapter 1: Introduction

Canada's population is aging. People live longer and healthier as a result of improvements in healthcare, public health and sanitation, which have also resulted in an increase in people living with non-communicable diseases, including dementia (World Health Organization (WHO) & Alzheimer's Disease International, 2012). Dementia has been defined as a clinical syndrome, not resulting from delirium, characterized by a decline of global cognition and memory with significant effects on day-to-day functioning (Lyketsos et al., 2006). Dementia is a major health problem affecting over 47 million people worldwide, and the number is expected to reach approximately 76 million by 2030, and 135 million by 2050 (WHO, 2015; Lyketsos et al., 2006). Presently, no cure for dementia exists and many older adults living with dementia require long-term care support (Whall & Kolanowski, 2004). Apart from the cognitive changes, older adults living with dementia often exhibit symptoms of disturbed perception and thought content, and moods or behaviours which have been referred to as the behavioural and psychological symptoms of dementia (BPSD) (Finkel, 2000).

BPSD include, but are not limited to wandering, agitation and/or restlessness, anxiety, shadowing, and vocalizations. BPSD are often described as problematic, disturbing, difficult, inappropriate and challenging because these behaviours are difficult to understand and manage (Algase et al., 1996; Brittain, Degnen, Gibson, Dickinson, & Robinson, 2017; Whall & Kolanowski, 2004). These negative descriptors are based on the perspectives and experiences of those who try to manage the behaviours, and not from the individuals expressing the behaviours (Algase et al., 1996; Dewing, 2005). Not until recently are these negative descriptors being changed to a more person-centered term, "responsive behaviours", which connotes that most behaviour expressed by older adults living with dementia is a response to a cue or trigger.

Responsive behaviours occur as a result of changes in the brain of older adults living with dementia, thereby affecting their memory, judgement, orientation, mood and behaviour (Alzheimer Society of Toronto, 2014). Another term that has been used to describe BPSD is “distressed behaviour”. Since behaviours may be seen as a form of communication (Mitty & Flores, 2007), describing wandering as a distressed behaviour demonstrates that the behaviour is acknowledged as a way in which older adults express their distress. For example, older adults living with dementia may wander when they feel uncomfortable or unsettled (Andrews, 2017). It has been suggested that wandering behaviour is a means of dealing with stress or a symptom of unmet needs (for example, pain, cold, hot, toileting) which older adults living with dementia may not be able to express directly. The behaviour may have benefits in terms of physical activity, as a therapeutic need for movement, and as a coping strategy (Algase et al., 1996; Andrews, 2017; Dewing, 2011; Song & Algase, 2008).

Wandering is defined as the inability of older adults living with dementia to find their way while pursuing a need or a goal (Algase et al., 1996). This definition by Algase et al. (1996) suggests a purpose, but wandering in long-term care (LTC) homes has also commonly been referred to as aimless walking. Dewing (2005) referred to wandering as a complex human activity having different forms that may occur within the same person and between different people over time. Wandering is not limited to older adults living with dementia who are ambulatory. The behaviour has also been defined as an aimless movement in wheelchair motion and is exhibited by older adults using assistive devices such as a walker or cane (Cipriani, Lucetti, Nuti, & Danti, 2014; Lai & Arthur, 2003). An often cited definition of wandering is “a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally disordered and/or spatially 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” (Algase, Moore, Vandeweerd & Gavin-Dreschnack, 2007, p. 696). The definition of wandering is contentious and discussed in detail in chapter two. For the purpose of this study, the Algase et al. (2007) definition as indicated above was used.

Wandering is often interpreted in such a way that it demeans the personhood of older adults living with dementia, specifically when an older adult who wanders is labelled as a “wanderer”. This term is not only derogatory, but also has negative consequences for the older adult being labelled and may impact the health and social care rendered to such an individual (Dewing, 2005). Negative images such as “elopement, endangered, taking care, getting lost and following up” are evoked by this term (Halek & Bartholomeyczik, 2012, p. 406). Furthermore, wandering is often described as disruptive and viewed by healthcare providers as a problem that needs to be prevented or controlled to minimize disruption to staff workload and resident care schedules (Wigg, 2010). However, little is known about wandering from the perspectives of older adults living with dementia. Due to the negative consequences for older adults who engage in wandering, there have been suggestions to change “wandering” to “walking around” (Halek & Bartholomeyczik, 2012). However, this study used the term wandering because this is the term that is commonly used in the literature.

To obtain a true understanding of the phenomenon of wandering, it is important to acknowledge what contributes to our perspectives, and place these perspectives aside (Munhall, 2012). While concerns about the ability of older adults living with dementia to make consistent and safe choices exist, it has been argued that even though these older adults experience cognitive impairment, much of their values, personality, and substantial memory remains intact (Landau, Auslander, Werner, Shoval, & Heinik, 2011; Whitlatch, Feinberg, & Tucke, 2005).

Most research has focused on formal and informal caregivers' perspectives of wandering behaviour. While we know from other areas of research with older adults living with dementia that it is possible to ask about their perspectives and receive their answers, there has been little research done directly with older adults who wander (Dewing, 2006; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Tanner, 2012; Whitlatch et al., 2005).

Purpose

The purpose of this study was to gain a better understanding about wandering behaviour primarily through the perspectives of older adults living with mild to moderate dementia residing in LTC homes. The study also looked at the perspectives of family members on wandering behaviour.

In Canada, LTC facilities provide not only 24-hour supervised care to older adults, but also professional health services and personal care, such as meals, laundry and housekeeping. The care provided by LTC facilities is governed by provincial and territorial legislations, thereby creating inconsistency in what facilities are called (such as nursing home, personal care home and residential continuing care facility) and the type of care offered (Government of Canada, 2004). In Winnipeg, Manitoba where this study was conducted, the LTC program offers a variety of services, including companion care, supportive housing, and personal care home services. Personal care homes in Winnipeg (sometimes called nursing homes) provide care services (such as meals, assistance with activities of daily living, nursing care, prescription drugs, physiotherapy and occupational therapy, routine laundry, and linen services) to older adults who can no longer look after themselves at home with family support and/or community services and are not eligible for supportive housing (Banerjee, 2007; Winnipeg Regional Health Authority (WRHA, n.d.)). For this study, personal care homes were referred to as LTC homes.

Theoretical Framework

The theoretical framework that guided this study is the Enriched Model of Dementia by Tom Kitwood. The Enriched Model of Dementia was developed on the principles of person-centered care. The model challenged the traditional way of thinking about dementia by focusing on the older adults living with dementia rather than on their disease or its symptoms (Kitwood, 1993; Kuhn & Verity, 2008). The Enriched Model of Dementia suggests that there are other factors that affect an older adult living with dementia apart from the neurological impairment caused by changes in the brain. The model proposes that the neurological impairment and these other factors affect how a person living with dementia acts, feels and thinks, and this is represented in a formula (Brooker & Surr, 2005; Kitwood, 1993) (see **Figure 1**).



Figure 1: The Enriched Model of Dementia (Kitwood, 1993)

(NI = neurological impairment, H = health and physical fitness, B = biography-life history, P = personality and SP = social psychology).

Research Questions

- 1) How do older adults living with mild to moderate dementia in LTC homes perceive their own wandering behaviour?
- 2) Using the components of the Enriched Model of Dementia, how do family members perceive the wandering behaviour of their relatives who are living with mild to moderate dementia in LTC homes?

“Perceive” in the context of this study was defined as becoming aware of oneself and one’s ability to interpret one’s environment.

Significance of the Study

This study is significant for a number of reasons. First, wandering is a common behaviour among older adults living with dementia. Globally, about seven million older adults every year are diagnosed with dementia, which means that one older adult is diagnosed with dementia every 4.1 seconds (WHO, 2015). Dementia and cognitive impairment are major leading contributors to disability, thereby leading to dependence among older adults and increasing the risk of being admitted into LTC homes (WHO, 2015). Wandering is common among older adults living with dementia who reside in LTC homes. In fact, the behaviour is one of the most common reasons for LTC home placement (Dewing, 2011; O’Connell et al., 2011). A gap in the literature exists and little is known about the perspectives of older adults living with dementia who exhibit wandering behaviour. According to Munhall (2012), “Each person we encounter can help us to discover what is best for him or her. The other person, not us, is truly the expert knower of himself or herself” (p. 21).

Second, wandering behaviour has been depicted as a problem, a challenge and a disruption because this area of research has focused on staff or much less often, family’s perspectives instead of on the perspectives of older adults living with dementia who exhibit this behaviour. The voices of older adults living with dementia who wander must be included in understanding and searching for appropriate clinical practice (Dewing, 2006). Alzheimer’s Disease International, the global voice on dementia is an organization that seeks to promote international and local action on dementia (Alzheimer’s Disease International (ADI), n.d.). They have been instrumental in advocating that countries develop a national dementia strategy. A

major principle of this strategy is to take social action to make communities inclusive of people living with dementia and supportive of those caring for people living with dementia. Canada recently launched a national dementia strategy on June 22, 2017, which has led to the creation of The Canadian Alzheimer's Disease and Dementia Partnership (CADDP) with a focus on research, prevention, and living well with dementia (Alzheimer Society of Canada, 2018b).

ADI has a sister organization, Dementia Alliance International (DAI) and to become a member of DAI, you must have received a diagnosis of dementia (Dementia Alliance International, 2017). These two organizations work together, hold joint conferences and at plenary sessions, the expert panels always have at least one member from DAI, someone who has been diagnosed with dementia to add their perspectives to the issues being discussed by academics and clinicians. This should be the new approach for clinical practice and research in wandering, and it was the approach of this study. In order to have a better understanding of wandering behaviour, the perspectives of older adults who exhibit this behaviour were the focus of this study.

Third, this study has generated findings through the perspectives of older adults living with mild to moderate dementia who wander and their families. These findings could not only help to better understand wandering from the perspectives of older adults who wander and their families, but also to change the negative approach towards wandering behaviour. The findings might create awareness of the need for alternative perspectives and individualized approaches to the behaviour. Older adults who wander can help healthcare providers discover what they want when they wander, how they feel when they wander, and how wandering might be beneficial for them.

Finally, this study added to the increasing body of knowledge on wandering behaviour and could form the groundwork for future research. Further research is needed in understanding the meaning of wandering behaviour and lived experiences of older adults who engage in this behaviour.

Self-Disclosure

Our personal or professional experiences shape how we collect, read, and interpret data. In this section, I will describe my stance as a qualitative researcher, that is, how my worldview, cultural values and beliefs might have affected my interpretation of the data of this study.

My passion for caring for older adults has its origin in my cultural values and belief. At a young age, I learned from my parents how to show respect to older adults, assist them with activities of daily living (ADL) and “keep them safe”. While growing up, my grandmother lived with my family for more than eight years before she passed away, and she required assistance with her ADLs. Throughout the period my grandmother was living with my family, my parents, siblings, and I were responsible for providing care to my grandmother. My grandmother had good vision and experienced mild cognitive impairment. Although she was independent with her mobility and could go to wherever she wanted, it was the responsibility of my family to ensure that she was safe when walking at home and in the community.

As a Registered Nurse (R.N.) working in a LTC home, my perspective on wandering prior to conducting the study was that the behaviour was beneficial but could also be unsafe. This perspective was partly based on my cultural values and belief while growing up and my clinical experience. In clinical practice, we seldom ask older adults why they engage in wandering behaviour or what they are looking for when they walk. Just like some of my nursing colleagues and health care aides (HCAs), I viewed wandering behaviour as disrupting to my

clinical routines, especially when residents wandered into other residents' rooms or unsupervised areas. I was aware of my perspectives on wandering behaviour and what I might be "bringing into" this study prior to conducting this study and how this perspective might affect my interpretation of the data. Therefore, I maintained self-reflection throughout the data analysis process by keeping a reflective journal (including observational notes) on my perspective, including my thoughts and biases. Excerpts from my reflective journal were presented in the trustworthiness and integrity of the study section. Moreover, participants' quotes were incorporated into the presentation of the findings. For example, the key theme, *Walking as a form of socialization* emerged from the perspectives of both residents and family members. However, a family member specifically mentioned that their relative walked for the purpose of socialization. Also, I ensured I had an ongoing discussion with my supervisor about my perspectives on wandering during our data analysis process.

Summary

As the number of older adults living with dementia continues to grow, healthcare providers will continue to provide care for older adults with wandering behaviour. This study explores wandering primarily from the perspectives of those who wander and also from their family members. Through this study, older adults living with mild to moderate dementia have a voice to express their perspectives about wandering. Their family members also expressed their perspectives on wandering behaviour.

Chapter 2: Literature Review

This study focused on understanding wandering behaviour from the perspectives of older adults living with mild to moderate dementia and their family members. It is important to recognize the influence not only of the neurological impairment but also of the psychosocial, environmental, biographical and personality factors on wandering behaviour as proposed by Kitwood through the Enriched Model of Dementia (Brooker & Surr, 2005; Kitwood, 1993). Moreover, what Kitwood stated about other factors contributing to behaviour fits well with two nursing models, the Need-driven Dementia-compromised Behaviour (NDB) and the Progressively Lowered Stress Threshold (PLST) models. These models focus on understanding responsive behaviours and are discussed in detail. This chapter also includes discussion on wandering behaviour including: its definition; patterns and types; prevalence; what wandering is not; benefits and potential risks; underlying causes; management; and a summary of the research literature on wandering.

The Enriched Model of Dementia

The Enriched Model of Dementia suggests that neurological impairment, and psychosocial, environmental, biographical and personality factors are related to wandering behaviour. (Dementia = NI+ H+B+P+SP).

NI (neurological impairment). The neurological impairment associated with dementia explains how changes in brain or memory function result in wandering (Brooker & Surr, 2005). Hope et al. (2001) suggested that the urge to wander in older adults living with dementia may be a consequence of brain damage. Neurological factors such as central nervous system damage, neurotransmitter imbalance, and changes in the circadian rhythm and motor ability have a connection with behaviours (Algase et al., 1996). Specifically, changes in the circadian rhythm,

particularly sleep disturbances, may result in high levels of anxiety, which subsequently increase movement, and wandering behaviour could be explained as a response to anxiety (Cipriani et al., 2014; Wigg, 2010). Memory function not only affects older adults' ability to perceive and interpret their environment or others' point of view, but also to plan a goal. A change in memory function, such as an attention deficit affects older adults' ability to keep a goal or destination in mind. Therefore, wandering behaviour may indicate older adults' inability to find their way and to pursue a need or goal (Algase, 2006; Algase et al., 1996; Brooker & Surr, 2005).

H (health and physical fitness). A diagnosis of dementia has consequences for older adults living with dementia. Sometimes healthcare providers ignore the feelings of older adults living with dementia because they believe that dementia interferes with the ability of older adults to give accurate accounts of their symptoms and emotions (Brooker & Surr, 2005; Lee, McConnell, Knafl, & Algase, 2015). Although it is important to acknowledge the role of neurological impairment in behaviours, it is equally important to avoid assumptions. Confusion may be an indication of various physical health problems, including urinary or chest infections, pain, constipation, dehydration and sedation (Brooker & Surr, 2005). Physical health problems, especially pain, urinary urgency, hunger or thirst may go undetected or worsen due to delayed treatment. Therefore, it is imperative to consider and ensure the physical fitness as well as the comfort of older adults living with dementia (Brooker & Surr, 2005). Sensory impairments such as visual impairment or hearing loss have been associated with social isolation (O'Connell et al., 2011). Sensory impairments, including any disorder of vision or perception change how older adults living with dementia experience and interpret their environment. For example, older adults diagnosed with visuospatial deficits, akathisia and those with agnosia and limbic changes cannot recognize familiar objects, places and people. These changes limit their ability to interact

socially, thereby contributing to sensory isolation and wandering (O'Connell et al., 2011). Wandering behaviour as a form of communication may be a reflection of the way older adults see and interpret their environment. The ability to see and interpret the environment accurately depends on good vision and cognitive abilities (O'Connell et al., 2011). Ensuring that older adults are wearing their eye glasses and functioning hearing aids could help in improving communication with them. Social activities that accommodate sensory and hearing impairments should be promoted among older adults living with dementia (O'Connell et al., 2011).

B (biography or life history). Due to changes in their brain, older adults living with dementia often experience short-term memory loss. As a result of this short-term memory loss and agnosia, some older adults living in LTC homes may not fully understand where they are (Brooker & Surr, 2005). Older adults who wander often use the behaviour as a coping strategy to make sense of their environment, while others wander in search of a place of safety and familiarity in an unfamiliar environment (Moore, Algase, Powell-Cope, Applegarth & Beattie, 2009; O'Connell et al., 2011). Moreover, older adults who used to walk regularly in the past, either for work or leisure may be more likely to wander in search of stimulation. Walking can also be a habit-forming activity or a means of dealing with stress as a lifelong pattern of coping with stress (Algase et al., 1996; Andrews, 2017; Dewing, 2005; Edensor, 2000).

Brooker and Surr (2005) reported that some structures of LTC homes may look like many older adults' former workplace. Therefore, in order to understand wandering behaviour, it is important to understand older adults' work or life history. Past experiences of vulnerability and trauma can also be relived as a result of dementia (Brooker & Surr, 2005). Getting to know older adults' past history is vital in providing person-centered care for older adults living with dementia (Brooker & Surr, 2005).

P (personality). Personality plays a vital role in determining an older adult's pattern of adjustment to the environment. Older adults with more sociable and outgoing personalities and those who engage in higher levels of social and leisure activities are more likely to wander (Dewing, 2005; Monsour & Robb, 1982). In addition, an older adult's strength and vulnerability affect his or her coping with the effects of dementia. It has been suggested that older adults who have valued being in control of their lives will have difficulties coping with the consequences of dementia and life in LTC homes compared to those who have allowed others to make decisions for them in the past (Brooker & Surr, 2005).

SP (social psychology). Social psychology represents the social and psychological environment of older adults living with dementia (Brooker & Surr, 2005). While the social environment involves social contacts, personal networks and healthcare providers, the social psychology represents the relationships of older adults with other people. The social psychology of the LTC home could either be supportive or detrimental to older adults living with dementia (Algase et al., 1996; Brooker & Surr, 2005). Staff could either encourage or discourage wandering behaviour. Due to the changes in the verbal abilities of older adults living with dementia, it is important that social relationships with these older adults are not only warm and accepting but also demonstrate person-centered care (Brooker & Surr, 2005). Not involving older adults in social interaction could lead to functional decline and increase older adults' risks of depression and mortality (Lee, Boltz, & Algase, 2017). Older adults living with dementia are vulnerable as they try to make sense of who they are and what is going on around them. Therefore, the focus of the relationship must be on older adults, and this can be developed through the day-to-day interactions (Brooker & Surr, 2005).

The Need-driven Dementia-compromised Behaviour (NDB) Model

Algase et al. (1996) proposed a model from which they studied the behaviours of older adults living with dementia by examining the purpose and meaning of the behaviour. The message of the model is that behaviours have meaning. While behaviours such as wandering may interrupt clinical care routines, there is a reason for such behaviours. With this understanding, evidence-based interventions for wandering can be developed (Algase et al., 1996). The NDB model proposed that behaviours are not entirely due to cognitive impairment because there are also contextual factors. According to the NDB model, the interaction of background factors and proximal factors, together produce need-driven behaviours, such as wandering.

The background factors are the characteristics that help to shape lasting behaviours and are risk factors for producing behaviours expressed by older adults living with dementia. The background factors include the neurological, cognitive abilities, mobility, personality, health status, and psychosocial history and are similar to the factors described in the Enriched Model of Dementia formula (Algase et al., 1996). The proximal factors, physiological and psychological need states (such as fatigue, pain, or hunger, affect) and the physical and social environments of light, noise, temperature, care routines and social contacts are also similar to the factors of the Enriched Model of Dementia (Algase et al., 1996; Koehn, Kozak & Drance, 2011; Kolanowski, 1999; Whall & Kolanowski 2004). Background factors, distinguished from proximal factors, are stable and non-amenable to interventions (Algase et al., 1996; Kovach, Noonan, Schlidt, & Wells, 2005; Mitty & Flores, 2007). It is not possible to reverse basic pathological processes caused by brain damage in older adults (Volicer & Hurley, 2003).

Behaviours such as wandering can be dismissed or viewed as a problem rather than symptoms of unmet needs (such as comfort) or the pursuit of a goal, which can lead to focusing on the behaviour rather than the need underlying the behaviour (Algase et al., 1996).

Consequently, an unmet need can have ‘cascading’ effects (consequences such as worsening of the need and behaviour) which affect not only the older adult living with dementia, but also the caregiver and the caregiving context (Kovach et al., 2005). Understanding the NDB model as well as the consequences of unmet needs is important in preventing this cascading effect. When behaviours are understood as expressions of goals or unmet needs, then interventions based on meeting these needs and goals can be put in place (Kovach et al., 2005).

The Progressively Lowered Stress Threshold (PLST) Model

The PLST model proposed that responsive behaviours occur when the internal or external environmental demands exceed the stress threshold of older adults living with dementia. The model viewed the contextual factors associated with behaviours as “person-environment fit and interaction”, specifically, an imbalance between the person-environment interaction (Richards & Beck 2004; Smith, Gerdner, Hall, & Buckwalter, 2004; Smith, Hall, Gerdner, & Buckwalter, 2006). It is important to recognize the factors that produce stress in older adults living with dementia. These factors could be internal such as pain and fatigue, or external such as noise or change in routine (Richards & Beck, 2004).

As suggested by the PLST model, older adults in the earlier stages of dementia have a higher stress threshold and are able to tolerate internal and external stimuli better than those in the more advanced or later stages (Gerdner, Buckwalter & Hall, 2005; Richards & Beck, 2004; Smith et al., 2004). The most common stressors that can trigger behaviours include physical stressors such as pain, discomfort, infection, acute illness and depression, fatigue, boredom,

change of environment, routine or caregiver, misleading stimuli or inappropriate stimulus levels, and affective response to loss (Stolley, Reed & Buckwalter, 2002; Lindsey & Buckwalter, 2009). Both the physical and psychosocial environment can have great emotional effects on older adults living with dementia (Koehn et al., 2011).

Wandering Behaviour

Definition of wandering. Although wandering is a common term, the behaviour is complex and has no commonly accepted definition. There is a great variety and range of complexity in the available definitions of wandering, from aimless movement to goal-oriented movement (Algase et al., 2007; Algase & Nelson, 2007; Cipriani et al., 2014; Dewing, 2005; Dewing, 2011; Halek & Bartholomeyczik, 2012; Lai & Arthur, 2003; Robinson, Hutchings, Corner, et al., 2006; Wigg, 2010). Moreover, the definitions are often debatable based on the individual and professional perspectives of the behaviour (Halek & Bartholomeyczik, 2012). From the perspectives of healthcare providers and family members, wandering is often defined as a challenging behaviour to manage in older adults living with dementia (Algase & Nelson, 2007; Brittain et al., 2017; Dewing, 2005; Halek & Bartholomeyczik, 2012; Lai & Arthur, 2003; Wigg, 2010). Although little is known about the perspectives of older adults who wander, their perspective is likely different from family members or healthcare providers (Dewing, 2006; O'Connell et al., 2011).

There have been debates around the use of the term, 'wandering' as inappropriate and derogatory. Suggestions have been made to change wandering to 'walking' or 'walking around'. These suggestions are based on the assumptions that older adults living with dementia may engage in the behaviour for a purpose, even though others may not understand this purpose, and that wandering connotes negative labelling (Alzheimer Scotland, 2009; Dewing, 2005; Halek &

Bartholomeyczik, 2012). Dewing (2011) suggested a more accurate term for wandering:

“wander-walking”, because this behaviour can also be exhibited while using a wheelchair.

Another suggestion is that wandering is a phase of dementia that is likely to pass as older adults living with dementia gradually lose their ability to walk in the later stages of dementia (Alzheimer Scotland, 2009; Hope et al., 2001).

Wandering has also been referred to as a normal human activity that people engage in during their lifetime (Halek & Bartholomeyczik, 2012). As important as these perspectives are, “calling wandering something different will not do anything to change the values and beliefs of practitioners, caregivers and society about the nature of wandering. And it is these values and beliefs that need to be addressed” (Dewing, 2005, p. 20). Wandering has also been described as long periods during which an older adult moves aimlessly or in a disoriented manner without being aware of such behaviour (Algase et al., 2007). Other terms that have been used to define wandering are hyperactivity and excessive walking (Hope et al., 2001). Excessive walking or activity is described as moving for a greater amount of the time while awake or being unable to sit for more than a few minutes at a time (Futrell, Melillo, Remington, & Butcher, 2014).

Patterns and types of wandering. Three patterns of wandering have been described that occur in repeated cycles: lapping, random and pacing (Algase, Beattie, & Therrien, 2001; Dewing, 2011). Lapping, also called “circuitous routes”, involves walking within a circuit or a circular pattern but sometimes can be irregular depending on the environment. For example, a LTC home with a linear hallway will make it difficult for an older adult to walk in a circuit or loop. Random wandering is not easily classified and involves frequent changes in direction and moving in a haphazard pattern while pacing is a repetitive back and forth walking movement. Random wandering is the most common pattern of wandering, especially among older adults

with severe cognitive impairment (Algase et al., 2001, p. 284; Algase, Antonakos, Beattie, Beel-Bates, & Yao, 2009). Older adults usually exhibit more than one pattern of wandering (Algase et al., 2009). The pattern of wandering expressed by older adults will determine the risk as well as the interventions for managing the behaviour (Algase et al., 2009; Dewing, 2011). Pacing may present with agitation and anxiety and can also occur in advanced dementia (Algase et al., 2001). Random wandering may not be amenable to nursing interventions (Algase et al., 2001). However, interventions focusing on directed attention, such as distractions have been suggested in managing this type of wandering during the early stages of dementia (Algase, Beel-Bates, & Beattie, 2003). In general, nursing interventions for all patterns of wandering should focus on meeting the physical and psychological needs of older adults as well as managing environmental factors such as light and noise levels (Algase et al., 2001; Algase, Beattie, Antonakos, Beel-Bates, & Yao, 2010).

Algase et al. (2009) identified three types of wandering: classic, moderate, and subclinical. Classic wandering is the most common type of wandering behaviour and is likely to be easily recognized by nursing staff. Older adults who express this type of wandering wander most during the day, often before mid-afternoon and have severe cognitive impairment, independence in mobility, and poor general health. Factors such as fatigue or stamina may be responsible for the earlier day time wandering among these older adults (Algase et al., 2009). Older adults exhibiting moderate wandering were reported to be less cognitively impaired, more independent in mobility and have better general health compared to those with classic type of wandering. Nursing staff are highly likely to recognize older adults who exhibit moderate wandering because these older adults tend to be more active and wander more later in the day (Algase et al., 2009). The subclinical wandering is the least often observed wandering behaviour

and may go unrecognized by nursing staff as wandering behaviour. This is because older adults with subclinical wandering wander less during the day but more early in the day. Older adults exhibiting subclinical wandering have mild cognitive impairment, but a similar level of mobility and poorer overall health compared to older adults with moderate type of wandering (Algase et al., 2009).

Prevalence of wandering. The prevalence of wandering varies depending on whether or not the behaviour is reported (Carr et al., 2010). More than 60% of older adults living with Alzheimer's disease or other types of dementia will develop wandering behaviour at some point in the disease course (Alzheimer's Association, 2016). Although wandering is commonly reported among older adults living with dementia in LTC homes, older adults in the community, especially those living alone also exhibit the behaviour and may not self-report the behaviour (Silverstein, Tobin, & Flaherty, 2002). Wandering behaviour has been reported in 63% and 17.4% of community-dwelling older adults (Hope et al. 1994; Klein et al., 1999) whereas 39% and 80% of nursing home residents exhibited wandering according to Cohen-Mansfield, Werner, Marx, and Freedman (1991) and Hope et al. (2001).

Although wandering occurs among both genders, the behaviour is more likely to occur in men than in women (Kiely, Morris, & Algase, 2000). Klein et al. (1999) studied 638 community-residing older adults and observed that wandering was more prevalent among males and those diagnosed with Alzheimer's disease. Moreover, wandering was reported among older adults with moderate to severe depression, delusions, hallucinations, and sleep disorders (Klein et al., 1999). Older adults using psychotropic medications, experiencing pain, and those with severe dementia and a pre-morbid lifestyle of higher activity levels have also been reported to be more likely to exhibit wandering behaviour (Cipriani et al., 2014; Kiely et al., 2000; Klein et al., 1999; Lai &

Arthur, 2003; McCurry et al., 1999; O'Connell et al., 2011; Silverstein et al., 2002). Wandering tends to occur more when older adults are alone, and the behaviour is a common reason for LTC home placement (Cipriani et al., 2014; Dewing, 2011; Lester, Garite, & Kohen, 2012; Moore et al., 2009; Silverstein et al., 2002; Yamakawa, Yoshida, Higami, Shigenobu, & Makimoto, 2014). At the same time, wandering is one of the most commonly cited reasons for refusal into LTC homes or discharge from LTC homes (Algase, 2006; Hope et al., 2001).

Two clinical manifestations of Alzheimer's disease are spatial disorientation and wayfinding difficulty (Algase, 2006; Marquardt, 2011). Since wandering behaviour is common among older adults living with Alzheimer's disease, the behaviour is often associated with spatial disorientation or getting lost and lack of wayfinding (Algase et al., 2007; Marquardt, 2011). Spatial disorientation relates to inability to link landmarks and routes. On the other hand, wayfinding is the process of finding one's way including "knowing where you are, knowing your destination, knowing (and following) the best route to the destination, recognizing the destination upon arrival, and finding the way back" (Marquardt, 2011, p. 77). The inability to locate familiar places, especially if they are new to a LTC home could result in a loss of autonomy for such older adults due to an unsuccessful search for familiar places (Marquardt & Schmiege, 2009).

What wandering is not. As important as understanding what wandering is, it is equally important to understand what wandering is not. Wandering is not just a mere symptom or accompanying consequence of dementia (Algase et al., 2007). Algase et al. (2007) clarified other terms that might be confused with wandering, such as general restlessness or agitation. Even though wandering encompasses a range of diverse behaviours, such as pacing, lapping, and exit seeking, wandering is often confused with the term agitation (Dewing, 2006; Halek & Bartholomeyczik, 2012). In the Cohen-Mansfield Agitation Inventory (CMAI) used to assess the

frequency and disruptiveness of agitated behaviours in older adults, wandering and pacing are classified as physical non-aggressive behaviour, and are described as “repetitive back and forth movement” (Cohen-Mansfield & Werner, 1999; Halek & Bartholomeyczik, 2012, p. 408).

However, it is important to understand that wandering is not the same as agitation or restlessness, nor is it associated with tension, restlessness or agitation (Algase et al., 2007; Halek & Bartholomeyczik, 2012).

Benefits and potential risks of wandering. Wandering itself is not likely to cause any harm (Dewing, 2011). In fact, the benefits of the behaviour are well documented in the literature (Robinson, Hutchings, Corner, et al., 2007). Wandering can be a form of physical exercise, thereby improving circulation and oxygenation, and decreasing the risk of contractures (Lai & Arthur, 2003). Physical exercise is also related to improved cognitive function, reduced risks of falls and mental health (Lindwall, Rennemark, Halling, Berglund, & Hassmén, 2006; Rolland et al., 2000; Sun et al., 2010). The benefits of wandering have also been described in the context of the behaviour being purposeful or goal-oriented, for example, a search for something that is lost or a familiar person/environment, or the need to perform a former role or responsibility, or get to a former workplace (Carr et al., 2010; Silverstein et al., 2002). Wandering also provides sensory and environmental stimulation for older adults and allows them to express control and agency (Dewing, 2011; Dickinson & McLain-Kark, 1998).

Although wandering may be beneficial, there are some risks or negative consequences associated with the behaviour (Dewing, 2011; Wigg, 2010). In fact, some researchers have concluded that all wandering is risky, perhaps due to the complexity of wandering and the risks (such as becoming lost) associated with it (Dewing, 2005; Silverstein et al., 2002). Some of these risks can be potentially life threatening. Sometimes, older adults living with dementia wander

aimlessly experiencing severe fatigue from not being able to sit down to eat meals, while others attempt to exit and wander into dangerous areas (Cipriani et al., 2014; Rowe & Bennett, 2003).

Rolland et al. (2006), in their study of 571 people living with Alzheimer's disease reported that people who exhibited wandering behaviour were undernourished. Older adults who wander are at risk of malnutrition, dehydration, getting lost, falling, sustaining injury, and death (Aud, 2004; Cipriani et al., 2014; Dewing, 2011; Kiely, Kiel, Burrows, & Lipsitz, 1998).

Particularly, wandering has been indicated as a major risk for falls, elopement, and discharge from LTC homes, while getting lost increases older adults' risk of mortality if they leave the LTC home and are exposed to low temperature in the winter or walk into busy streets (Algase, 2006; Ali et al., 2016; Rowe et al., 2011). Rowe and Bennett (2003) conducted a retrospective study involving 93 older adults living with dementia who became lost in the community and reported that 87% were found dead in secluded areas such as woods, fields, ditches, and bodies of water. The causes of death from the most common to the least included exposure, drowning, sustaining an injury or a fall, getting hit by a vehicle, and "asphyxiating in mud". Unsafe and unsupervised wandering and elopement that result in physical harm and death can lead to litigation issues for healthcare organizations and healthcare providers (Algase, 2006; Meek, 2014; Rodriguez, 1993).

Older adults living with dementia may wander into other LTC home residents' rooms or intrude into other residents' personal space (Snellgrove, Beck, Green, & McSweeney, 2013). This type of activity has been referred to as "Boundary Transgression" (BT) with ensuing altercations, loss of privacy, physical harm and becoming lost, all of which impact the quality of life of older adults (MacAndrew, Fielding, Kolanowski, O'Reilly, & Beattie, 2017; Shinoda-Tagawa et al., 2004). MacAndrew, Fielding, et al. (2017) in their observational study of seven

independently ambulant residents reported that wandering involving BT was associated with frequent movement, random ambulation, and occurred during peak activity on the units. In a case-control study of incidents of residents injured by another resident in LTC homes, injuries frequently reported included fractures, dislocations, reddened areas; lacerations and bruises or hematoma were the most common injuries (Shinoda-Tagawa et al., 2004). Among the characteristics of injured residents in the study were cognitive impairment and wandering behaviour. Older adults who wander into other residents' rooms are at risk of injury leading to major morbidity and possibly mortality (Shinoda-Tagawa et al., 2004).

Due to the time and effort directed to monitoring older adults who wander, especially when they enter others' rooms and disrupt their belongings (Snellgrove et al., 2013), wandering increases staff workload, may decrease staff morale, and is associated with staff turnover (Robinson, Hutchings, Corner, et al., 2006). Staff may avoid interacting with older adults who wander, thereby resulting in decreased nursing care and social interactions (Robinson, Hutchings, Corner, et al., 2006).

Causes of wandering. The cause of wandering is unknown, but as indicated from the NDB and PLST models, triggers for the behaviour have been identified as environmental conditions (such as ambivalent temperature and sensory stimulation) and internal conditions (such as physiological needs) (Futrell, Melillo, & Remington, 2010). Physical or psychological needs such as food, water, toileting, security or companionship may cause an older adult to wander (Alzheimer's Association, 2009; Andrews, 2017; Tilly & Reed, 2008). Environmental triggers, such as understimulation from poor lighting, too much distraction, noise, crowding and clutter, unfamiliar or new surroundings and changes in staff assignment, roommates or care routine can lead to overstimulation and the desire to walk (Algase et al., 2010; Hamilton, Harris,

Le Clair, & Collins, 2010). Another trigger for wandering may be medication side effects. Therefore, it is important to assess any medications older adults may be using and their side effects when planning interventions for wandering behaviour (Futrell et al., 2014). The neurochemical changes in the brain may be responsible for wandering by altering the body chemistry, thereby resulting in high levels of felt anxiety. In response to the high levels of anxiety, older adults may increase ambulation or movement. Therefore, wandering may be interpreted as the body's response to anxiety and attempts to reduce anxiety (Wigg, 2010).

Restlessness and hyperactivity can occur as a result of changes in the brain. Older adults living with dementia may also walk in order to remember a forgotten action. Those in the later stages of dementia often 'time-travel', that is, they mix up past and present and begin a search for someone or something in the past (Dewing, 2011). Other reasons older adults living with dementia wander include: lifelong habits, personality, work, and a coping strategy to adjust to a new environment (Dewing, 2011; O'Connell et al., 2011). Emotional expressions have been associated with wandering behaviour. Lee, Algase, and McConnell (2014) observed that positive emotional expression was positively related to wandering behaviour, whereas negative emotional expression was negatively related to wandering. The authors proposed that older adults who are sad or angry may prefer to sit alone or stay in their rooms, rather than walk around. On the contrary, those who are happy or experiencing pleasant emotions may engage in physical activity such as walking around.

Wandering may also be related to delirium, and it is important to differentiate older adults who often wander from those who may do this on a temporary basis. Wandering behaviour may be an indication that older adult is suffering from a side effect of medication, physical condition or an underlying ill health that is unaddressed or untreated such as delirium

(Carr et al., 2010; O'Connell et al., 2011). Delirium, a medical emergency can be an acute sudden onset change in mobility or cognition, a fluctuating symptom occurring throughout the day or hour, and fluctuations in activity (Hamilton et al., 2010). Delirium can be difficult to recognise in older adults living with dementia and often goes undetected due to their limited ability to communicate or express their discomfort using language. Therefore, assessing for a change in the behaviour and health of older adults who otherwise would not wander and treating any underlying cause are vital in reducing wandering in such individuals (Hamilton et al., 2010; O'Connell et al., 2011). For this study, staff who were familiar with resident care and were able to identify residents who often wander assisted in the screening of residents.

Management of wandering. Due to the complexity of wandering behaviour, interventions geared towards its management are subjective and based on institutional and professional definitions of the behaviour (Halek & Bartholomeyczik, 2012; Wigg, 2010). Specifically, in clinical practice, wandering is often viewed as a behavioural problem that needs to be prevented or controlled (Wigg, 2010). Although the focus of this study was not on the structural context of the management of wandering, the structure of LTC homes and staff/resident ratio play a role in the management of the behaviour (Silverstein et al., 2002). For example, the design and structure of some LTC homes have been reported to contribute to the use of restraints, such as locked units and geriatric chairs in such facilities (Wigg, 2010). Moreover, locked units are utilized in LTC homes to control the behaviour of older adults at risk for wandering or those who have the potential for harming themselves or others. However, living in a locked unit can lead to isolation, a loss of autonomy, and social isolation and affect the quality of life of older adults as well as the quality of care they receive in LTC homes (Tufford, Lowndes, Struthers, & Chivers, 2018). Both the LTC homes where the study was done utilized

the locked unit system to prevent residents who wander from leaving the units unsupervised. Interventions such as changing or modifying the environment, also referred to as environmental restraints, have been implemented in managing wandering (Alzheimer Society of Canada, 2007). For many years, the focus of practice on the management of wandering has been on how to prevent or eliminate the behaviour using physical and chemical restraints (Dewing, 2011).

Research suggests that physical restraints (not easily removed by the resident to restrict their movement) such as tethers and wheelchair lap trays are not only ineffective, but also harmful to residents' physical and emotional health, thereby resulting in pressure sores, infection, anxiety, distress and physical violence (Engberg, Castle, & McCaffrey, 2008; Robinson, Hutchings, Corner, et al., 2006). The use of pharmacological interventions, such as antipsychotics or antidepressants in managing behaviour has also raised concerns, especially because their use is associated with falls, high morbidity and mortality rates (Gill et al., 2007; Raetz, 2013; Robinson, Hutchings, Corner, et al., 2006; Tilly & Reed, 2008). Based on this evidence, physical restraints and pharmacological interventions are not considered as a first choice for managing wandering in clinical practice (Gill et al., 2007; Robinson, Hutchings, Corner, et al., 2006). Physical restraints and pharmacological interventions may be used in situations where severe harm is anticipated (Robinson, Hutchings, Corner, et al., 2007). Despite the fact that evidence does not support the use of physical restraints and pharmacological interventions, these interventions are used in practice. The reason for their use has been based on the need to prevent severe harm to older adults who wander, as well as to other LTC home residents (Robinson, Hutchings, Corner, et al., 2007).

Non-pharmacological interventions. Recently the focus has changed from the prevention of wandering to the promotion of safe wandering (Dewing, 2011). The management of safe

wandering involves the use of non-pharmacological interventions. These interventions include the use of electronic tagging and tracking devices, behavioural approaches, exercise, music therapy, carer interventions, sensory therapies such as aromatherapy and multi-sensory environment, physical barriers, non-subjective barriers such as locked units, environmental modifications, and subjective barriers, such as camouflage and strips of tape (Dewing, 2011; Robinson, Hutchings, Dickinson, et al., 2007). Non-pharmacological interventions have been suggested as a safer option in managing wandering (Robinson, Hutchings, Dickinson, et al., 2007).

Environmental modifications include the use of grid lines in front of exit doors, providing a secure walking area, maintaining low stimuli, creating a homelike environment, and subjective barriers. Although environmental modifications have been reported to be effective in managing wandering behaviour, there is little empirical evidence to support these interventions (Gu, 2015; Hodgkinson, Koch, Nay, & Lewis, 2007). Roberts (1999) observed 20 older adults with wandering behaviour over a period of one year and found that the use of mirrors and camouflage (covering door knob or lock with a cloth panel) was effective in preventing elopement in most cases while floor patterns, that is, placing strips of insulating tape in front of an exit door was the least effective intervention in reducing exiting behaviour. The use of black tape to alter the exit door was reported to significantly reduce the number of escape attempts by an older adult who exhibited wandering behaviour (Padilla, González, Agis, Strizzi, & Rodríguez, 2013).

According to Dewing (2011) modification of the care environment can lead to a safer place for older adults to walk around. In addition, the need to identify and reduce “unsupervised access to exits and high-risk outside areas of the premises” has also been pointed out (Dewing, 2011, p. 496). Although environmental modification is needed to keep older adults safe, focus

should be placed on creating “a more positive caring environment”, which can contribute significantly to reducing the prevalence of the risks associated with wandering such as elopement (Gu, 2015, p. 456). Alvord et al. (2005) and Silverstein et al. (2002) pointed out the need for a therapeutic supportive environment and adequate staffing with required training to supervise older adults who wander. For example, a LTC home environment incorporating wandering paths can be supportive of older adults who wander. Wandering paths are “the circulation space the residents use for moving around” such as hallways with a continuous path or circular loop and simple visual cues or artworks/objects to support therapeutic walking (Silverstein et al., 2002, p. 81). Maintaining clutter-free pathways is also important in keeping older adults safe (Silverstein et al., 2002). Marquardt, Bueter, and Motzek (2014) conducted a systematic review of the impact of the design of the built environment on people living with dementia in LTC homes and reported that environmental or visual cues such as signposting were effective in helping older adults find their way around.

Behavioural interventions in managing wandering behaviour focus on identifying the factors or triggers, such as actions and inactions by healthcare providers, poorly fitting hearing aids, eye glasses, and dentures, which can lead to complications of wandering (Dewing, 2011; Gu, 2015). Beattie, Algase, and Song (2004) performed a multiple case design study to determine the effect of the systematic use of a behavioural nursing intervention, such as communication strategies on meal time behaviour of three older adults with wandering behaviour who resided in a LTC home. The nursing intervention was developed based on identified proximal factors (physiological need and social interaction) of the NDB model. The use of two communication strategies, focused conversation about the meal, eating and social comments related to the mealtime experience, and specific elements of social behaviour (smiling, eye

contact) was successful. The authors reported that all participants were able to sit at the table longer and eat more food during the intervention, but their body weight remained the same throughout the study.

Electronic tagging/tracking or microchips involves the use of a surveillance device, such as a wristband, to monitor and safeguard people who wander through satellite technology and advanced technology, such as the use of Global Positioning System (GPS). GPS helps in tracking discreetly the spatial activity of older adults living with dementia who wander, and send information through the mobile phone network to a personal computer, a call-centre or a mobile phone, thereby ensuring their safety and reducing their risks of harm (Landau, Werner, Auslander, Shoval, & Heinik, 2010; White & Montgomery, 2014). These systems have been reported to be effective in quickly locating residents and older adults who wander (Hodgkinson et al., 2007; White & Montgomery, 2014; Wigg, 2010). In particular, the use of electronic devices prevents premature placement into LTC homes and helps to keep older adults at home longer (White & Montgomery, 2014). Miskelly (2004) evaluated the effectiveness of an electronic bracelet which generated an alarm on a pager when the residents made attempts to leave the unit in four LTC residents for six months. It was concluded that the system was successful in detecting wandering activities, including wandering outside, wandering into an “at risk area”, and removal of the bracelet.

The use of physical and psychosocial interventions such as exercise and music therapy may reduce the incidence of disruptive wandering behaviour (Hodgkinson et al., 2007). Cox, Nowak, and Buettner (2011), in their exploratory study involving seven LTC home residents, reported that a violin music intervention significantly reduced pacing/aimless wandering among participants.

Although a number of studies exist of non-pharmacological interventions, only a few of them are recent. Moreover, the literature has concluded overall that there is no robust evidence to support non-pharmacological interventions in managing wandering, and many of these interventions are of small sample sizes and require more rigorous research. Despite the limited evidence, the use of non-pharmacological interventions continues in clinical practice (Algase, 2006; Gu, 2015; Hodgkinson et al., 2007; Lai & Arthur, 2003; Price, Hermans, & Evans, 2001; Robinson, Hutchings, Corner, et al., 2006; Robinson, Hutchings, Corner, et al., 2007).

A person-centered approach to care and other care decisions in LTC homes is needed. It has been suggested that a team approach in managing wandering should not only involve the views of healthcare providers and families, but also of older adults who exhibit the behaviour (Robinson, Hutchings, Corner, et al., 2007; White & Montgomery, 2014). Considering experiential knowledge as a way of knowing and learning, and exploring the perspectives of those who wander can provide the basis for understanding wandering (Dewing, 2006). Andrews (2017) pointed out the importance of being respectful and gentle when asking questions of older adults who wander in attempt to exit such as “Where are you going?”, “What is it you want?”, and “Can I help you?” (p. 322). These approaches and questions would help in understanding the purpose of wandering or walking in these older adults, thus facilitating rather than preventing it.

Ethical concerns. Not only insufficient evidence, but also ethical concerns exist around the use of pharmacological and non-pharmacological interventions in managing wandering. Although wandering behaviour has been described as both beneficial and risky, balancing the rights of people who wander and the risks of wandering often results in ethical dilemmas for healthcare providers (Robinson, Hutchings, Corner, et al., 2006; Woolford, Weller, & Ibrahim, 2017). For example, the use of microchips, or electronic tracking or tagging devices has raised

ethical concerns about people's right to autonomy versus safety and security, and privacy (Robinson, Hutchings, Corner, et al., 2006; White & Montgomery, 2014). Concerns about violation of the privacy of older adults living with dementia involve another person checking their "whereabouts at any given point" and not being able to remove the attached tracking device (White & Montgomery, 2014). The use of GPS is becoming more common; however, its use also presents serious ethical dilemmas about who should make decisions about tracking older adults living with dementia (Landau et al., 2010; Landau et al., 2011; White & Montgomery, 2014), as wandering is common among older adults living with moderate to severe dementia, raising questions about their ability to comprehend the use of electronic tracking (White & Montgomery, 2014).

Questions are being asked about the values, dignity and invasion of the privacy of older adults living with dementia when deciding on the use of electronic technologies (Alvord et al., 2005; Landau et al., 2011; Wigg, 2010). The views of healthcare providers and that of the families may differ when it comes to the use of electronic device in managing wandering. Decisions about whether or not to use an electronic device are based on the need to create a secure environment for older adults living with dementia while maintaining their autonomy or privacy. Healthcare providers value safety and residents value freedom. Issues related to preventing stigma, dehumanization and threats to personal autonomy are significant in the use of electronic devices (Landau et al., 2011).

Electronic tagging systems are also high-cost interventions (Gu, 2015). To date, there are no research studies on the quality of care and the experience of those who wander or the cost-effectiveness of using any of these non-pharmacological interventions. In general, healthcare providers base their decisions to use non-pharmacological interventions on the ethical principle

of non-maleficence for fear of litigation (Robinson, Hutchings, Corner, et al., 2007).

Interventions such as exercise and music therapy are considered distraction activities and are used frequently in clinical practice because of their benefits and low risk. Ethical concerns associated with distraction interventions have not yet been reported (Robinson, Hutchings, Corner, et al., 2006).

Healthcare providers have the ethical duty to maintain the autonomy of older adults living with dementia while minimizing risks to themselves and others. However, the concept of risk is controversial and has changed over the years from “good or bad”/ “gain or loss” to “negative and dangerous” (Robinson, Hutchings, Corner, et al., 2007). This change of concept shapes how healthcare providers and families of people living with dementia view wandering behaviour and accept interventions in managing the behaviour (Robinson, Hutchings, Corner, et al., 2007). In healthcare, risk is often conceptualized as something that must be controlled or avoided (Robinson, Hutchings, Corner, et al., 2007). Risk is often associated with harm for people living with dementia because they are perceived to be vulnerable to harm (Robinson, Hutchings, Corner, et al., 2007). Moreover, the ethical decision of who should be protected and kept safe is challenging and difficult, especially when it involves older adults living with dementia. Therefore, the past and present perspectives and wishes of older adults living with dementia must be taken into consideration when making decisions about the use of electronic tracking (White & Montgomery, 2014).

Summary

It is imperative to consider the state of the literature on wandering behaviour. The literature suggests that empirical research studies are needed on wandering, especially from the perspectives of older adults living with dementia (Dewing, 2006; Gu, 2015; Lai & Arthur, 2003;

Robinson, Hutchings, Corner, et al., 2006). Older adults living with dementia who wander are labelled as “wanderers” (Dewing, 2005; Halek & Bartholomeyczik, 2012) and as long as they are labelled this way, they may not be seen as people with choices. The perspectives of healthcare providers and their interpretation of wandering might interfere with the care they provide to older adults who wander (Algase et al., 1996; Algase & Nelson, 2007; Dewing, 2005). This requires a change in perspective that only begins with an understanding of the behaviour from the perspectives of older adults who wander (Dewing, 2006).

Chapter 3: Research Design and Methods

In this chapter, the design of the study, including how the researcher gained access to the site and the recruitment process are discussed. Procedures for data collection and data analysis and ethical considerations for the study are presented. Strategies used to enhance the trustworthiness and integrity of the study are also described.

Interpretive Description

This study used interpretive description methodology. Interpretive description is a disciplinary approach to qualitative research with emphasis on generating knowledge for application in applied health disciplines (Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, 2016). One of the strengths of interpretive description is that it provides an analytic logical qualitative approach to clinical description in an interpretive way. It is based on the assumption that “there will be some theoretical knowledge, critical pattern observation, and scientific basis within which all studies of human health and illness phenomena are generated” (Thorne, Kirkham, & O’Flynn-Magee, 2004, p. 5). Interpretive description was chosen based on its strength and because it provides an integrative and conceptual description of a clinical phenomenon by identifying key themes and patterns within expressed subjective perspectives (Thorne, 2016; Thorne et al., 2004). It generates relevant findings with application of knowledge to inform practice. This study aimed to gain a better understanding about wandering behaviour primarily through the perspectives of older adults living with mild to moderate dementia residing in LTC homes. The study also looked at the perspectives of family members on wandering behaviour.

As stated by Thorne (2016), studies using interpretive description are conducted as “naturalistic”, taking into consideration the comfort and ethical rights of participants and this is

another strength of interpretive description. The epistemological standpoint of interpretive description is embedded in the principle of naturalistic inquiry. This allows the researcher to study participants in their natural state. Therefore, “no manipulation on the part of the inquirer is implied and the inquirer imposes no a priori units on the outcome” (Lincoln & Guba, 1985, p. 8). This was the approach of this study.

Recruitment, Site, and Sample

The researcher approached five LTC homes in Winnipeg, Manitoba. Two LTC homes agreed to recruit and screen potential participants (residents and their family members). The researcher met with the Director of Care (DOC) and Assistant DOC of the LTC homes to request access to their facilities and assistance in identifying and recruiting residents and their family members, which were granted. A letter requesting access to the LTC home, including a copy of the consent forms (Appendices D, G.1, G.2, and G.3) and the Research Ethics Board certificate of approval from the University of Manitoba Education Nursing Research Ethics Board (ENREB) (Appendix K) with preliminary information about the study and staff involvement was also provided. The two sites used for the study were WRHA accredited LTC homes in Winnipeg, Manitoba. Both LTC homes offer personal and long-term care services to more than 150 older adults, and one of the LTC homes had a specialized dementia care unit. Both LTC homes have linear (not circular) hallways with locked units (with keypads) and patio/gardens (with keypads) where residents can walk around with supervision from the staff during summer.

At the first LTC home, the screening of potential participants was delegated to the social worker. At the second LTC home, the researcher met with all the unit coordinators and provided information sheets about the study (Appendix E), including the researcher’s contact information and the Dewing Wandering Screening Tool (part B) (see Appendix B). Posters (Appendix F)

about the study were posted in the LTC home and clarification about the study was also provided to staff, as needed. Staff (social worker and unit coordinators) of the two LTC homes assisted in the screening process by completing the Dewing Wandering Screening Tool (part B) and identified potential participants (residents) for the study. The screening tool consists of two parts; A (pre-dementia) and B (currently) with dichotomous questions for yes or no answers. The items on part A of the Dewing Wandering Screening Tool described the resident's past wandering/walking activity. These items are discussed in chapter four. Part B is discussed here (Dewing, 2005).

A total of ten participants (residents) met the inclusion criteria: older adults living with mild to moderate dementia with wandering behaviour; age 65 or older with ability to answer simple questions in English based on clinical judgment and a Cognitive Performance Scale (CPS) score of one to three; living in a LTC home for more than two months; and having a family member who visits more than once a month who also showed interest in participating in the study. Family members in this study broadly included friends as long as they could consent on behalf of the residents and knew their life histories. One of the ten residents had a family member who lived outside of the province and visited less than once a month but showed interest in the study and so was included in the study.

The transition to LTC homes can be challenging for older adults and no guidelines exist on the time it takes for older adults to adjust to their new surroundings. The time for older adults to "settle in", that is, adjust to living in LTC homes may take up to one to two months after admission (Heliker & Scholler-Jaquish, 2006; Lee, Woo, & Mackenzie, 2002; Wilson, 1997). Some of the challenges in getting settled have been attributed to the environment of a new facility and unfamiliar staff (Heliker & Scholler-Jaquish, 2006). Therefore, the time since

admission (more than two months) was one of the inclusion criteria for this study. Exclusion criteria for this study included older adults who were experiencing severe anxiety, walking impairment or psychosis, who tended to shadow, and who were wards or clients of the Manitoba Government's Public Trustee Office. Residents who tended to shadow (follow) staff members were excluded because this behaviour prohibits the confidential walking interview technique used in this study. The researcher interviewed older adults during walking and if shadowing were to take place, the presence of the staff member would breach the confidentiality of the interview. Since an interview with a family member was important in obtaining the resident's life history, residents who had no family members other than being the clients of the Manitoba Government's Public Trustee Office were also excluded from the study.

The researcher contacted family members who showed interest in participating in the study via email and phone conversations and scheduled a meeting with them and the residents in the LTC home (when possible) to discuss the study and sign the consent forms. Of the ten potential participants (residents), two residents and their family members were unable to participate in the study. One resident was admitted into the hospital during the course of the study, and one family member who was willing to be interviewed did not want the relative to be interviewed. The remaining eight residents and their family members were eligible to participate in the study.

Six items in total were completed by the staff on the wandering screening tool, part B (see Appendix B) for the eight participants (residents). Item number one focused on knowing whether the resident had moved between or within a LTC home. Four of the eight residents were reported to have moved within their LTC homes in the last year. Item number two addressed the exclusion criterion (shadowing) for the study and none of the residents were reported to shadow

staff members. Item number three described resident's moving activity, and of the eight residents, only two were described as moving around frequently with difficulty in sitting still for more than a few minutes. The next two items on the wandering screening tool focused on whether or not the resident entered other residents' rooms or made attempts to leave a safe place. These items were also addressed by family members during the family interview and are presented in the profile of family members section in chapter four. As reported by the staff, two residents engaged in entering other residents' rooms and making attempts to leave a safe place, four engaged in one of these activities (entered other residents' rooms), and the remaining two did none of these activities. Only two of the eight residents were reported to have left a safe place and got lost. If any of the above questions were answered "yes", in the Dewing Wandering Screening Tool, the resident is most likely engaging in some type of wandering and may be at risk or have the potential to engage in a more risky type of wandering (Dewing, 2005).

Written consents were obtained from eight family members who also signed on behalf of the residents. Ongoing verbal consent was obtained from the residents by asking residents if it was okay for the researcher to walk with them and ask them questions throughout the course of the interview. Family members were also reminded that they and their relatives could withdraw from the study at any point with no consequences. A step-by-step layout of the process of recruiting participants for the study is in Appendix A.

Data Collection Procedure

Data collection began following ethical and access approvals and after obtaining consents from family members. Two groups of participants (n = 16; eight residents and eight family members) participated in the study. All data collected were kept confidential. The computer where all data were stored was secured with passwords to restrict access to only the researcher

and the thesis supervisor. The data collection procedure for the participants (residents and family members) is discussed below.

Family members. An interview was conducted with family members (prior to the walking interview with the residents) in a private room at the LTC home, and other mutually agreeable locations, to obtain information about their relatives. The family interviews lasted 20 to 30 minutes and were audio-recorded. Questions related to each resident's social characteristics and health such as age, gender, marital status, date of admission, visual, hearing or mobility aids use, memory, history of walking and psychosocial environment were asked (see Appendix I). The interview was semi-structured with probes and the two sets of questions were designed to address the non-neurological impairment components of the Enriched Model of Dementia (Kitwood, 1993): health; biography; personality; and social psychology as well as family support and any concerns that the family may have in relation to walking. The interview questions were initially developed by the researcher and her supervisor and were revised based on suggestions from the researcher's committee members. Examples of the family interview questions include: "How often do you visit?" "How much does your family member walk in the LTC home?" (responses were a ten-point visual analogue scale where one represents very little and ten represents most of the time), "How do you describe your family member's overall health?" and "How do you describe your family member's overall memory?" (included responses with five-point categories, "excellent", "very good", "good", "fair" and "poor"), and "How important was walking in your family member's earlier life?" with a ten-point visual analogue scale where one represents not important and ten represents very important. Other questions asked were "Do you ever walk with your family member?" "Do the staff encourage/discourage your walking with

your family member?” “Do you worry about how much your family member walks?” “What are your concerns?”

Information about the resident’s past history of walking was obtained from the family using the Dewing Wandering Screening Tool, part A [three items that asked about their relative’s past history of walking, walking as a coping strategy, personality characteristics (see Appendix B)]. These questions include: “Does this person have a history of being a regular walker, whether as a hobby or as part of their daily life?” “Has this person regularly used walking as a means of thinking things through, coping, dealing with stress or cooling off?” “Does this person have a history of being extremely sociable or are they known to have an outgoing personality?” (Dewing, 2005). If the answer to any question was yes, probes (follow-up questions) were used (such as could you tell me more about that?) Probes were also considered for questions answered “no”. For example, when questions on the use of walking as a hobby were answered “no”, the follow-up question was “What other type of physical activity does your relative engage in”? For any of the items in Part A answered “yes” and a diagnosis of dementia, especially Alzheimer’s is present, the resident is at risk of wandering or has the potential to wander, especially if they become excessively under or over-stimulated (Dewing, 2005). The wandering screening tool was developed by Dewing in 2005 during her doctoral study on wandering and has not been empirically tested (see Appendix C for the permission letter by Dewing to use her tool). However, the screening tool identified other factors that may affect older adults living with dementia as proposed by the Enriched Model of Dementia.

Residents. Residents living with mild to moderate cognitive impairment were identified by the staff using their CPS scores of one to three and participated in a walking interview. Information about the cognitive status of residents is included in the CPS of the Minimum Data

Set (MDS). The CPS evaluates “the cognitive status of the resident using information on the resident’s ability to make daily decisions, make themselves understood, and their memory impairment” with scores ranging from zero to six (Manitoba Centre for Health Policy, 2011, para. 1). A score of zero is assigned for “intact”, one for “borderline intact”, two for “mild impairment”, three for “moderate impairment”, four for “moderate/severe impairment”, five for “severe impairment” and six for “very severe impairment” (CIHI, 2013). The CPS was developed by Morris et al. (1994) and is validated against the scores of the Mini-Mental State Examination (MMSE). For example, a CPS score of zero is equivalent to an MMSE score above 25, one to 22, two to 19, three to 15, four to seven, five to five and six to one (Canadian Institute for Health Information (CIHI), 2013; Morris et al., 1994). Residents with CPS scores of one to three were eligible to participate in the study.

The MDS, where the CPS is located is the care assessment component of the Resident Assessment Instrument (RAI) and provides standardized comprehensive assessment of the functional, medical, psychosocial and cognitive status of residents (Morris et al., 1994). The RAI 2.0 is a comprehensive assessment data of the preferences, needs and strengths of residents living in WRHA LTC homes to guide individualized care planning and monitoring. The assessment data is usually completed when the resident is admitted to the facility, then reassessed every three months or when there is a significant change in their clinical status (CIHI, 2012).

The Walking Interview

An interview was done while walking with the residents to capture their moment of walking. Over the years, researchers have used walking as a means of interacting with participants and to determine the significance of location (place) to individuals (Evans & Jones, 2011). Additionally, walking interviews provide the opportunity for researchers to explore an

individual's perspectives and knowledge of where they live. Walking interviews are commonly used by geographers, social scientists and health researchers to understand the relationship between individuals and place (Anderson, 2004; Evans & Jones, 2011). Although the focus of this study was not on the geographical context of walking, the researcher chose the walking interview method because it allows for "a more spontaneous set of interactions" and participant observation (Holton & Riley, 2014, p. 60). Participant observation not only allows researchers to 'deliberately immerse' themselves in the worlds of the people being studied, but also to be part of their everyday 'rhythms and routines' through observation (Anderson, 2004, p. 255). Moreover, walking interviews are likely to generate richer data and knowledge through collaboration and participants' connections to their environments (Evans & Jones, 2011).

There are different types of walking interviews, including the go-alongs, participatory walking interviews and bimbling, which are commonly discussed in the literature. For go-alongs and participatory walking interview methods the participant determines the route, while in bimbling neither the researcher nor the participant knows the route (Evans & Jones, 2011). The word bimbling originated in the British Army as slang. Bimbling, meaning "aimlessly walking" or going for a walk, is a term researchers have used to define the need to have time away or disengage oneself from a stressful life. Bimbling creates an opportunity for reminiscence through an understanding of relationship between individuals and place (Anderson, 2004).

Go-alongs are the most commonly used type of walking interview. The two most common approaches for go-alongs are walking along (walk-alongs), with the participants and riding along (ride-alongs) with the participants (Kusenbach, 2003, p. 464). The go-along is a blend of interview and participant observation, where researchers follow participants around (Butler & Derrett, 2014; Evans & Jones, 2011; Kusenbach, 2003). The go-along walking

interview allows the researcher to ask questions, listen and observe as participants walk and interact with their physical and social environment. However, the pitfall of this method occurs when researchers attempt to be more active and decide to take participants to an unfamiliar place. This can further limit the researcher's understanding of the participants' "authentic practices and interpretations" (Kusenbach, 2003, p. 464). The type of walking interview used for this study is the "go-along" where the researcher always followed the older adults' walking patterns or routines.

One walking interview per resident was done. During the walking interview, a Sony® ICD Recorder, a digital audio recorder with a Sony clip style omnidirectional microphone (small lapel) clipped onto the researcher's clothes or jacket was used to record conversations between the researcher and residents. The digital audio recorder has a built-in Universal Serial Bus (USB) which plugs directly into the computer for quick transfer of the file (Sony of Canada Ltd, 2018). The use of a small lapel microphone enabled the researcher to focus more on the conversations with the residents rather than the audio recorder thereby reducing unnecessary distractions. Each resident and family member interview audio recording was first saved to the researcher's computer and later transferred to a Dropbox site. The Dropbox site was password protected and created with limited access to only the researcher, her supervisor, and the transcriptionist. The transcriptionist signed a pledge of confidentiality (Appendix J) before accessing the site. The use of the Dropbox site made it easy for the researcher to add new files of interviews once completed and the transcriptionist was able to view the added interviews as uploaded. Also, the researcher had quick access to transcripts once transcribed and uploaded by the transcriptionist on the site.

Closed-ended and open-ended probing questions were asked during the interview to reflect any underlying causes of wandering behaviour, that is, unmet needs, environmental

triggers and past history of walking (see Appendix H for a list of interview items). The probing questions were initially developed by the researcher and her supervisor and were revised based on suggestions from the researcher's committee members. Examples of closed-ended questions include: "Do you enjoy walking?" "Are you bored? (Is there something that you would like to do?)" and "Does walking make you feel good?" An example of open-ended question was "How are you feeling about walking right now?" Residents' responses are discussed in the result section.

The walking interview included participant (resident) observation, where the researcher observed residents' nonverbal behaviours (such as facial expressions, body language and interaction with others) during the walking interview and recorded these behaviours in her reflective journal, after the walking interview. Participant observation was conducted to allow the researcher to observe the participant's behaviour in their natural environment and to become part of their everyday life (Anderson, 2004). Moreover, participant observation provided opportunity for reflection upon behaviour and context observed in the participant's natural environment or setting. However, participant observation allows the researcher to observe only what the participant is doing and not why they are engaging in what they are doing (Thorne, 2016). Participant observation in this study meant that the researcher observed residents' walking activities and behaviours and asked residents questions related to what was observed and their life histories as presented by family members.

The reflective journal, including observational notes and self-reflections was kept during the course of the study to record and reflect upon observations during the walk, and provided a description of context. The journal also included the researcher's observed patterns of residents'

wandering. The reflection part of the journal emphasizes the researcher's thoughts and feelings about the process of the study and any insights.

Data Analysis Process

Data analysis for this study involved concurrent data collection and analysis and iterative process (Thorne et al., 2004). Concurrent data collection and analysis for this study involved a review of audio recordings and transcripts after each data collection to check the need for more probes during the interview and to make sense of the data. By doing this, the researcher was able to establish the need to review and change one of the Resident Participants Interview Items (Appendix H) based on the responses received from the residents. For example, as agreed by the supervisor, item number 12 was changed from "Are you depressed?" to "Are you sad?" Data were collected in the form of demographic profiles, interviews and reflective journal (including observational notes) and analyzed as: demographic data analysis and interview and reflective journal analysis.

Demographic data analysis. Data obtained from family members provided a profile of their relatives (sociodemographics and health characteristics) and were analyzed at a group level using univariate analysis (frequencies) and measures of central tendency, as appropriate.

Interviews and reflective journal analysis. The analytic process started with the first interview with family, followed by the resident interview. The analysis continued until the researcher was able to make sense of the emerging themes leading to meaningful interpretation of residents' and family members' perspectives on wandering. The digital audio recordings of the interviews were transcribed using the services of a transcriptionist who signed a pledge of confidentiality (Appendix J). Transcripts were checked by the researcher for missing data and inaudible words or phrases. Digital audio recordings were listened to by the researcher to fill in

inaudible words or phrases. Some interviews were conducted where there was background noise. Consequently, some inaudible words or phrases of some interviews could not be filled in. Qualitative data analysis software program, NVivo 11 (student version) was used to enter transcripts and reflective journal data, and to manage all data. NVivo was used in organizing and sorting of data.

As proposed by Thorne et al. (2004), the researcher did not bracket her preconceptions about wandering behaviour. However, self-reflection was maintained throughout the study and data analysis process by keeping a reflective journal (including observational notes) on thoughts and assumptions. A reflective journal was completed by the researcher following interviews and shared with the researcher's supervisor. Keeping a self-reflective journal facilitated reflexivity and allowed the researcher to examine and clarify any personal assumptions and goals during the course of the study (Ortlipp, 2008). In addition, reflexivity helped the researcher to avoid "clinging" to her assumptions, thereby preventing "premature closure" of themes that were emerging (Thorne et al., 2004, p. 5). Although there is limited research on the use of reflective journals in the research process, the researcher used the journal to create transparency in the research process by examining her assumptions (Ortlipp, 2008). These assumptions, along with excerpts from the researcher's journal, are discussed in the trustworthiness and integrity section.

At the initial phases of data analysis, the researcher immersed herself in the data to comprehend it (make sense of the whole) by reading the transcripts several times prior to beginning coding. These phases have been described as a time to react to the initial pieces of data and the researcher continued in the phases until she observed phrases and comments from the data that "caught" her attention and were unusual (Thorne, 2016). Ideas generated from reading and engaging in the data repeatedly, including any patterns, were noted and highlighted in the

transcript and reflective journal by the researcher prior to coding. These ideas were discussed with the researcher's supervisor who also read the transcripts several times to understand and get a sense of the data.

The coding process was an inductive process whereby the researcher engaged in reading through the data repeatedly to identify any statements or "aha" moments that were relevant to the research questions. The coding process involved grouping data from the transcripts and reflective journal, including observational notes with similar characteristics or ideas. Data with similar characteristics were examined for alternative meanings of what could convey participants' perspectives on wandering before they were highlighted and assigned a name. The use of creative coding such as colour codes also helped with the inductive process (Thorne et al., 2004). For example, words or statements in transcripts related to residents being sociable were coded with yellow thereby making it easier for the researcher to identify patterns within the data. The initial coding of the data was done independently by the researcher and then jointly by the researcher and her supervisor. Codes were compared for similarities and differences and were further discussed until a consensus was reached.

Data with similar characteristics, including the ideas generated at the initial phases of the analysis were further examined for repeated patterns and represented the key themes (Thorne et al., 2004). Furthermore, linkages between data from family members were explored with participant observation data to generate an interpretive description of participants' perspectives on wandering behaviour. For example, data on previous and current walking behaviour of resident participants and concerns about their walking obtained from family members were analyzed for links between the resident participant's walking behaviour and the components of the Enriched Model of Dementia. Data analysis began with the family interview transcripts,

developing key themes. Data on resident participants' perspectives on wandering were then analyzed as a group to examine key themes across participants before comparing these key themes to those of the family members. Relationships between key themes from resident participants and family members were interpreted using a visual representation. The visual representation was discussed in chapter five.

The researcher is aware of her role as an "interpreter" in "generating findings" for this study. Therefore, several ongoing discussions were held with the researcher's supervisor with regard to the process of coding, emerging findings (key themes and sub-themes) as well as interpretation of the findings (Thorne et al., 2004). The researcher and her supervisor discussed any differences during the analysis process until a consensus was reached on the codes, key themes and sub-themes.

Trustworthiness and Integrity of the Study

Several strategies were used to enhance the trustworthiness and integrity of the study. The criteria for establishing the trustworthiness of a study are credibility, transferability, dependability, and conformability (Lincoln & Guba, 1985). For research findings to be credible there must be a logical flow of the research process from the research question being consistent with the stated epistemological standpoint to how data is being interpreted from sources using interpretive strategies (Thorne, 2016). The research questions for this study were developed based on the gap identified in the literature on older adults' perspectives on wandering behaviour and the Enriched Model of Dementia. Clear articulation of the analytic process is one way the credibility of the findings of this study were enhanced. Interpretive description method was used to analyze the data and data interpretation incorporated participant quotes and represented the description of participants' perspectives on wandering behaviour. Other techniques for

improving credibility of the findings included peer debriefing (providing an external check on the analysis process), triangulation, and any methods making it possible to check preliminary findings and interpretations against archived raw data (Lincoln & Guba, 1985). Peer debriefing was achieved using reflective journals (including observational notes), and researcher triangulation (Lincoln & Guba, 1985). To achieve peer debriefing and triangulation, the researcher's supervisor performed an independent review of the data and compared the results with the researcher on an ongoing basis during the analysis stage of the study. Also, the researcher's supervisor served as the external check during the process of interpreting data, exploring meanings and clarifying interpretations. To further enhance credibility, the researcher kept an audit trail of the data, participant observation and her experiences as documented in the reflective journal to confirm patterns that were emerging from the data. According to Thorne (2016), an audit trail is "an explicit reasoning pathway along which another researcher could presumably follow" (p. 235). The audit trail also included notes of the researcher's biases and preconceptions about wandering and the study.

Another criterion for establishing trustworthiness is transferability. Transferability is being able to transfer the results of the findings of a study to other settings or groups (Lincoln & Guba, 1985). The researcher is expected to provide "thick description" of data to enable potential appliers to make the decision on whether or not the study findings are transferrable to other settings or groups (Lincoln & Guba, 1985). Although the researcher could not conclude the transferability of the study findings, a range of information is provided about the study participants, research methods, including data collection and data analysis process, findings, and recommendations. This range of information may aid transferability of study findings to other older adults and care settings.

Dependability refers to the conformity of the study findings if the study were repeated with the same participants under the same circumstances (Polit & Beck, 2017). There can be no credibility without dependability (Lincoln & Guba, 1985). One of the strategies the researcher used to achieve dependability included maintaining an audit trail through a reflective journal, including observational notes. The researcher also met with her supervisor on an ongoing basis to discuss research methods and compare findings, thereby aiding dependability.

Conformability refers to objectivity and demonstrates an agreement between two or more people on data accuracy, findings, interpretations, and recommendations (Lincoln & Guba, 1985; Polit & Beck, 2017). Conformability establishes that the interpretations of the data are not a result of the researcher's bias or perspectives and represent participants' information (Lincoln & Guba, 1985; Polit & Beck, 2017). To achieve conformability, the researcher maintained an audit trail. The researcher and her supervisor discussed any differences during the analysis process until a consensus was reached on study findings and interpretation of the findings. The researcher was transparent about her research process and reporting of study findings. In addition to keeping an audit trail, the researcher maintained reflexivity. The researcher noted in her journal her personal biases, preconceptions and past and present experiences providing care for older adults with wandering behaviour that might have impacted her interpretation of the study findings and shared the same with her supervisor. This strategy is described as "clarify the bias" and helped to create transparency in the research process (Creswell, 2013, p. 251).

The following preconception and biases were identified: *Looking back to when I first started working in [LTC homes] and with older adults living with dementia, I viewed wandering behaviour as unsafe. Just like my colleagues, I directed all my nursing interventions to controlling the behaviour. Because it was difficult to control the behaviour sometimes, I became*

frustrated, especially when I believed the behaviour was disrupting my routines. Over the years, my perspective has changed and I don't control the behaviour anymore. However, I still worry about how unsafe the behaviour (wandering) may be for older adults who wander into other residents' rooms or elope. The ensuing altercations, including the possibility of being "attacked" by other residents still worry me and sometimes make me feel the behaviour is unsafe. Also, the consequences of elopement such as physical harm and possible death get me concerned and worried about older adults who wander. I have to consciously work on these preconception and biases as I proceed with my study (Excerpts from the researcher's journal).

The researcher also made comments in her journal about her past experiences providing care for older adults living with dementia who exhibited wandering behaviour, and how this might have contributed to any biases about wandering in the study: *I thought on several occasions, I genuinely sought to understand why my residents wandered but didn't know how to go about it. Even though I know it is possible to ask older adults living with dementia simple questions and receive their answers, I must admit that I am a little bit nervous and unsure how this study would turn out. I worry if I would be able to receive their answers even after doing this in my practice many times. I think I'm having a mixed feeling about this; a feeling of confidence and excitement that I can do this based on my years of experience providing care for older adults and communicating with them; and another feeling of anxiety about getting enough participants and the simple answers that I anticipated. What if I am wrong? What if this is not possible?* (Excerpts from the researcher's journal.)

In addition to the approaches to measure trustworthiness identified by Lincoln and Guba (1985), the researcher used other strategies such as member checking. Member checking was attempted in the course of the study by asking some of the residents and families to confirm what

they might have mentioned to the researcher during the walking interviews and in the course of the study about why they wander. For example, the researcher asked a female resident participant, *I know you told me that you, you feel good when you walk, it makes you healthy?* and the participant replied *oh yeah*. Another participant was able to confirm that he enjoys walking for his health because it is *good exercise*. The researcher also asked another participant, *So I was asking you why do you walk, you said for your health...* and the participant replied *For my health reasons*. A family member was also able to confirm when asked the second time if her father has a history of being a regular walker and whether walking was a part of his work life and leisure activities.

Ethical Considerations

Ethical considerations were observed throughout the study. All qualitative studies involving humans require ethical approval and participants' interests and needs must be respected while using their information (Thorne, 2016). Ethical approval for the study was obtained from the University of Manitoba Education Nursing Research Ethics Board (ENREB). Ethical approval was also obtained from the WRHA as requested by one of the LTC homes used for the study. To ensure the study was ethically acceptable, procedures for recruitment and data collection followed the Tri-Council Policy Statement (TCPS) 2: Ethical Conduct for Research Involving Humans (Government of Canada, 2015). In particular, ethical considerations were followed for research involving older adults and participants who cannot consent for themselves due to a lack decision-making capability. The characteristics of the resident participants in this study such as age and living with dementia made them vulnerable, thereby requiring extra precautions when involving them in research. Therefore, the researcher requested consent from family members on behalf of the resident participants regardless of whether or not resident

participants could give consent. However, ongoing verbal consent was obtained from the resident participants (see Appendices G.1, G.2 and G.3 for the consent forms). Moreover, a voluntary, fully informed and ongoing verbal consent was obtained from the resident participants throughout the course of the interview. Both the resident and family participants were reminded that participation was voluntary and that they could withdraw from the study at any point in time with no consequences. They were also reassured that withdrawing from the study would not affect the care that the resident was receiving in the LTC home.

Due to the nature of the walking interview technique used in this study, some interviews were conducted while walking with resident participants in public places. There was the possibility of other residents, families, or staff members hearing the conversations between the researcher and the participants. An acknowledgement of this was added to the consent forms and reviewed with resident participants and their families while signing the consent forms (see Appendices G.1, and G.2).

Older adults living with dementia are a vulnerable population and depending on the resident participant's stage of dementia, mood and preferences, and the goal of walking, some participants may enjoy walking with the researcher while others may not. Although most participants seemed to enjoy the researcher's company, one of the participants requested to walk alone 20 minutes into the walking interview and the researcher granted her request. The researcher was also aware that talking with the researcher during the walk might create some degree of anxiety for some participants, thereby leading to agitation. Therefore, the researcher was vigilant for early signs of agitation and withdrew from walking with such participants when needed.

All participants were assigned an identification (ID) number and given pseudo names to protect their identity and confidentiality. The paper linking participants names and numbers was placed in a safe cabinet with a password and accessed only by the researcher. The Dropbox site created for transferring the audio recordings of interviews and easy access of transcripts was password protected with limited access only to the researcher, her supervisor, and the transcriptionist. The transcriptionist also signed a pledge of confidentiality (Appendix J). The researcher's computer where data were stored was password-protected and the researcher's supervisor had access as necessary. All research data will be stored for seven years and then destroyed permanently. During the informed consent process, resident participants and their families were notified that the information gathered in the study may be published or presented in public forums (such as LTC homes and academic conferences) but that their confidentiality will be maintained. As part of the ethical considerations and as discussed with family members during the informed consent process, feedback about the study and summary of results were sent to family members and resident participants.

There was no direct benefit to participants from participating in this study other than adding their perspectives to our understanding of wandering behaviour. All participants (residents and family members) who participated in the study were offered an honorarium of five-dollar gift cards. The honorarium was offered to participants even if they chose to withdraw from the study.

Summary

This study utilized interviews from residents and family members as well as a reflective journal, including observational notes, to collect data on wandering behaviour from the perspectives of older adults living with dementia and their family members. The research

methods were appropriate and allowed the researcher to address the research questions. The researcher maintained self-reflections throughout the course of the study using her journal to record observations (verbal and non-verbal) during her visits and interviews and to reflect upon observations to provide a description of context. The reflective journal (including the observational notes) was also used to reflect on the researcher's perspective on wandering throughout the study. Data analysis involved examining the perspectives of older adults and their family members using qualitative analysis methods to generate key themes. Study findings are presented in the next chapter.

Chapter 4: Results

In this chapter, the findings of the study are presented. First, a description of the study sample, that is, sociodemographics and health characteristics, walking history of residents, and previous walking history of residents (from the Dewing Wandering Screening Tool) is presented. Second, the profile of family members (relationship to the residents, frequency of visiting, walking activities with their relatives, and whether or not encouraged by staff to walk with their relatives) is also briefly presented. Third, from the transcripts of family interviews and walking interviews with residents, key themes and sub-themes that emerged from the perspectives of family members and residents on walking are presented. In addition, walking- and not walking-related concerns from residents and family members and other findings such as positive comments from family members about the LTC home and the staff are discussed. Lastly, participant observation and reflection findings, including the researcher's walking related concerns as observed prior to and during the walking interviews are presented in this chapter. The researcher's reflective journal (including the observational notes) was used to reflect on the researcher's perspective on wandering throughout the study.

Wandering in this chapter is described as walking because this term is more commonly used and understood by residents and their families in LTC homes where the study was performed. However, both terms (walking and wandering) are used interchangeably in this chapter. The study aimed to answer the following research questions:

- 1) How do older adults living with mild to moderate dementia in LTC homes perceive their own wandering behaviour?
- 2) Using the components of the Enriched Model of Dementia, how do family members

perceive the wandering behaviour of their relatives who are living with mild to moderate dementia in LTC homes?

Description of the Study Sample

Although both residents and their family members were interviewed, the description of the study sample (residents) presented in this section comes from family members who reported on behalf of their relatives. No sociodemographic data, health characteristics, and walking history of the study sample described in this section was collected from resident participants. In this section, resident participants will simply be referred to as participants.

Sociodemographics. A purposive sample of eight participants ($n = 8$) living with mild to moderate dementia participated in the study. Demographic information of the study sample is presented in **Figure 2**. Of the eight participants, four (50%) were males and four (50%) were females. The gender of the sample was slightly different from the usual demographics seen in LTC homes in which the majority of residents are females (Banerjee, 2007). The participants' ages ranged from 80 to 95 years old with the majority ($n = 5$, 62.5%) between 81-90 years (Mean 86.63). Participants were predominantly married ($n = 5$, 62.5%), and the remainder were divorced, single, and widowed. The dates of admission of the participants ranged from 2015 to 2017; five were admitted between May and August 2017 while the remaining three were admitted in 2016 and 2015 respectively, suggesting that most participants were new to the LTC home during data collection. The literature suggests that older adults may wander to make sense of their environment or be in search for familiarity in an unfamiliar environment (Moore et al., 2009). Three (37.5%) participants were admitted from the community, three (37.5%) from another LTC home, and two (25%) from the hospital. Four (50%) of the participants were

staying in locked units of the LTC homes. Data were collected between August 29 and November 6, 2017.

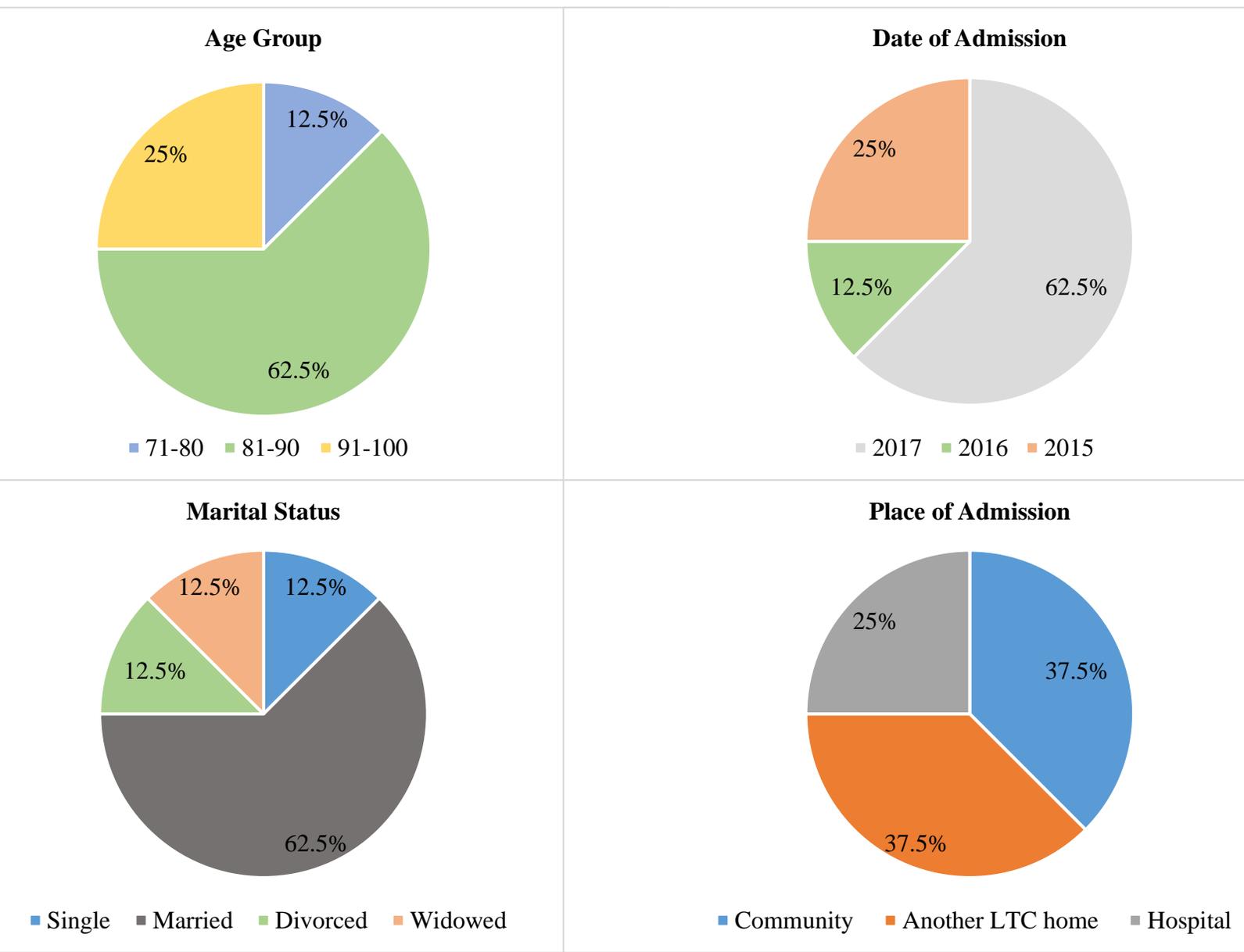


Figure 2: Sociodemographics of the sample (n = 8)

Half (50%) of the participants were reported to use one or more assistive devices such as visual, hearing, and mobility aids. The use of assistive devices is presented in **Table 1**. One participant was reported as not using any of the assistive devices while one used all of the devices. Wandering behaviour may provide sensory and environmental stimulation for older adults with sensory impairments, thereby allowing them to express control and agency (Dewing, 2011; Dickinson & McLain-Kark, 1998).

Table 1: Use of assistive devices

Assistive Device	Yes	No
Visual aids (glasses)	*5	2
Hearing aids	2	6
Mobility aids (walker)	4	4

*Note: One of the participants wore glasses but was legally blind and was not included in this table.

Although two of the participants were reported as having glasses, they did not wear them often. Four (50%) of the eight participants used mobility aids (walkers), which is speculated to be different from the demographic of LTC homes where the use of mobility aids is more common among older adults. Although Song and Algase (2008) in their study reported that there was no significant correlation between mobility and wandering, wandering is shaped by personal characteristics such as mobility status according to the NDB model (Algase et al., 1996). Half (50%) of the participants in this study were reported to be independent in their walking.

Health characteristics. The overall health of most participants (n = 6, 75%) was described as either good or very good and other participants' overall health was described as excellent and fair. Colombo et al. (2001) described the older adults with wandering behaviour in their study as clinically healthy. Although the focus of this study was not to identify types of wandering behaviour, the overall health of participants as reported by family members correlates with moderate wandering. Moderate wandering is characterized by being active and having better general health condition compared to other types of wandering (Algase et al., 2009). It can be speculated that the majority of participants in this study exhibited moderate type of wandering based on two reasons. First, older adults who exhibit this type of wandering behaviour generally have good health. Second, this type of wandering is easily recognized by nursing staff, as the case in this study where the staff assisted in identifying potential participants who exhibited wandering behaviour (Algase et al., 2009).

Family members were also asked to describe their relatives' overall memory. Only one (12.5%) of the eight participants was reported by a family member as having a very good memory; four participants had a poor memory while the remaining three had a fair memory. Although the researcher did not have access to the actual CPS scores of participants, residents in this study had CPS scores of one to three because this was an inclusion criterion as identified by staff. Several studies have also reported that wandering correlates with high cognitive impairment (Hope et al., 2001; Kiely et al., 2000; Song & Algase, 2008). In a cohort study by Holtzer et al. (2003), it was concluded that the prevalence of wandering behaviour increased with decline in cognitive status. Furthermore, wandering behaviour has been reported to be characterized by short-term (recent) and long-term (remote) memory problems (Cipriani, 2014; Kiely et al., 2000). The majority (n = 6, 75%) of the participants in this study were reported by

their family members as having retained more of their long-term memory, but were having problems with short-term memory.

Walking history. The walking history of participants as described in this section includes any walking activity in the present and past, walking into other residents' rooms, any attempt to leave the LTC home, and previous walking history from the Dewing Wandering Screening Tool.

Present and past walking activity. The first question asked was, how much does your relative walk in the LTC home on a scale from one to ten? Family members rated the walking of most participants ($n = 7$, 87.5%) as five and above, with a range of two to ten, two being the lowest and ten the highest. The past and current walking histories of participants were compared (**Figure 3**). Specifically, how important was walking in the participant's earlier life (past) and how important is walking currently were compared. For the majority of the participants ($n = 5$, 62.5%), it indicated that walking was important in their current lives, and as important or more in their current life than in their earlier lives. Two reasons family members gave why current walking was important in participants' current life were because "it's all they have to do" and "to stave off boredom". The literature suggested that wandering can be a lifelong habit or a symptom of an unmet need or boredom (Algase et al., 1996; Dewing, 2011; O'Connell et al., 2011).

Family members were also asked to provide information about their relatives' earlier lives, which included work life and any leisure activities. Five (62.5%, two women and three men) of the eight participants were reported to be active in sports when younger. Female participants were also reported being active by walking as a tourist or around the house doing chores and gardening. As reported by a family member about his relative:

He's also a very active person too, his whole life pretty much...he always was fit, you know he'd ride his bike and he'd go, he was a marathon runner, so he'd go running. And then he liked to walk everywhere, so and ride his bike too...it was a little different when he was working, you know in the evening he would go for a run, but when he was retired he'd walk every day, usually to get the newspaper and it was pretty far and then walk to the grocery store, walk, and he'd always, like sometimes he'd be walking for, he'd do maybe five walks and each one like probably an hour you know. Like he would walk for at least probably four hours a day.

Another family member described his relative as a good athlete who participated in several sports.

When Dad was young he was an extremely, extremely good athlete...he played hockey semi-professionally and he also played a lot of baseball at a very very high level. So in his youth he was extremely fit and very very, very athletic, like slim and in great shape.

In addition to the literature confirming that wandering can be a lifelong pattern as it was for most participants in this study, older adults who walked regularly in the past for work or leisure are more likely to wander to fulfil former role or responsibility, or in search of a former workplace (Carr et al., 2010; Silverstein et al., 2002). One of the participants was described by his family member as a very hardworking man who was used to walking and working.

And we always walked and my husband's a very hardworking man, he's worked all his life and he's, he's walked and worked hard...you know so he's, he's a builder...he builds, he's a plumber, electrician...a farmer, everything...he's a jack of all trades.

One of the female participants was reported to be a gymnastic instructor by her family member:

She graduated as a gym instructor...so she walks two, three hours a day.

When asked if walking was important in the earlier lives of their relatives, only three of the eight family members (37.5%) indicated that walking was less important in the lives of their relatives while one family member's rating of the importance of walking both in the participant's past and current life remained the same (**Figure 3**). Factors that might have contributed to changes in the importance of walking, that is, why walking became less important for some participants, included lack of motivation and expressed pain as reported by family members and one of the participants. One family member reported that his relative became less active after he turned 40 years:

So in his youth he was extremely fit and very very, very athletic, like slim and in great shape...but unfortunately from the time that he turned about 40...I don't know if it's a generational thing, it may be a generational thing where they don't do sports after a certain age, and once he had finished playing hockey and once he had finished playing baseball he didn't join like an old-timer's league for baseball or for hockey or barely do anything like that, he just stopped.

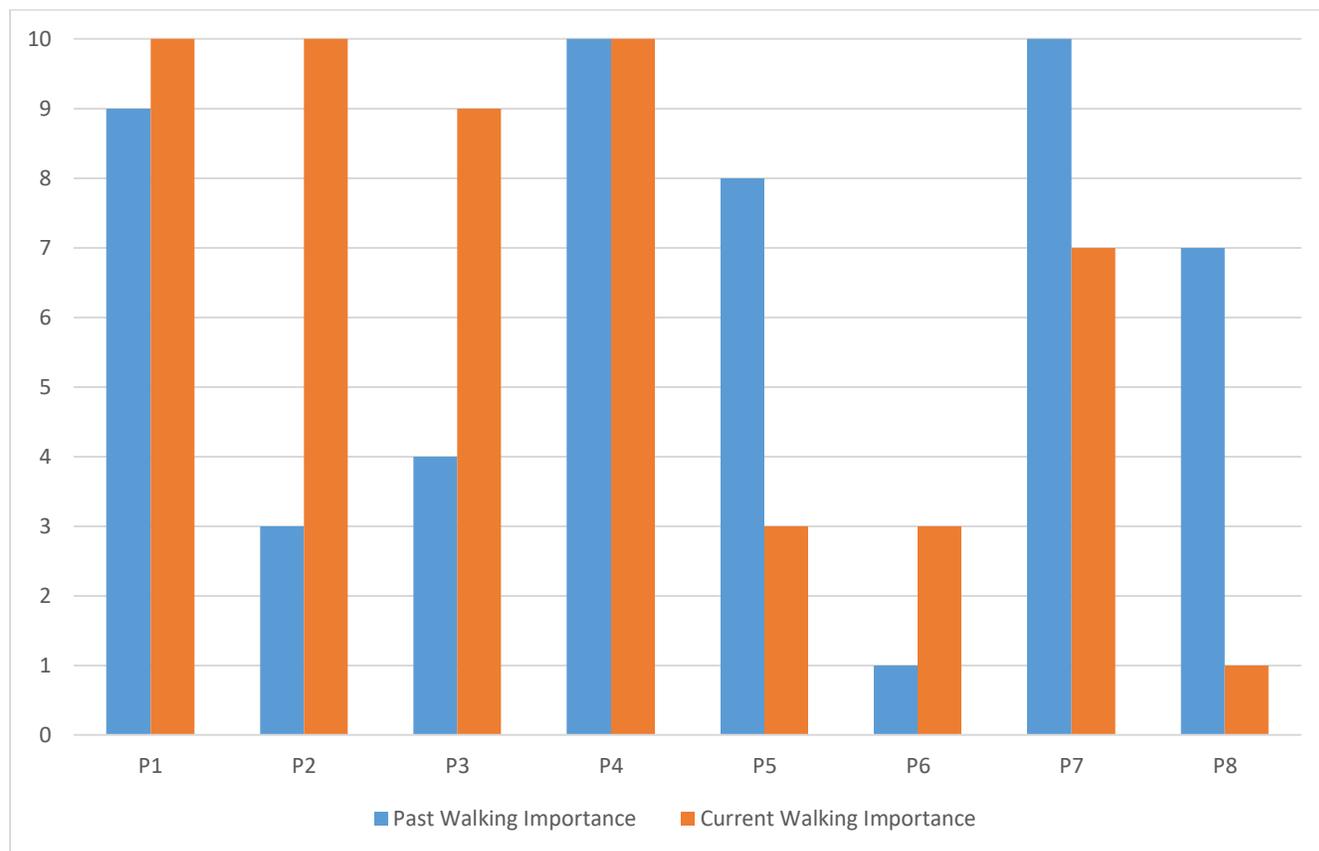


Figure 3: Walking history of participants (n = 8, P = participant)

Walking into other residents' rooms. During the screening process, staff reported that four (50%) participants entered other residents' room. Likewise, four (50%) family members responded "yes", "yes, regularly", "yes, a lot of the time", and "yes, not often" to the question about their relatives entering other residents' rooms and stated it was the reason for moving their relatives to a locked unit. It was well documented in the literature that older adults who wander often engage in wandering into other residents' rooms, also known as boundary transgression

(BT) (MacAndrew, Fielding, et al., 2017; Shinoda-Tagawa et al., 2004). One family member described his relative's wandering into other residents' rooms:

It's definitely some or a lot of the time because she, that's why she was moved to this area is that she was walking into peoples' rooms...and so she got moved to the locked ward.

Interestingly, another family member mentioned that all residents on the specialized dementia unit wandered into one another's rooms.

I have found him sitting in another room right across from him in a chair and I said what are you doing here, you know so I take him, take him into his room, so they do and they all do that over there though, that's you know...that ward there that's what they do, they wander in and out, in and out, lay on somebody else's bed and stuff like this.

Only one family member stated he was unsure of his relative entering other residents' rooms while the remaining three responded "no". One family member also reported that the relative was "always in the same person's room at the end of the hall".

Here we'll often find her in somebody else's room where she claims it's her room, and interestingly enough its almost always the same person's room.

Attempts to leave the LTC home (elopement). Of the eight family members, four (50%) reported their relatives had made several attempts to leave the LTC home and two had actually left. One left with visitors (who came in to visit with another resident) while one was found on a "handicapped bus" outside of the LTC home. An attempt to leave or leaving a safe place (elopement) is one of the major risks of wandering behaviour (Lester et al., 2012; Moore et al., 2009). Here is a family member's report:

And he doesn't just walk with us, and he escapes. When I, when I say escapes I mean it...he's been, he's been located trying to force the doors open or between the two sets of doors there he's, he's tried to escape and, and he gets upset when people stop him and he's a bit frustrated because he's wanted to leave and he's kept on saying, I want to go home, I want to be with Mom...he will attempt to elope or flee about once or twice a day.

Another family member reported that the relative left the LTC home but was found seven hours later.

So a few people were going outside that way and going in [with] their family members and he went out with them and was talking and then the door closed and didn't alarm and he actually was gone for seven hours...when they found him I went and met him and he was totally fine, and it was a hot day and he had no water, food, but he was totally fine...and actually the, the personal care home, they, they were very good about it, you know they actually had someone come and wire that door the next day.

One family member mentioned that their relative often verbalized the desire to leave the LTC home but had not attempted to leave. Four (50%) of the eight participants wore wanderguard bracelets (tracking devices used to prevent an older adult at risk of getting lost from leaving the LTC without supervision), which family members reported might have made it difficult for them to leave the LTC home unnoticed.

He doesn't want to stay there, he doesn't like being locked in,, he hates being locked in...well he has a wanderguard so he, he wouldn't get far if he wanted to but they've told me that he has, that he's not. He complains about, he says he wants to get out more often but he hasn't, he hasn't actually tried to do it... he wants to go home.

Some family members reported that their relatives were unable to leave the LTC home because they were staying in the locked unit.

So he wears that and he doesn't like it and sometimes he'll go up to the door and he wants to get out and of course you can't get out.

Previous walking history from the Dewing Wandering Screening Tool. Additional information about the participant's walking activity using the Dewing Wandering Screening Tool, part A (see Appendix B) was collected from family members. Family members were asked if their relatives had a history of being a regular walker, whether as a hobby or part of their daily life to which five (62.5%) family members answered "yes". Family members were also asked if their relatives regularly used walking as a means of thinking things through, coping, dealing with stress or cooling off. The majority ($n = 5$, 62.5%) of family members reported that their relatives used walking as a coping strategy and a means of dealing with stress. The literature also suggests that wandering or walking could be a lifelong habit (Dewing, 2011). One family member reported that their relative currently (not in the past) used walking as a means of cooling off. A family member provided an example of the participant in the past pacing back and forth while having conversations on the phone.

The tool also asked if participants "had a history of being extremely sociable or known to have an out-going personality" to which all family members answered "yes". Participants were reported to be fun-loving, enjoyed interacting with people and were involved in several social activities and other volunteer work. According to the Enriched Model of Dementia, an older adult's outgoing personality could contribute to wandering behaviour (Kitwood, 1993). Here is one of the family members' report:

She always seemed to, to like visiting with other people...well she always seemed to enjoy talking to people and just generally.

Profile of Family Members

After family members completed the consent forms for themselves and on behalf of their relatives, basic descriptive data were collected from eight family members about themselves.

Relationship. Family members reported their relationships to their relatives, three were sons, two were daughters, one was a wife, one was a niece, and one was a friend.

How often do you visit? Family members were asked how often they visited their relatives. Frequency of visiting varied from once every six weeks to every day with the majority visiting once or twice a week.

Walk with relatives. All family members reported walking with their relatives during their visit. Most family members (n = 6, 75%) reported that staff members have encouraged them to walk with their relatives; one (12.5%) reported that the staff discouraged them while one (12.5%) reported that the staff neither discouraged nor encouraged them to walk with their relatives.

Staff supervision during walking. Family members were asked whether their relatives might need more or less or about the same level of staff supervision during walking. Of the eight family members, three (37.5%) reported about the same level of staff supervision needed, two (25%) reported more staff supervision, and one (12.5%) reported less staff supervision needed. Two (25%) reported that their relatives did not need any staff supervision.

Resident Participants' Perspectives on Walking

In this section, findings that address the research question number one, *How do older*

adults living with mild to moderate dementia in LTC homes perceive their own wandering behaviour? are presented. Resident participants have been assigned pseudo names.

The walking interviews with residents occurred within ten weeks of recruitment depending on factors such as time of the day, pattern of wandering, and resident's preference/mood and lasted between 20 and 38 minutes. The researcher spent one to two days getting to know the resident and become familiar with their routines prior to conducting the walking interview. During these initial visits, the researcher walked with the resident. This helped the researcher to establish rapport with the resident and observe their walking activities (patterns) and behaviours on the units. The amount of time spent with each resident prior to the interview varied from 30 minutes to 120 minutes depending on the mood of the resident and the type of activity the resident was engaged in while visiting. For example, one of the residents was watching a hockey game when the researcher visited and requested that the researcher visit on another day. Another resident was observed to be agitated during the visit and the researcher immediately notified the nurse on the unit who attended to the resident and he later became calm. Spending time with the residents prior to the interview to get to know them was also considered participant observation, thereby allowing the researcher to establish rapport with the residents.

The transcripts from residents are mostly positive about walking and two things were identified as negative and discussed as concerns in the section of resident participants' walking- and not walking-related concerns. Six key themes comprise the interpretive description of the perspectives of participants on walking: 1) Walking as enjoyable, 2) Walking for health benefits, 3) Walking as purposeful, 4) Walking as a form of socialization, 5) Walking as a lifelong habit, and 6) Walking to be with animals. These key themes are discussed in this section. The participants' quotes formed the sub-themes and are presented with the key themes in **Table 2**.

Walking as enjoyable. The first key theme, *Walking as enjoyable*, was commonly expressed by all participants during the walking interview. All participants (n = 8) reported that they enjoyed walking when asked. Specifically, seven participants (87.5%) expressed that they liked walking and five participants (62.5%) stated that walking was good or made them feel good. Some of the words used by participants to describe walking as enjoyable were “*I just enjoy it*”, “*It makes me feel good*”, “*Walking is good for me*”.

Researcher: *So if I may ask what makes you walk around?*

Richard: *I just enjoy it.*

Sam, one of the participants who reported that he walked every day was asked about his daily walk and responded that walking made him feel good.

Researcher: *So how do you like walking every day, how does it make you feel?*

Sam: *Good, it makes me feel good, yeah yeah... walking is good for me, I've been walking around for quite a while now so.*

Researcher: *And how does that make you feel?*

Sam: *It makes me feel good.*

Most family members shared the same perspectives of walking being good as their relatives. Family members reported a desire for their relatives to keep walking because they felt walking is good. This perspective is discussed further in the family participants' perspectives section. Wandering has been described as beneficial in the literature and older adults may wander for the purpose of enjoyment (Alzheimer Scotland, 2009; Robinson, Hutchings, Corner, et al., 2007). One of the benefits of walking as expressed by participants in this study was to enjoy the “*fresh air and breeze*”. Lisa reported walking for the fresh air.

Researcher: *Why do you walk?*

Lisa: Why? Because it's nice to walk.

Researcher: Does it make you feel good?

Lisa: Oh yeah...walking is good, fresh air.

This study was carried out during summer and fall periods in 2017, and depending on the weather, interviews were done while walking with participants inside or outside, for instance around the courtyards of the LTC home. The majority of participants who were interviewed while walking around the courtyards reported that they walked because of the fresh air and breeze. However, Dave, who had his interview inside the LTC home, also expressed the same reason for walking. Dave further stated that he enjoyed walking because of the mosquitoes, which the researcher thought was interesting to see how the participant was able to link his reason for enjoying walking to the current season of the year.

Researcher: ...tell me what do you enjoy about walking?

Dave: I, I like walking and fresh air and the breeze and the mosquitoes.

Robinson, Hutchings, Corner, et al. (2007) in their study on the perspectives of different stakeholders in the management of wandering in dementia explored the views of six people living with mild dementia. Similar to this study, they found that the participants perceived walking as enjoyable and reported that they enjoyed walking for the fresh air.

Also, it was fascinating to see how Sarah described what she liked about walking in relation to her sense of smell.

Researcher: What do you like about walking out?

Sarah: Well its, its, its smells good.

Language problems such as difficulty finding words and naming objects are common symptoms of dementia, especially Alzheimer's disease. The use of related words and word

substitutions as in Sarah's description of her walking is not uncommon among those living with dementia (De Araújo, Lima, Nascimento, De Almeida, & Da Rosa, 2015). Perhaps, Sarah's description of her walking as smelling good was a substitute for the "fresh air and breeze".

Other participants also described walking as "*a good past time*" and "*fun*". Here is John's view of walking:

Researcher: *So are you always looking for something when you walk around?*

John: *No, no, I usually go for fun and exercise.*

Similarly, Richards stated:

Researcher: *So if I may ask what makes you walk around?*

Richard: *I just enjoy it...yeah it's, it's a good pastime.*

Walking for health benefits. The second key theme, *Walking for health benefits*, describes participants' perspectives on walking because of the health benefits they derived from walking. Wandering has been described in the literature as an activity with many health benefits such as physical exercise (Dewing, 2006; Lai & Arthur, 2003; Robinson, Hutchings, Corner, et al., 2007). Similarly, seven of the eight (87.5%) participants in this study reported that they walked for health benefits. John expressed that walking is "*good exercise*".

Researcher: *So how do you feel about walking right now?*

John: *Well I enjoy it because it's good exercise.*

Similarly, Helen stated that:

Researcher: *Can you please tell me why you walk around?*

Helen: *Hmm, exercise.*

Family members shared similar perspectives of their relatives walking for health benefits. In particular, a family member stated that "exercise is good". The health benefits of walking as

expressed by family members are discussed further in the family perspectives on walking section.

Other participants mentioned that they walked because they wanted to keep fit and stay healthy. For example, Richard, who used to be an athlete, reported that he enjoyed walking to keep his “*legs in shape*”.

Researcher: *So if I may ask what makes you walk around?*

Richard: *I just enjoy it. Yeah...it keeps your legs in shape. I enjoyed walking as an athlete.*

Researcher: *Okay, you used to be an athlete?*

Richard: *Yeah.*

Researcher: *As an athlete you're used to walking a lot and yeah.*

Richard: *Oh yeah. Yeah, I like keeping in shape.*

Lisa, in her description of the need to walk to stay mentally healthy, used the word “cuckoo”.

Researcher: *So do you think walking is very healthy for you?*

Lisa: *Yeah...*

Lisa: *'Cause you have to walk too, if you don't walk it's no good. You going to be cuckoo.*

Researcher: *So walking is really good?*

Lisa: *Yeah.*

Other health benefits of walking as reported by participants include for muscles and bone strength and keeping active. Some participants also stated they walked because “others” suggested to them that walking is good. In particular, Lisa commented it was not good for her to be sedentary and that her doctor recommended that she walk.

Researcher: *I know you told me that you, you feel good when you walk, it makes you healthy.*

Lisa: *Oh yeah.*

Researcher: *What other things do you think walking does for you?*

Lisa: *The doctor said you have to walk. Because too much sit down no good. The doctor said you have to walk. Because you sit all the time you sit down, I'm afraid it's no good, you have to walk.*

Researcher: *So your doctor said it's not good to sit down all the time?*

Lisa: *Yeah, no, no. You have to walk because I know the, the foot, the feet, you know they have to be strong you know 'cause you walk and they'll be stronger.*

Apart from walking because others told them it was good to walk, Dave expressed his desire to keep walking to stay healthy and to keep him away from the LTC home. He also reported that he had been sedentary and needed to walk to prevent further complications. The literature has established a link between sedentary activities and mortality (Rezende, Rey-López, Matsudo, & Luiz, 2014; Pavey, Peeters, & Brown, 2015). This is Dave's comment:

Researcher: *I was asking why do you walk?*

Dave: *For my health reasons.*

Researcher: *Okay, can you tell me a little bit more about that?*

Dave: *Sure.*

Researcher: *Okay.*

Dave: *Well I try and, I do it because they tell me it's good for you. And I want to stay healthy and stay away from these places. I spend a lot of time in that chair, I spend too much time, I spend too much time sitting like that.*

Researcher: *Um-hmm.*

Dave: *These things can develop and then you haven't fully recovered and you come down here and you walk.*

Walking as purposeful. The third key theme, *Walking as purposeful*, represents walking for a purpose and goal. Walking as purposeful describes where participants reported they were going during the interview and included that they were looking for someone or something. Seven of eight (87.5%) participants expressed having a purpose for their walking. However, Helen who had aphasia was unable to tell the researcher specifically what she was looking for when walking. This is her response:

Researcher: *Any time you walk around are you always looking for something or someone, are you always looking for someone or something?*

Helen: *So many times.*

One of the purposes or goals of walking as expressed by participants in this study was the desire to go home to see their family or be with their spouse and kids. Here is John's response:

Researcher: *So where are you off to now, where are you going to?*

John: *I'm going, I'm going to go home after this.*

Likewise, Sam's response was:

Researcher: *Hi, are you going somewhere?*

Sam: *Yeah, I'm going home...I'm going to go home and see my, see my wife and three kids and that's it, maybe will be coming back, I don't know, I don't know what to do yet... I just enjoy going home now.*

Researcher: *Are you looking for something?*

Sam: *No, no, no, no, I, I just got to go home for a bit.*

Researcher: *Okay.*

Sam: *To see my family and then come back here.*

During the family interview some family members also expressed that their relatives walked for a purpose, such as wanting to go home. This is further discussed in the family participants' perspectives on walking section. Other participants expressed that the purpose for walking was related to spending time with their family, as expressed by Lisa.

Researcher: *Is there any particular thing you're going to see or you're just walking around?*

Lisa: *Yeah, sometimes they come, my, my kids yeah and we go for a walk.*

When asked where he was going during the walking interview, Richard stated he was going to the door, which might indicate a desire to get out. Richard's family reported that he had made several attempts to escape during their visit. His walking activity was described as "walking to escape".

Researcher: *So where are you going now?*

Richard: *To the door.*

Walking as a lifelong habit. The fourth key theme, *Walking as a lifelong habit*, describes walking as related to lifelong habit and routinely expressed by participants. Participants' perspectives were that walking was a normal activity that had been part of their day-to-day life since they were younger. Seven of eight (87.5%) participants expressed walking as a lifelong habit. Barbara reported that she was used to walking.

Researcher: *So why do you walk around?*

Barbara: *Well I'm used to it.*

Researcher: *When you were younger, were you used to walking around?*

Barbara: Yeah.

During the interview two of the participants (25%) also reported walking a lot when they were younger. John mentioned that:

John: *I have done lots of walking in my life you know. I walked a lot in my life you know.*

Researcher: *So it looks like you love walking, you enjoy walking.*

John: *Well I usually walk a lot....every morning I usually go and walk, several hours.*

Researcher: *Oh, so where do you, do you normally go?*

John: *Usually around the home.*

According to Lisa:

Lisa: *I know, I was young at that time. I walked lots when I was young.*

Researcher: *So you walked lots when you were younger, oh okay.*

Lisa: *Yeah, when I was young.*

Researcher: *Okay. Oh that's good. And now you are, you are getting old and you are still walking around.*

Lisa: *I have to walk.*

Older adults may engage in wandering because they are used to walking all their life or as part of their long-term routine. The majority of family members also confirmed during the interview that their relatives had a history of being a regular walker. Two participants, Richard and Sam who used to be athletes reported that were used to walking as athletes. Sam, especially, used to be a marathon runner.

Sam: *When I go out now I'll be walking pretty fast, even run a little bit.*

Researcher: *Oh I know how to walk fast too. So why do you walk so fast?*

Sam: That's what I do all the time. I used to run. Well ran or walked...but I've slowed down a bit, slowed down. I do a lot of walking and a bit of running.

Researcher: So you're used to walking and running?

Sam: Well used to it yeah... I walk pretty fast and I run a bit...walking is good for me, I've been walking around for quite a while now so...well I'm so used to walking.

Richard said that he enjoyed walking as an athlete:

Richard: I worked, I walked a lot...and after that I enjoyed walking as an athlete...as an athlete you're used to walking a lot and yeah.

Walking as a form of socialization. The fifth key theme, *Walking as a form of socialization*, describes participants' perspectives on walking as a means to socialize with others. Six of eight (75%) participants reported that they walked for socialization. Participants also expressed they liked walking with other residents in the LTC home. Some of the reasons participants gave include having time to engage others in conversations and to express their viewpoints. Here is John's view of walking:

Researcher: So what do you like about walking?

John: Well you got time to talk.

Researcher: You get time to talk?

John: Yeah...if you have something to say.

Researcher: Uh-huh.

John: Express your viewpoints and see, see if you're going the right road I guess and that's about all.

Dave also reported that he was sociable.

Dave: And I'm a social guy.

Researcher: *Okay, you're a social guy.*

Dave: *Right. I can talk and get involved with discussions.*

Another reason participants expressed they walked was meeting with friends. Sam expressed that he walked to meet with people and greet them.

Sam: *...well I have friends down there hey...as I'm walking I meet people, how are you, and all that stuff yeah....you know we walk around here, you meet, you meet.*

Interestingly, Sarah and Barbara mentioned that they walked because of their friends or others. Sarah said:

Researcher: *So what makes you to keep walking now, what makes you to, to decide to walk?*

Sarah: *A friend of mine (chuckle.)*

Barbara also indicated:

Researcher: *Okay, a friend of yours, is she always walking?*

Barbara: *Yeah.*

Researcher: *So tell me why do you walk around?*

Barbara: *Well I have a good group there.*

Also, the researcher observed that some participants, mainly women walked together in groups. An unmet need such as social interaction may be a trigger for wandering behaviour (Algase et al., 1996). Although studies on wandering for the purpose of socialization are generally limited, older adults who are more sociable, such as those who engage in social and leisure activities have been reported to engage more in wandering behaviour (Dewing, 2005; Monsour & Robb, 1982). During the family interview, some family members shared with the

researcher that their relatives walked for the purpose of meeting people and socializing with them.

Walking to be with animals. The sixth and last key theme, *Walking to be with animals*, describes participants' desire to be with animals while walking. One of the LTC homes used for the study had pets (a dog and a bird) that visited and lived in the home. During the walking interview, two (25%) participants demonstrated interest in being with animals and stated that they enjoyed their company. Although the participants did not express directly that they walked to be with animals, they stopped by to speak to and play with the pets during the walking interview. Lisa's niece reported that her aunt walked for the purpose of finding animals. Dave, one of the participants expressed when he liked to walk:

Researcher: *What time of the day do you like to walk?*

Dave: *Oh when the birds are chirping.*

Although older adults may wander for the purpose of companionship, that is, meeting people, the researcher did not find any study on older adults wandering for the purpose of enjoying the company of animals. This is a new finding and will be discussed further in the discussion section.

Table 2: Summary of key themes and sub-themes for resident participants' perspectives on walking

Key themes	Sub-themes
Walking as enjoyable	<ul style="list-style-type: none"> • I just enjoy it • It's good • Fresh air and breeze • Good pastime • Fun and exercise
Walking for health benefits	<ul style="list-style-type: none"> • Keeps legs in shape • It's good exercise • I want to stay healthy • If you don't walk it's no good • You going to be cuckoo
Walking as purposeful	<ul style="list-style-type: none"> • I just got to go home • A desire to be with family • Looking for family • Looking for someone or something
Walking as a lifelong habit	<ul style="list-style-type: none"> • I'm used to it • Lots of walking in my life • Enjoyed walking as an athlete • That's what I do all the time
Walking as a form of socialization	<ul style="list-style-type: none"> • You got time to talk • As I'm walking I meet people • I like people • I have a good group there
Walking to be with animals	<ul style="list-style-type: none"> • When birds are chirping

Resident Participants' Walking- and Not Walking-Related Concerns

In this section, resident participants' walking-and not walking-related concerns are discussed. Most often, older adults living with dementia who wander are not asked if they have any concerns related to their walking. Therefore, older adults' concerns related to walking in LTC homes are not apparent in the literature. One resident in particular, Dave, expressed concerns related to loss of privacy. He said that people tend to approach him because of his sociability. Here is Dave's comment:

***Researcher:** Do you like it when you walk around?*

***Dave:** Yeah, the only thing is if I want privacy, I find it hard because I know so many people, they all want to say hello, which is okay.*

***Researcher:** Yes, um-hmm.*

***Dave:** And I'm a social guy.*

***Researcher:** Okay, you're a social guy.*

***Dave:** Right. I can talk and get involved with discussions.*

Dave also expressed his concern about living in a LTC home, and Alzheimer's disease, including its effects on other residents living in the LTC home.

***Researcher:** Are you concerned about anything? Are you worried about anything?*

***Dave:** I'm worried because I, this place here is not my favourite kind of place.*

***Researcher:** Why did you say that?*

***Dave:** Pardon, because it isn't. Living together with people like this guy and people who are incapacitated and ill and that's what you got here right...the majority of people are like that...it's not the best kind of environment for you.*

***Researcher:** You think it's not the best kind of environment for you?*

Dave: *No, I don't think so. I don't believe so.*

Researcher: *Um-hmm. But you know people are here for a reason because they need supervision with their care.*

Dave: *That's right, people are gonna be taken care of... and they [other residents] waddle back and forth...this is, you know the people that bother me when I see the worse, is people with Alzheimer's, terrible disease.*

Researcher: *Hmm.*

Dave: *You ever see it?*

Researcher: *Yes, I've seen a lot of that.*

Dave: *And these people are walking here with somebody and they could be anywhere, it just bothers me when I see them, well they have to be somewhere but you know anyway there's no cure, you know how to deal with it.*

Another resident, Sam, also expressed concerns about the noise level and crowding in the LTC home. This concern will be discussed further in the section of environmental triggers for wandering.

Family Participants' Perspectives on Walking

In this section, family participants' perspectives on their relatives' walking are presented. This section addresses the research question number two, *Using the components of the Enriched Model of Dementia, how do family members perceive the wandering behaviour of their relatives who are living with mild to moderate dementia in LTC homes?* The factors contributing to wandering behaviour as proposed by the Enriched Model of Dementia are: neurological impairment, health and physical fitness, biography-life history, personality, and social psychology (Kitwood, 1993). The family participants interview questions (Appendix I) were

developed using these factors. These factors were also used to explore the past and current histories of walking of resident participants and the perspectives of their family members on their wandering behaviour. Key themes and sub-themes as well as family concerns are discussed.

Six key themes comprise the interpretive description of the perspectives of family members on walking: 1) Walking for health benefits, 2) Walking as a coping strategy, 3) Walking is good, 4) Walking as purposeful, 5) Walking as a form of socialization, 6) Walking to find animals. These key themes and sub-themes are discussed and presented in **Table 3**. Beyond these perspectives, walking-and not walking-related concerns as expressed by family members are also presented in this section. Positive comments about LTC homes from family members are also presented.

Walking for health benefits. The first key theme that emerged from the family members' perspectives on wandering was *Walking for health benefits*. Five (62.5%) of eight family members reported that their relatives achieved health benefits from walking and they wanted them to continue to walk. Lisa's niece reported weight loss as a benefit of walking for her aunt:

Lisa's niece: She's been a lot more active, she's, her health has gotten a lot better, I find her memory has been a little bit better since she's been here, she's lost some weight as a result of her walking. And she's moving a lot faster as a result now.

Researcher: Hmm. Okay. So it looks like she's getting more benefits from walking.

Lisa's niece: She is, she is yeah.

Richard's son pointed out the health implications of not walking as related to losing muscles and strength in legs. Walking has been reported in the literature as a form of exercise, thereby preventing health problems (Lai & Arthur, 2003).

I only worry about that if you aren't moving then there's some health implications I would think about that, around just using your muscles or not using your muscles. And so it's more about the strength of his legs and the less he walks the less likely they'll stay strong, so that's not good health wise.

Similar to some resident participants' reports of their walking as a form of exercise, family members also related walking to exercise and a meaningful activity. Helen's friend reported that walking kept Helen busy.

She can walk as much as she wants, the more the better, exercise is good...she's up and walking and busy and, and you know and I think she is.

Walking as a coping strategy. The second key theme that emerged from the family members' perspectives on wandering was *Walking as a coping strategy*. Five (62.5%) family members reported that their relatives seemed to use walking as a means of coping with frustrating situations or problems. Older adults may walk when they feel stressed or anxious (Algase et al., 1996; Wigg, 2010).

Richard's son stated:

He now seems to get, when there's a frustrating situation he's got the mechanisms of just getting away from it. He doesn't understand odd behaviour, he doesn't, why are people yelling, why are people doing this...so sometimes he will just get up and leave.

John's wife reported her husband's previous coping strategy:

Now my husband when he's building something and he'll find he's got himself into a little problem he doesn't, so when you, so he can maybe walk around outside or sometimes overnight he can think about it and he comes up with a solution. And so he, he's always, my husband's always thinking...he's walking, thinking, yeah.

Sam's daughter mentioned that her father was always walking when he got frustrated in his early stages of dementia.

Early stages of the dementia he would get frustrated...he would always go for a walk and then when he came back he'd be fine, either he forgot about it or dealt with it, but yes, yeah that was very, yeah he did that quite a bit.

Walking is good. The third key theme, *Walking is good*, emerged as family members described the walking behaviour of their relatives. Four (50%) of eight family members reported that walking is good for their relatives and wanted them to continue walking when asked.

Barbara's son mentioned that:

I think it's probably good for her to be walking.

Richard's son also stated that:

It's good to have him mobile and I think it's because he, unless he's going somewhere he's fairly sedentary otherwise.

Similarly, Dewing (2006) examined the perspectives of older adults that were recruited through an international network for people living with dementia in the community and in a LTC home. Dewing reported that the participants in her study described wandering as a natural and good thing. Walking as good could be related to other benefits associated with walking such as maintaining good health. (Lai & Arthur, 2003). Sarah's daughter mentioned that her mother walked a lot during the night but reported the need for her to keep walking because she thought walking was good for her.

I think she was walking a lot during the night and then she was very sleepy when we'd be visiting her during the day here and I can usually tell if she's been up a lot at night

because during our visit she'll fall asleep....so it was more during the night, otherwise I think it's probably good for her.

Walking as purposeful. The fourth key theme, *Walking as purposeful*, was described as walking for a purpose or objective. Three family members described their relatives' walking as purposeful. Richard's son said that his father walked for the purpose of going to places. Richard's son further stated that his father walked to stave off boredom.

He doesn't walk a great deal and, and when he walks its, its inching 'cause it's not, he's fairly focused in his objectives...he goes places 'cause he has a reason to go places, it's part of his character. And when he does get up to, to, he's either purposefully going for a meal or returning to his room....and you can get him to go walk and he resists less because I think honestly he's bored. I think it's a way to stave off the boredom.

Richard's son also reported that his father wanted to leave the LTC home every day to go home.

...between the two sets of doors there he's, he's tried to escape and, and he gets upset when people stop him and he's a bit frustrated because he's wanted to leave and he's kept on saying, I want to go home, I want to be with mom.

Sarah's daughter gave the same reason for her mother's walking; to prevent boredom.

I have asked her you know why she's walking and she'll say because she's bored.

Walking as a form of socialization. The fifth key theme from the family members' perspectives on wandering was *Walking as a form of socialization*. Only two (25%/) family members reported that their relatives walked to socialize with others. As reported by Richard's son, walking was considered a form of socialization for his father:

It [walking] may give him some socialization.

The other family member, Sam's daughter expressed that her dad was a very active person who loved encountering people and socializing with them.

He's, he very much loves social interactions, so he does, when he is walking he loves encountering people along the way and talking to him. So I kind of think that's why he does it, but he's also a very active person too, his whole life pretty much so yeah.

Walking to find animals. The last key theme, *Walking to find animals*, describes walking as a means of finding animals to enjoy their company. Only Lisa's niece reported that her aunt liked the company of animals.

Lisa's niece: Walking she, I knew a few reasons, I think I know why she likes to walk around here.

Researcher: *Okay.*

Lisa's niece: She likes to go, she likes to find animals and there's a dog and a bird here...and she likes their company.

Currently, no studies exist on wandering for the purpose of finding animals. This is a new finding and will be discussed further in the discussion section.

Table 3: Summary of key themes and sub-themes for family participants' perspectives on walking

Themes	Sub-themes
Walking for health benefits	<ul style="list-style-type: none"> • Better memory • Lost some weight • Moving a lot faster • Legs stay strong • Exercise is good
Walking as a coping strategy	<ul style="list-style-type: none"> • He'll just get up and leave • Walking and thinking
Walking is good	<ul style="list-style-type: none"> • It's good to be walking • It's good to have him mobile • It's probably good for her
Walking as purposeful	<ul style="list-style-type: none"> • A reason to go places • Stave off the boredom • Because she is bored • Keeps on saying, I want to go home
Walking as a form of socialization	<ul style="list-style-type: none"> • Some socialization • Loves socialization • Encountering people and talking • A very active person
Walking to find animals	<ul style="list-style-type: none"> • Likes to find animals • She likes their company

Family Participants' Walking-Related Concerns

Family members reported the following concerns about their relatives' walking:

Entering other residents' rooms and ensuing violence. Specific concerns reported by family members as related to their relatives entering other residents' rooms included other residents "getting mad" and becoming "violent" towards their relatives. Consequently, the relatives were moved to a specialized dementia care unit in the LTC home as reported by Richard's son and Sarah's daughter. According to Sarah's daughter:

Well my concern is that the person in there might be violent and that's what happened upstairs is it was a man's room and he hit her because he was upset that she was in his room and she didn't understand, and so he hit her, so we were called about that and shortly after she was moved here. Now there are still residents here that I, my mother is not a violent person, there are some people with dementia that are violent, but she's not at all. She's very timid, so I'm worried that if she goes into somebody's room that they might attack her or hit her.

Richard's son also recounted how his father was physically assaulted and hurt three times for walking into another resident's room:

A lot, a lot of the other residents don't understand dementia or his, his condition. So they get very mad when he walks into their rooms...which is, which is probably normal for dementia. But there was a very big gentleman who had actually physically assaulted him and hurt him fairly seriously three times...and it was another, another patient with dementia and he basically slammed my dad behind a door and kept slamming him, there was blood on the back of the door and everything, it was quite severe. And he told the staff that my dad was, was in his house trying to steal his \$300...and another time he, he

attacked him again, but this time he was, and again he was in this gentleman's room...and then this gentleman kept looking for him to, to assault him. Because it had become a pattern, so they moved dad out. And yet they're assaulting your father so you want to avenge him but you really, you can't because it really is their disease...and the situations could be reversed easily at some point.

The incidents described above are a common occurrence in LTC homes and of a great concern to family members because of the negative outcomes (injuries) related to their relatives entering other residents' rooms (MacAndrew, Beattie, O'Reilly, Kolanowski, & Windsor, 2017).

John's wife reported concerns about other residents walking into her husband's room and other residents' rooms.

They [other residents] wander into his room, they lay on his bed and stuff like that...that ward there that's what they do, they wander in and out, in and out, lay on somebody else's bed and stuff like this.

Sarah's daughter reported that she observed that her mother was always in the same resident's room:

Here we'll often find her in somebody else's room where she claims it's her room, and interestingly enough it's almost always the same person's room.

Falls and risk for falls. Family members in this study expressed concerns about their relatives either falling or being at risk for falls as a result of their wandering.

I think she should be independent as long as, as long as she can [walk]...but she's falling and usually it happens between moving from the chair to her walker...or that back and forth and if the chair is not anchored...and she gets up to try and get up and then the chair moves.

John's wife reported that he had fallen five times while living in the LTC home.

He has fallen five times here...and I don't know why he fell, but he fell five times...well one time he said there was some water on the floor...and he slipped there and otherwise I don't know why, just maybe getting out of bed too fast, I couldn't tell you for sure...you know. Sometimes the bed is quite high.

Risk for falls and falls remain one of the risks associated with wandering behaviour (Aud, 2004; Cipriani, 2014). Barbara's son reported that, even with staff ensuring that she was wearing proper footwear, he was still worried that his mother would fall.

I guess there's always the risk of a fall, but they seem to be pretty good about making sure she has the right kind of footwear.

Sarah's daughter brought up concerns about her mother's fatigue and risk for falls as related to night-time wandering. Interestingly, Sarah's daughter also reported a desire for her mother to keep walking despite her risk for falls.

I worry about her walking around at night and that maybe she's a bit sleepy that she might fall and she has had a few falls, but I'd rather her be mobile than not.

LTC home physical environment. Another concern reported by family members was related to the physical environment of the LTC home. As reported by Sarah's daughter that the hallways of the LTC home and her mother's lack of perception of depth made her walk into the wall repeatedly when walking.

I think it would be ideal if they had personal care homes where they'd be more of an oval or a circle...because what I've noticed and I'm sure you're going to see that when she walks, and apparently its quite common is she doesn't seem to have the perception of depth anymore so she's walking down a hall and she'll bang into the wall before she

turns and then when she hits the wall she turns and goes down until she hits the next wall. So I wonder if it was circulate if she would have the concept of going around.

Problems with orientation and wayfinding have been reported among older adults living with dementia who exhibit wandering behaviour (Algase et al., 2007; MacAndrew, Beattie et al., 2017). One of the consequences associated with wayfinding as reported by family members is falls. Helen's friend also reported her concerns about her friend walking outside of the LTC home unsupervised and falling.

I don't worry so much about this environment unless she goes, unless you go outside and it's not even on the sidewalk or the sidewalk has a slant...or the ground is really rough, that's a little bit more difficult isn't it.

Although locked units or the use of door alarms are implemented for safe wandering, John's wife expressed her concern about this and the size of the LTC home.

Well I tell you that the, the place where he is right now is very small and it's a locked unit and he doesn't like that he wears a bracelet...like I said the place is not very big.

Not enough staff supervision. There should be adequate monitoring and close supervision when older adults wander into unsupervised areas (Algase et al., 2003; Silverstein et al., 2002). Also, older adults who often forget to use their walkers require appropriate supervision due to their risk for falls. It was not surprising when Sarah's daughter described her concerns about her mother's need for more staff supervision while walking.

Well I think she could probably use more just 'cause sometimes she'll start walking without her walker, so if you're not there to supervise I think she would be okay, but you know I don't know and she often forgets her walker because even though she's been

using it the whole time she's been in here, it was never a part of her life and she probably feels that she doesn't have a reason to use it.

John's wife also mentioned the need for staff to check on her husband often to be safe.

When he first came here and he fell five times I was really quite concerned because why did he fall? ...and was there, was there anybody coming into his room and checking to make sure that he's okay? Do they come and, do they, do they, do they do a check every so often? With people that do fall, I don't know. I'm not here all the time, I don't know what happens you see. I know when they change staff at 3:00 the guy comes in and checks to see if the patient is there.

Not walking enough. Three family members reported concerns about their relatives not walking enough in the LTC home. John's wife mentioned that:

Sometimes he'll go up to the door and he wants to get out and of course you can't get out. So there isn't really that much, 'cause it's only 20 people there, so there isn't that much walking around there.

As reported by Barbara's son:

I have found more often than not she doesn't seem to be [walking], you know I'll often find when I get here she's asleep. Or she's sitting at the table eating.

Dave's son reported that his father had not been walking much in the LTC home and that he was worried about the health problems that might result from not walking enough:

Well he's never been much of a walker like in the last ten years but I, I guess I only worry about that if you aren't moving then there's some health implications I would think about that, around just using your muscles or not using your muscles.

Walking to escape. Richard's son brought up concerns about his father's walking to escape (elopement). Elopement is another risk associated with wandering behaviour (Halek & Bartholomeyczik, 2012). Here is Richard's son report:

I am beyond worrying about the amount he walks...probably about a third of the time when he does walk it's to escape.

Family Participants' Not Walking-Related Concerns

Family members also reported concerns about their relatives that were not walking related.

Health concerns. Specific concerns about participants' health as reported by family members were related to chronic conditions such as arthritis, chronic obstructive pulmonary disease (COPD), cancer, hypertension, Parkinson's disease, and other health conditions such as sore knees and having a hard time eating (swallowing).

Helen's friend spoke of her concerns about Parkinson's disease and its effect on her friend's mobility.

Well the biggest issue right now is the Parkinson's Disease and how gradually mobility and muscle strength is, is weakening.

Sarah's daughter mentioned that her mother always complained of pain even when taking analgesic.

She complains about her knees being sore every now and then, I don't know if it's a habit, she often rubs her knees, I know the staff has started giving her Tylenol for that.

Memory changes concerns. When asked if family members had any specific concerns about their relatives' memories, several concerns were expressed about short-term memory loss, particularly the impact of forgetfulness and confusion and the need to constantly remind their

relatives of things or events and to explain why they were living in a LTC home. Other concerns were related to dementia and its progression and not recognizing family members. Dave's son stated:

He has times when he kind of gets his grandkid's names mixed up, sometimes thinks I'm in town when I'm not...he definitely has moments where, where you can just know that he doesn't remember certain things at certain times.

Lisa's niece expressed concerns about telling her aunt about deaths occurring in their family, especially the death of her husband.

***Lisa's niece:** I'm concerned she is going to forget who I am one day soon...I find that she shows signs of that already with her grandchildren recently. And I worry you know as more deaths occur in our family, do I tell her? Do I not tell her? Is it worth it? Those are my type of concerns with her, what's right and what's wrong, how to handle certain situations and you know I never bring up the death of her, her husband anymore 'cause I don't feel it's necessary to bring up those memories, but I wonder if she remembers that or if she knows where he is.*

***Researcher:** Every time you talk to her about that does she remember?*

***Lisa's niece:** She does, she ends up remembering and she gets very sad. Very, very sad, so I don't like to bring it up, there's no point, especially she forgets in the next 10, 15 minutes.*

A concern from Sarah's daughter was related to her mother's inability to understand why other residents yell and scream in the LTC home.

She doesn't understand why she's with all these old people, she doesn't understand she's with these people who are yelling and screaming.

John's wife reported her concerns about not knowing what to tell her husband who was always asking to go home. Older adults living with dementia may experience difficulty with thought process and ability to understand complex things (Alzheimer Society of Canada, 2018a). Therefore, dealing with the effects of dementia could be overwhelming for family members. This is John's wife concern:

...and when I go with him I, I always bring him back and he you know, you know that's another thing it's very, I wish somebody could tell me that, how, how do you, how do you approach a husband who wants to go home all the time? How do you say that you can't come home with me right now? And nobody has ever given me an answer yet.

Limited activities. Concerns about limited activities in the LTC home were also reported by family members. Older adults may wander as a result of boredom (Algase et al.1996). As stated by John's wife:

It's not too much activity, like you know I mean the girl takes him for his activity, but how limited is that?...it's really nothing too physical you know.

Lisa's niece also mentioned that:

My concerns are more is she lonely or is she occupied?

Other Findings from Family Members

Other findings of this study include positive comments from family members about LTC homes and staff.

Positive comments about LTC homes and staff. Half (50%) of the family members made positive comments about the LTC home being the right one for their relatives for safety and security. Family members also commended the staff for walking with their relatives and ensuring they had the right kind of footwear. It was interesting to hear some family members

commend the staff of the two LTC homes for walking with their relatives and ensuring their safety and security. These positive comments could be rewarding for staff, knowing that their efforts to keep older adults safe are recognized and appreciated. A complete list of these positive comments is presented in **Table 4**.

Table 4: Family participants positive comments about LTC homes and staff

Family Participants	Positive Comments
Sam's daughter	<i>They really keep a good, they have a lot of safety, security.</i>
Lisa's niece	<i>Since she's been here she's been a lot more active... she's more encouraged here and there's a bigger space, whereas her husband would never encourage that</i>
Barbara's son	<i>I guess there's always the risk of a fall, but they seem to be pretty good about making sure she has the right kind of footwear. Based on, on the people that I've seen her nobody looks like they're violent or anything like that...So I, I can't see that that would be a problem, a conflict problem. It seems to me they, they, they try to sort of keep people who are sort of compatible in the same, yeah.</i>
Dave's son	<i>They really try hard to kind of literally make him get out of his chair and walk, but if he had his choice he would probably never...we had an occupational therapist...they assessed his walker to make sure it was the right model and height and size and all that, for how it is that he gets around right now...since he's been there, that it's the right one for him and he gets around pretty good with it, he uses it well, initially he didn't know how to use the walker, he'd sort of stand like in it versus with it out in front of him... They're doing good, yeah.</i>

Participant Observation and Reflection Findings

Participant observation by the researcher and environmental triggers for wandering and researcher's walking-related concerns are discussed in this section.

The researcher spent one to two days to get to know each participant, familiarize herself with their routines and observe their behaviours prior to the walking interview. This type of observation was considered as participant observation for this study. A reflective journal was kept throughout the study to record and reflect upon observations prior to and during the walk, and observations of wandering as well as nonverbal behaviours of participants.

Wandering pattern of participants. The researcher observed that the wandering pattern of the majority ($n = 6$; 75%) of participants was random. The remaining two participants displayed an irregular type of movement, that is, lapping which might have been due to the design of the LTC home, with linear hallways. This might make it difficult for the participants to walk a loop (Algase, et al., 2001; Marquardt, 2011). However, one of the participants, Sam displayed more than one type of wandering (random and pacing) and appeared agitated prior to and during the interview. Also, the participants who exhibited random wandering also displayed BT, that is, they frequently entered other residents' rooms.

Nonverbal behaviours of participants. The nonverbal behaviours of participants observed included facial expressions and emotions as related to wandering and interaction with others. The facial expressions and emotions of participants varied and reflected being happy, confused, bored, and anxious. This is an excerpt from the researcher's journal:

Lisa is a very pleasant, happy woman. She loved and really enjoyed walking, especially going outside and walking as a form of socialization. She also loved the company of animals. We stopped by to see a dog and the bird during her walk. She talked a lot about

herself, family and the staff during the interview - said good things about her family and staff and how she loved the [LTC home].

Most of the participants appeared happy and only one participant was anxious during the interview about getting out to meet his family as he expressed that his wife and kids were waiting for him at home.

Sam loves to walk, he is always walking and seems not to be tired of walking. Observed to be talking to quite a few residents in the [LTC home] during the walking interview. He seemed to enjoy talking and walking (socializing) with other residents and encouraging them also to walk. He kept verbalizing during the interview that he was going to meet his wife (appeared anxious). Although he didn't verbalize this directly, I think he might be experiencing boredom. Apart from going to meet his wife and family, he might also be walking to relieve boredom.

Although Helen had aphasia, she was observed to be smiling a lot during the interview. *Helen loves to walk! Although she has aphasia and experienced some difficulty communicating using words, she nodded a lot and smiled during the interview. Her interview was the shortest but she was able to express herself slowly. I was happy to get her perspectives on why she walks.*

Positive emotional expressions have been linked with wandering behaviour in older adults living with dementia (Lee et al., 2014). Four (50%) family members reported that their relatives were happy and always smiling. Lisa's niece stated:

When you meet her you'll see she's always happy, smiling.

According to Sam's daughter:

He was happy when he was walking...he was always happy just because he could walk, so but you know when it was, in winter or raining he would always be looking out the window, he'd want to get there.

All the participants appeared to enjoy walking with the researcher; however, one participant requested to walk alone later on in the interview, which was granted. Although some participants were confused about where they were, the majority were observed to be interacting well with other residents and staff. Participants who were confused had difficulty with wayfinding, attempted to exit the LTC home several times, and were also observed to be entering other residents' room several times.

Environmental triggers for wandering. Sam mentioned during the interview that there were too many people and was observed moving away from a place he reported was “confusing”. This might be one of the reasons for his walking as suggested by Algase et al. (2010) and Algase et al. (1996). According to Sam during the interview:

Sam: There's too many people...everyone's yapping and yapping, it's too much...this is confusing, this area.

Researcher: This area, oh.

Sam: Well it's all over, people, there's some here, some here.

Researcher's walking-related concerns. The researcher's walking-related concerns as observed prior to and during the walking interviews include participants' wayfinding difficulty, need for more staff supervision, and walking other residents' rooms and are discussed in this section.

Wayfinding difficulty. The greatest concern of the researcher about participants' walking is wayfinding difficulty. This is related to BT and associated consequences as reported by

MacAndrew, Beattie et al. (2017). Wayfinding difficulty could also increase an older adult's risk for falls. John had difficulty with wayfinding and was a high risk for falls as reported by his wife.

There were some concerns about his [John's] wayfinding and I had to redirect him many times. Although he walks independently, he seems unsteady on his feet at times, and his inability to find his way at times makes him a great risk for falls. The wife mentioned that he had fallen five times since coming to the [LTC home]. He definitely needs some supervision with his walking.

Other concerns of the researcher as related to wayfinding difficulty include walking into obstacles and walls and exit-seeking by some participants. Exit-seeking behaviour could be a result of wayfinding difficulty. This is an excerpt from the researcher's journal about Barbara, one of the participants:

Barbara had some difficulty with wayfinding and required supervision during the walking interview to be safe and not bump into things, especially walls. Apart from concerns about her wayfinding, Barbara was exit-seeking, always walking into an exit and required guidance to change her direction frequently.

The physical environment of the LTC home where the study was done could have contributed to wayfinding difficulty for some participants. For example, Sarah wandered in a linear direction and experienced wayfinding difficulty during the walking interview. Moreover, her daughter reported observations about Sarah banging into walls while walking.

I observed that Sarah had some difficulty with wayfinding. She wandered in a linear direction until she hit the wall or met with an obstruction, and then tried to turn around again. Sarah required occasional supervision during the walking interview to be safe in her walk and not bang or bump into objects or persons. The daughter also mentioned her

concern with Sarah bumping into something when walking (described as banging into the wall before she turns and then when she hits the wall she turns and goes down until she hits the next wall).

Need for more staff supervision. Another concern of the researcher is that some participants needed more staff supervision to be safe with their walking. Specific areas the researcher observed where participants needed supervision included to suggest rest periods when participants wandered into other residents' rooms and exit areas, and outside of the LTC home or less supervised areas such as the courtyard. Although the researcher observed that the LTC home staff encouraged some participants to walk, supervised and served snacks, including fluids at scheduled times, some participants required cues to rest when tired.

I also observed that Barbara got tired easily from walking and required occasional cues to rest but it's good that she mentioned to me once or twice that she was tired.

Another participant, John was observed to be running out of breath and needed to be reminded to rest to catch his breath and keep himself hydrated while walking.

Researcher: *It looks like you're getting tired, do you want to come back and maybe go inside and take a rest?*

John: *Oh I don't know.*

Researcher: *Yeah, I think you should.*

John: *Yeah. A little out of breath.*

Researcher: *Yeah, I think maybe you should sit down and catch your breath.*

John: *Yeah. Usually it never bothers me the breath, but it does a little now getting older has taken its toll.*

The researcher also asked John what he should be doing when he feels while walking.

Researcher: *So any time you walk around and you feel tired, what do you do?*

John: *Not too much that what I'm doing right now.*

Researcher: *Um-hmm. So when you feel tired what do you do, if you feel tired?*

John: *Well I can't really say what I do.*

Researcher: *Yeah because sometimes when you walk around and you feel tired it's always good to sit down...just to catch your breath.*

John: *Yeah, you've got a good point...it's nice to get a little breather.*

Researcher: *So do you drink water a lot?*

John: *Now and then, not too much, a lot of times I don't drink enough.*

Researcher: *You don't, oh I think you should be drinking enough water because when you walk around you need, you need to keep yourself hydrated.*

John: *Yes, it's a good thing.*

Furthermore, John was observed to be looking down during the interview.

Researcher: *So any time you walk around.*

John: *Look down.*

Researcher: *Look up, make sure you look up not...look down.*

John: *You're not kidding.*

Researcher: *So that you don't bump into something.*

John: *That's true.*

Dave reported that his knees were sore and needed supervision to rest. He also needed a reminder to request pain medications when necessary.

He [Dave] mentioned to me prior to the interview that he used to walk but not so much as his knees were sore. He takes some pain meds, which he stated doesn't help very much.

Pain might play a big role in the changes in his walking activity [lack of motivation to walk]. He needed education about getting some rest periods while walking and requesting pain meds as needed or maybe a better pain control (pharmacological and non-pharmacological).

Although Sam was wearing a wanderguard bracelet, he required frequent supervision because of his several attempts to exit the LTC home (exit-seeking behaviour) and also as verbalized during the interview. Sam had prior histories of elopement as reported by his daughter and asked the researcher several times during the interview how to get out of the LTC home. This is an excerpt from the researcher's journal followed by an excerpt from the interview transcript.

Sam stays in a locked unit and requires frequent supervision because of his exit seeking and unsafe escape/elopement activities as verbalized during the interviews with him and by his daughter.

Sam: *I know how to get through the fence...now I got to squeeze through that fence, I know how to do that too, I did it last week.*

Researcher: *Oh so what did you do to the fence?*

Sam: *Well I just squeezed through.*

Researcher: *You just squeezed through? I hope you didn't get hurt.*

Sam: *No, no...no, I didn't get caught, not this window, but you know what I've got to go out the front...see that big building there, I've got to walk down that way, so I just want to, I get out there through the fence and then down, yeah I'll be here tomorrow.*

Walking into other residents' rooms. This was a major concern of the researcher. Some participants were observed to be entering other residents' rooms and required cues and supervision to keep them out of others' rooms and be safe.

Sam was observed to be entering other residents' rooms on several occasions, especially the first room on the unit and on one occasion, he went to the window and stated that he was trying to close the window, spotted holding the window handles.

Family members have also reported concerns about their relatives entering other residents' rooms, which resulted in resident-to-resident violence, and on some occasions relatives were being moved to a specialized dementia care unit.

Summary

Eight participants, including their family members (n = 16) participated in this study and shared their perspectives on walking. The first research question the study aimed to answer was: *How do older adults living with mild to moderate dementia in LTC homes perceive their own wandering behaviour?* All the participants expressed that they enjoyed walking and a significant number (87.5%) described walking as beneficial. Majority of the participants (75%) mentioned that they liked walking as a form of socializing with other residents in LTC homes while two (25%) walked for the purpose of companionship with animals. The second research question was: *Using the components of the Enriched Model of Dementia, how do family members perceive the wandering behaviour of their relatives who are living with mild to moderate dementia in LTC homes?* In this study, most (62.5%) family members described their relatives' walking for the purpose of health benefits and as a coping strategy. There were significant overlaps in the perspectives of participants and that of their families such as walking being

enjoyable and good, walking for health benefits, walking as purposeful, walking to socialize with others, and walking to be with or find animals.

Various walking- and not walking-related concerns were shared by participants and family members. One participant expressed concerns about wanting privacy while walking and effects of Alzheimer's disease on other residents living in the LTC home. Another participant expressed concerns about the noise level and crowding in the LTC home. Family members' concerns include relatives entering other residents' rooms and ensuing violence, falls and risk for falls, the LTC home physical environment, the need for staff supervision during walking, relatives not walking enough, walking to escape, health and memory changes, and limited activities in the LTC home. Family members also made positive comments about the LTC home being the right one for their relatives and staff ensuring resident safety and security.

Participant observation was conducted by the researcher. Most participants (75%) displayed random wandering while the remaining two displayed lapping. Only one participant displayed more than one pattern of wandering (random/pacing). The emotions of participants in this study were expressed as being happy, confused, bored, and anxious. Environmental triggers for wandering behaviour were identified as noise and crowding. Finally, researcher's concerns as observed prior to and during the interviews were discussed and include: wayfinding difficulty, a need for more staff supervision during walking, and participants entering other residents' rooms.

Chapter 5: Discussion of the Findings

This chapter discusses the findings of this study within the context of existing literature and the Enriched Model of Dementia. The discussion begins with addressing the research question number one, followed by the research question number two. Residents' and family members' concerns as well as participant observation and reflection findings are discussed. Further into the analysis of the data, a significant overlap in key themes of the perspectives of residents and their family members on wandering behaviour became evident. As a result, these key themes emerged: *walking as enjoyable and good; walking for health benefits; walking as purposeful; walking as a lifelong habit; walking as a form of socialization; and walking to find and be with animals* and are incorporated into the discussion addressing the research questions. The exception is the key theme, *walking as a coping strategy* generated only from the family members' perspectives. The visual representation of the key themes is also discussed. Wandering in the context of this discussion is described as walking when reporting on both participants' perspectives and these two terms are used interchangeably throughout this chapter. Resident participants are referred to as participants and their families as family members in this section. The strengths and limitations of the study are identified in this chapter. Recommendations for nursing practice, future research, and conclusion are provided.

Research Question Number One

This study added to the body of literature on wandering behaviour because it explicitly focused on the perspectives of older adults who wander. This section addresses the first research question for this study: *How do older adults living with mild to moderate dementia in LTC homes perceive their own wandering behaviour?* In regard to the first research question, participants' responses were apparent as well as not apparent in the literature, thus making the

findings of this study to be both consistent and not consistent with the literature. This is so because there are limited empirical studies on the perspectives of those living with dementia who wander.

Walking as enjoyable and good. Although the literature has well documented that wandering is viewed as problematic and challenging (Algase & Nelson, 2007; Dewing, 2005; Halek & Bartholomeyczik, 2012; Lai & Arthur, 2003; Wigg, 2010), the participants in this study perceived wandering differently. This study has elicited a different perspective on wandering from those who engaged in the behaviour, that is, walking as an enjoyable activity. In line with walking being an enjoyable activity, family members also described the walking behaviour of their relatives as a good thing and further expressed the desire for their relatives to continue walking. *Walking as enjoyable and good* is one of the key themes in this study that are not consistent with the literature.

This study suggests that participants perceived walking as enjoyable to make them feel good and for the fresh air and breeze. Previous work by Dewing (2006) and Robinson, Hutchings, Corner, et al. (2007) examined the perspectives of older adults living with dementia. However, this study was different in terms of not only including the perspectives of older adults living with mild dementia in LTC homes, but also of those living with moderate dementia. The participants in Dewing's study were a mix of people living with dementia in the community and a LTC home but their stage of dementia could not be established in the report while those of Robinson and colleagues were identified as living with mild dementia.

Walking as enjoyable also signifies the need for the participant to leave an enclosed or confined place such as the LTC home to enjoy the fresh air and breeze. Most LTC homes, including the sites for this study have locked units and use door alarms to monitor or restrict

(control) the movement of residents, especially those at risk of getting lost. Physical confinement, which is a form of social control is described as a means of protecting those who wander (Wigg, 2010). Although locked units can provide “a sense of safety and security”, it can also be an indication of who has power over accessing and exiting the LTC home and make older adults feel entrapped and excluded (Tufford, et al., 2018). Moreover, the use of locked units has been described as non-subjective barriers (Robinson, Hutchings, Dickson, et al., 2007), which may contribute to the feeling of living in a “confined” or “enclosed” environment. As stated in this study by John’s wife that her husband “hates being locked in” suggested the feeling of not being in control or loss of autonomy. On the other hand, walking especially when done outside of the LTC home, such as in the courtyard by participants in this study brought the feeling of enjoyment for the fresh air and breeze. Similarly, Dewing (2006) wrote about a participant in her study who reported that she “felt too much was made of wandering by those in power as a way of controlling her or people like her” (p. 243). Therefore, walking may lead to an expression of control or autonomy and agency for such residents (Dewing, 2011). Furthermore, walking was described as “a good pastime and fun”, which signified an activity participants engaged in regularly as a hobby for the purpose of fun and enjoyment or lifelong habit. If walking was reported as being enjoyable and good, then the need to promote interventions that focus on healthy walking or wandering for older adults living with dementia in LTC homes becomes imperative.

Walking for health benefits. One of the health benefits of wandering as described in the literature is that walking is a form of physical exercise or physical activity (Dewing, 2006; Robinson, Hutchings, Corner, et al., 2006; Lai & Arthur, 2003). Therefore, *Walking for health benefits* is not an unusual finding in this study and was commonly expressed by both residents

and family members. Walking was suggested as good for many health reasons. Specifically, walking was perceived by both participants (residents and family members) as a form of exercise to remain healthy and to maintain muscles and bone strength. Several studies supported these findings and reported that physical exercise improves circulation and oxygenation, prevents contractures, promotes cognitive function, reduces depression, and risks of developing cardiovascular and metabolic diseases, osteoporosis and falls (Lai & Arthur, 2003; McPhee et al., 2016; Rolland et al., 2000; Sun et al., 2010; Taylor et al., 2004). *Walking for health benefits* was analyzed differently from the key theme, *Walking as enjoyable and good* because *Walking for health benefits* emphasized the specific health benefits participants reported they or their relatives derived from walking.

Family members specifically mentioned that walking contributed to weight loss, improved memory, and improved mobility for their relatives. To support this finding, Pahor and colleagues (2014) in their randomized clinical trial of physical activity in older adults reported that physical activity intervention such as walking helps maintain mobility by reducing major mobility disability in older adults. Disability in their study was described as the inability of participants to complete a 400-m walk test within 15 minutes without sitting and without the help of another person or walker. Walking is also reported to maintain appetite (Volicer, Van Der Steen, & Frijters, 2013). Furthermore, low intensity walking was among the activities that were concluded to be effective in reducing older adult's risks of developing obesity and muscle weakness (McPhee et al., 2016).

Participants in this study also perceived walking as a means of keeping active and fit. The importance of remaining active, and not sedentary was mentioned. Being sedentary such as sitting down for too long was described as not good because of health complications.

Particularly, participants who used to be athletes stressed the role walking played in keeping their legs in shape. The association between sedentary behaviour and health outcomes of older adults has been well established in the literature. The greater the time older adults spend in sedentary activities, such as sitting, the higher their risk of mortality (Pavey et al., 2015; Rezende et al., 2014). Pavey et al. (2015) in their longitudinal study on sitting time and mortality in older women concluded that sitting for more than eight hours a day increased older women's risk of dying within the next nine years.

One of the most striking findings of this study was that participants engaged in wandering behaviour to maintain mental health, considering wandering behaviour has been associated with depression in the literature (Kiely et al., 2000; Klein et al., 1999; Logsdon et al., 1998). An exception is a study by Cohen-Mansfield and Marx (1989) who reported no relationship between depression and wandering. In this study, participants related walking to being healthy and the need to stay healthy mentally was also related to walking. This finding is important because no study has reported that older adults living with dementia perceive wandering as a means of maintaining their mental health.

Although this study focused on wandering behaviour, walking as a form physical activity has been associated with mental health in the literature. Sun et al. (2010) in their study reported an inverse association between physical activity such as walking and different aspects of health, including mental health and cognitive status. Similarly, Lindwall et al. (2006) examined the relationship between light and strenuous exercise (such as walking, jogging, high-intensity walking) and depression. They concluded that older adults who were inactive had the highest depression scores compared to those who were actively involved in light and strenuous exercises. In addition to previous work by Sun et al. (2010) and Lindwall et al. (2006) highlighting the

importance of keeping older adults active, the findings of this study are promising in changing the negative perspectives of wandering as problematic and disruptive to a meaningful activity. Moreover, since the focus of walking in the literature is to maintain health, the same perspective is needed for wandering behaviour.

Walking as purposeful. *Walking as purposeful* was another remarkable finding of this study because it signifies that walking was done to achieve a purpose or goal. Family members also shared this perspective with their relatives. Wandering has been defined as “aimless” walking in the literature (Algase et al., 2007; Cipriani et al., 2014; Lai & Arthur, 2003). Therefore, this study suggested a different perspective of wandering being a purposeful activity. We need to look carefully at our definition of wandering as “aimless” walking because this is limited to our own perspective or understanding of what wandering is.

Dewing (2006) sought to include the knowledge or experiential expertise of people living with dementia in her studies and reported that participants engaged in wandering to achieve a particular purpose or purpose. Some of the purposes for wandering as reported by Dewing included to avoid other people living in the community or to get away from noise. This study confirms the work by Dewing about people living with dementia engaging in wandering for a purpose. However, this study establishes a different purpose for wandering such as going to places, especially home, and a desire to be with family or spend time with family.

Clinical experts have suggested that older adults who wander may engage in the behaviour for a purpose even when others do not understand this purpose (Andrews, 2017; Dewing, 2011). Similarly, some participants in this study expressed that they were going somewhere or looking for someone or something even when they were unable to describe further their purpose or goal of walking. Also, some participants repeatedly stated that they had to be

somewhere and “would be back later”. This may indicate a search for a familiar person (such as spouse or kids) or place (previous home), something that is lost, or the need to perform a former role or responsibility or get to a former workplace (Algase et al., 1996; Brooker & Surr, 2005; Carr et al., 2010; Silverstein et al., 2002).

Interestingly, walking was perceived as an expression to leave the LTC home and not always related to going home or being with the family for some participants in this study. The researcher observed some participants to be walking frequently toward exit doors, some even tried opening the doors several times during the study. These participants also verbalized that they were going to the door or trying to get out when asked by the researcher. These observations were confirmed by family members during the family interview. Furthermore, some family members reported that their relatives were always walking to the door, “trying to escape” and to “relieve boredom”. Walking to escape is a major concern to family members and healthcare providers because it is often associated with elopement and remains one of the major risks of wandering behaviour (Aud, 2004; Rowe & Bennett, 2003). However, residents who make attempts to escape from a LTC home may do so for many reasons, including an unmet need or to relieve boredom (Algase et al., 1996). A new perspective on wandering not apparent in the literature established by this study was that walking to escape is a purposeful activity.

Wandering may have beneficial and therapeutic effects of reliving boredom (Robinson, Hutchings, Corner, et al., 2006; Price et al., 2001). For some participants in this study, walking was a means of occupying themselves, which could bring a sense of purpose. As postulated by the NDB model, all behaviour has meaning. The findings of this study indicated that wandering behaviour, including walking to escape (elopement) should not be dismissed as a problem which could further lead to focusing on the behaviour rather than the need underlying the behaviour

(Algase et al., 1996). Rather, wandering should be viewed as a symptom of an unmet need or pursuit of a goal or purpose.

Walking as a lifelong habit. This finding of *Walking as a lifelong habit* describes walking as a normal activity that has become a part of the daily lives of most participants in this study. There are limited empirical studies on wandering as a lifelong habit. Based on clinical observations, wandering could be a lifelong habit that older adults living with dementia engage in (Dewing, 2011, O'Connell, 2011). This study confirms walking as a lifelong habit for the participants living with dementia in LTC homes. Furthermore, participants who used to walk regularly in the past, either for work, leisure, or as a means of coping with stress are more likely to wander in search of stimulation (Algase et al., 1996; Andrews, 2017; Dewing, 2005).

According to the Enriched Model of Dementia, knowing the life history of an older adult could help in understanding if wandering behaviour is a regular habit or routine for such an older adult (Brooker & Surr, 2005). During the family interview, the majority of family members reported that their relatives had a history of being a regular walker prior to coming to the LTC home. Moreover, walking can be a habit-forming activity and also a means of increasing physical activity for those who live sedentary as reported by resident and family participants in this study (Edensor, 2000).

Walking as a form of socialization. This study added to the limited body of empirical literature on wandering as a form of socialization. As found in this study, walking provided the opportunity for participants to socialize with others by engaging them in conversations. Family members also reported that their relatives were socially active and perceived that they walked to socialize with other people in the LTC home. This study finding is congruent with previous work by Monsour and Robb (1982) examining the differences in the psychosocial lifestyles of people

who wandered and those who did not wander. Those who wandered were reported to engage in a higher level of social and leisure activities than those who did not. The need for social interaction may be a trigger for wandering behaviour. Older adults who wander are drawn to each other as observed in this study (Algase et al., 2010). Moreover, these older adults may wander for social stimulation as indicated in this study (Algase et al., 1996; Lai & Arthur, 2003; Robinson, Hutchings, Corner, et al., 2006). It has been suggested that dementia may affect an older adult's level of social engagement (Algase et al., 1996). The findings of this study support this claim to some degree. However, most participants in this study maintained moderate/higher level of social engagement and were observed to engage and interact well with other residents and staff in the LTC home. Significantly, 75% of participants reported walking for the purpose of socialization, which may be an indication of loneliness or boredom, thus, establishing that walking is a good activity.

Wandering behaviour is often associated with spending time alone, loneliness or social isolation (Algase et al., 1996; Price et al., 2001). Therefore, activities that promote social interaction and companionship such as staff-resident interactions have been suggested as a way of reducing or managing wandering in the literature (Algase et al., 1996; Cipriani et al., 2014; Gu, 2015; Moore et al., 2009; Logsdon et al., 1998). This has been the focus of most studies, particularly, in regard to wandering involving exit-seeking and into an unsupervised area. Two empirical studies reported on the effects of increasing social interactions in managing wandering behaviour. It was concluded that social interactions reduced wandering behaviour in participants (Allen-Burge, Stevens, & Burgio, 1999; Goldsmith, Hoeffler, & Rader, 1995). Another study by Beattie et al., (2004) studied the effects of communication strategies on meal time behaviour of older adults with wandering behaviour. These strategies were reported to be effective in

preventing wandering and keeping older adults longer at the table during meal time. The need to promote social interaction to manage wandering behaviour has been suggested. However, this study poses if walking is good, why should our focus of promoting social interaction among older adults be on reducing wandering behaviour? Rather, our focus should be on implementing meaningful activities to promote social interaction among older adults.

Also, it has been reported that staff may avoid interacting with those who wander with the consequence of decreased social interactions, which may be related to the time and efforts directed into supervising residents who wander (Robinson, Hutchings, Corner, et al., 2006). In this study, the researcher observed the need for staff to continuously redirect participants from entering other residents' room and going into unsupervised areas. Therefore, specific activities addressing excessive walking and walking into other residents' rooms or unsupervised areas should be employed in LTC homes.

Some researchers have reported that wandering is more common among males (Kiely et al., 2000; Klein et al., 1999) while some concluded there was no significant association between gender and wandering (Hope et al., 2001). Another interesting finding in this study was that some participants, mostly women, were more likely to walk together in small groups. The participants verbalized that they enjoyed walking with other residents and also encouraged others to walk with them. According to a meta-analysis report by Kassavou, Turner, and French (2013), women participated more in walking groups than men. However, interventions that promote walking in groups for both genders were reported to increase physical activity (Kassavou et al., 2013). The finding of this study about women walking in groups is noteworthy and raises questions about the need for more gender difference studies on wandering behaviour. Perhaps, women who exhibit wandering behaviour are more comfortable walking in groups with benefits

of providing support to one another. However, little is known about this speculation from the perspectives of people living with dementia who wander.

In general, there are limited studies on the perspectives of those who wander expressing the behaviour as a form of socialization. Most studies focus on promoting social interaction to reduce wandering behaviour. The findings of this study suggests a new perspective on wandering and support the need to promote walking as a means of socialization, and not reduce wandering behaviour.

Walking to find and be with animals. This key theme, *Walking to find and be with animals*, was analyzed differently and not included under the key theme, *Walking as purposeful* because it provides a new finding about participants' perspectives on walking, which is to be with animals (pets). This finding was surprising and indicates participants' interest in not only being with animals but also enjoying their company. A family member, Lisa's niece also reported during the interview that her aunt walked to find animals and that she loved their company. Several studies have examined the effects of animal-assisted therapy (AAT) on older adults living with dementia and have concluded that AAT improves socialization behaviours and decreases agitated behaviours (Perkins, Bartlett, Travers, & Rand, 2008; Sellers, 2006). However, no studies have reported on animals and wandering behaviour.

In order to promote meaningful activities for older adults, some LTC homes have employed the use of the Eden Alternative®. The Eden Alternative® philosophy focuses on creating a home-like environment for older adults and providing adequate stimulation for older adults (Volicer & Hurley, 2003). The Eden Alternative incorporates the use of pets or AAT into LTC homes to decrease loneliness among older adults and support wandering (Algase et al.,

2003; Volicer & Hurley, 2003). However, more studies are needed on the effects of Eden Alternative on wandering behaviour.

Research Question Number Two

This section addresses the second research question for this study: *Using the components of the Enriched Model of Dementia, how do family members perceive the wandering behaviour of their relatives who are living with mild to moderate dementia in LTC homes?* The discussion of the findings in this section is linked to the Enriched Model of Dementia. Similar to the findings of participants' perspectives on wandering, there were things consistent as well as not consistent with the literature about the findings of family members' perspectives on wandering. However, most of these findings as related to the second research question were consistent with the literature because most often we interview family members, and not those who wander.

Notably, there was family agreement with most of the responses their relatives provided during the walking interview. The majority of the key themes on the perspectives of family members on wandering behaviour overlap the resident participants' perspectives and had been discussed in the previous section. *Walking as a coping strategy* was the only key theme generated specifically from family members' perspectives and is discussed in this section.

The components or factors contributing to wandering behaviour as postulated by the Enriched Model of Dementia are: the neurological impairment, health and physical fitness, biography-life history, personality, and social psychology (Kitwood, 1993; Kuhn & Verity, 2008). This study focused on older adults living with mild to moderate dementia, thus residents living with mild to moderate dementia who exhibit wandering behaviour were included as the study sample. The drive to wander has been suggested as a consequence of brain damage in older adults living with dementia (Hope et al., 2001). Therefore, older adults with cognitive

impairment exhibit wandering behaviour more than those without cognitive impairment (Holtzer et al., 2003; Hope et al., 2001; Song & Algase, 2008). Consistent with the literature about wandering behaviour commonly characterized by short and long-term memory problems, most participants in this study were reported to have poor or fair memories (Broker & Surr, 2005; Cipriani, 2014; Kiely et al., 2000). However, some of the participants were also reported to have problems with their short-term memory and seemed to retain most of their long-term memory. Therefore, this study supports previous researchers' work and takes a similar stance about older adults' ability to maintain much of their values, personality, and substantial memory despite having cognitive impairment (Landau et al., 2011; Whitlatch, Feinberg, & Tucke, 2005).

As reported by family members, the majority of participants' health was either good or very good, which corroborates the study by Colombo et al. (2001). Their findings indicated that people who wandered were clinically healthy. Similarly, this study indicates that it is healthy to walk and walking is healthy. The life and walking histories of participants obtained from family members in this study indicate that walking was very important to most resident participants in addition to having a history of being a regular walker. These findings confirm the perspectives of participants on wandering as a lifelong habit to fulfil former role or responsibility (Algase et al., 1996; Carr et al., 2010; Dewing, 2011; Silverstein et al., 2002). Men do engage more in sports, indicating a cohort effect (McPhee et al., 2016). Similarly, in this study, the majority, especially male participants were described as being very active in sports for several years.

According to the Enriched Model of Dementia, personality determines how an older adult will adjust to the environment, such as living in the LTC home and could contribute to wandering behaviour (Kitwood, 1993). Participants in this study were reported to be sociable, and friendly with an outgoing personality. Older adults who engage more in wandering

behaviour are likely to be sociable or engage more in social and leisure activities (Dewing, 2005; Monsour & Robb, 1982). Therefore, the participant's history of "being sociable" and having an "outgoing personality" were important data contributing to the findings of this study.

Walking as a coping strategy. According to the Progressively Lowered Stress Threshold (PLST) model, behaviours such as wandering occur when the internal (such as pain or fatigue) or external environmental factors or demands (such as noise) exceed the stress threshold of older adults living with dementia. This is further viewed as "person-environment fit and interaction" or an imbalance between the person and the environment interaction (Richards & Beck 2004; Smith et al., 2006; Smith et al., 2004). Therefore, the need to walk can result from stress (Andrews, 2017). Walking as a coping strategy in this study indicates that participants used walking as a means of coping or dealing with frustrating situations, such as stress or problems. Stress could be a trigger for wandering behaviour for participants in this study. Moreover, family members confirm that walking was a lifelong pattern of coping or dealing with stress for their relatives (Algase et al., 1996; Andrews, 2017; Dewing, 2005; Dewing, 2011; Richards & Beck 2004; Song & Algase, 2008).

In addition, some participants in this study were reported to have a history of stressful events in their lives and used walking as a means of thinking things through and dealing with work and family-related problems in the past. This confirms the literature that older adults with a history of stressful events in their lives exhibited wandering behaviour more (Cohen-Mansfield & Marx, 1989). In a similar study by Monsour and Robb (1982), people with wandering behaviour experienced more stressful life events and tended to walk more under stress than those who did not exhibit the behaviour. Furthermore, walking has been linked with thinking in the literature which helps in clearing "uncertainty and tension" even though this is not always the

case for older adults living with dementia (Brittain et al., 2017; Edensor, 2000). If walking helps with thinking, then there should be a rethink of our perspectives on wandering behaviour from aimless walking to a means of dealing with stress or tension.

A Visual Representation of the Key Themes

Based on Thorne's (2016) suggestion, the researcher used an open box as a visual representation of her findings (see **Figure 4**). The box represents wandering behaviour and each side of the box represents the key themes of residents and family members' perspectives on wandering. Each side fits together in the box and helps in representing wandering behaviour. The researcher's interpretation of the open box in this study suggests the need to change our perspective from "boxing up" wandering behaviour to "allowing" older adults to walk freely to enjoy what is in the box.

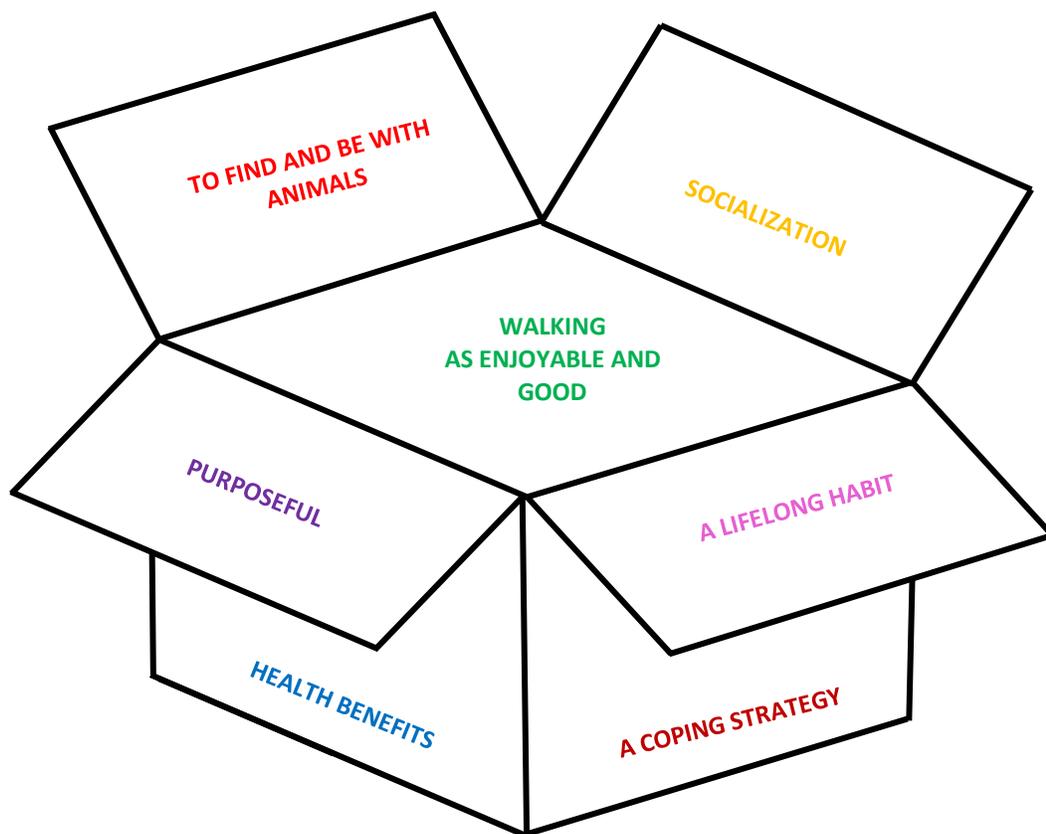


Figure 4: A visual representation of the key themes of the study

Residents' Concerns

This section discusses walking- and not walking-related concerns as expressed by resident participants in this study.

One of the participants, Dave, expressed concerns about loss of privacy as related to his walking and the effects of Alzheimer's disease on other residents living in the LTC home. Most discussion on privacy as related to wandering in the literature focuses on the use of electronic tracking or tagging device in monitoring the movement of older adults (Landau et al., 2010; Robinson, Hutchings, Corner, et al., 2006; White & Montgomery, 2014; Wigg, 2010). However, some studies have reported challenges regarding the privacy of those living in LTC homes. Some of the challenges of living in a LTC home include lack of privacy, limited movement, and safety concerns. These challenges are partly due to differences in the needs of residents who have dementia and those who do not have dementia living together and the LTC home environment (Cutler & Kane, 2002; Fiveash 1998). Residents of different ages and care needs living together in a LTC home is one of the major contributors to loss of privacy (Fiveash, 1998).

Fiveash (1998) explored eight residents' experiences in LTC homes and living in the public domain such as the LTC home was one of the major themes that contributed to loss of privacy for participants in the study. According to Fiveash, participants expressed "distress" regarding living with residents who were "sick" and "disabled" and also reported that there were "too many people" living in the LTC home and they had no private place of their own. These findings confirm the concern reported by Dave in this study about living together with other residents who were "incapacitated and ill". Another perspective to privacy as suggested by Algase et al. (1996) and Price et al. (2001) is that wandering behaviour could be a means of

spending time alone. Therefore, Dave's concerns about privacy in this study may signify an expression of the need to spend time alone.

Loss of privacy as verbalized by Dave remains one of the challenges of living in a LTC home as discussed by Fiveash (1998). Some LTC homes, including the sites for this study had private rooms on the units. In fact, some of the participants including Dave were staying in private rooms. The findings of this study as related to loss of privacy indicated that we should not equate private room with private environment. We should make it a common practice in LTC homes to ask older adults living with dementia about their concerns, especially regarding their walking and living in LTC homes.

Wandering behaviour is common among older adults living with Alzheimer's disease (Lai & Arthur, 2003). Dave's expression of Alzheimer's disease being a "terrible disease" and being bothered about other residents affected by the disease reflects common knowledge of the disease. Alzheimer's disease has been referred to as a "fatal disease" affecting all aspects of older adults' life, including their thoughts, feelings, and, actions (Alzheimer Society of Canada, 2018a, para. 1). As further expressed by Dave, currently there is no cure for Alzheimer's disease. However, medications are available to manage cognitive symptoms such as memory loss, thinking and reasoning, language and motor skills (Alzheimer Society of Canada, 2018a).

Another finding of this study was related to how environmental triggers such as noise and crowding contributed to wandering behaviour for some participants. One of the participants, Sam reported concerns about the noise level and crowding in the LTC home. Older adults living with dementia are reactive to the environment (Algase, Antonakos, Beattie, Beel-Bates, & Song, 2011). Algase et al. (2011) in their study confirms a positive relationship between crowding and higher sound level in the environment. According to the NDB model, proximal factors which

include the physical environment (light, noise, crowding, ambiance, ambient temperature and humidity) are triggers for wandering behaviour (Algase et al., 1996; Algase et al., 2010). Environmental triggers could lead to overstimulation and the desire to walk (Dewing, 2006). Likewise, an environment that is less stimulating could contribute to boredom and lead to wandering (Algase et al., 2010; Futrell et al., 2010; Hamilton et al., 2010). Regardless of how we view the environment, the physical environment remains a possible trigger for wandering behaviour in older adults living with dementia.

Family Members' Concerns

This section discusses the walking and not-walking related concerns as reported by family members in this study. Due to similarities in some of the concerns observed by family members and the researcher, concerns as noted by the researcher during participant observation are incorporated into the discussion in this section.

Entering other residents' rooms and ensuing violence. This concern was also observed by the researcher but no violence was witnessed by the researcher during the study. Older adults who exhibit wandering behaviour often wander into other residents' rooms, (boundary transgression, BT) and disrupt or take their belongings (Alvord et al., 2005; MacAndrew, Beattie, et al., 2017; Shinoda-Tagawa et al., 2004; Snellgrove et al., 2013). The behaviour is common in LTC homes and due to cognitive impairment and problems with wayfinding, older adults may wander into both private and public space alike (MacAndrew, Beattie, et al., 2017). This behaviour often results in altercations and violent reactions from other residents because it not only jeopardizes the physical safety of older adults but also their emotional well-being and quality of life (Cutler & Kane, 2002; MacAndrew, Fielding, et al., 2017, Snellgrove et al., 2013). In fact, older adults who wander into other residents' personal space put themselves in harm's

way (Shinoda-Tagawa et al., 2004, p. 591) and can become a “victim”. This unwanted intrusion usually leads to repeated physical assaults and subsequent transfer of victims to a specialized dementia care unit as reported by family members in this study. This report was consistent with the findings of Shinoda-Tagawa et al. (2004) that residents who had experienced a physical injury were at “high risk for quick subsequent reinjury even if some preventive efforts might have been made” (p. 596).

In addition, family members’ concerns about other residents walking into their relatives’ rooms and their relatives wandering into the same resident’s room were similar to the report of the study by Snellgrove and colleagues (2013). In their descriptions of resident-to-resident violent incidents in nursing homes, a participant (staff member) gave an account of a resident who continuously went into another resident’s room to use the bathroom. Furthermore, MacAndrew, Beattie et al. (2017) in their study explored the perspectives of the LTC home staff and family members on wandering-related BT. It was concluded that the behaviour was need-driven with triggers such as the need to re-enact a past life experience, be with a loved one, or find familiar things in an unfamiliar environment. Knowing when and where the behaviour will happen has been suggested as the best strategy for preventing BT. However, inadequate staff/resident ratio in LTC home remains a major barrier in optimizing this strategy. Some family members in this study have reported the need for more staff supervision during their relatives walking activities. Another suggestion to identify residents at risk of BT includes the use of a validated assessment tool such as the Revised Algate Wandering Scale-Long Term Care (MacAndrew, Beattie et al., 2017).

Falls and risk for falls. Falls, including risk for falls are associated with wandering behaviour and are major safety concerns in LTC homes (Cipriani et al., 2014; Dewing, 2011;

Kiely et al., 1998; Rowe et al., 2011). In a study by Colombo et al. (2001), older adults who exhibited wandering behaviour fell three times more than those who did not exhibit the behaviour. Moreover, older adults who had experienced a fall are at risk of falling again as reported by some family members in this study (Tilly & Reed, 2008). There were also reported concerns about night-time wandering by family members in this study. Wandering has been commonly reported among older adults experiencing sleep disturbances (Klein et al., 1999; Spring, Rowe, & Kelly, 2009). Older adults living with dementia experience changes in the sleep-wake cycle and often awake at night, leaving their beds. This night-time activity could result in falls when not supervised (Greenblum & Rowe, 2012; Spring et al., 2009) as reported by family members in this study. Apart from falls, night-time wandering could also result in other serious consequences for older adults, such as getting lost and death and increase caregivers' stress (Klein et al., 1999; Spring et al., 2009). McCurry et al. (1999) studied 205 older adults living with Alzheimer's disease in the community and wandering was reported among the behaviours associated with night-time awakenings that were disturbing to family members. This finding is similar to the finding of this study about night-time wandering.

LTC home physical environment. The architectural design of the physical environment of a LTC home plays a key role in the older adult's spatial orientation and wayfinding (Marquardt, 2011; Marquardt et al., 2014). The LTC home physical environment may further influence the pattern of wandering displayed by older adults and also contribute to risks outcomes for older adults (Marquardt et al., 2014; Wigg, 2010). For example, Sarah's daughter reported that her mother's wayfinding difficulty and repeated walking into the wall might have been as a result of the L-shaped hallways in the LTC home. Marquardt and Schmiege (2009) in their analysis of the effects of architectural structure of a LTC home on resident's wayfinding

supported these findings. The authors concluded that residents in their study found their way better in straight circulation systems than in any layout with a shift in direction such as L-shaped hallways. Marquardt and Schmiege further reported that a LTC home with very long hallways and numerous shifts in direction interfered with the resident's wayfinding. In contrast, looped hallways allow for walking without interference or "hitting dead ends" (Passini, Pigot, Rainville, & Tétreault, 2000, p. 689).

Also, there were positive findings on the effects of LTC homes with simple structures (architectural designs) and smaller units on resident's wayfinding and orientation. "The number of residents and the size of the living area constitute the most significant factor on a resident's orientation" (Marquardt & Schmiege, 2009, p. 335). Residents living with dementia have been reported to find their way best in LTC homes with small units consisting of a fewer number of eight to ten residents (Marquardt & Schmiege, 2009). The findings of this study suggests the need to reconsider the design of a LTC home environment as well as its effects on an older adult's wayfinding ability.

Staff supervision. Family members reported concerns about their relative's need for more staff supervision while walking. The researcher also observed the need for some participants to have more staff supervision during the study. Older adults who exhibit unsafe wandering such as those who wander into other residents' rooms, exit-seek or walk to escape (elope), and forget to use their walkers are all at risk for falls. These older adults often require redirection and staff supervision to be safe (Dewing, 2011; MacAndrew, Fielding, et al., 2017; Moore et al., 2009; Silverstein et al., 2002). Furthermore, walking outside of the LTC home unsupervised could be risky and unsafe for participants as reported by family members. This is especially true for older adults with wayfinding problems and sensory or visual impairments and

would require staff supervision to be safe with their walking (Algase et al., 1996; O'Connell et al., 2011).

To further support the findings of this study, MacAndrew, Fielding, et al. (2017) stated that older adults who displayed BT have been reported to accidentally exit from a safe environment, become lost and unable to return home without help. Therefore, staff supervision becomes imperative in keeping such older adults safe. However, one of the barriers to providing adequate supervision to residents who wander inside or outside of the LTC home is inadequate staff/resident ratio (MacAndrew, Beattie, et al., 2017; Wigg, 2010). Wigg (2010) examined how residents' wandering behaviour and associated risks were monitored in two LTC homes using two different forms of technology such as locked units and surveillance (motion detectors). The LTC home with motion detectors was reported to incorporate exercise and had adequate staff/resident ratio of one to four while the other home using locked units had staff/resident ratio of one to eight. Moreover, not having adequate staff to supervise residents outside of the LTC home was cited as one of the reasons for using locked units. Wigg reported that the LTC home with motion detectors and adequate staff/resident ratio provided more support and attention to residents who wandered, thereby reducing risks of wandering. It was concluded that changes must be made to staff/resident ratios to "accommodate the need for staff to wander with residents" (Wigg, 2010, p. 299).

Not walking enough. Concerns about participants not walking enough in the LTC home may be related to limited activities in the LTC home, inadequate staff supervision, or an unmet need such as pain (Algase et al., 1996; Wigg, 2010). Pain is a physical condition that can contribute to wandering and impact the quality of life of older adults (Futrell et al., 2014; O'Connell et al., 2011). Apart from contributing to wandering, pain may also limit an older

adult's movement, reduce social activities, cause sleep disturbance, anxiety and depression, and affect psychological wellbeing (O'Connell et al., 2011). O'Connell et al. (2011) reported that "residents with cognitive impairment are just as likely as residents without cognitive impairment to experience pain" (p. 68). How limited activities might contribute to not walking enough is discussed under the section of limited activities.

Walking to escape (elopement). Wandering is a major risk for elopement and getting lost with dangerous consequences, thereby increasing older adults' risk of mortality (Aud, 2004; Meek, 2014; Padilla et al., 2013; Rowe & Bennett, 2003). The thoughts of relatives getting lost and the resultant death could create anxiety for family members (Brittain et al., 2017). Likewise, family members in this study expressed concerns about the consequences of walking to escape for their relatives. Brittain et al. (2017) explored experiences of older adults living with dementia and those caring for them. They reported that family members of those living with dementia expressed "generalized sense of worry" about losing their relatives if they wandered away and got missing. Although the probability of a resident wandering away (eloping) is uncertain, all residents with cognitive impairment who ambulate are assumed to be at risk of wandering away (Aud, 2004). Aud (2004) conducted an exploratory study of 62 elopement incidents in LTC homes of which the majority were females, 29 residents had histories of attempting to elope and 22 successfully eloped. Participants in this study who had left the LTC homes had prior histories of elopement as reported by their family members, thus making this finding consistent with the study by Chung and Lai (2011) who found that 80% of older adults who eloped had prior history of elopement.

According to Rodriguez (1993), 45% of elopement happens within the first 48 hours of residents' admission into a LTC home, elopement resulting in injuries within 48 hours to 72

hours of their stay, and 80% in residents with chronic wandering behaviour (wandering all the time). Therefore, time of admission (living in a LTC home for more than two months) was an important criterion in this study to control for factors such as a new environment, which could affect participants' wandering behaviour and the results of this study. Nevertheless, resident participants in this study who were reported by family members to walk as a means of escaping might do so as a result of dementia, unmet needs or unfamiliar environment (Aud, 2004; Moore et al., 2009; Algase et al., 2006).

Injuries associated with elopement have been well documented in the literature. In a review of elopement incidents by Aud (2004), 32% of residents who eloped from LTC homes sustained injuries with falls, hypothermia, hyperthermia, and death. Specifically, 13 residents sustained falls with bruises and abrasion while seven sustained falls that required admission to hospitals of which one died from complications of pneumonia (Aud, 2004). Elopement that results in physical harm and death can lead to litigation cases and claims (Algase, 2006; Meek, 2014; Rodriguez, 1993). An insurance claim study by Rodriguez (1993) reported that 70% of elopement claims in nursing homes resulted in resident deaths and were related to "negligent supervision". Therefore adequate supervision is necessary when providing care for older adults with wandering behaviour.

Wayfinding difficulty. The researcher's walking-related concerns as observed during the study also include wayfinding difficulty. Wayfinding difficulty is one of the most striking findings for the researcher in this study and at the same time of a great concern. Wandering behaviour is often associated with wayfinding difficulty as confirmed in this study (MacAndrew, Beattie, et al., 2017). Safety concerns related to wayfinding difficulty have been reported in the literature. Specifically, walking without supervision could be unsafe and risky for older adults

with wayfinding difficulty (Algase et al., 1996; Algase et al., 2007; Marquardt, 2011). This could also lead to exit-seeking behaviour and falls as reported by family members in this study.

Moreover, sensory impairments, including vision loss or perception change affect how older adults perceive their environment, thereby affecting their behaviour and ability to find their way (O'Connell et al., 2011). In addition, the design of a LTC home could have contributed to the participants' spatial orientation (getting lost) and wayfinding in this study (Marquardt, 2011).

Other concerns by family members were related to their relatives' chronic health conditions (such as COPD, hypertension, Parkinson's disease), memory changes, and limited activities in LTC homes.

Health concerns and memory changes. Older adults are living longer as a result of advancement in healthcare, which has also resulted in an increase in the number of older adults living with chronic illnesses who require LTC support (Lovell, 2006). Most older adults living in LTC homes have chronic conditions and functional disabilities (Harper-Ice, 2002). As suggested by the Enriched Model of Dementia, the health and physical fitness of an older adult living with dementia contribute to behaviour. Short-term memory changes, including living with dementia could also complicate symptoms of chronic conditions for older adults. For example, cognitive impairment may contribute to inability of older adults living with dementia to give accurate accounts of their symptoms, thereby causing delay in treatment and worsening of symptoms (Brooker & Surr, 2005).

Limited activities. Older adults living in LTC homes often experience isolation, loneliness, boredom, and negative self-esteem (Harper-Ice, 2002). These older adults may wander as a result of an unmet need such as to relieve boredom (Algase et al.1996; Volicer et al., 2013). As dementia progresses, older adults often find it difficult to concentrate for any length of

time; therefore, they may wander to keep themselves occupied (Dementia Australia, n.d.). The finding of limited activities in the LTC home as reported by family members in this study resonates well with the study by Harper-Ice (2002). The author examined how nursing home residents spend their day and concluded that despite emphasis being placed on promoting activities in LTC homes, not a lot has changed in 25 years. Further report was that 65% of the time, residents living in LTC homes do “little or nothing”, with more time being spent in their rooms, sitting, and alone. A similar study explored the perspectives of older adults living with dementia on activity involvement in LTC homes. Residents were reported to not have “limited opportunities and motivation for activities” (Tak, Kedia, Tongumpun, & Hong, 2015, p. 182). Walking inside and outside of the LTC home was considered important among several available activities for residents.

The need to promote meaningful activities for older adults living in LTC homes, especially those living with dementia has been well advocated for in the literature. Engaging older adults in meaningful activities can provide a sense of self-esteem, purpose and promote quality of life (Harper-Ice, 2002; Tak et al., 2015). Volicer et al. (2013) analyzed the relationship between wandering in LTC homes residents with cognitive impairment and involvement in meaningful activities. Residents were classified as either displaying modifiable wandering (easily modified by staff) or nonmodifiable wandering (not easily modifiable by staff). They concluded that involvement of residents in meaningful activities resulted in fewer residents exhibiting nonmodifiable wandering.

Noteworthy are the diverse needs of older adults living in LTC homes that cannot be met by one-size-fits-all type of activity. Structured activities might have contributed to concerns related to limited activities in this study. Therefore, activities in LTC homes must be planned and

tailored to meet the individual older adult's needs. Planning meaningful activities must also take into consideration collaboration of all staff members as well as involvement of older adults and their families (Tak et al., 2015).

Participant Observation and Reflection

This section presents the researcher's reflection and discusses the findings of participant observation.

The walking interview technique was used to interview older adults who wander. The researcher could not find any other study on wandering behaviour that had used this technique. Although one walking interview per resident was done, the researcher speculates that having more than one walking interview could have further enhanced the findings of the study such as identifying other triggers of wandering for participants apart from noise and crowding. Saturation played a role in the decision to not go for a second walking interview. During the review of the audio recordings of the interview, the researcher heard the same comments again and again indicating that a data saturation had been reached (Saunders et al., 2018).

The walking interview technique was considered good for this study because of its incorporation of participant observation. Participant observation in this study was carried out while getting to know the participants prior to the walking interview as well as during the walking interview. The walking interview technique allowed the researcher to follow participants around wherever they went, thereby allowing their walking activity to occur as naturally as possible without any interference. Participant observation in this study provided the opportunity for the researcher to get to know not only the participants a little bit more, but also the units as well as the staff. The researcher also had the opportunity to observe the layout of the units,

common areas for residents, where exit doors were located and the outside space in the LTC home.

Participant observation allowed the researcher to observe participants' wandering pattern, how participants interacted with other residents and staff in the LTC home, their facial expressions and mood, and how staff also interacted with the participants. For example, one of the participants, Helen, had aphasia and experienced some difficulty communicating. She could not participate in the study as other participants because of the difficulty in expressing herself verbally. The researcher was able to build on non-verbal cues to gather information on her perspectives through participant observation. Participant observation provided this great opportunity to include the perspectives of residents like Helen whose "voice" might not have been added to the body of knowledge on wandering.

Another opportunity the researcher had was to observe and ask participants questions about their life histories as provided by their family members during the family interview. Overall, the experience of the walking interview technique with participant observation was a wonderful experience which had enriched the findings of this study that would otherwise not have been possible. Information gathered during the participant observation and walking interview was recorded in the reflective journal and added to the description of the study findings.

The wandering pattern of participants was noted during participant observation. The pattern of wandering for most participants in this study was random. This finding was consistent with the literature about random wandering being the most common pattern of wandering among older adults (Algase et al., 2001; Algase et al., 2009). Although random wandering is not easily

classified and involves frequent changes in direction, the design of the physical environment of both LTC homes might have contributed to this finding (Marquardt & Schmiege, 2009).

Furthermore, random wandering may contribute to other risks associated with the behaviour such as entering other residents' rooms (BT) (Algase et al., 2009; Marquardt et al., 2014; Wigg, 2010). Specifically, BT has been associated with random wandering in the literature (MacAndrew, Fielding, et al., 2017). Similarly, in this study, participants who exhibited random wandering also displayed BT. It has been reported that random wandering does not always respond to nursing interventions as observed by the researcher in this study (Algase et al., 2001). It is not unusual for older adults to exhibit more than one pattern of wandering as found in one participant, Sam who exhibited random and pacing wandering patterns. Furthermore, pacing presented with agitation and anxiety in this participant and might signify an unmet need (Algase et al., 2001). Sam showed early signs of agitation when the researcher approached to start the walking interview with him. The researcher was vigilant for these early signs of agitation, withdrew from walking with him and notified the nurse. The interview was later completed when Sam was calm and demonstrated readiness to walk with the researcher.

Another finding during participant observation was related to various emotions (happy, confused, bored, and anxious) displayed by participants in this study. Older adults living with dementia still maintain the ability to express emotion (Lee et al., 2015). Although research is limited in the area of emotions and wandering behaviour, emotions have been related to behaviours in older adults living with dementia (Cipriani et al., 2014; Lee et al., 2014; Mayhew, 2005). Apart from being associated with dementia, unrelated confusion may signify unmet needs such as pain (Brooker & Surr, 2005; O'Connell et al., 2011). Positive and pleasant emotional expressions such as being happy have been associated with wandering behaviour while negative

emotions such as being sad are associated with sitting alone and not walking around (Lee et al., 2014).

The Enriched Model of Dementia suggested that the LTC home environment could support or harm older adults living with dementia (Algase et al., 1996; Brooker & Surr, 2005). The social psychology represents the social networks, including the environment and how older adults relate with other people in the environment (Brooker & Surr, 2005). Social interaction between residents and staff play a major role in promoting the psychosocial well-being of older adults living with dementia (Lee et al., 2017). Lee et al. (2017) examined the relationship between staff-resident interactions and psychosocial well-being (positive and negative emotional expressions) of people living with dementia. They reported that positive interaction, and not negative interaction was significantly associated with positive emotional expressions.

Wandering could be an emotional response to the environment and older adults are sensitive to the emotions of those around them (Mayhew, 2005; Yao & Algase, 2008). For example, an older adult may respond to the healthcare provider's emotional expressions of anxiety, anger or frustration by becoming anxious (Mayhew, 2005). Therefore, the need for healthcare providers to maintain "a calm demeanor, even in the midst of extreme frustration" has been suggested (Mayhew, 2005, p. 150).

Strengths

The ability of all resident participants in this study to communicate their perspectives on wandering to a certain degree irrespective of their cognitive impairment was a strength in this study. This study has demonstrated that it is possible to ask older adults living with dementia simple questions and receive their responses. Resident participants in this study expressed how they felt and what they wanted when they walked. Considering the gap in the literature on the

perspectives of older adults on wandering behaviour, the findings of this study are important in adding to the body of knowledge on wandering behaviour and for future intervention studies.

This is the first known study that utilized the walking interview technique to include the perspectives of older adults living with mild to moderate dementia in LTC homes in our understanding of wandering behaviour. The walking interview technique (go-along) was unique and allowed the researcher not only to follow resident participants around but to capture their moment of walking in their natural environment. This technique had participant observation incorporated into it, thereby allowing the researcher to ask questions, listen and observe as resident participants walked and interacted with their physical and social environment (Butler & Derrett, 2014; Evans & Jones, 2011; Kusenbach, 2003). Through observation of resident participants' connections to their environments, richer data and knowledge have been generated using this technique (Evans & Jones, 2011). The researcher also got to know the participants more and ensured ongoing verbal consent was obtained from all participants. Additionally, multiple methods including resident and family interviews, and a reflective journal with observational notes were used to generate key themes on the perspectives of resident participants and their family members on wandering behaviour.

This study had demonstrated the ability of older adults living with mild to moderate dementia to communicate their perspectives. Moreover, there was significant overlap in the perspectives of resident participants and their family members. This overlap indicates the validation of what residents said. Therefore, this study as well as some other studies in the literature confirm that residents living with dementia could (validly) answer simple questions. Also, these findings suggest that we may still be able to understand older adults' walking activity through their family members even when they are unable to communicate, for example, when in

later stages of dementia. These findings raise questions for future studies. Can we rely on family members to provide adequate description of the walking behaviour of older adults living with severe dementia who are unable to communicate?

Limitations

Despite these strengths, there were several limitations to this study. First, the researcher's perspective and preconceptions about wandering might affect her interpretation of the data. The researcher is conscious of "what she brings in" and there were procedures to minimize any personal bias. These procedures include coding independently and then jointly with her supervisor and maintaining a reflective journal (including observational notes) during the study.

Second, having two LTC homes with similar physical design such as linear hallways might have affected the findings of the study. The linear hallways might have contributed to the researcher's interpretation of the participants' pattern of wandering and the walking-related concerns reported by the researcher such as the wayfinding difficulty. However, several strategies were put in place to ensure the trustworthiness and integrity of this study.

Third, this study depended on a convenient sample of ambulatory resident participants (older adults) living with mild to moderate dementia who could respond to simple questions. The perspectives of older adults living with severe dementia (advanced or later stages of dementia) and those using wheelchairs were not recruited into this study. Although the intent of the researcher was to better understand the perspectives of older adults living with mild to moderate dementia, wandering behaviour is also common among older adults living with severe dementia. Moreover, wandering is not limited to older adults who are ambulatory, the behaviour also involves wheelchair motion (Cipriani et al., 2014; Lai & Arthur, 2003). Apart from significant memory loss, older adults living with severe dementia may experience severe difficulty in

communication and carrying out activities of daily living and these may be challenging for their family members (Alzheimer's Society, 2018). The walking interview technique used in this study might not allow for walking with older adults who use wheelchair without any discomfort. In this regard, inclusion and exclusion criteria were set to allow the researcher to achieve the aim of the study.

Fourth, the researcher's inability to observe and interview at times that were optimal for participants' preference, mood, and energy levels was a limitation to this study. The researcher spent one to two days to get to know participants prior to the interview and asked family members and staff the optimal time to walk with participants. However, the researcher could not ascertain that the time interview was done was optimal for participants, which might have influenced the results of the study. Most participants enjoyed having a companion while some demonstrated agitation and anxiety on a few occasions during the study. Moreover, the researcher's presence might have contributed to the agitation for some participants. On one occasion, a participant requested to walk alone 20 minutes into the interview, of which her request was granted. The researcher ensured ongoing verbal consent was obtained from all participants.

Recommendations for Practice

The findings of this study suggest the need for a reconceptualization of wandering behaviour from aimless walking and disruptive to an enjoyable, purposeful and beneficial activity. The need to change the negative perspective associated with wandering behaviour is imperative in clinical practice. As demonstrated in this study, older adults living with mild to moderate dementia were able to provide their perspectives on walking and how walking was good and beneficial to them. We need to accept what wandering means to these older adults.

Learning from older adults' perspectives on wandering also calls for a need and strategic ways to develop a new broader interpretation of wandering. One of such ways is for healthcare providers to begin to ask older adults exhibiting wandering behaviour simple questions about why they walk. Knowing the life history/story, including any walking history of newly admitted older adults into the LTC home is highly recommended. Additionally, older adults and their families should be involved in developing an individualized plan of care related to wandering behaviour. Family concerns as well as recommendations should be given full consideration and addressed accordingly.

Considering the benefits of walking, supervised walking program both inside and outside of the LTC home should be incorporated into activity programs in LTC homes with collaboration of residents and family members. Although walking is important and beneficial to older adults, it is worth noting that walking could become excessive to the point of older adults forgetting to drink enough fluid, eat or take restful periods. Therefore, these older adults may be at risk of developing dehydration, malnutrition and other complications associated with excessive walking. Strategies to manage these risks should be developed. Keeping older adults engaged in meaningful activities is also recommended to reduce excessive walking. Family members have expressed several safety concerns related to wandering. Therefore, adequate staff supervision during walking becomes crucial in keeping older adults safe, thereby reducing risks associated with the behaviour. The goal of care should be on promoting safe walking for older adults. Assessment of older adults at risk of consequences of wandering such as using a validated assessment tool should also be considered and incorporated into care planning (MacAndrew, Beattie, et al., 2017).

The physical and social environments play key roles in helping older adults adjust to their environment. Therefore, modification of both environments is recommended. The design of the LTC homes, especially the hallways must be built in a way that limits shifts in direction (Marquardt & Schmieg, 2009). Healthcare providers should pay attention to environmental triggers, including noise and crowding and the effects of such on older adults. The social environment of older adults must also be taken into consideration. The goal of promoting socialization among older adults should not be to reduce wandering behaviour. Rather, walking should be encouraged to promote socialization in older adults. The new finding of this study suggests that older adults may engage in walking to find and be with animals. Therefore, regular use of pets is recommended to foster older adults' interaction with animals, considering this might be beneficial in providing companionship for some older adults. LTC homes may consider embracing the practices of the Eden Alternative. However, more studies are needed on the effects of these practices on wandering behaviour.

Future Research

This study has included the perspectives of older adults living with dementia in LTC homes and added to the limited body of experiential knowledge on wandering behaviour. In addition, this study will form the groundwork for future studies on testing interventions to promote safe and healthy walking for older adults living with dementia. However, future research is needed to further explore the meaning of wandering behaviour and the lived experiences of older adults who engage in this behaviour. Research on wandering behaviour should be inclusive of older adults as participants and experts of their own behaviour. We need to continue to include their voice in our search for appropriate clinical practice. Also, future research is needed in examining the potential gender differences on wandering behaviour.

This is the first known study to use the walking interview technique to conduct interviews with older adults living with dementia. Future studies on wandering behaviour should consider using this interview technique, especially in exploring the meaning of place to older adults exhibiting wandering behaviour. This study has also identified a new finding on the use of animals (pets) as a means of promoting companionship for older adults. Therefore, future research examining the effects of animals on improving socialization for older adults living with dementia who exhibit wandering behaviour is needed.

Conclusion

This study has included the perspectives of older adults living with dementia on wandering behaviour. From the perspectives of participants (residents) and their family members, walking was an activity that is enjoyable, beneficial, and purposeful. Wandering was also an expression of unmet needs such as a desire to be with family and socialize, and to relieve boredom, and a lifelong habit and coping strategy. The new finding from this study was that older adults walk to find and be with animals. Including the perspectives of older adults who exhibit wandering behaviour as experts could lead to a reconceptualization of wandering behaviour, most importantly, from being disruptive to an activity that is meaningful.

Risks associated with wandering are still present and of a great concern to family members. Strategies to manage these risks should be developed. However, our sole focus should not be on these risks. Our goal of care should be on delivering person-centered care to these older adults. The less we see wandering behaviour as a problem, the more we begin to see the benefits associated with the behaviour. Older adults living with dementia will continue to remain the experts in the area of their own wandering behaviour and their voices are important in our

search for answers on wandering behaviour. We need to learn from them and correspondingly change our thinking about wandering behaviour.

References

- Algase, D.L. (2006). What's new about wandering behaviour? An assessment of recent studies. *International Journal of Older People Nursing*, 1(4), 226-234.
doi:10.1111/j.1748-3743.2006.00043.x
- Algase, D., Antonakos, C., Beattie, E., Beel-Bates, C., & Song, J. (2011). Estimates of crowding in long-term care: Comparing two approaches. *HERD: Health Environments Research & Design Journal*, 4(2), 61-74. doi:10.1177/193758671100400206
- Algase, D.L., Antonakos, C., Beattie, E.R.A., Beel-Bates, C.A., & Yao, L. (2009). Empirical derivation and validation of a wandering typology. *Journal of the American Geriatrics Society*, 57(11), 2037-2045. doi:10.1111/j.1532-5415.2009.02491.x
- Algase, D.L., Beattie, E.R.A., Antonakos, C., Beel-Bates, C.A., & Yao, L. (2010). Wandering and the physical environment. *American Journal of Alzheimer's Disease & Other Dementias*, 25(4), 340-346. doi:10.1177/1533317510365342
- Algase, D.L., Beattie, E.R.A., & Therrien, B. (2001). Impact of cognitive impairment on wandering behavior. *Western Journal of Nursing Research*, 23(3), 283-295.
doi:10.1177/01939450122045159
- Algase, D.L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and other Dementias*, 11(6), 10-19. doi:10.1177/153331759601100603
- Algase, D.L., Beel-Bates, C., & Beattie, E.R.A. (2003). Wandering in long term care. *Annals of Long-Term Care: Clinical Care and Aging*, 11(1), 33-39. Retrieved from <https://pdfs.semanticscholar.org>

- Algase, D.L., Moore, D.H., Vandeweerd, C. & Gavin-Dreschnack, D.J. (2007). Mapping the maze of terms and definitions in dementia-related wandering. *Aging and Mental Health, 11*, 686–698. doi:10.1080/13607860701366434
- Algase, D.L., & Nelson, A. (2007). *Evidence-based protocols for managing wandering Behaviours* [Ebrary]. Retrieved from <http://umb-primo-prod.hosted.exlibrisgroup.com>
- Ali, N., Luther, S., Volicer, L., Algase, D., Beattie, E., Brown, L.,... Joseph, I. (2016). Risk assessment of wandering behavior in mild dementia. *International Journal of Geriatric Psychiatry, 31*(4), 367-374. doi:10.1002/gps.4336
- Allen-Burge, R., Stevens, A.B., & Burgio, L.D. (1999). Effective behavioural interventions for decreasing dementia-related challenging behaviour in nursing homes. *International Journal of Geriatric Psychiatry, 14*(3), 213-228. doi 10.1002/(SICI)1099-1166(199903)14:3<213::AID-GPS974>3.0.CO;2-0
- Alvord, M., Armstrong-Ross, K., Belcher, A., Biggi, S., Brusio, D., Clifford, M.,... Tunney, C. (2005). Creating effective system to manage wandering behavior: Guidance for long-term care facilities in New York State. Retrieved from <https://www.nccdp.org/WanderingBehavior5-10-05Final.pdf>
- Alzheimer's Association. (2009). *Dementia care practice recommendations for assisted living residences and nursing homes*. Retrieved from https://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf
- Alzheimer's Association. (2016). *Three out of five people with Alzheimer's disease will wander*. Retrieved from http://www.alz.org/norcal/in_my_community_18411.asp
- Alzheimer's Disease International (ADI). (n.d.). *Our vision, mission and strategic plan*.

- Retrieved from www.alz.co.uk/vision-and-aims
- Alzheimer Scotland. (2009). *When people with dementia walk - guidance for carers*. Retrieved from <https://www.alzscot.org/assets/0000/0161/walking.pdf>
- Alzheimer Society of Canada. (2007). *Restraints*. Retrieved from www.alzheimer.ca
- Alzheimer Society of Canada. (2018a). *Alzheimer's disease*. Retrieved from <http://alzheimer.ca/en/Home/About-dementia/Alzheimers-disease>
- Alzheimer Society of Canada. (2018b). *Canada's national dementia strategy*. Retrieved from <http://www.alzheimer.ca/en/Home/Get-involved/Advocacy/National-dementia-strategy>
- Alzheimer Society of Toronto. (2014). *What are responsive behaviours*. Retrieved from <http://www.alzheimer.ca/en/on/We-can-help/Resources/Shifting-Focus/What-are-responsive-behaviours>
- Alzheimer's Society. (2018). *The later stages of dementia*. Retrieved from <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/late-stages>
- Anderson, J. (2004). Talking whilst walking: A geographical archaeology of knowledge. *Area*, 36(3), 254–261. doi:10.1111/j.0004-0894.2004.00222.x
- Andrews, J. (2017). “Wandering” and dementia. *British journal of Community Nursing*, 22(7), 322-323. Retrieved from <http://web.a.ebscohost.com.uml.idm.oclc.org/>
- Aud, M.A. (2004). Dangerous wandering: Elopements of older adults with dementia from long-term care facilities. *American Journal of Alzheimer's Disease and Other Dementias*, 19(6), 361-368. doi:10.1177/153331750401900602
- Banerjee, A. (2007). An overview of long-term care in Canada and selected provinces and territories. Retrieved from

- http://www.womenandhealthcarereform.ca/publications/banerjee_overviewLTC.pdf
- Beattie, E., Algase, D., & Song, J. (2004). Keeping wandering nursing home residents at the table: Improving food intake using a behavioral communication intervention. *Aging & Mental Health*, 8(2), 109-116. Retrieved from <http://web.a.ebscohost.com.uml.idm.oclc.org/>
- Brittain, K., Degnen, C., Gibson, G. Dickinson, C., & Robinson, L. (2017). When walking becomes wandering: Representing the fear of the fourth age. *Sociology of Health & Illness*, 39(2), 270-284. doi:10.1111/1467-9566.12505
- Brooker, D., & Surr, C. (2005). *Dementia care mapping: Principles and practice* (2nd ed.). United Kingdom: Bradford Dementia Group.
- Butler, M., & Derrett, S. (2014). The walking interview: An ethnographic approach to understanding disability. *The Internet Journal of Allied Health Sciences and Practice*, 12(3), 254-262. Retrieved from <http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=1491&context=ijahsp>
- Canadian Institute for Health Information (CIHI). (2012). *Data quality documentation, continuation care reporting system, 2010-2011*. Retrieved from https://secure.cihi.ca/free_products/CCRS_Data_Quality_Doc_2010-2011_EN.pdf
- Canadian Institute for Health Information (CIHI). (2013). *Describing outcome scales (RAI-MDS 2.0)- CIHI*. Retrieved from https://www.cihi.ca/en/outcome_rai-mds_2.0_en.pdf
- Carr, D., Muschert, G.W., Kinney, J., Robbins, E., Petonito, G., Lydia Manning, L., & Brown, J.S. (2010). Silver alerts and the problem of missing adults with dementia. *The Gerontologist*, 50(2), 149-157. doi:10.1093/geront/gnp102
- Chung, J., & Lai, C. (2011). Elopement among community-dwelling older adults with dementia.

- International Psychogeriatrics*, 23(1), 65-72. doi:10.1017/S1041610210000657
- Cipriani, G., Lucetti, C., Nuti, A. & Danti, S. (2014), Wandering and dementia. *Psychogeriatrics*, 14(2), 135–142. doi:10.1111/psyg.12044
- Cohen-Mansfield, J., & Marx, M. (1989). Do past experiences predict agitation in nursing home residents? *International Journal of Human Development*, 28(4), 285-294. doi: 10.2190/4KLN-5341-DC4K-FN1M
- Cohen-Mansfield, J. & Werner, P. (1999). Longitudinal predictors of non-aggressive agitated behaviors in the elderly. *International Journal of Geriatric Psychiatry*, 14(10), 831–844. doi:10.1002/(SICI)1099-1166(199910)14:10<831::AID-GPS29>3.0.CO;2-A
- Cohen-Mansfield, J., Werner, P., Marx, M., & Freedman, L. (1991). Two studies of pacing in the nursing home. *Journal of Gerontology*, 46(3), M77–M83. doi:10.1093/geronj/46.3.M77
- Colombo, M., Vitali, S., Cairati, M., Perelli-Cippo, R., Bessi, O., Gioia, P., & Guaita.(2001). Wanderers: Features, findings, issues. *Archives of Gerontology and Geriatrics*, 33, 99-106. doi:10.1016/S0167-4943(01)00127-3
- Cox, E., Nowak, M., & Buettner, P. (2011). Managing agitated behaviour in people with Alzheimer’s disease: The role of live music. *The British Journal of Occupational Therapy*, 74(11), 517–524. doi:10.4276/030802211x13204135680866
- Creswell, J.W. (2013). *Qualitative inquiry and research design: Choosing among five approaches*. London: Sage Publication Inc.
- Cutler, L.J., & Kane, R.A. (2002). Environments for privacy, safety, and movement of persons with dementia maximal privacy + moderate barriers = minimal intrusion. *Alzheimer's Care Quarterly*, 3(1), 50-54. Retrieved from <http://ovidsp.tx.ovid.com.uml.idm.oclc.org/>

- De Araújo, A., Lima, D., Nascimento, I., De Almeida, A., & Da Rosa, M. (2015). Language in elderly people with Alzheimer's disease: A systematic review. *Revista CEFAC, 17*(5), 1657-1662. doi: 10.1590/1982-021620151754215
- Dementia Alliance International. (DAI). (2017). *Dementia Alliance International*. Retrieved from <https://www.dementiaallianceinternational.org/>
- Dementia Australia. (n.d.). *Wandering*. Retrieved from <https://www.dementia.org.au/national/support-and-services/carers/behaviour-changes/wandering>
- Dewing, J. (2005). Screening for wandering among older persons with dementia. *Nursing Older People, 17*(3), 20-24. Retrieved from web.ebscohost.com
- Dewing, J. (2006). Wandering into the future: Reconceptualizing wandering "A natural and good thing". *International Journal of Older People Nursing, 1*(4), 239-249. Retrieved from <http://web.b.ebscohost.com.proxy2.lib.umanitoba.ca/>
- Dewing, J. (2011). Dementia care: Assess wander walking and apply strategies. *Nursing & Residential Care, 13*(10), 494-496. Retrieved from <http://web.ebscohost.com.proxy2.lib.umanitoba.ca>
- Dickinson, J.I., & McLain-Kark, J. (1998). Wandering behavior and attempted exits among residents diagnosed with dementia-related illnesses: A qualitative approach. *Journal of Women & Aging, 10*(2), 23-24. doi:10.1300/J074v10n02_03
- Edensor, T. (2000). Walking in the British countryside: Reflexivity, embodied practices and ways to escape. *Body and Society, 6*(3-4), 81-106. doi:10.1177/1357034X00006003005
- Engberg, J., Castle, N., & McCaffrey, D. (2008). Physical restraint initiation in nursing homes and subsequent resident health. *The Gerontologist, 48*(4), 442-452. doi: 10.1093/geront/48.4.442

- Evans, J., & Jones, P. (2011). The walking interview: Methodology, mobility and place. *Applied Geography*, 31(2), 849–858. doi:10.1016/j.apgeog.2010.09.005
- Finkel, S. (2000). Introduction to behavioural and psychological symptoms of dementia (BPSD). *International Journal of Geriatric Psychiatry*, 15(S1), S2–S4.
doi:10.1002/(sici)1099-1166(200004)15:1+<s2::aid-gps159>3.0.co;2-3
- Fiveash, B. (1998). The experience of nursing home life. *International Journal of Nursing Practice*, 4(3), 166-174. doi:10.1046/j.1440-172X.1998.00062.x
- Futrell, M., Melillo, K., & Remington, R. (2010). Evidence-based guideline: Wandering. *Journal of Gerontological Nursing*, 36(2), 6-16. doi:10.3928/00989134-20100108-02
- Futrell, M., Melillo, K.D., Remington, R., & Butcher, H.K. (2014). Evidence-based practice guideline: Wandering. *Journal of Gerontological Nursing*, 40(11), 16–23.
doi:10.3928/00989134-20140911-01
- Gerdner, L.A., Buckwalter, K.C., & Hall, G.R. (2005). Temporal patterning of agitation and stressors associated with agitation: Case profiles to illustrate the progressively lowered threshold model. *Journal of the American Psychiatric Nurses Association*, 11(4), 215-222. doi:10.1177/1078390305281178
- Gill, S., Bronskill, S., Normand, S., Anderson, G., Sykora, K., Lam, K.,...Rochon, P. (2007). Antipsychotic drug use and mortality in older adults with dementia, *Annals of Internal Medicine*, 146(11), 775-786. doi:10.7326/0003-4819-146-11-200706050-00006
- Goldsmith, S.M., Hoeffler, B., & Rader, J. (1995). Problematic wandering behaviour in the

- cognitively impaired elderly. A single-subject case study. *Journal of Psychosocial Nursing and mental Health Services*, 33(2), 6-12. Retrieved from <https://www.ncbi.nlm.nih.gov/umc/oclc.org/>
- Government of Canada. (2004). *Long-term facilities-based care*. Retrieved from www.canada.ca/en/health-canada/services/home-continuing-care/long-term-facilities-based-care.html
- Government of Canada. (2015). *TCPS2 (2014): Tri-council policy statement: Ethical conduct for research involving humans*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
- Greenblum, C., & Rowe, M. (2012). Nighttime activity in individuals with dementia: Understanding the problem and identifying solutions. *Journal of Gerontological Nursing*, 38(5), 8-11. doi:10.3928/00989134-20120410-02
- Gu, L. (2015). Nursing interventions in managing wandering behavior in patients with dementia: A literature review. *Archives of Psychiatric Nursing*, 29(6), 454–457. doi:10.1016/j.apnu.2015.06.003
- Halek, M., & Bartholomeyczik, S. (2012). Description of the behaviour of wandering in people with dementia living in nursing homes-a review of the literature. *Scandinavian Journal of Caring Sciences*, 26(2), 404-413. doi:10.1111/j.1471-6712.2011.00932.x
- Hamilton, P., Harris, D., Le Clair, J.K., Collins, J. & P.I.E.C.E.S Consult Group, Issuing body. (2010). *Putting the P.I.E.C.E.S. together: A learning resource for providers caring for older adults with complex physical and cognitive/mental health needs and behavioural changes* (6th ed., rev. / P.I.E.C.E.S. Consult Group; Pam Hamilton, Diane Harris, Kenneth Le Clair, Joanne Collins.. ed.). CA: Shop for Learning Publishing Services.

- Harper-Ice, G.H. (2002). Daily life in a nursing home. Has it changed in 25 years? *Journal of Aging Studies, 16*(4), 345-359. doi:10.1016/S0890-4065(02)00069-5
- Heliker, D., & Scholler-Jaquish A. (2006). Transition of new residents to long-term care: Basing practice on residents' perspectives. *Journal of Gerontological Nursing, 32*(9), 34-42.
Retrieved from <http://web.a.ebscohost.com.uml.idm.oclc.org/>
- Hirschman, K.B., Joyce, C.M., James, B.D., Xie, S.X., & Karlawish, J.H.T. (2005). Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *The Gerontologist, 45*(3), 381–388. doi:10.1093/geront/45.3.381
- Hodgkinson, B., Koch, S., Nay, R., & Lewis, M. (2007). Managing the wandering behaviour of people living in a residential aged care facility. *International Journal of Evidence-Based Healthcare, 5*(4), 406–436. doi:10.1111/j.1479-6988.2007.00078.x
- Holton, M., & Riley, M. (2014). Talking on the move: Place-based interviewing with undergraduate students. *Area, 46*(1), 59–65. doi:10.1111/area.12070
- Holtzer, R., Tang, M., Devanand, D.P., Albert, S.M., Wegesin, D.J., Marder, K.,...Stern, Y. (2003). Psychopathological features in Alzheimer's Disease: Course and relationship with cognitive status. *Journal of the American Geriatrics Society, 51*(7), 953-960.
doi:10.1046/j.1365-2389.2003.51308.x
- Hope, T., Keene, J., McShane, R.H., Fairburn, C.G., Gedling, K., & Jacoby, R. (2001). Wandering in dementia: A longitudinal study. *International Psychogeriatrics, 13*(2), 137–147. doi:10.1017/s1041610201007542
- Hope, T., Tilling, K.M., Gedling, K., Keene, J.M., Cooper, S.D. & Fairburn, C.G. (1994). The structure of wandering in dementia. *International Journal of Geriatric Psychiatry, 9*(2), 149–155. doi:10.1002/gps.930090209

- Kassavou, A., Turner, A., & French, D. (2013). Do interventions to promote walking in groups increase physical activity? A meta-analysis. *International Journal of Behavioral Nutrition and Physical Activity*, *10*(18), 1-12. doi:10.1186/1479-5868-10-18
- Kiely, D.K., Kiel, D.P., Burrows, A.B. & Lipsitz, L.A. (1998). Identifying nursing home residents at risk for falling. *Journal of the American Geriatrics Society*, *46*(5), 551-555. doi:10.1111/j.1532-5415.1998.tb01069.x
- Kiely, D.K., Morris, J.N., & Algase, D.L. (2000). Resident characteristics associated with wandering in nursing homes. *International Journal of Geriatric Psychiatry* *15*(11), 1013-1020. doi:10.1002/1099-1166(200011)15:11<1013::AID-GPS226>3.0.CO;2-X
- Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry*, *8*(7), 541-545. Retrieved from <http://web.b.ebscohost.com.uml.idm.oclc.org/>
- Klein, D.A., Steinberg, M., Galik, E., Steele, C., Sheppard, J.M., Warren, A.,...Lyketsos, C. G. (1999), Wandering behaviour in community-residing persons with dementia. *International Journal of Geriatric Psychiatry*, *14*(4), 272-279. doi:10.1002/(SICI)1099-1166(199904)14:4<272::AID-GPS896>3.0.CO;2-P
- Koehn, S.D., Kozak, J.F., & Drance, E. (2011). The Problem with Leonard': A critical constructionist view of need-driven dementia-compromised behaviours. *Dementia*, *11*(6), 725-741. doi:10.1177/1471301211421264
- Kolanowski, A. (1999). An overview of the need-driven dementia-compromised behavior model. *Journal of Gerontological Nursing*, *25*(9), 7-9. Retrieved from [proxy2.lib.umanitoba.ca/document delivery](http://proxy2.lib.umanitoba.ca/document%20delivery)

- Kovach, C.R., Noonan, P.E., Schlidt, A.M., & Wells, T. (2005). A model of consequences of need-driven, dementia-compromised behavior. *Journal of Nursing Scholarship*, 37(2), 134–140. doi:10.1111/j.1547-5069.2005.00025_1.x
- Kuhn, D., & Verity, J. (2008). *The art of dementia care*. New York: Delmar Cengage Learning.
- Kusenbach, M. (2003). Street phenomenology: The go-along as ethnographic research tool. *Ethnography*, 4(3), 455–485. doi:10.1177/146613810343007
- Lai, C.K.Y., & Arthur, D.G. (2003). Wandering behaviour in people with dementia. *Journal of Advanced Nursing*, 44(2), 173-182. doi:10.1046/j.1365-2648.2003.02781.x
- Landau, R., Auslander, G.K., Werner, S., Shoval, N., & Heinik, J. (2011). Who should make the decision on the use of GPS for people with dementia? *Aging & Mental Health*, 15(1), 78–84. doi:10.1080/13607861003713166
- Landau, R., Werner, S., Auslander, G.K., Shoval, N., & Heinik, J. (2010). What do cognitively intact older people think about the use of electronic tracking devices for people with dementia? A preliminary analysis. *International Psychogeriatrics*, 22(08), 1301–1309. doi:10.1017/S1041610210001316
- Lee, K.H., Algase, D.L. & McConnell, E.S. (2014). Relationship between observable emotional expression and wandering behavior of people with dementia. *International Journal of Geriatric Psychiatry*, 29(1), 85–92. doi:10.1002/gps.3977
- Lee, K.H, Boltz, M., & Algase, D.L. (2017). Does social interaction matter psychological well-being in persons with dementia? *American Journal of Alzheimer's Disease & Other Dementias*, 32(4), 207-212. doi:10.1177/1533317517704301
- Lee, K., McConnell, E., Knafl, G., & Algase, D. (2015). Pain and psychological well-being among people with dementia in long-term care. *Pain Medicine*, 16(6), 1083-1089. doi:10.1111/pme.12739

- Lee, D.T.F., Woo, J., & Mackenzie, A.E. (2002). The cultural context of adjusting to nursing home life: Chinese elders' perspectives. *The Gerontologist*, 42(5), 667–675.
doi:10.1093/geront/42.5.667
- Lester, P.E., Garite, A., & Kohen, I. (2012). Wandering and elopement in nursing homes. *Annals of Long-Term Care: Clinical Care and Aging*, 20(3), 32-36. Retrieved from <http://www.annalsoflongtermcare.com/article/wandering-and-elopement-nursing-homes>
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. London: Sage Publications, Inc.
- Lindsey, P.L., & Buckwalter, K.C. (2009). Psychotic events in Alzheimer's disease: Application of the progressively lowered stress threshold model. *Journal of Gerontological Nursing*, 35(8), 20-27. Retrieved from proxy2.lib.umanitoba.ca/
- Lindwall, M., Rennemark, M., Halling, A., Berglund, J., & Hassmén, P. (2006). Depression and exercise in elderly men and women: Findings from the Swedish national study on aging and care. *Journal of Aging and Physical Activity*, 15(1), 41-55. doi:10.1123/japa.15.1.41
- Logsdon, R.G., Teri, L., McCurry, S.M., Gibbons, L.E., Kukull, W.A., & Larson, E.B. (1998). Wandering: A significant problem among community residing individuals with Alzheimer's disease, *The Journals of Gerontology*, 53B(5), 294-299.
doi:10.1093/geronb/53B.5.P294
- Lovell, M. (2006). Caring for the elderly: Changing perceptions and attitudes. *Journal of Vascular Nursing*, 24(1), 22–26. doi:10.1016/j.jvn.2005.11.001
- Lyketsos, C.G., Colenda, C.C., Beck, C., Blank, K., Doraiswamy, M.P., Kalunian, D.A., & Yaffe, K. (2006). Position statement of the American association for geriatric psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. *The American Journal of Geriatric Psychiatry*, 14(7), 561-573.

doi:10.1097/01.JGP.0000221334.65330.55

MacAndrew, M., Beattie, E., O'Reilly, M., Kolanowski, A., & Windsor, C. (2017). The trajectory of tolerance for wandering-related boundary transgression: An exploration of care staff and family perceptions. *The Gerontologist*, *57*(3), 451–460

doi:10.1093/geront/gnv136

MacAndrew, M., Fielding, E., Kolanowski, A., O'Reilly, M., & Beattie, E. (2017). Observing wandering-related boundary transgression in people with severe dementia. *Aging & Mental Health*, *21*(11), 1197-1205. doi:10.1080/13607863.2016.1211620

Manitoba Centre for Health Policy. (2011). *Term: Cognitive performance scale*. Retrieved from <http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=104136>

Marquardt, G. (2011). Wayfinding for people with dementia: A review of the role of architectural design. *Health Environments Research & Design Journal*, *4*(2), 75-90.

doi:10.1177/193758671100400207

Marquardt, G., Bueter, K., & Motzek, T. (2014). Impact of the design of the built environment on people with dementia: An evidence-based review. *Health Environments Research & Design Journal*, *8*(1), 127-157. doi:10.1177/193758671400800111

Marquardt, G., & Schmiege, P. (2009). Dementia-friendly architecture: Environments that facilitate wayfinding in nursing homes. *American Journal of Alzheimer's Disease and Other Dementias*, *24*(4), 330-340. doi:10.1177/1533317509334959

Mayhew, M. (2005). The growing challenge of Alzheimer Disease part 2. *The Journal for Nurse Practitioners*, *1*(3), 149-156. doi:10.1016/j.nurpra.2005.09.014

McCurry, S.M., Logsdon, R.G., Teri, L., Gibbons, L.E., Kukull, W.A., Bowen, J.D...Larson, E.B. (1999). Characteristics of sleep disturbance in community-dwelling Alzheimer's

- disease patients. *Journal of Geriatric Psychiatry and Neurology*, 12(2), 53-59.
doi:10.1177/089198879901200203
- McPhee., J.S, French, D.P, Jackson, D., Nazroo, J., Pendleton, N., & Degens, H. (2016). Physical activity in older age: Perspectives for healthy ageing and frailty. *Biogerontology*, 17(3), 567-580. doi:10.1007/s10522-016-9641-0
- Meek, P.D. (2014). Resident and patient elopements: An overview of legal issues and trends. *Journal of Legal Nurse Consulting*, 25 (2), 18-21. Retrieved from <http://web.b.ebscohost.com.proxy2.lib.umanitoba.ca/>
- Miskelly, F. (2004). A novel system of electronic tagging in patients with dementia and wandering. *Age and Ageing*, 33(3), 304–306. doi:10.1093/ageing/afh084
- Mitty, E., & Flores, S. (2007). Assisted living nursing practice: The language of dementia: Theories and interventions. *Geriatric Nursing*, 28(5), 283–288. doi: 10.1016/j.gerinurse.2007.08.009
- Monsour, N., & Robb, S. (1982). Wandering behavior in old age: A psychosocial study. *Social Work*, 27(5), 411-416. Retrieved from <http://www.jstor.org/stable/23714006>
- Moore, H.D., Algase, D.L., Powell-Cope, G., Applegarth, S., & Beattie, E.R.A. (2009). A framework for managing wandering and preventing elopement. *American Journal of Alzheimer's Disease and Other Dementias*, 24(3), 208–219.
doi:10.1177/1533317509332625
- Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L.A. (1994). MDS cognitive performance scale[®]. *Journal of Gerontology*, 49(4), M174–M182.
doi:10.1093/geronj/49.4.m174
- Munhall, P.L. (2012). *Nursing research: A qualitative perspective* (5th ed.). Sudbury,

- MA: Jones & Bartlett Learning.
- O'Connell, B., Crowe, J., Gilbee, A., Johnson, S., Ockerby, C., Ostaszkiwicz, J.,... Tran, C. (2011). *The Tri-focal model of care: Education program for residential aged care*. Geelong, AU: Deakin University.
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13(4), 695-704. Retrieved from <http://nsuworks.nova.edu/tqr/vol13/iss4/8>
- Pahor, M., Guralnik, J.M., Ambrosius, W.T., Blair, S., Bonds, D.E., Church, T.S.,... Williamson, J.D. (2014). Effect of structured physical activity on prevention of major mobility disability in older adults: The LIFE Study Randomized Clinical Trial. *JAMA*, 311(23), 2387–2396. doi:10.1001/jama.2014.5616
- Padilla, D.V., González, M.T.D., Agis, I.F., Strizzi, J., & Rodríguez, R.A. (2013). The effectiveness of control strategies for dementia-driven wandering, preventing escape attempts: A case report. *International Psychogeriatrics*, 25(03), 500–504. doi:10.1017/s1041610212001810
- Passini, R., Pigot, H., Rainville, C., & Tétreault, M.H. (2000). Wayfinding in a nursing home for advanced dementia of the Alzheimer's type. *Environment and Behaviour*, 32(5), 684-710. doi:10.1177/00139160021972748
- Pavey, T.G., Peeters, G., & Brown, W.J. (2015). Sitting-time and 9-year all-cause mortality in older women. *British Journal of Sports Medicine*, 49(2), 95-99. doi:10.1136/bjsports-2012-091676

- Perkins, J., Bartlett, H., Travers, C., & Rand, J. (2008). Dog-assisted therapy for older people with dementia: A review. *Australasian Journal On Ageing*, 27(4), 177-182.
doi:10.1111/j.1741-6612.2008.00317.x
- Polit, D.F., & Beck, C.T. (2017). *Nursing research: Generating and assessing evidence for nursing practice* (10th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Price, J.D., Hermans, D., & Evans J.G. (2001). Subjective barriers to prevent wandering of cognitively impaired people. *Cochrane Database of Systematic Reviews*, 1, 1-12. doi: 10.1002/14651858.CD001932.
- Raetz, J. (2013). A nondrug approach to dementia. *Journal of Family Practice*, 62(10), 548-557.
Retrieved from <http://web.a.ebscohost.com.uml.idm.oclc.org/>
- Rezende, L.F.M., Rey-López, J.P., Matsudo, V.K.R., & Luiz, O.D. (2014). Sedentary behaviours and health outcomes among older adults: A systematic review. *BMC Public Health*, 14, 333-342. doi:10.1186/1471-2458-14-333
- Richards, K.C., & Beck, C.K. (2004). Progressively lowered stress threshold model: Understanding behavioural symptoms of dementia. *American Geriatrics Society*, 52(10), 1774-1775. Retrieved from proxy2.lib.umanitoba.ca/
- Roberts, C. (1999). The management of wandering in older people with dementia. *Journal of Clinical Nursing*, 8(3), 322–323. doi:10.1046/j.1365-2702.1999.0225a.x
- Robinson L, Hutchings D, Corner, L, Beyer F, Dickinson H, Vanoli A,....Bond, J. (2006). A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health Technology*

- Assessment*, 10(26), 1-126. Retrieved from <http://www.journalslibrary.nihr.ac.uk/>
- Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K., & Bond, J. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk & Society*, 9(4), 389–406. doi: 10.1080/13698570701612774
- Robinson, L., Hutchings, D., Dickinson, H.O., Corner, L., Beyer, F., Finch, T.,...Bond, J. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: A systematic review. *International Journal of Geriatric Psychiatry*, 22(1), 9–22. doi:10.1002/gps.1643
- Rodriguez, J. (1993). Resident falls and elopement. *Nursing Homes: Long Term Care Management*, 42(4), 16. Retrieved from <http://web.a.ebscohost.com.uml.idm.oclc.org/>
- Rolland, Y., Gillette-Guyonnet, S., Nourhashémi, F., Andrieu, S., Cantet, C., Payoux, P.,... Vellas, B. (2006). Wandering and Alzheimer's type disease. Descriptive study. *The Internal Medicine Journal*, 24(3), 333s-338s. doi:10.1016/S0248-8663(03)80692-6.
- Rolland, Y., Rival, L., Pillard, F., Lafont, C., Rivère D, Albaréde J, & Vellas, B. (2000). Feasibility [corrected] of regular exercise for patients with moderate to severe Alzheimer disease. *The Journal of Nutrition, Health & Aging*, 4(2), 109-113. Retrieved from <https://www.ncbi.nlm.nih.gov.uml.idm.oclc.org/>
- Rowe, M.A., & Bennett, V. (2003). A look at deaths occurring in persons with dementia lost in the community. *American Journal of Alzheimer's Disease & Other Dementias*, 18(6), 343-348. doi:10.1177/153331750301800612
- Rowe, M.A., Vandever, S.S., Greenblum, C.A., List, C.N., Fernandez, R.M., Mixson,

- N.E., & Ahn, H.C. (2011). Persons with dementia missing in the community: Is it wandering or something unique? *BMC Geriatrics, 11*(1), 1-8. doi:10.1186/1471-2318-11-28
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B. & Burroughs, H. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity, 52*(4), 1893-1907. doi:10.1007/s11135-017-0574-8
- Sellers, D.M. (2006). The evaluation of an animal assisted therapy intervention for elders with dementia in long term care. *Activities, Adaptation, and Aging, 30*(1), 61-67. doi:10.1300/J016v30n01_04
- Shinoda-Tagawa, T., Leonard, R., Pontikas, J., McDonough, J.E., Allen, D., & Dreyer, P.I. (2004). Resident-to-resident violent incidents in nursing homes. *JAMA, 291*(5), 591–598. doi:10.1001/jama.291.5.591
- Silverstein, N.M., Tobin, T.S., & Flaherty, G. (2002). *Dementia and wandering behavior: Concern for the lost elder* [e-book]. Retrieved from <http://web.b.ebscohost.com.uml.idm.oclc.org/>
- Smith, M., Gerdner, L.A., Hall, G.R., & Buckwalter, K.C. (2004). History, development, and future of the progressively lowered stress threshold: A conceptual model for dementia care. *The American Geriatrics Society, 52*(10), 1755-1760. doi: 10.1111/j.15325415.2004.52473.x
- Smith, M., Hall, G.R., Gerdner, L.A., & Buckwalter (2006). Application of the progressively lowered stress threshold model across the continuum of care. *Nursing Clinics of North America, 41*(1), 57-81. doi:10.1016/j.cnur.2005.09.006

- Snellgrove, S., Beck, C., Green, A., & McSweeney, J.C. (2013). Resident-to-resident violence triggers in nursing homes, *Clinical Nursing Research*, 22(4), 461-474. doi: 10.1177/1054773813477128
- Song, J., & Algase, D. (2008). Premorbid characteristics and wandering behavior in persons with Dementia. *Archives of Psychiatric Nursing*, 22(6), 318-327. doi:10.1016/j.apnu.2007.10.008
- Spring, H.J., Rowe, M.A., & Kelly, A. (2009). Improving caregivers' well-being by using technology to manage nighttime activity in persons with dementia. *Research in Gerontological Nursing*, 2(1), 39-48. doi:10.3928/19404921-20090101-10
- Stolley, J.M., Reed, D., & Buckwalter, K.C. (2002). Caregiving appraisal and interventions based on progressively lowered stress threshold model. *American Journal of Alzheimer's disease and other dementia*, 17(2), 110-120. doi:10.1177/153331750201700211
- Sun, Q., Townsend, M.K., Okereke, O.I., Franco, O.H., Hu, F.B., & Grodstein, F. (2010). Physical activity at midlife in relation to successful survival in women at age 70 years or older. *Archives of Internal Medicine*, 170(2), 194-201. doi:10.1001/archinternmed.2009.503
- Tak, S.H., Kedia, S., Tongumpun, T.T., & Hong, S.H. (2015). Activity engagement: Perspectives from nursing home residents with dementia. *Educational Gerontology*, 41(3), 182-192. doi:10.1080/03601277.2014.937217
- Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21(3), 296-306. doi: 10.3109/09638237.2011.651658
- Taylor, A.H., Cable, N.T, Faulkner, G., Hillsdon, M., Narici, M., & Van DerBij, A.K. (2004).

- Physical activity and older adults: A review of health benefits and the effectiveness of interventions. *Journal of Sports Sciences*, 22(8), 703-725. doi: 10.1080/02640410410001712421
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). New York, NY: Routledge Taylor & Francis Group.
- Thorne, S., Kirkham, S.R. & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing Health*, 20(2), 169–177. doi:10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I.
- Thorne, S., Kirkham, S.R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-11. doi:10.1177/160940690400300101
- Tilly, J., & Reed, P. (2008). Falls, wandering, and physical restraints: A review of interventions for individuals with dementia in assisted living and nursing homes. *Alzheimer's Care Today*, 9(1), 45-50. Retrieved from <http://web.a.ebscohost.com.proxy2.lib.umanitoba.ca/>
- Tufford, F., Lowndes, Struthers, & Chivers, (2018). "Call security': Locks, risk, privacy and autonomy in long-term residential care". *Ageing International*, 43(1), 34-52. doi:10.1007/s12126-017-9289-3
- Volicer, L., & Hurley, A.C. (2003). Review article: Management of behavioral symptoms in progressive degenerative dementias. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 58(9), M837–M845. doi:10.1093/gerona/58.9.M837
- Volicer, L., Van Der Steen, J.T., & Frijters, D. (2013). Involvement in activities and wandering

- in nursing home residents with cognitive impairment. *Alzheimer Disease & Associated Disorders*, 27(3), 272-277. doi:10.1097/WAD.0b013e31826d012e
- Whall, A.L., & Kolanowski, A.M. (2004). Special Section—Behavioral symptoms of dementia: their measurement and intervention. Editorial: The need-driven dementia-compromised behavior model—a framework for understanding the behavioral symptoms of dementia. *Aging & Mental Health*, 8(2), 106–108. doi:10.1080/13607860410001649590
- White, E.B., & Montgomery, P. (2014). Electronic tracking for people with dementia: An exploratory study of the ethical issues experienced by carers in making decisions about usage. *Dementia*, 13(2), 216-232. doi:10.1177/1471301212460445
- Whitlatch, C.J., Feinberg, L.F., & Tucke, S.S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*, 45(3), 370–380. doi:10.1093/geront/45.3.370
- Wigg, J.M. (2010). Liberating the wanderers: Using technology to unlock doors for those living with dementia. *Sociology of Health & Illness*, 32(2), 288–303. doi:10.1111/j.1467-9566.2009.01221.x
- Wilson, S.A. (1997). The transition to nursing home life: A comparison of planned and unplanned admissions. *Journal of Advanced Nursing*, 26(5), 864–871. doi:10.1046/j.1365-2648.1997.00636.x
- Winnipeg Regional Health Authority (WRHA). (n.d.). *Long term care program services*. Retrieved from <http://www.wrha.mb.ca/ltc/pch/index.php>
- Woolford, M.H., Weller, C., & Ibrahim, J.E. (2017). Unexplained absences and risk of death and

injury among nursing home residents: A systematic review. *Journal of the American Medical Directors Association*, 18 (4), 366.e1-366.e15.

doi:10.1016/j.jamda.2017.01.007.

World Health Organization (WHO) & Alzheimer's Disease International. (2012). *Dementia: A public health priority*. Retrieved from

http://www.who.int/mental_health/neurology/dementia/en/

World Health Organization (WHO). (2015). *The epidemiology and impact of dementia. Current state and future trends*. Retrieved from

http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf?ua=1

Yamakawa, M., Yoshida, Y., Higami, Y., Shigenobu, K., & Makimoto, K. (2014). Caring for early-onset dementia with excessive wandering of over 30 kilometres per day: A case report. *Psychogeriatrics*, 14(4), 255–260. doi:10.1111/psyg.12075

Yao, L., & Algase, D. (2008). Emotional intervention strategies for dementia-related behaviour: A theory synthesis. *Journal of Neuroscience Nursing*, 40(2), 106-115.

Retrieved from <http://ovidsp.tx.ovid.com.uml.idm.oclc.org/>

Appendices

Appendix A. Recruitment Process for Participants

- 1) Obtained ethical approval from ENREB.
- 2) Requested access to the two LTC homes for the study from the DOC/ADOC. Sent a letter, including a copy of the consent form and ethical approval with preliminary information about the study and staff involvement (screening of residents). The DOC/ADOC identified staff who worked full-time and were familiar with resident care, and were willing to assist in the screening process.
- 3) Obtained WRHA ethical approval.
- 4) Met with the staff who were willing to assist in the screening process to provide the Dewing Wandering Screening Tool (part B), information sheets about the study and any other clarification about the study as needed.
- 5) Screening of the residents by staff to identify potential participants (residents and family members) who met the inclusion criteria.
- 6) Staff provided information sheets about the study, including researcher's contact information to family members. Interested family members were free to contact the researcher to learn more about the study.
- 7) Researcher followed up on family members who showed interest by speaking to them and the residents at the same meeting and requested written consent from family members who also signed on behalf of their relatives. Verbal consent was obtained from the residents.
- 8) A free, fully informed and ongoing verbal consent was obtained from the residents throughout the course of the study

Appendix B. Screening for Wandering (Dewing, 2005)

Table 1 Screening for wandering (Dewing 2005)
Part A (pre-dementia)
<input type="checkbox"/> Does the person have a history of being a regular walker, whether as a hobby or as part of their daily life? Yes/No
<input type="checkbox"/> Has the person regularly used walking as a means of thinking things through, coping, dealing with stress or cooling off? Yes/No
<input type="checkbox"/> Does the person have a history of being extremely sociable or are they known to have an out-going personality? Yes/No
Part B (currently)
In the last year has the person:
<input type="checkbox"/> moved home (or been moved between or within a care setting)? Yes/No
<input type="checkbox"/> shadowed or closely followed a relative/carer around for prolonged periods? Yes/No
<input type="checkbox"/> moved around more frequently and had difficulty in sitting still for more than a few minutes? Yes/No
<input type="checkbox"/> entered into others' personal areas to investigate their belongings or to rummage? Yes/No
<input type="checkbox"/> made attempts to leave a safe place? (Note: the place must be well known to the person) Yes/No
<input type="checkbox"/> left a safe place and got lost? (Note: the place does not have to be known to the person) Yes/No
If the answer to any question in Part A is yes and there is a diagnosis of dementia (especially Alzheimer's), then the person is at risk of wandering or has the potential to wander if they become excessively under or over-stimulated cognitively. Repeat the screening within a specified time period and implement a therapeutic plan to enable safe wandering.
If the answer to any question in Part B is yes, it is highly likely that the person is engaging in one type of wandering and may be at risk or have the potential to undertake a more risky type of wandering. Consider a full assessment, including detailed observation, and implement a therapeutic plan to enable safe wandering.

from the person with dementia's perspective of risk, nor from their perspective of their own well-being (Clarke *et al* 2004) and what they need to do to maintain their well-being (Reed *et al* 2004). In order to maintain self-identity and agency the balance may need to be tipped in favour of risk taking rather

phone with another practitioner, caregiver or family member. This is useful for many community-based practitioners or for those who want to screen for wandering in a structured way prior to admission, especially if something has been found in care records indicating wandering or wandering-related activity. Using a structured tool to screen for wandering can also provide a teaching tool for use with family members and learners, such as nursing students, so that they have an opportunity to develop their understanding of wandering and its characteristics.

Evidence to support use of the screening tool

The tool itself has been developed from an extensive appraisal of the literature on wandering as part of a travel scholarship and a doctoral study investigating wandering, but as yet it has not been empirically tested and is therefore offered here for further critique.

The research literature shows a clear association between wandering and dementia, especially of the Alzheimer's type. Yet not all persons with dementia will wander or wander in a way that is risky to themselves or others. Several possible explanations for wandering have been proposed, including cognitive decline (Logsdon *et al*, 1998 Martino-Saltzman *et al* 1991), agitation (Colombo *et al* 2001), unmet needs (Stokes 2001), personality, spatial deficits and way-finding deficits (Algase *et al* 2003). In part each of these explanations may have something to offer but none of them fully explains wandering and all its types or patterns.

As part of person-centred gerontological practice, screening needs to take account of, and preferably commence with, the person's biography, personality and known routines and lifestyle choices. This screening tool for wandering considers three key biographical and personality factors that are also known to influence wandering and wandering-related activity in dementia. First, people with a known preference for regular walking as part of their life (either work or leisure) have been found to be more likely to wander. Second, walking used regularly as a means of coping, dealing with stress or 'cooling off' is important to note (Coons 1988,

Appendix C. Letter of Permission to Use the Dewing's Wandering Screening Tool

Hello Adebusola

Thank you for both your emails. Well done on making the effort to contact and network with me.

I'm delighted that you are researching the topic of wander-walking. I tend now to refer to it in this way now, to try and normalise it more. Therefore, I also avoid thinking and calling wander-walking a behaviour as it is a complex human activity. Maybe something for you to think over? However, its wonderful to see you taking an interest in this topic and I wish you well for your study. Please get in touch if I can be of further assistance.

I am giving you permission to use my screening tool on the three conditions you set out in your email:

- I will use the tool only for the purpose of my research study.
- I will include the copyright statement on all the copies of the tool
- I will send a copy of my completed research study to your attention upon completion of the study.

I especially look forward to reading your study and seeing how useable the tool is and what your recommendations are for its future development. I have taken the liberty of attaching summary of my doctoral research that you might like to read.

Kind regards Jan

Professor Jan Dewing

Sue Pembrey Chair of Nursing & Director of The Centre for Person-centred Practice Research

Division of Nursing

School of Health Sciences

Queen Margaret University

Queen Margaret University Drive

Musselburgh

East Lothian

EH21 6UU

Email: JDewing@qmu.ac.uk

Tel: +44 (0) 7985181615

http://www.qmu.ac.uk/research_knowledge/centre-for-person-centred-practice-research.aspx?quicklinks=Null&sa=GO

Professor II

Bergen & Stord Haugesund University Colleges Norway

Visiting Professor

Google Chrome

Appendix D. Letter to the Director of Care (DOC)



UNIVERSITY
OF MANITOBA

[insert date]

Address of the PCH

College of Nursing

Request for Access into Personal Care Home (PCH) and Assistance

Dear [insert name of the DOC],

I am a Master's student from the College of Nursing, Rady Faculty of Health Sciences, University of Manitoba. I am requesting access into your facility and the assistance of your staff in recruiting participants for my research project. The title of my research project is "Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate Dementia in Long-term Care Homes", under the supervision of Dr. Lorna Guse. The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults living with mild to moderate dementia residing in long-term homes (also known as personal care homes) and their family members. Ethical approval has been obtained from the University of Manitoba Education Nursing Research Ethics Board for this research project. I am requesting permission to do this research project in your personal care home (PCH).

I will like to request the assistance of your staff members who are familiar with resident care to screen potential resident participants for the research project. Two groups of participants will be participating in this research project: 6-10 residents living with dementia who exhibit wandering behaviour, and their family members (6-10). Inclusion criteria include, residents living with mild to moderate dementia who exhibit wandering behaviour: 1) 65 years of age or older; 2) can answer simple questions (based on clinical judgment and a score of 1 to 3 on their Cognitive Performance Scale (CPS) in the Minimum Data Set; and 3) have a family member who visits more than once a month. Family members can include friends as long as they are the ones who can sign on behalf of the residents who are not capable of giving written consent. Exclusion criteria are older adults who are experiencing severe anxiety, walking impairment, psychosis, who tend to shadow, and who have no family members other than the public trustees will also be excluded.

Staff members who are willing to participate in this research project will be asked to complete Dewing wandering screening tool, part B (see attached). Staff will also be asked to provide an information sheet (see attached) that describes the research project and the researcher's and her supervisor's contact information to family members. A poster (see attached) about the research project will also be posted in the PCH. The researcher would like to attend the Resident and

Family Councils to provide information about the research project. Interested family members are free to contact the researcher or her supervisor to learn more about the research project. If family members prefer to have staff members give the researcher their contact information, this will be acceptable.

Please also find attached to this letter a copy of the ethical approval and the consent forms for the project.

Upon completion of the project, feedback/summary of findings about the research project will be provided to resident and family participants within four weeks and two months and explained as needed. Summary of findings will also be given to the staff and Resident and Family Council. If you require any further information, please don't hesitate to contact me at [REDACTED] or umadekoa@myumanitoba.ca or my supervisor, Dr. Guse at 204 474-8113 or lorna.guse@umanitoba.ca. or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca.

Please complete the following sections below if you are interested in supporting this project in your PCH and email one copy of this letter to me.

I agree to the following:

My staff will assist with screening and provide an information sheet to residents and families.

Yes No

A poster explaining the project may be posted in the PCH

Yes No

The researcher will be allowed to the Resident and Family Council to explain the project.

Yes No

Director's signature _____ Date _____

Researcher's signature _____ Date _____

Thank you for your time and consideration.

Sincerely,

Adebusola Adekoya.

Appendix E. Research Project Information Sheet

College of Nursing



UNIVERSITY
OF MANITOBA

Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate Dementia in Long-term Care Homes.

Residents and family members are invited to participate in a research project at _____ personal care home (PCH). The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults living with dementia residing in PCHs and their family members.

We are looking for resident participants who:

- are 65 years of age or older living with dementia
- like to walk and wander on the units
- can answer simple questions in English
- have a family member who visits more than once a month.

As a resident participant, you will be invited for an interview or series of interview, depending on your preferences, which will be done while the researcher walks with you. The researcher will be asking you questions about the nature of your walking.

As a family member participant, you will be invited for an interview, estimated to take 20-30 minutes to provide information about your relative's life history and past walking history.

In appreciation for your time, all participants will receive a \$5 gift card.

If you would like to participate in this research project or have questions, please do not hesitate to call the researcher, Adebisola Adekoya, at [REDACTED] or umadekoa@myumanitoba.ca or the research supervisor, Dr. Lorna Guse at 204 474-8113 or lorna.guse@umanitoba.ca.

This research has been approved by the University of Manitoba Education Nursing Research Ethics Board. Complaints and concerns can be directed to the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca.

Appendix F. Poster on Research Project



College of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone 204-474-7452
Fax 204-474-7682

Wandering Behaviour from the Perspectives of Older Adults Living with Mild-Moderate Dementia in Long-term Care Homes




Residents and family members are invited to participate in a research project at [REDACTED]. The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults living with dementia residing in PCHs and their family members.

As a resident participant, you will be invited for an interview or series of interview, depending on your preferences, which will be done while the researcher walks with you. The researcher will be asking you questions about the nature of your walking.

As a family member participant, you will be invited for an interview, estimated to take 20-30 minutes to provide information about your relative's life history and past walking history.

In appreciation for your time, all participants will receive a \$5 gift card.

If you would like to participate in this research project or have questions, please do not hesitate to call the researcher, Adebisola Adekoya, at [REDACTED] or umadekoa@myumanitoba.ca or the research supervisor, Dr. Lorna Guse at 204 474-8113 or lorna.guse@umanitoba.ca.

This research has been approved by the University of Manitoba Education Nursing Research Ethics Board. Complaints and concerns can be directed to the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca.

Appendix G.1. Information and Written Consent Form (Resident Participant)



College of Nursing

Research Project Title: Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate Dementia in Long-term Care Homes.

Researcher (Principal Investigator) and Contact Information: Adebusola Adekoya
Master's Student, College of Nursing
Rady Faculty of Health Sciences, University of Manitoba.

Research Supervisor and Contact Information: Dr. Lorna Guse
Associate Professor, College of Nursing, Rady Faculty of Health Sciences
Room 383, Helen Glass Centre for Nursing, 89 Curry Place
University of Manitoba, Winnipeg, MB, R3T 2N2
204 474-8113

Sponsor: Fort Garry Legion Poppy Trust Fund Research Grant

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Please be rest assured that your participation is voluntary and will not affect the care that you are receiving in this personal care home (PCH), [REDACTED]

Purpose of the Research

The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults like you who are living with dementia in long-term care (LTC) homes and their family members.

Research Procedures

In this research project, you will be invited for an interview or several interviews, which will be done while the researcher walks with you. This type of interview is called a walking interview and allows the researcher to accompany you and observe while having conversations with you about the nature of your walking. This will help the researcher to gain a better understanding about why you walk from your perspective. However, if at any time, you do not want the researcher to walk with you, and you indicate this by saying it or showing discomfort, the researcher will leave. In case you are showing any form of discomfort, the researcher will notify your nurse and ensure that you are attended to. The researcher will also follow up with you to ask how you are feeling and if it is okay to keep walking with you and asking questions. During the walking interview, it is possible that others such as staff, family member, or other residents may hear our conversations.

The walking interview will be audio-taped and may take place over a few days or a few weeks (the total time involved is not known at this stage) depending on your preference. Prior to the interview, the researcher will spend about 1-2 days with you to get to know you and help familiarize herself with you. Examples of questions that the researcher will ask during the walk include: “Do you enjoy walking?” “Are you bored?” “Are you in pain?” “How are you feeling about walking right now?” and “Does walking make you feel good?” Your family member will also be invited for an interview which will be audio-taped and is estimated to take 20-30 minutes to provide information about your age, gender, marital status, date of admission, use of hearing/visual aids, health status, memory and life history, including personality, previous hobbies and history of walking. Knowing your life history will help the researcher to get to know you more.

Feedback about the research project will be given to you and your family member after data collection by the researcher in a room in [REDACTED]. A brief (1-3 pages) summary of results will be provided (usually between four weeks to two months) after the completion of the project by 11/2017 via email or mail depending on your preference.

You can withdraw from this project at any time without penalty by telling the researcher in person, by telephone, or by email. The data collected will be destroyed unless you give permission to keep it in the project.

Risks and Discomforts

There are no risks to you for participating in this research project. The risks are the everyday risks that you would experience as you walk in the PCH home. If you feel uncomfortable, the researcher will leave. You can stop participating in the project if you are experiencing any discomfort while participating in the project. The researcher will ask you from time to time if it is okay to keep walking with you and asking questions.

Benefits

There will not be a direct benefit to you and your family member from participating in this research project. You and your family member will be given a \$5 gift card each as a token of appreciation. If you decide to withdraw from the project, you will still get the gift card.

Costs

There is no cost for participating except than your time spent while with the researcher.

Confidentiality

All the information that is collected from you and your family member will be kept confidential. All interviews with you and your family members will be audio-taped and transcribed by a transcriptionist and the transcriptionist will sign a pledge of confidentiality. The tapes will be destroyed by erasure once transcription is completed. You and your family member will be assigned an identification (ID) number and the paper linking your names and numbers will be placed in a locked cabinet separately from where the hard copies of transcribed interviews are stored and will only be accessed by the researcher. All transcribed interviews will be saved in an encrypted flash drive and kept confidential and secure in a locked cabinet in the researcher's home and the supervisor's office (383 Helen Glass Centre of Nursing). Only the researcher, Adebisola Adekoya and her supervisor, Lorna Guse will have access to the encrypted flash drive. The computer where all your information is stored will be secured with passwords and the researcher is the only one with access to her computer. All confidential data collected from you and your family member will be stored for seven years and then destroyed by erasure or shredding (hard copies) by 09/2024. Information gathered in this research project may be published or presented in public forums such as PCHs, Resident and Family Councils, and academic conferences. A Facebook page or YouTube video may also be created. However, your name and other identifying information will not be used or revealed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial

consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the University of Manitoba Education Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Resident Participant's signature _____ Date _____

Researcher's signature _____ Date _____

I wish to receive a summary of findings:

Yes, please send them by email ground at the address given below.

No

Appendix G.2. Joint Consent Form (Resident and Family Participants)



College of Nursing

Research Project Title: Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate Dementia in Long-term Care Homes.

Researcher (Principal Investigator) and Contact Information: Adebusola Adekoya
Master's Student, College of Nursing
Rady Faculty of Health Sciences, University of Manitoba.
[REDACTED]

Research Supervisor and Contact Information: Dr. Lorna Guse
Associate Professor, College of Nursing, Rady Faculty of Health Sciences
Room 383, Helen Glass Centre for Nursing, 89 Curry Place
University of Manitoba, Winnipeg, MB, R3T 2N2
204 474-8113

Sponsor: Fort Garry Legion Poppy Trust Fund Research Grant

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

All information contained in this form will be explained to you word for word. Your family member will sign this form on your behalf as needed. Please be rest assured that your participation is voluntary and will not affect the care that you are receiving in this personal care home (PCH), the [REDACTED]

Purpose of the Research

The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults like you who are living with dementia in long-term care (LTC) homes and their family members.

Research Procedures

In this research project, you will be invited for an interview or several interviews, which will be done while the researcher walks with you. This type of interview is called a walking interview and allows the researcher to accompany you and observe while having conversations with you about the nature of your walking. This will help the researcher to gain a better understanding about why you walk from your perspective. However, if at any time, you do not want the researcher to walk with you, and you indicate this by saying it or showing discomfort, the researcher will leave. In case you are showing any form of discomfort, the researcher will notify your nurse and ensure that you are attended to. The researcher will also follow up with you to ask how you are feeling and if it is okay to keep walking with you and asking questions. During the walking interview, it is possible that others such as staff, family member, or other residents may hear our conversations.

The walking interview will be audio-taped and may take place over a few days or a few weeks (the total time involved is not known at this stage) depending on your preference. Prior to the interview, the researcher will spend about 1-2 days with you to get to know you and help familiarize herself with you. Examples of questions that the researcher will ask during the walk include: “Do you enjoy walking?” “Are you bored?” “Are you in pain?” “How are you feeling about walking right now?” and “Does walking make you feel good?” Your family member will also be invited for an interview which will be audio-taped and is estimated to take 20-30 minutes to provide information about your age, gender, marital status, date of admission, use of hearing/visual aids, health status, memory and life history, including personality, previous hobbies and history of walking. Knowing your life history will help the researcher to get to know you more.

Feedback about the research project will be given to you and your family member after data collection by the researcher in a room in the [REDACTED]. A brief (1-3 pages) summary of results will be provided (usually between four weeks to two months) after the completion of the project by 11/2017 via email or mail depending on your preference.

You and your family member can withdraw from this project at any time without penalty by telling the researcher in person, by telephone, or by email. The data collected will be destroyed unless you and your family member give permission to keep it in the project.

Risks and Discomforts

There are no risks to you for participating in this research project. The risks are the everyday

risks that you would experience as you walk in the PCH home. If you feel uncomfortable, the researcher will leave. You can stop participating in the project if you are experiencing any discomfort while participating in the project. The researcher will ask you from time to time if it is okay to keep walking with you and asking questions.

Benefits

There will not be a direct benefit to you and your family member from participating in this research project. You and your family member will be given a \$5 gift card each as a token of appreciation. If you decide to withdraw from the project, you will still get the gift card.

Costs

There is no cost for participating except than your time spent while with the researcher.

Confidentiality

All the information that is collected from you and your family member will be kept confidential. All interviews with you and your family members will be audio-taped and transcribed by a transcriptionist and the transcriptionist will sign a pledge of confidentiality. The tapes will be destroyed by erasure once transcription is completed. You and your family member will be assigned an identification (ID) number and the paper linking your names and numbers will be placed in a locked cabinet separately from where the hard copies of transcribed interviews are stored and will only be accessed by the researcher. All transcribed interviews will be saved in an encrypted flash drive and kept confidential and secure in a locked cabinet in the researcher's home and the supervisor's office (383 Helen Glass Centre of Nursing). Only the researcher, Adebisola Adekoya and her supervisor, Lorna Guse will have access to the encrypted flash drive. The computer where all your information is stored will be secured with passwords and the researcher is the only one with access to her computer. All confidential data collected from you and your family member will be stored for seven years and then destroyed by erasure or shredding (hard copies) by 09/2024. Information gathered in this research project may be published or presented in public forums such as PCHs, Resident and Family Councils, and academic conferences. A Facebook page or YouTube video may also be created. However, your name and other identifying information will not be used or revealed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the University of Manitoba Education Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Resident Participant's signature (if able) _____ Date _____

Family Participant's signature _____ Date _____

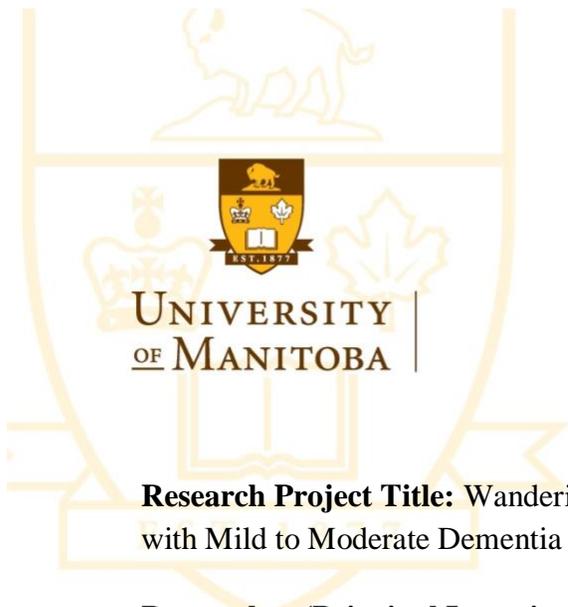
Researcher's signature _____ Date _____

I wish to receive a summary of findings:

Yes, please send them by email ground at the address given below.

No

Appendix G.3. Information and Written Consent Form (Family Participant)



College of Nursing

Research Project Title: Wandering Behaviour from the Perspectives of Older Adults Living with Mild to Moderate Dementia in Long-term Care Homes.

Researcher (Principal Investigator) and Contact Information: Adebusola Adekoya
Master's Student, College of Nursing,
Rady Faculty of Health Sciences, University of Manitoba

Research Supervisor and Contact Information: Dr. Lorna Guse
Associate Professor, College of Nursing, Rady Faculty of Health Sciences
Room 383, Helen Glass Centre for Nursing, 89 Curry Place
University of Manitoba, Winnipeg, MB, R3T 2N2 204 474-8113

Sponsor: Fort Garry Legion Poppy Trust Fund Research Grant

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Please be rest assured that your participation is voluntary and will not affect the care that your family member is receiving in this personal care home (PCH), the [REDACTED]

Purpose of the Research

The purpose of this research project is to gain a better understanding about wandering behaviour through the perspectives of older adults who are living with dementia in long-term care (LTC) homes and their family members.

Research Procedures

In this research project, you will be invited for an interview which will be audio-taped to provide information about your family member such as age, gender, marital status, date of admission, use of hearing/visual aids, health status, memory, and life history, including personality, previous hobbies and history of walking. Your participation in this research project will take 20-30 minutes in a room in the [REDACTED] or another mutually agreeable locations. Please be rest assured that your participation is voluntary and your decision to participate or not to participate will not affect the care your family member is receiving.

Knowing the life history of your family member will help the researcher to get to know them more. Your family member will also be invited for an interview, which will be done while walking with them. This type of interview is called a walking interview and allows the researcher to accompany your family member and observe while having conversations about the nature of their walking. This will help the researcher to gain a better understanding about why your family member walks from their perspective. This interview will be conducted over a few days or a few weeks (the total time involved is not known at this stage) depending on your family member's preference and will be audio-taped. Prior to the interview, the researcher will spend about 1-2 days with your family member to get to know them and help familiarize herself with them. Examples of questions that the researcher will ask during the walk include: "Do you enjoy walking?" "Are you bored?" "Are you in pain?" and "Does walking make you feel good?".

Feedback about the research project will be given to you and your family member after data collection by the researcher in a room in the [REDACTED]. A brief (1-3 pages) summary of results will be provided (usually between four weeks to two months) after the completion of the project by 11/2017 via email or mail depending on your preference.

You can withdraw from this project at any time without penalty by telling the researcher in person, by telephone, or by email. The data collected will be destroyed unless you give permission to keep it in the project.

Risks and Discomforts

No risks are anticipated in this research project. The risks are the everyday risks that your family member would experience as they walk in the PCH home. The researcher will ask your family member from time to time if it is okay to keep walking with them and asking questions. If your family member feel uncomfortable, the researcher will leave. You or your family member can stop participating in the project if you are experiencing any discomfort while participating in the project.

Benefits

There will not be a direct benefit to you and your family member from participating in this research project. You and your family member will be given a \$5 gift card each as a token of appreciation. If you decide to withdraw from the project, you will still get the gift card.

Costs

There is no cost for participating except than your time spent while with the researcher.

Confidentiality

All the information that is collected from you and your family member will be kept confidential. All interviews with you and your family members will be audio-taped and transcribed by a transcriptionist and the transcriptionist will sign a pledge of confidentiality. The tapes will be destroyed by erasure once transcription is completed. You and your family member will be assigned an identification (ID) number and the paper linking your names and numbers will be placed in a locked cabinet separately from where the hard copies of transcribed interviews are stored and will only be accessed by the researcher. All transcribed interviews will be saved in an encrypted flash drive and kept confidential and secure in a locked cabinet in the researcher's home and the supervisor's office (383 Helen Glass Centre of Nursing). Only the researcher, Adebisola Adekoya and her supervisor, Lorna Guse will have access to the encrypted flash drive. The computer where all your information is stored will be secured with passwords and the researcher is the only one with access to her computer. All confidential data collected from you and your family member will be stored for seven years and then destroyed by erasure or shredding (hard copies) by 09/2024. Information gathered in this research project may be published or presented in public forums such as PCHs, Resident and Family Councils, and academic conferences. A Facebook page or YouTube video may also be created. However, your name and other identifying information will not be used or revealed.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the University of Manitoba Education Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Family Participant's signature _____ Date _____

Researcher's signature _____ Date _____

I wish to receive a summary of findings:

Yes, please send them by email ground at the address given below.

No

Appendix H. Resident Participants Interview Items (including probes)

1. Are you going somewhere? (Where are you going?)
2. Where are you off to? (Can I go there with you?)
3. Do you enjoy walking? (Why do you enjoy it? Or not enjoy it)
4. Are you bored? (Is there something that you would like to do? What is it?)
5. Does walking make you feel good? (Why does it make you feel good? Or not good?)
6. Do you need something? (Are you hungry? Thirsty?)
7. Are you looking for something? (Please tell me what you are looking for? Maybe I can help you find it.)
8. What's down there? (Down the hall?) (Is there something that you need to find? What is it?)
9. Are you in pain? (Where does it hurt? Please show me where it hurts?)
10. Do you have to use the toilet? (Are you looking for a toilet?)
11. How are you feeling about walking right now? (Good? Bad? Tired? Upset? Angry?)
12. Are you sad? (Does walking take the edge off so you are not focused on your mood?)
13. Are you nervous about something? (Does walking keep you calm?)
14. Do you feel worried? (Does walking make you less worried?)
15. Why do you walk?

Other probes will be used depending on responses.

Good _____ Fair _____ Poor _____

(Do you have any specific concerns about your family member's health? What are your concerns?)

11. How do you describe your family member's overall memory? Excellent _____ Very good _____

Good _____ Fair _____ Poor _____

(Do you have any specific concerns about your family member's memory? What are your concerns?)

12. How important was walking in your family member's earlier life?

1= not important |-----| 10=very important
 1 2 3 4 5 6 7 8 9 10

(Was walking part of your family member's work life? Was walking part of your family member's leisure activities?)

13. In the PCH, how important is walking currently in your family member's life?

1= not important |-----| 10=very important
 1 2 3 4 5 6 7 8 9 10

14. Do you have any safety concerns about the PCH environment and your family member's walking? (Do you think your family member might need more or less or about the same staff supervision during walking?)

15. Does your family member ever walk into other residents' rooms? (If so, is this a concern for you?)

16. Has your family member ever attempted to leave or actually left the PCH? (If so, is this a concern for you?)

Appendix J. Pledge of Confidentiality



Rady Faculty of
Health Sciences

College of Nursing

I, _____, employee of _____,
agree to maintain full confidentiality in regards to any and all research and quality assurance data
received in the course of my work as an employee.

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be intentionally or inadvertently revealed during the collection or handling of research and quality assurance data, or in any associated documents.
2. To store all research and quality assurance data and materials in a safe, secure location as long as they are in my possession.

I am aware that I may be held responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the research and quality assurance data to which I will have access.

Staff Member's Signature

Staff Member's Name (printed)

Date: _____

Appendix K. Research Ethics Board Certificate of Approval



UNIVERSITY
OF MANITOBA

Research Ethics
and Compliance

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

PROTOCOL APPROVAL

TO: **Adebusola Adekoya** (Advisor: Lorna Guse)
Principal Investigator

FROM: **Todd Duhamel, Vice Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2017:061 (HS20991)**
**“Wandering Behaviour from the Perspectives of Older Adults Living with
Mild-Moderate Dementia in Long-term Care Homes”**

Effective: July 19, 2017

Expiry: July 19, 2018

Education/Nursing Research Ethics Board (ENREB) has reviewed and approved the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Approval is granted only for the research and purposes described in the application.
2. Any modification to the research must be submitted to ENREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
5. A Study Closure form must be submitted to ENREB when the research is complete or terminated.
6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

Funded Protocols:

- **Please mail/e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer in ORS.**