# “Women who made it ‘Home’”: An Exploratory Study of the Experiences of Cognitively Well Women Living in Long-Term Care with Cognitively Impaired Older Adults

By

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# Abstract

The meaning of ‘home’ for older adults in long-term care (LTC) settings is not well understood. Furthermore, how living with cognitively impaired older adults may affect the meaning of ‘home’ is under researched. The goal of this study was to explore how living with cognitively impaired older adults affects the meaning of ‘home’ for cognitively well female older adults residing in LTC. A convenience sample of eleven female cognitively well older adults was selected from four LTC settings in Winnipeg, Manitoba, Canada. The eleven women were interviewed to determine their meaning of ‘home’ prior to and following placement in the LTC setting. Two key questions posed to the women were, *“Do you consider (name of LTC setting) to be ‘home’?”* and *“How does living with confused people affect the meaning of home?”* Eight of the women considered the LTC setting where they reside to be ‘home’. Nine of the women indicated that living with cognitively impaired older adults does not affect their meaning of ‘home’. These findings suggest two things. First, that most cognitively well female older adults create a new ‘home’ for themselves when they move to the LTC setting. Second, that many cognitively well female older adults demonstrate compassion and acceptance of living with fellow residents who have cognitive impairment and may exhibit disruptive behaviours.

# Chapter One: Introduction

The purpose of this study is to explore the lived experience of cognitively well older female adults residing with cognitively impaired older adults in some of the long term care (LTC) settings in Winnipeg, Manitoba, Canada. This study examines how living everyday life in this environment affects the meaning of ‘home’ for cognitively well older female adults. This chapter includes: the statement of the problem; the research goals, objectives, and assumptions; the significance of the research; and a summary.

## Statement of the Research Problem

The life experience of cognitively well older female adults in the LTC setting has not garnered much research attention. In 2010, cognitively well older female adults in the LTC setting have little or no voice albeit not for the efforts of American researchers such as Gubrium (1993), Fiveash (1998) and Hammer (1999). Gubrium (1993) and Hammer (1999) reported that between 50-60 percent of older adults in the LTC setting do not feel that they can call the LTC setting in which they reside ‘home’. Fiveash (1998) reported that some older adults found living in the LTC setting constraining and dehumanizing. All three researchers provided a rich description of the lives of their subjects in LTC settings. In Canada, the lives and characteristics of older adults in the LTC setting will be examined through the research of Levesque, Cossette and Potvin (1993) and Chappell and Reid (2000) as well as through other sources such as Health Canada (2002), The Alzheimer’s Society of Canada (2008) and the Winnipeg Regional Health Authority (WRHA) (2008).

Since Gubrium’s (1993), Fiveash’s (1998) and Hammer’s (1999) research, the characteristics of older adults in LTC settings has changed dramatically, which among other factors, can be attributed to population aging (Chappell & Reid, 2000). According to the United Nations (2002) even though the segment of the population known as older persons is growing rapidly in less industrial regions of the world, the more industrial regions currently have the highest proportions of older persons. According to the World Health Organization (WHO) (2010), population aging is occurring in almost every country around the world. Although most of this increase is evident in developing countries, population aging is considered a global phenomenon (United Nations, 2002; WHO, 2010). Population aging is occurring as a result of declining fertility rates and longer life expectancy (United Nations, 2002; WHO, 2010). Adults who are 65 years and older are currently the fastest growing segment of the population in Canada (Health Canada, 2002). Health Canada (2002) predicts that seniors 85 years and older will reach 1.6 million by 2041, making up 4 percent of the overall Canadian population. On a global perspective, from 2000 until 2050, the WHO (2010) predicts that the world’s population aged 60 and over will rise from 600 million to 2 billion. The relevance of these numbers relates to all aspects of health systems and health care delivery from local to global scales.

A key health issue related to population aging is the prevalence of Alzheimer’s disease and related dementias. The Alzheimer’s Society of Canada (2008) estimates that in the year 2008 there were 547, 000 Canadians over 65 with Alzheimer's disease or a related dementia. That number is the equivalent of one in 13 Canadians. Among the oldest-old, that is, those who are 85 years and older, one in three Canadians have Alzheimer's disease or a related dementia (Alzheimer’s Society, 2008). According to the Alzheimer’s Society of the United Kingdom (2008), there are currently more than 24 million people in the world with Alzheimer's or a related disease and this number is estimated to rise to 80 million by the year 2040. This is out of a global population of 8.58 billion (United Nations, 2009) thus as the population ages so follows an increased prevalence of Alzheimer’s disease and related dementias.

The cognitive impairment that accompanies Alzheimer’s disease and related dementias has been associated with behavioural symptoms such as wandering, agitation, and aggression, as well as, vocalizations that are known to be disturbing, disruptive and antisocial and are predictive of placement in LTC settings (National Advisory Council on Aging, 1996). In LTC settings more than twice as many older adults have some form of dementia than those who do not (The Alzheimer’s Society of Canada, 2007; Conn, 2002; Hunt, 2007; Gruber-Baldini, Stuart, Zuckerman, Simoni-Wastila, & Miller, 2007). In Manitoba the Winnipeg Regional Health Authority (WRHA) LTC settings have approximately 70 percent of older adult residents who have some form of dementia (WRHA, 2008).

Specifically in Winnipeg, Manitoba, from 2004 to 2007, 47.4 percent of older adults in LTC settings had a diagnosis of dementia, not including Alzheimer’s disease (WRHA, 2008). In Winnipeg LTC settings, 12.5 percent of older adults were cognitively intact, 14 percent had very mild cognitive impairment, 11.8 percent had mild cognitive impairment, 28.5 percent had moderate cognitive impairment, 5.3 percent had moderate to severe cognitive impairment, 15.9 percent had severe cognitive impairment, and 12 percent had very severe cognitive impairment (WRHA, 2008). Not including very mild cognitive impairment, 73.5 percent of older adult LTC residents were considered to have significant cognitive impairment (WRHA, 2008). These numbers are based on data collected from non- proprietary[1] personal care homes (PCH) and do not include older adults from proprietary personal care homes as the software assessment tool (resident assessment instrument minimum data set (RAI-MDS)) used to collect the data had not been implemented in the proprietary PHCs at the time of the report (WRHA, 2008). The total number of PCHs in the WRHA is 38, of which the majority (n = 25) are proprietary.

During the last forty years in the United States, the integration of cognitively impaired older adults into living spaces with cognitively well older adults in the LTC setting is a result of mental health hospital closures and LTC older adults getting older and thus more at risk for cognitive decline (Riter, 1995). The usual practice has been to segregate older adults with the most severe behavioural symptoms into special care units (SCU). The SCUs generally have a small bed capacity, provide higher staff-to-resident ratios, and operate with knowledgeable caregivers to meet the needs of the older adults who present challenging behaviours. Although it is less common, some LTC settings have units reserved for cognitively well older adults. In these LTC settings, there is not always sufficient space for the demand resulting in the integration of cognitively impaired older adults with cognitively well older adults. Segregating cognitively impaired older adults from cognitively well older adults has not been a standard practice in the LTC setting (Riter, 1995).

## Research Goals and Objectives

How does the experience of residing with cognitively impaired older adults affect the meaning and essence of ‘home’ for cognitively well older adults? Neither the

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[1] Personal Care Homes (PCH) are residential facilities for predominantly older persons with chronic illness or disability, also known as nursing homes. They may be proprietary (for profit) or non-proprietary. Non-proprietary PCHs may further be classified as secular or ethno-cultural (associated with a particular religious faith or language other than English) as well as either freestanding or juxtaposed with an acute care facility.

meaning of ‘home’ for cognitively well older adults residing in the LTC setting nor the meaning of ‘home’ for cognitively impaired older adults residing in the LTC setting has been widely studied. Nonetheless, this study addresses the perceptions, the meaning, and the essence of ‘home’ for cognitively well older female adults in LTC settings who cohabit with cognitively impaired older adults.

The goal of this study was to examine the experience of ‘home’ for cognitively well older female adults who live in LTC settings with other older adults who have Alzheimer’s disease or a related dementia. The lived experience of cognitively well older adults who cohabit with cognitively impaired older adults is essential information to provide guidance to decision-makers who set policy to improve the lives of all older adults in LTC settings.

The following objectives guide the research:

1. To examine the perspective of the meaning of ‘home’ prior to and after LTC setting admission amongst cognitively well female older adults.
2. To explore the lived experience of cognitively well female older adults in the LTC setting.
3. To explore how living with cognitively impaired older adults affects day-to-day life of cognitively well older female adults.
4. To explore how living with cognitively impaired older adults affects the meaning of ‘home’ for cognitively well older female adults.

The research sample is eleven cognitively well female older adults in four non-proprietary LTC settings in Winnipeg who were interviewed face-to-face during December of 2009. The investigator explored six domains related to the concept of ‘home’ drawn from the literature: the physical, social, spiritual, spatial, temporal, and emotional (Angus, Kontos, Dyck, Mckeever, & Poland, 2005; Brummett, 1997; Dyck, Kontos, Angus, & McKeever, 2005**;** Dovey, 1985; Hammer, 1999; Hepworth, 1999**;** Werner, Altman, & Oxley, 1985), which were used as a guiding framework for the interview questions and data analysis.

The literature review for this study revealed that some research had been conducted on the meaning of ‘home’ in the LTC setting (Werner, Altman, & Oxley, 1985; Brummett, 1997; de Veer & Kerkstra, 2001; Gubrium, 1993; Hammer, 1999; Kahn, 1999). In addition, other research had been conducted on how living with cognitively impaired older adults affects day-to-day life of those who are cognitively well (Gorman, 1996; Teresi, Holmes, & Monaco, 1993). Conversely, scant research has examined the lived experience of the cognitively well resident in the LTC setting (Fiveash, 1998; Gubrium, 1993) and no research was found on how living with cognitively impaired older adults in LTC settings, affects the meaning of ‘home’ for cognitively well older adults.

### Research Assumptions

Two assumptions must be declared from the outset. The following assumptions held by the investigator originated from work experience in one of the larger LTC settings in Winnipeg, Manitoba for five years as a Unit Coordinator. A Unit Coordinator is responsible for the care of older adults in a designated unit including directing, coordinating, and managing care and activities in meeting the psychosocial, physical, and spiritual needs of the residents. Observations made during this period lead the investigator to assume that cognitively well older adults experienced significant stress and dissatisfaction from living with cognitively impaired older adults. This prompted the investigator to question whether or not cognitively well older adults could ever feel and accept the LTC setting as their ‘home’. For the first assumption, the investigator believed that cognitively well older adults might feel at ‘home’ and call the LTC setting ‘home’ provided all older adults living together were cognitively well. The second assumption held by the investigator was that if given the choice to live within a homogeneous population or to live within an integrated population that cognitively well older adults would choose to reside within a homogeneous population of residents like themselves.

## Significance of this Research

Previous research has explored how multiple factors affect the meaning of ‘home’ for older adults in the LTC setting, (Gubrium, 1993); yet, there has been little interest in the impact of a single factor, such as living with cognitively impaired older adults. Imrie (2004) examined disability, embodiment and the meaning of ‘home’ although not just in the LTC setting. Angus, Kontos, Dyck, McKeever, and Poland (2005) investigated the personal significance of ‘home’ however this study focused on receiving long-term ‘home’ care in the community, and not life in the LTC setting. Hammer (1999) explored the systems of meaning that older adults establish when they relocate to alternative care settings. In that work, the alternative care settings were not LTC settings exclusively. This literature provides a wealth of information on the meaning of ‘home’; however such studies often have a broad scope of interest and diverse settings, rather than a specific lens into LTC life. Thus there is a clear need for this study.

There has been related research conducted on the concept of ‘home’ and the LTC setting however the focus has been on other subject matter such as; integration versus

Special Care Units (SCU) from the perspectives of older adults, staff, family members, and the environment (Morgan, Stewart, D’Arcy & Werezak, 2004); predictors of satisfaction (Lee, Lee & Woo, 2005); attitudes, environmental structure and routine: an administrator’s perspective (Samuelson, 2003); how segregation and integration help cognitively impaired older adults (Haitsma, Lawton, & Lkeban, 2000); how the concept of ‘home’ in nursing homes has been realized in common living areas (Hauge & Haggen, 2007); the health of older adults with and without supports (Zurakowski, 2000); and coping and adjusting with the transition to a nursing home (Porter & Clinton, 1992). Although these studies provide insights into aspects of life in the LTC setting, the findings are not directly applicable to this study because these studies do not address the meaning of ‘home’ from the perspective of cognitively well older adults.

Little is known about how cognitively well older adults are adjusting and transitioning to living in the LTC setting while cohabiting with cognitively impaired older adults. The impact of this experience on the essence of ‘home’ for cognitively well older adults is unknown. This study addresses the knowledge gap that exists and it contributes to the understanding of how cohabiting with cognitively impaired older adults influences the meaning of ‘home’ for cognitively well older adults in the LTC setting.

Nurses play a primary role in responding to the needs of all older adults living in the LTC setting. Findings from this research can educate nurses by giving voice to cognitively well older adults living in the LTC setting. This research also provides guidance to health care professionals, administrators, and politicians in making informed decisions that affect the future of all older adults in LTC settings. Finally, this research can lead to further interest and related studies conducted by other researchers.

## Summary

This chapter has provided an introduction to this study and background on the situation that cognitively well older female adults currently are experiencing in LTC settings. The characteristics of older adults in LTC settings have changed, possibly to the detriment of a small group of cognitively well, yet physically frail, older adults. The goal and objectives of this study have been stated clearly and the investigator’s assumptions have been identified. The significance of the research was outlined. In Chapter Two, a more detailed review of the literature is provided.

# Chapter Two: Literature Review

## Introduction

The meaning of ‘home’ is a personal and subjective concept. The general expectation is that most people experience safety and security in the privacy of the dwelling that they call ‘home’. Cognitively well older adults in the Long-term Care (LTC) setting cohabiting with cognitively impaired older adults may or may not have a sense of ‘home’. This study gives voice to cognitively well older female adults to ascertain their sense of ‘home’, with the intention of improving institutional living.

This chapter provides: a history of institutional care of older adults; definitions of ‘cognitively impaired’ and ‘cognitively well’; the experiences of cognitively well older adults living with cognitively impaired older adults in LTC settings; a conceptual guide to the domains of ‘home’; and the meaning of ‘home’ in LTC settings.

### A Brief History of the Institutional Care of the Older Adult

On a global scale and for centuries, older adults who could not care for themselves, had no family to care for them, and could not afford to hire someone to care for them, received no support from the state (Forbes, Jackson, & Kraus, 1987). In the early Christian and medieval periods the Christian Church, in what is now the Middle East, deployed institutions throughout the third and fourth centuries to care for the destitute (Forbes, et al., 1987). There were three separate types of institutions, the Gerontochia for older adults, the Nosochomia for people who were sick, and the Ptochia for people who were poor (Forbes, et al., 1987). During medieval times the purpose of these institutions became unclear and infirmary almshouses and Houses of Pity took in the destitute regardless of age or physical condition (Forbes, et al., 1987).

In the 1600’s Canada, New France followed the practices of France in caring for older adults and destitute people (Forbes, et al., 1987). The Church had primary responsibility for this charge and in 1688 opened the Bureaux des Pauvres (Office of the Poor) in Quebec, Trois Rivieres, and Montreal to care for the poor, aged, and destitute (Forbes, et al., 1987). Some time later, the authorities built general hospitals in Quebec in 1692, Montreal in 1694, and Trois Rivieres in 1702 to address the problem of the poor and destitute (Forbes, et al., 1987). The able bodied were expected to work and the sick and the disabled were cared for by the staff in the general hospitals (Forbes, et al., 1987).

In the early 1800’s in Canada, Lower Canada was under British rule. Care for the sick, foundlings and orphans, older adults, and the destitute continued to be provided by private philanthropy and the Church (Forbes, et al., 1987). Additional support was required to meet the demands placed on hospitals and in 1801 the government of Lower Canada allocated one thousand pounds per annum for three years to religious foundations caring for those in need (Forbes, et al., 1987). In 1818, subsidy to religious foundations was incorporated by the legislature of Lower Canada. The only regulation surrounding the use of these subsidies was accounting for how the monies were spent (Forbes, et al., 1987).

Prior to 1830, in Upper Canada, there was little support for destitute people and older adults as the local community rejected the idea of poorhouses (Forbes, et al., 1987). Municipal councils, not the Church, had primary responsibility for their care (Forbes, et al., 1987). Municipal councils determined who received welfare through a rigorous screening process based on an applicant’s assets, earning potential, and morals (Forbes, et al., 1987). An acceptable practice at this time was to auction off able-bodied poor for work and as boarders to the lowest bidder (Forbes, et al., 1987). In 1830, due to urban growth, a fluctuating economy, and seasonal employment the government made grants to York Hospital in the town of York (Toronto) and the Female Benevolent Society of Kingston (Forbes, et al., 1987). Subsequently in 1837, the government of Upper Canada passed legislation that would see Toronto build one of the first houses of industry at public expense (Forbes, et al., 1987).

In pre-confederation Canada the house of industry (also known as the poorhouse) was the earliest legislated social program in response to poverty (Tyler 2009). In 1801 in New Brunswick, the first operational poorhouse was a renovated gristmill (Telegraph Journal 2002). By 1890, the Ontario Provincial Government passed the Houses of Refuge Act, which offered grants of up to $4000 to acquire 45 acres of land for the purpose of building a poorhouse farm (Tyler 2009). In 1903, in Ontario, additional legislation was passed to ensure that every county would have a poorhouse (Tyler 2009). For 60 years, poorhouses would be shelters for the destitute, homeless, and the elderly (Tyler 2009). The oldest surviving example of a poorhouse in Canada is in Wellington County, Ontario. The Wellington County Poorhouse which opened in 1877 became a ‘home’ for the aged in 1947 and since 1975 has been a national historic site and museum (Tyler 2009).

In the United States of America, in the early 1900’s, a common theme was nurses’ concern for the health and care of older adults (Warden-Saunders, 1999; Zinn, 1999). Some nurses adopted older adults and cared for them in their own homes (Warden-Saunders, 1999) while others fought to standardize care of older adults in county poorhouses (Zinn, 1999). The conditions of the poorhouses were often dreary, inadequate, and disease-infested (Zinn, 1999). People were “jammed together shoulder-to-shoulder” with prostitutes, criminals, orphans, and the mentally ill, segregated only by gender, regardless of marital status (Zinn, 1999). Sanitation, food, clothing and sleeping arrangements were deficient with little medical attention or nursing care (Zinn, 1999). The deplorable state of the poorhouse was directly attributed to the lack of women in positions of authority, lack of nursing care, and lack of standards (Zinn, 1999).

In 1935 in the United States, the Social Security Act was passed setting off a chain of events that would result in the construction of the contemporary LTC setting (Warden-Saunders, 1999; Zinn, 1999). Although care and conditions for older adults in the LTC setting would improve for most, it was not a guarantee for all. Slum landlords were more interested in the revenue generated from operating a home than in standards of care and needs of older adults (Zinn, 1999). The living conditions included grossly inadequate nutrition, lack of care, bleak environments void of decoration and the basic comforts of ‘home’, as well as a lack of social and recreational activities (Zinn, 1999). The state of poorhouses in Canada was somewhat better than that of the USA as there were medical services available. However, the mixed population and segregation by gender was similar. Under these histories, the poorhouse was the first model of LTC settings in both Canada and the United States.

In the United States and prior to 1965, older adults with cognitive impairment exhibiting behavioural and psychological symptoms were treated in mental health hospitals (Riter, 1995). After 1965, there was a federal initiative to close mental health hospitals and deinstitutionalize those with mental health problems. In Canada, over the last 45 years mental health patients have been similarly deinstitutionalized with the closing of psychiatric hospital beds including the complete closure of some psychiatric hospitals (Jones, 2000; Sealy & Whitehead, 2004). The closing of psychiatric beds combined with population aging has resulted in LTC settings integrating cognitively impaired older adults with cognitively well older adults (Riter, 1995). Prior to this deinstitutionalization, the LTC setting had primarily housed cognitively well older adults who required more physical assistance (Riter, 1995) than mental health treatment.

Sealy and Whitehead (2004) examined the policy of deinstitutionalization of psychiatric services over a 40-year period in Canada. All provinces implemented some level of deinstitutionalization (Sealy & Whitehead, 2004). In 1965 the total number of all psychiatric beds in all provinces was 69,128 (Sealy & Whitehead, 2004). By 1981 there were 20,301 beds, a 70.6 percent reduction (Sealy & Whitehead, 2004). Between 1985 and 1999 deinstitutionalization continued across Canada (Sealy & Whitehead, 2004). Manitoba closed a total of 2,529 beds, a 68.6 percent reduction for the province (Sealy & Whitehead, 2004).

During this period of deinstitutionalization, another process known as transinstitutionalization was occurring. Transinstitutionalization is “an increase in the number of mental health beds in general hospitals and the growth of community-based outpatient services for people with mental health illness” (Sealy & Whitehead, 2004: 250). Martens, Fransoo, Burland, Burchill, Prior, and Ekuma (2007) explored the link between the use of home care services and of the LTC setting by older adults with mental health illness in Manitoba. From 1998-2003, of those older adults being admitted to a LTC setting, 75 percent had one or more mental health disorder diagnoses (Sealy & Whitehead, 2004). During the same period, of those older adults already residing in a

LTC setting, 87 percent had one or more mental health disorder diagnoses (Sealy & Whitehead, 2004). They concluded, “mental illness is a driving force behind the use of home care and the LTC setting by older adults” (Sealy & Whitehead, 2004:589).

In 2010, cognitively well older adults are not being housed with prostitutes, criminals, and orphans and the conditions of the LTC setting are far superior to those of the standard poorhouse of the1900’s. Nevertheless, in many LTC settings, cognitively well older adults are being housed with cognitively impaired older adults who have mental health diagnoses or who present with behavioural and psychological symptoms that accompany Alzheimer’s disease and related dementias. These challenging behaviours create an environment that may be distressing for cognitively well older adults.

### Definitions of Cognitive Impairment and Being Cognitively Well

The resident assessment instrument minimum data set (RAI-MDS), LTC version, is currently used as an assessment tool in Winnipeg’s LTC settings (as well as in over 30 countries) to assess resident functional and cognitive levels. The RAI-MDS has a cognitive performance scale (CPS) that measures cognitive impairment or cognitive wellness and is calculated based on five RAI-MDS elements (comatose, short-term memory, cognitive skills for daily decision-making, making self understood, eating), which measure cognitive wellness or impairment (see Table 2.0) (RAI-MDS 2.0 Resource Manual, 2002). In Table 2.0, the CPS score is compared to the Mini-Mental Status Exam (Folstein, Folstein & McHugh, 1975), one of the most widely used cognitive impairment screening tools. The lower the MMSE score (range of 0 to 30) the more likely that cognition is impaired and there is a traditional cut-off score of 22/23 that divides those who are considered cognitively well from those who are considered to be cognitively impaired. The MMSE scoring system and cut-off scores vary according to the age and education of the older adult (Crum, Anthony, Bassett & Folstein, 1993).

Table 2.0

*RAI Cognitive Performance Scale*

| CPS | Description | MMSE |
|---|---|---|
| 0 | Intact | 25 |
| 1 | Borderline intact | 22 |
| 2 | Mild impairment | 19 |
| 3 | Moderate impairment | 15 |
| 4 | Moderate-severe impairment | 7 |
| 5 | Severe impairment | 5 |
| 6 | Very severe impairment | 1 |

According to the Resident Assessment Instrument-Home Care Manual Canadian version second edition (2002), cognitive impairment is defined as:

> “characterized by a wide array of disabilities which affect virtually all aspects of life and function. Included are forgetfulness for both recent and distant events, confusion, difficulty in finding words or understanding speech, and failure to function appropriately and normally in social circumstances.”

This definition of cognitive impairment provided by RAI-MDS is sufficiently inclusive and is utilized for this study as part of the inclusion criteria for recruitment of cognitively well older adults.

‘Cognitively well’ is a designation defined as an individual having no cognitive disabilities, intact memories for both recent and distant events, no confusion, the ability to articulate speech well, and the comprehension of meaning of both verbal and written information, and is functionally appropriate in social circumstances. As well, it infers that the older adult is alert and oriented to person, place and time, able to express needs, has decision-making capacity about day-to-day life and activities, and has good insight and judgement.

## The Lived Experience of Cognitively Well Older Adults in Long-Term Care

Jaber “Jay” F. Gubrium is known as a specialist in the field of aging and the life course, health and illness, social interaction, identity, qualitative methods, and narrative analysis. Long before researchers were investigating the topic of older adults in the LTC setting, Gubrium explored everyday life and the lived experience in the LTC setting (Gubrium, 1993). In the early 1970’s Gubrium was doing pioneering work, looking for answers to questions about outcomes of life, daily living in the LTC facility, the meaning of ‘home’ and family, self-perception, health, aging, and death. His interviews with older adults revealed mixed feelings, attitudes and varied perspectives on living in the LTC setting (Gubrium, 1993).

Gubrium’s research revealed common characteristics of human behaviour. Some older adults described everyday life as a positive experience (the ‘good’); some depicted a bleak existence (the ‘bad’), while others portrayed a state of in between; neither good nor bad, just existing (the ‘in between’) (Gubrium, 1993). The narratives of older adults appeared to centre on three areas of life: everyday life with people, everyday life with activities, and their worldview of everyday life.

Older adults, who described everyday life as being ‘good’, focused on positive attributes of people in general. They valued family visits and feeling close to family (Gubrium, 1993). They saw people as being nice and staff providing good care. These older adults attached themselves to other resident’s family members and enjoyed being with the same roommate for many years (Gubrium, 1993). They appreciated getting along with people, with friends checking in on each other, and having many friends on site (Gubrium, 1993).

Older adults who described life as ‘good’ were dynamically engaged in life, which included seeking out opportunities to be active in their environment (Gubrium, 1993). The activities that they listed meant belonging to the Sunshine Group and this encompassed doing things for others, such as, making birthday and welcome cards, making pillows, quilts, baskets, and change purses, and being friendly greeters and visitors for new residents (Gubrium, 1993). These older adults looked forward to getting up in the morning, having breakfast, and then waiting patiently for something to do (Gubrium, 1993). Morning was described as a leisurely time to enjoy while getting ready for the rest of the day (Gubrium, 1993). Older adults engaged in life spoke of church groups coming in with children for songfests, and even though they could no longer sing they could still listen (Gubrium, 1993). They spoke of going out for family visits but looked forward to coming back and being missed by friends when they were away (Gubrium, 1993). Everyday life was about walking around the facility, doing everyday things, and talking with different people who would be encountered in the LTC setting (Gubrium, 1993).

Older adults such as these who lived with a worldview that was optimistic and hopeful also embraced acceptance with a purpose in life, not just tolerance, and connected with, and developed attachments to others. They hoped that there was more life to live. These older adults had made up their minds that this was their ‘home’. They believed that now that they were older, things that were once difficult were made a little bit easier for them. Older adults actively engaged in life were able to express love for everyone (humankind) and wanted to help others (Gubrium, 1993).

In Gubrium’s study, older adults who described everyday life as ‘bad’ also described life as consisting of primarily negative experiences including losing people to death and losing those who stopped visiting them in the LTC setting. There was also the view that cohabiting with either cognitively well older adults or older adults with cognitive impairment resulted in a loss of privacy. They did not view living in the LTC setting as an opportunity for making new friends. When confronted by cognitively impaired older adults they reported resorting to the use of verbal and physical aggression as a means of defence. These older adults reported that living close to “the worse ones” was a hardship for them (Gubrium, 1993).

Older adults who described life as ‘bad’ were also detached and disengaged from their community, including social and physical activities of the LTC setting. These older adults could not find anything good to say about activities in the LTC setting. Some reported that there were no activities going on and yet attended physical therapy sessions three times a week. There was much ruminating about what was wrong with the LTC setting in which they now lived. These older adults also presented with low levels of self-esteem and self-worth; they described themselves as useless and unable to contribute to society (Gubrium, 1993).

For those older adults who lived with a world view that was pessimistic contemplating life was all about what they did not want to become, being unable to care for themselves, and being in a wheelchair equated to being helpless. Feelings of “nothing to look forward to” were prevalent. Encountering cognitively impaired individuals meant seeing only their deficits and not the person inside. These older adults worried about becoming like the cognitively impaired older adults. They reported that there was no religious practice in the LTC setting and could not find spirituality within themselves. Some described having thoughts of suicide and reported feeling empty and lonely. A strong sense of ‘life is not worth living’ was repeatedly verbalized including statements such as, “I have thought of taking my life” (Gubrium, 1993:31), “my life is nothing” (Gubrium, 1993:31), “I just wish I could die today” (Gubrium, 1993:31), :There’s nothing to look forward to” (Gubrium, 1993:57), “I’m nothing now” (Gubrium, 1993:31), “I’m just drifting” (Gubrium, 1993:63), “But when you’re like this… you’re just trouble” (Gubrium, 1993:57).

Older adults, who described life as neutral (that is not ‘good’ or ‘bad’) had an attitude of reserved acceptance (Gubrium, 1993). These older adults spoke of interacting with other older adults even though the older adults were cognitively impaired and could not make sense out of being in the LTC setting (Gubrium, 1993). When they spoke of activities in the LTC setting it was clinically based activities such as blood sugar monitoring or nurses reporting to doctors or having eye surgery that failed or even the LTC setting staff threatening to send older adults to hospital for care if they were non-compliant with physician ordered regimes (Gubrium, 1993). These older adults also reported that “not much happens” in the mornings but did not include this statement to be all inclusive of the facility (Gubrium, 1993). Their worldview was one of accepting that there are nice times, sad times, and happy times in the LTC setting with a “matter of fact” attitude that ‘this is just the way life is’ (Gubrium, 1993). Some older adults spoke of being ready for death but were not suicidal as they were leaving the timing of their deaths ‘in God’s hands’ (Gubrium, 1993).

Along with Gubrium’s (1993) work, two other studies offer a basis for understanding the essence of ‘home’ cognitively well older adults in LTC. Fiveash (1998) explored the resident’s experience of living in the LTC setting. Fiveash (1998) conducted an ethnographic study of eight articulate older adults in two 80-bed LTC facilities in New South Wales, Australia. In this study the data revealed four major themes: “against my will”, “living in a public domain”, “cultural implications of living with others”, and “the impact of LTC residency”. Similarly to Gubrium (1993), Fiveash (1998) found that for some older adults living in the LTC setting was acceptable, while for other older adults, living in the LTC setting was constraining and dehumanising.

Hammer (1999) examined the lived experience of feeling at ‘home’ for older adults relocated to alternative care settings. Hammer (1999) conducted a qualitative study of 10 relocated older adults in three settings (one life care and two long-term care facilities) in the United States. From the data 14 themes emerged within the context of “at home” (privacy, respect, affection, security, autonomy, commonality, significance) versus “not at home” (intrusion, disrespect, disdain, fear, dependency, discordance, anonymity) (Hammer, 1999). As in Gubrium’s (1993) and Fiveash’s (1998) work, this study revealed that older adults who felt “at home” described strong feelings of satisfaction with life, security, autonomy, and purpose (Hammer, 1999). Older adults who felt “not at home” described feelings of anxiety, anger, depression, and displayed a strong desire to be elsewhere (Hammer, 1999).

In Fiveash’s (1998) and Hammer’s (1999) studies, the participants reported similar negative attitudes to those in Gubrium’s (1993) research. Some participants focused on the lack of privacy, having no peace and quiet and on feelings of shock and disbelief on seeing so many disabled people, which provided a constant and unwelcomed reminder of their own inevitable decline (Fiveash, 1998; Hammer, 1999). Participants reported feeling like they were living in a prison, as they were not allowed to leave the LTC setting (Fiveash, 1998; Hammer, 1999). There were reports of being irritated and assaulted by other residents (Fiveash, 1998; Hammer, 1999). Participants described living in fear, and living with the verbally and physically disruptive behaviours of cognitively impaired older adults (Fiveash, 1998; Hammer, 1999). There were reports of being irritated and assaulted by other older adults including being struck over the head (Fiveash, 1998; Hammer, 1999). Older adults provided examples such as cognitively impaired older adults who urinated in the corner of the bedroom and took their teeth out during meals leaving them on the table to the discomfort of cognitively well older adults (Fiveash, 1998). Participants reported feeling powerless, subservient, and too frightened to report rough handling by staff, believing that they had to acquiesce to fit in (Fiveash, 1998; Hammer, 1999).

### Living with Cognitively Impaired Older adults in Long-Term Care

Currently there are neither standards of practice for the LTC setting to segregate cognitively well older adults from cognitively impaired older adults, nor are there clearly understood criteria for this segregation when it occurs. Much research has focused on the benefits and detriments of integration for those older adults who are cognitively impaired however not many studies have explored the perspective of those older adults who are cognitively well. Five selected studies will be assessed and discussed here as to whether or not integration is an acceptable way of life for cognitively well older adults living in the LTC setting (Teresi, Holmes, & Monaco, 1993; Oh, 2006; Gorman, 1996; Ragneskog, Gerdner, & Hellstrom, 2001; Levesque, Cossette, & Potvin, 1993).

Teresi et al. (1993) explored the effects of commingling cognitively well older adults with cognitively impaired older adults in the LTC setting. Teresi et al. (1993) conducted a study of 77 cognitively well older adults integrated with cognitively impaired older adults in the LTC setting and hypothesized that the cognitively well older adults would be negatively affected in relation to depression/demoralization, satisfaction with their environment, and satisfaction with life. They found that the quality of life of cognitively well older adults integrated with cognitively impaired older adults in the LTC setting may be compromised by proximity.

Oh (2006) explored the experience of stroke patients sharing rooms with cognitively impaired patients in the LTC setting. He conducted a phenomenological study of sixteen stroke patients to explore experiences in sharing rooms with cognitively impaired patients. The findings indicated that stroke patients “were being seriously affected by intense, deeply disturbing, and persistent experiences.” (Oh, 2006:839).

Gorman (1996) explored the experiences of cognitively well older adults integrated with cognitively impaired older adults in the LTC setting. He carried out a phenomenological study of six cognitively well older adults in relation to what the unsociable behaviour of cognitively impaired older adults meant to them. Three themes emerged (enervation, disenfranchisement, coping) suggesting that cognitively well older adults in the LTC setting experience fatigue, exhaustion, and anxiety in attempting to adapt to their exposure to the unsociable behaviour exhibited by cognitively impaired older adults.

Ragneskog et al. (2001) explored how the integration of cognitively well adults with cognitively impaired adults affected their perception of quality of care. They conducted a study in hospital wards, the LTC setting, and residential homes in the Gothenburg, Sweden area via a mailed questionnaire with a 71.25 percent response rate. The results suggested that cognitively well adults may experience feelings of anxiety, fear, and irritation in relation to exposure to agitated behaviours displayed by other residents.

Finally, Levesque et al. (1993) tested a model of the willingness of cognitively well older adults’ to cohabit with cognitively impaired adults in the LTC setting. They conducted a study of 435 cognitively well older adults living on integrated units from 19 LTC facilities in Montreal, Quebec, Canada. Almost all participants were female, almost all had a private room, and the mean age was 81.7 years. In contrast to the previous studies, Levesque et al. (1993) reported that many of the cognitively well older adults in their study presented few negative comments about living in integrated units.

Research suggests that in the LTC setting, when cognitively well older adults are integrated with cognitively impaired older adults the cognitively well older adults report low life satisfaction and poor quality of life (Teresi, et al., 1993; Oh, 2006; Gorman, 1996; Ragneskog, et al., 2001). In four separate studies (Teresi, et al., 1993; Oh, 2006; Gorman, 1996; Ragneskog, et al., 2001) there were similar reports by cognitively well older adults living in integrated settings, including accounts of emotional distress, feelings of being unsafe, feelings of living in fear (fear for their physical safety and fear of becoming cognitively impaired) and at the same time living in a state of resignation. They also expressed feelings of anger and powerless to change the dynamics that caused these feelings (Teresi, et al., 1993; Oh, 2006; Gorman, 1996; Ragneskog, et al., 2001). These cognitively well older adults were not satisfied in their environment and found that it eventually affected their morale and self-esteem (Teresi, et al., 1993; Oh, 2006; Gorman, 1996; Ragneskog, et al., 2001).

Ragneskog, et al., (2001), Teresi et al., (1993) Oh (2006), and Gorman (1993) indicated that the behavioural and psychological symptoms, including agitated behaviours and aggression, exhibited by cognitively impaired older adults could lead to cognitively well older adults becoming anxious, afraid, and irritated. Ragneskog et al. (2001) found that integration is particularly challenging for cognitively well older adults at meal times and during recreational activities and they reported becoming apathetic and acquiescent in coping with their shared home environment (Ragneskog et al., 1996).

In contrast to Teresi et al. (1993), Oh (2006), Gorman (1996), and Ragneskog et al. (2001), Levesque, Cossette, and Potvin (1993) discovered four factors that explain why cognitively intact older adults may be more likely to want to cohabit with cognitively impaired older adults. The four factors that emerged were: alert older adults’ level of negative emotional reactions to living with cognitively impaired older adults, their knowledge of confusion, the level of disturbance generated by behavioural and psychological symptoms, and the benefits of cohabitation for the cognitively impaired as perceived by cognitively well older adults (Levesque et al., 1993).

In this study (Levesque et al., 1993) there were few negative emotions experienced and there were few behavioural and psychological symptoms observed.

Cognitively well participants reported few expected advantages of segregation as well as few disadvantages to integration for themselves (Levesque et al., 1993). As well, cognitively well participants envisioned few advantages for cognitively impaired older adults to live on an integrated unit (Levesque et al., 1993).

Knowledge of cognitive impairment was positively related to cognitively well participants’ willingness to live on an integrated unit (Levesque et al., 1993). Information about cognitive impairment and behavioural and psychological symptoms has only become known since 1983, yet knowledge of cognitive impairment enhanced willingness to live on an integrated unit (Levesque et al., 1993).

Higher incidences of behavioural and psychological symptoms increased the frequency of negative emotional experiences leading to less willingness to live on an integrated unit (Levesque et al., 1993). There were significant negative correlations between the frequency that cognitively well participants observed behavioural and psychological symptoms, the disturbance that was generated related to behavioural and psychological symptoms and willingness to live on an integrated unit (Levesque et al., 1993). Observing disturbances related to behavioural and psychological symptoms had much more impact on willingness to live on an integrated unit than did the percentage of cognitively impaired older adults (Levesque et al., 1993). Results revealed that, in this study, 67 percent of cognitively well participants were willing to live on an integrated unit (Levesque et al., 1993).

Overall, integration with cognitively impaired older adults appears to be an unsettling or uneasy way of life for cognitively well older adults in the LTC setting. Although there may be benefits for cognitively impaired older adults based on four of the previous five studies, the burdens seem to outweigh the benefits for cognitively well older adults.

## The Meaning of ‘Home’

Recently there has been an interest in studying the ‘home’ as a “therapeutic landscape”. Therapeutic landscape as defined by Gesler (1996:96) is, “a landscape where the physical and built environments, social conditions, and human perceptions combine to produce an atmosphere, which is conducive to healing”. The majority of literature on the home as a therapeutic landscape focuses on the older adult’s ‘home’ being converted into a treatment centre (Martin, Nancarrow, Parker, Phelps, & Regen, 2005) or short-stay respite and the city as therapeutic landscape (Conradson, 2005; Wakefield & McMullan, 2005) as opposed to the LTC setting becoming ‘home’. It remains to be seen if future work in this area will proceed to look at the reverse situation, as this study does, in attempting to understand if a therapeutic environment, that is, the LTC setting, can truly be seen as one’s ‘home’. Perhaps, the therapeutic landscape studies and this study share a common feature, that is, the fluid nature of ‘home’.

In the previous section, the concept of ‘home’ was used without providing a definition of ‘home’. In Gubrium (1993), Fiveash (1998), and Hammer (1999) no definition of ‘home’ was provided. ‘Home’ is a word so commonly used and expressed in society that it would seem easy to conceptualize however this is not the case. There is a distinction between the concept of ‘home’ and house. Describing a house as a concrete place of structure, material, and design makes it immediately apparent that ‘home’ is much more than just a physical entity. ‘Home’ is an intangible abstract concept not so easily described. What is and feels like ‘home’ to one person may not be or feel like ‘home’ to others.

People have ‘homes’ to meet such basic needs as shelter and security. Yet there are many more aspects to ‘home’ than just the physical elements of structure and function. For this study, it was necessary to review literature on the meaning of ‘home’ and develop a framework that defined ‘home’ so that cognitively well female older adults could understand and respond to questions derived from the objectives. The domains and qualities of ‘home’ as described next are not to be interpreted as mutually exclusive and these domains and qualities are relatively fluid and overlap with one another. Note that the domains and concepts of ‘home’ are fluid and flowing. They are not meant to be interpreted as silos that stand alone but should be conceptualized just as ‘home’ and life are experienced, intertwined and meshed together.

*Physical.* Physical qualities of ‘home’ are described by Brummett (1997), Dovey (1985), Hammer (1999), and Hepworth (1999) as providing for safety, security, and protection within a demarcated territory with physical boundaries allowing occupants to control access. Privacy and physical boundaries not only provide protection but also allow one to socially engage with others or seek seclusion from society (Angus, Kontos, Dyck, Mckeever, & Poland 2005; Dovey, 1985; Hammer, 1999; Hepworth, 1999). The LTC setting may not be a safe, secure, comfortable environment with clearly defined and understood boundaries. This may be related to some older adults sharing rooms and other shared residential living conditions. Can we expect older adults to call the LTC setting ‘home’ under these conditions?

*Social.* According to Brummett (1997) and Hammer (1999) social qualities of ‘home’ include self-expression, self-identity, a sense of continuity, and how we expect to be perceived by others which are sub-characteristics of self-protection and self-symbol. Hammer (1999) assigns both moral and aesthetic dimensions to the meaning of ‘home’ stipulating that this is dependent on the individuals inhabiting the place. Brummett (1997) and Dovey (1985) promote choice and opportunity ascribing that one may explore interests as well as engage and interact with people of one’s choosing. Dovey (1985) takes the social element of ‘home’ in a completely different direction by suggesting that ‘home’ as social order is a manner of relating to the environment in a way that transcends the meaning of ‘home’ from any one location to another by recreating patterns of living. Is it possible to recreate the patterns of one person amongst the patterns of hundreds of people in a facility setting? A challenging scenario to build a new ‘home’ in! This may be compounded by people who are indistinguishable in large groups. Self-expression and self-identity can become blended in the midst of the numbers.

*Spiritual.* Spiritual qualities of ‘home’ center and delineate ‘home’ as a sacred place where one can retreat to from the outside world (Brummett, 1997). Privacy and territoriality encompass the ideals of solitude, reflection, unwanted intrusion, personal and familial boundaries including the control that one has over them (Brummett, 1997). ‘Home’ is living history in a place that has meaning and implication for the individual that impacts a person in all aspects of their being (Hammer, 1999). ‘Home’ is an inherent part of the individual’s identity. It is a place of identity exchanges between individuals and dwelling (Dovey, 1985). The preservation of identity and self-worth are dependent on a sense of ‘home’ (Hammer, 1999). According to Williams (2002:144), place identity “is the construction of self within the world and its connectedness to place and environment.” An example of this is the personal attachments to places where one was born and/or grew up, which are often referred to as a “home town”.

Transcending into an existential-self is reliant on operating from a ‘home’ base, a haven or a sanctuary (Hammer, 1999). Dovey (1985) states an important aspect of ‘home’, albeit perhaps an obvious one, when he describes ‘home’ as a place one goes to for rest, to be nurtured, to replenish energies, and to rejuvenate one’s spirits. How do these qualities fit into an environment where one cannot always control intrusion? This includes intrusion from schedules and structure, rules and policies, staff and other older adults? What parts of an institution can an individual call ‘home’? How does one find spirituality in such a large dwelling?

*Spatial.* Spatial qualities of ‘home’ speak to familiarity and order, which signify that comfort, relaxation, familiarity, understanding and sense of place are experienced at ‘home’ (Angus, Kontos, Dyck, Mckeever, & Poland, 2005; Brummett, 1997; Hammer, 1999). Control and autonomy permits one to have control over one’s environment (Angus, Kontos, Dyck, Mckeever, & Poland, 2005; Brummett, 1997). Repetitive and recurring activities associated with ‘home’ can occur on a daily, weekly, monthly, annually, or some regularly expected frequency creating a rhythm of repetitive events (Werner, Altman, & Oxley, 1985). Recurrent repetition of actions and meanings and the regular movement of people, places, and processes create a sense of rhythm. Establishing regular rhythmic patterns provides a sense of ‘home’ contributing to the transformation of a house to a ‘home’ (Werner et al., 1985). An example of patterning that reinforces the sense of ‘home’ is the practice of leaving ‘home’ and returning ‘home’. Whether it is a short leave on a daily basis or a long leave on an annual basis, there is a sense of belonging when one returns ‘home’ after a long day at work and after a vacation away from ‘home’. According to Hammer (1999:12) “These movements are so basic to all life forms they are considered universal”.

‘Home’ has distinct boundaries that allow the occupants to control behaviour within a given territory (Dovey, 1985). To be at ‘home’ is to know where you are; it means to inhabit a secure centre and to be oriented to self and space (Dovey, 1985). Dovey presents an interesting perspective by suggesting that ‘home’ can be a room inside a house, a house within a neighbourhood, a neighbourhood within a city, and a city within a nation. Based on this concept of ‘home’, could the routines, schedules, and common practices of LTC instil a sense of security and belonging to older adults?

*Temporal.* Stability and predictability are temporal qualities of ‘home’ (Brummett, 1997; Dovey, 1985). Brummett (1997) describes stability and predictability as relationships within the ‘home’ that change only when one desires. Dyck, Kontos, Angus, and McKeever (2005) explored boundary management which can be equated to having control over ‘home’ space and the people, objects, and territory within it. Werner et al. (1985) considers relationships between people and environment to be dynamic, flowing, and changing yet they still link people to ‘homes’. Personal possessions in ‘homes’ have meaning associated with the occupants and their ‘home’, an attached story that reveals the importance of the object to the owner (Werner et al., 1985). This contributes to the development of place attachment and place identity which bonds people to their environment (Werner et al., 1985; Williams, 2002). ‘Home’ is therefore; a highly complex system that includes ordered relations with place, an order that orients one in space and time, and in society (Dovey, 1985).

There are many losses that an individual experiences upon moving into a LTC facility. An individual must relocate themselves by finding stability, predictability, and order in their new environment. They must make sense of downsizing their possessions and redevelop place identity and place attachment, which may be an even greater struggle when residing with cognitively impaired older adults, something they may have little dealings with or nor experience of.

*Emotional.* According to Dovey (1985:34) “Home is an emotionally based and meaningful relationship between dwellers and their dwelling places”. Brummett (1997) coined the terms ‘vessel of memory’ and ‘vessel of the soul’, to refer to personal belongings and their symbolic meaning, as they represent our memories of personal family life. The concepts of connectedness and belonging signify the exchange of love and affection in our ‘home’ (Brummett, 1997). ‘Home’ is a place where we connect with peers and friends (Brummett, 1997). The ‘home’ environment is generally predictable and at times taken for granted (Dovey, 1985). *Ideally*, at ‘home’ we can relax within the stability of routine behaviour and experience (Dovey, 1985). Dovey (1985) explores the old adage “home is where the heart is” affixing ‘home’ with descriptors such as “identity”, “affective”, “emotional as well as to care about”, “to be familiar with”, and “to know what to expect”. Hammer (1999:12) conducted a study of the lived experience of being at ‘home’ in assisted living centres and reported, “that in some situations, the loss of a loved one was equated with losing one’s emotional home”.

Feeling connected as opposed to detached, making warm and happy memories, and identifying with a new ‘home’ are the tasks of all older adults relocating to the LTC setting. Unfortunately, not all older adults living in the LTC setting are able to accomplish this task. What interferes with the process of taking emotional ownership of one’s new ‘home’; uncertainty, disruptions, disturbances, unfamiliar events, or unexpected events? Does anyone know?

In conclusion, ‘home’ has a distinct concrete physical component along with social, spiritual, spatial, temporal, and emotional elements. ‘Home’ ideally allows an individual to control access to personal space and provides protection. ‘Home’ encourages freedom of expression and development of one’s identity including perception of self and others. Individuals attach moral and aesthetic values to the meaning of ‘home’. At ‘home’ engaging and interacting with others is a choice, including the coordination of social activities. ‘Home’ encompasses such concepts as solitude, reflection, lack of unwanted intrusion, boundaries and retreat, and when combined can create a haven. ‘Home’ solicits an understanding and a sense of place while living with rhythmic patterns of activities and traditions of one’s own creation. ‘Home’ is ideally signified by predictability and stability that an individual finds with “feeling at home”. Collecting meaningful possessions within the ‘home’ allows place attachment and place identity creating bonds between people and their environment. Emotionally speaking, “home is where the heart is”. How does living with cognitively impaired older adults fit with these qualities? Can we truly expect older adults to call the LTC setting ‘home’ after reflecting on all that creates ‘home’ and all that is part of the LTC setting?

## The Meaning of ‘Home’ in the Long-Term Care Setting

While there has been some research on the concept of ‘home’ in the LTC setting, the focus of these studies have been tangential to this study’s focus on the perspectives of cognitively well female older adults who live in LTC settings. For example, studies sometimes focus on predictors of satisfaction, attitudes, environmental structure and routine (Lee, Lee, & Woo, 2005); or take an administrator’s perspective on making the LTC setting a true ’home’ not just “home-like” (Samuelson, 2003). Some have examined how segregated and integrated units help cognitively impaired older adults (Haitsma, Lawton, & Lkeban, 2000); or examine how the concept of ‘home’ in the LTC setting has been realized through the use of common living rooms (Hauge & Haggen, 2007). Added to this is the large literature on creating a home-like atmosphere, pioneered by Thomas’ Eden Alternative. These studies are important within their own context but they do not address the four objectives of this study and certainly lack the perspective of cognitively well older adults and their meaning of ‘home’.

A few other studies are noteworthy in their view of ‘home’ and LTC settings. Imrie (2004) examined disability, embodiment and the meaning of “home” although not just in the LTC setting. Angus, Kontos, Dyck, McKeever, and Poland (2005) investigated the personal significance of ‘home’ however this study focused on receiving long-term community based services. Hammer (1999) explored the systems of meaning that individuals establish regarding ‘home’ for older adults who had relocated to alternative care settings. Gubrium’s (1993) and Hammer’s (1999) studies are unique in that they were undertaken from the perspective of the resident. Hammer (1999) interviewed older adults in alternative care settings and found that some of them had great difficulty establishing a sense of ‘home’. Sixty percent of older adult residents stated that they did not feel at ‘home’, thirty percent of the participants described feeling at ‘home’ in their present environment, and ten percent reported ambivalence (Hammer, 1999). The following testimonials from Hammer’s (1999) work provide strong evidence of what life is like for some of the cognitively well older adults in the LTC setting:

> “I don’t know exactly how to describe the feeling of being at home, but there is one thing about home, once you lose the feeling you can never get it back.” (Hammer, 1999:13).
>
> “I’ve been here for four years and I’m not at home.” (Hammer, 1999:14).
>
> “Home is the freedom to do just as you please and that will always distinguish this place from home” (Hammer, 1999:14).

The notion described by these older adults is that at ‘home’ an individual is his or her own boss or that one is in charge of oneself and this seems to be lacking in the LTC setting as described here. Not surprisingly, participants who described themselves as not at ‘home’ (60%) withdrew, became detached from their environment, and were preoccupied with their loss (Hammer, 1999). Hammer (1999:14) found that, “those participants who did not feel at ‘home’ seemed preoccupied with resolving the situation of perceived homelessness”. Participants who described themselves as “at home” were actively engaged in their environment (Hammer, 1999). They reported feeling that they were living their lives in a way that fit with their identity (Hammer, 1999).

Gubrium (1993) interviewed 58 older adults in order to explore the experience of everyday life in the LTC setting. Twenty-four older adult residents were followed for one year and their stories provide illustrations of their perception of ‘home’. Gubrium asked questions about life’s outcomes, the meaning of ‘home’, health, aging and death. He asked two questions that are of interest to this study, “Now that you’ve been here for ----, does it feel like ‘home’? What would it have to be like for it to be like home?” Of the twenty-four participants interviewed 50 percent reported that the LTC setting felt like ‘home’ and the other 50 percent report that it was not ‘home’ (Gubrium, 1993).

Gubrium inferred ten themes from the responses of the older adults and catalogued each of the older adult participants under one of the themes (see Table 2.1). A brief description of Gubrium’s (1993) ten themes is provided (see Table 2.1), as well as, some of the stories of the participants.

Table 2.1

*Gubrium’s (1993) Ten Themes*

| Themes | Comments |
|---|---|
| **“Worried to Death”** illustrated worry, disappointment, and thoughts about death. Worry is about loss of identity and growing frailty. | (Rita, Rebecca, and Roland) “But he’s not well. I’m so worried about him. …I wish I could feel better because my sugar goes up. …that can’t even remember anything or talk funny, or they’re really lost. … I don’t want to get like that. …I know it’s coming to me… the way I feel. So I don’t want to live too long.” |
| **“Making a New Home”** reflected positive memories of earlier life emphasizing how participants viewed their current situation and possible future. Conversely, negative life histories might have contributed to participants’ abilities to establish a positive life experience for the first time in their life. | (Martha, Jane, and Ruby) “After I got here and I was here for a while, I found out that it was best for me. …You either try to get along well or you don’t and I’m a person who tries to get along. … They tried to make me comfortable… I guess I had to have the feel of it myself. I guess once I began to understand, it started to feel like home. When I found out that I couldn’t be with my son, I couldn’t be in his home and I got it through my head that I had to make the best of it, that’s when I began to feel a little different. That’s when I began to feel that I really would have to make up my mind that this was my home.” |
| **“It’s Come to This”** encompassed an overwhelming focus on fate. This is referred to as a sense of uselessness and a forced sedentary lifestyle with no purpose. | (Myrtle and Alice) “Well life looks like to me like a big blob! That’s just what it looks like exactly, because what good am I? ... I’m a burden, you see. … I’m a bump on a log. I’m absolutely useless. I’m just sitting here, a menace, just, you might say, worthless. I hope I don’t have to live the rest of the year out because there’s no point.” |

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| In **“Loving the Lord”** participants gained meaning from existential beliefs. Earthly experiences took on meaning in relation to a higher power. Looked forward to the future feeling secure in their faith. | (Julia and Mary) “I think the Lord’s been good to me. I been in church all my life. …The Lord provides, bless Him.<br>I try to be a nice person. I try to be a good Christian and I think. …the Lord has been real sweet to me or I wouldn’t feel that way. I have had a lot of sad things happen to me, but I think the Lord … I think we got to look up to Him. …I look to heaven, to go to heaven and be up there with the Lord. The Bible say if we do right, we’ll rejoice.” |
| **“Vigilant”** was about intrusion into personal space. All older adults were expected to maintain their role and social norms. | (Bea and Betty) “You have to in the world. It’s dog eat dog. People will bite your head off if you don’t watch it. You got to watch out for number one…. They got no respect for no one. You have to keep an eye on ‘em day and night. … You have to keep an eye on ‘em all the time. The treatment stinks.” |
| **“Travellers”** included older adults who traveled extensively in their job or career and spent a lot of years on the road. LTC offers care, security, and shelter for the tired traveling man and refuge from the strain of moving from place to place. | (Jake and Peter) “I tell ya, … it used to mean, well it meant I quit for the season. I took a two week vacation and I went back home to Millsburg. That was home. Otherwise, leave the house locked up, let someone I knew very well take care of it for me, and then we’d hit the road. … Home … yeah, it’s been about the same. It’s a place to go back to and forget show business, forget everything, just sit down and relax and enjoy the distance. Home’s about the same now as it’s always been.” |
| **“Sisters”** was about the benefit of having family members or significant others living in LTC together is that a life once shared continues to be a source of meaning for daily living. The quality of life for relatives in LTC together is rooted in experiences from their past. | (Lula and Lily) “And you don’t have no one to talk to here. Maybe the nurse when they bring you the meal or something like that, but other than that, you don’t have anybody to discuss nothing with. Lily and I talk together, we talk. It’s much better to be in the room with her than to be with someone I don’t know. … Well, because we have things to talk about, life and the other person. That means a lot to talk about things you’ve had dealings with and doing together and enjoying things together … We’re company for each other. We talk about what we did when … right now if we was able to do it, what we would do, like fishing and different things like that. … Other than that, we just have to live up life like that. Fishing we can’t do anyway, but we talk about it.” |
| **“Spouses”** who resided in the same LTC facility bring their life experiences and stories meshing this part of their life with the past. Life together is linked by emotional love. There is expression of not only mutual respect but of cherished routines, physical attraction and affirmations of desire. | (Jane and Tom, and Don and Sue) “I’ve got nobody else outside of my wife. I’ve got a younger brother still living some place. I don’t know if he’s living or dead. …Home? Well, a place where my wife and I could have a place together. Wherever she’s at is home for me. … The only thing that went through my mind was that I wanted to be where she was. … She was here a month ahead of me. I missed her. It wasn’t home when she was out of the house. …we’ve got a good home here; we’re together. I mean at my age, going on 83, I’m not asking much more than that … just to be together with her and lover her up.” |
| **“Disabled”** was about being physically challenged people | (Grace, Opal, and Celia) “Yesterday I was typing …at the new typewriter. I’m going to type today when I get up … type a note. |

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|---|---|
| bring experience with disability with them to LTC. LTC is a base of support to meet their needs allowing them to carry on as before. | I’ll do it this afternoon. No, I won’t do it this afternoon either ‘cause I’ll have the Browns to watch play ball. The Cleveland Browns; they’re in the playoffs. I love television. … I watch TV all the time because I watch soap operas. … If I’m still here, I hope I’ll be doing just the same thing I’m doing now, only with a better back I hope.” |
| **“Knowledgeable”** was a theme specific to one participant. She spent ten years as a nurse as a state surveyor inspecting nursing homes, hospitals, and home health agencies for quality of care. She also worked as a public health nurse and nurse educator. She was knowledgeable about nursing homes in ways that most older adults are not. | (Karen) “I am thinking very seriously of getting myself a word processor and doing an interesting analysis of nursing homes. I’ve surveyed them. I’ve lived in them. I’ve lived in four or five. I’m acquainted with the federal regs and I’m acquainted with the state regs in two states fairly thoroughly and I’m working on my third one. … the fact that I’ve got a bowel problem related to my illness. The bowel problem is important to me because I don’t want to be in position where I shit in public, excuse me. So I’m very compulsive about the darn thing because I know if I am taken care of in the morning, I will probably not have a boo-boo in the afternoon, and I have done this on occasion. These are the things that are important to me.” |

Kahn (1999) completed a study on participants adapting to the dual nature of the LTC setting as institution and as ‘home’. The process that participants successfully used to adapt to the dual nature of the LTC setting, “making the best of it”, was determined to be the all-encompassing theme. The following sub themes: a) recognizing the ambivalence of their living environment and situation, b) downplaying negative aspects of it, c) having no other options, and d) using their will to transcend and create a home were also identified (Kahn, 1999).

In Kahn’s (1999) study, feedback from the participants revealed that LTC is a kind of ‘home’, but not quite ‘home’. Participants reported that an individual is not on his/her own schedule for meals and bedtime but what can one expect when you are one of many, many people (Kahn, 1999). Noisy older adults and paging overhead were viewed as disturbances (Kahn, 1999). Examples of benefits of life in the LTC setting were fewer trips to hospital as compared to when living at ‘home’, being afraid at ‘home’ but living at ease in the LTC setting, and having someone to take care of you (Kahn, 1999).

Although life in the LTC setting was described as restrictive and regimented it was also described as supportive and the best place to be, all things considered (Kahn, 1999). “Making the best of it” was described as having to make oneself happy and getting use to it (Kahn, 1999). When participants first moved in they felt unsettled. It was months later that “making the best of it” came to be a way of life in the LTC setting.

In a Canadian study, Lapuk (2007) found that 75 percent of older adults he interviewed indicated that the LTC setting was their ‘home’. Of the 25 percent that reported that the LTC setting was not their ‘home’, one resident presented the concept of having two ‘homes’, the one he returns to visit in the community and the second one in the LTC setting. Lapuk’s study focused on aggression in the LTC setting and found that older adults did not seem to connect the aggressive acts they witnessed or encountered with their sense of ‘home’.

In the Netherlands, cognitively well and cognitively impaired are cared for in separate wards or separate institutions (de Veer & Kersktra, 2001). In their 2001 study they examined cognitively well older adults. The study explored determinants of feeling at ‘home’ in the LTC setting specifically the notion of privacy (de Veer & Kerkstra, 2001). It should be noted that privacy in the LTC setting was high on the political agenda in the Netherlands for a number of years leading up to the study and therefore others chose the variable privacy, not the participants or the investigator (de Veer & Kerkstra, 2001). Privacy was defined by government policy and encompassed multiple concepts such as structural privacy related to space and building, feelings of privacy related to resident-centeredness, in particular the attitudes of nurses, privacy as the opportunity to live one’s own life and refers to respect for autonomy, and lastly the attitude of older adults towards each other (de Veer & Kerkstra, 2001). The results found that the percentage of older adults who experienced feeling at ‘home’ varied amongst the LTC settings studied (de Veer & Kerkstra, 2001). In particular, feeling at ‘home’ was strongly associated with privacy defined as perceived attitudes of nurses and perceived disturbances caused by other older adults (de Veer & Kerkstra, 2001). de Veer and Kerkstra concluded that privacy in the LTC setting varies significantly. This implies that feeling at ‘home’ is not only individually determined but also influenced by the LTC setting’s management policy.

### Summary

This chapter provided a brief historical review of LTC settings in Canada and the United States and revealed that in the 1900’s cognitively well older adults were housed with mentally ill people in poorhouses. In 2010 cognitively well older adults are cohabiting with cognitively impaired older adults in the LTC setting with much improved living conditions. Second, this chapter looked at the lived experience of cognitively well older adults in the LTC setting. Human nature/personality emerged as a key influence on how older adults perceived life in the LTC setting. There are those that believe life is ‘good’ and thus live a good life, those that believe life is ‘bad’ and thus live a poor life, and those that live somewhere between ‘good’ and ‘bad’ in a neutral existence.

Third, the literature on living with cognitively impaired older adults in the LTC setting was examined. This section also included definitions of cognitively impaired and cognitively well. Most of the studies reviewed suggested that cognitively well older adults would prefer not to cohabit with cognitively impaired older adults and that there can be discomfort and distress associated with this living arrangement. Fourth, the domains and qualities of home as explored in the literature were identified. These domains and their qualities provide a framework for questions and probes that would gain responses in relation to the study’s goal and objectives.

Finally, the literature on the meaning of ‘home’ in the LTC setting was explored. Many older adults in the LTC setting have difficulty establishing a sense of ‘home’. This has been reportedly related to loss of control over one’s daily routine, loss of privacy, and more importantly an inability to protect oneself from the intrusion of other older adults’ disruptive, aggressive, and/or socially inappropriate behaviours.

Lastly, by extracting universal concepts from the literature a working definition of ‘home’ was developed. The qualities of ‘home’ were formatted into six domains: physical, social, spiritual, spatial, temporal, and emotional. These domains are used to develop secondary questions for the interview process and structure the data analysis.

There are two elements that distinguish this study from other studies. First, the research is purely from the perspective of cognitively well, female older adults. Second, the study examines how living in the LTC setting with cognitively impaired older adults affects the meaning of ‘home’ for those female older adults who are cognitively well.

Chapter Three will describe in detail how this study was designed and accomplished.

# Chapter Three: Methods

This study is an exploratory, descriptive cross-sectional study of the meaning of ‘home’ for cognitively well older adults cohabiting with cognitively impaired older adults in Long-term Care (LTC) settings in Winnipeg, Manitoba. This chapter provides information on: research design; setting (including a brief description of the physical presentation of each of the facilities); study sample; ethical and access approvals; measurement; data collection and data analysis. The data were assessed using the Lincoln and Guba (1985) framework of trustworthiness. The chapter ends with a summary.

## Research Design

Given that the current relevant research has not focused exclusively on how living with cognitively impaired older adults affects the meaning of ‘home’ for cognitively well older adults, this study is exploratory. Three studies were identified which focused on a similar topic to this study. The first is by Hammer (1999) who explored the systems of meaning that older adults established to describe the essential structure of the lived experience of adjusting to feeling at ‘home’ when they relocated to alternative care settings (one life-care and two LTC facilities). The second was conducted in the early 1970’s when Gubrium (1993) explored everyday life in the LTC setting, by posing questions that addressed life’s outcomes, daily living in the facility, the meaning of ‘home’ and family, self-perception, health, aging, and death. The third was conducted by Fiveash (1998) who explored articulate residents living in LTC settings in New South Wales, Australia. Fiveash (1998) studied the general experiences of LTC life and offered an opportunity for older adult residents to voice their opinions about their understanding of their residential situation. Although these three researchers studied similar areas of interest they in fact have not explored the specific focus of this study.

The study is descriptive and aims to meet the four research objectives by describing what cognitively well older adults had to say about the meaning of ‘home’ in LTC, and how living with cognitively impaired older adults affected their meaning of and attachment to ‘home’. The study was conducted at one point in time and is thus, cross-sectional.

## Study Setting

Within the province of Manitoba, LTC settings are referred to as personal care homes (PCHs) rather than nursing homes. The Winnipeg Regional Health Authority (WRHA) (one of eleven regional health authorities in Manitoba) PCH Program has a vision and mission statement that provides guidance and direction to all PCHs under its umbrella. The WRHA (2009:1) vision statement is for the PCH Program, “To care for individuals in the most home-like environment possible, given their preference and based on their particular needs.” The WRHA (2009:1) mission statement is, “To provide 24-hour professional nursing services to eligible individuals who can no longer manage independently at ‘home’ with family support and/or community services like Home Care.”. However, there is not a statement or definition of what constitutes “home-like” within the PCH setting.

Within the WRHA PCH Program there are 38 PCHs with a total of 5,719 beds. The number of beds in individual facilities ranges from 57 to 314, with the average number of beds being 154 (WRHA, 2009). In order to increase the potential for variation in response to questions, the investigator chose to conduct interviews in four individual

LTC settings. The four LTC settings chosen were Kildonan Personal Care Centre (PCC), Lions PCC, Calvary Place PCH and The Convalescent Home of Winnipeg. All four PCHs are under the jurisdiction of the WRHA and are accredited by Canadian Council on Health Services Accreditation (CCHSA)[2]. The selected LTC settings were somewhat smaller than the average with 120 private beds in Kildonan PCC, 116 private beds in Lions PCC, 100 private beds in Calvary Place PCH and The Convalescent Home of Winnipeg having 12 private beds, 12 semi-private beds and 60 rooms with greater than two beds per room. These specific facilities were chosen, as the Directors of Care are known to be receptive and supportive of graduate students conducting research projects, which they demonstrated in supporting this study.

Kildonan PCC, the newest of the four, is located in a residential neighbourhood along the bank of the Red River on the outskirts of the city. The entrance and foyer are well lit with a significant amount of space for older adults and visitors. The nursing station is visible upon entering the building, thus one would know straight away where to seek out assistance, if needed. The community dining room and chapel can be seen through large sized windows from the front walkway. The rooms are easily found, being situated down the hallways of the facility. Many people were walking about or propelling themselves in wheelchairs, yet the facility did not appear crowded when the site was visited. The grounds are park-like and very spacious. The staff were observed being friendly and helpful to older adults and visitors.

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[2] CCHSA is an independent, non-profit, non-government organization incorporated in 1958. Its mission is to promote excellence in the provision of quality health care and the efficient use of resources in health organizations throughout Canada. This is accomplished through an established accreditation program. CCHSA draws on the expertise of 360 current health care professionals and accredits more than 3,000 sites, services, and programs across Canada.

Lions’ PCC is located in the city’s busy downtown area situated on a major thoroughfare. Lions’ PCC has the appearance of a large high-rise apartment building and may be particularly well-suited to people who have called a high-rise apartment building ‘home’ for any earlier part of their life. Upon visiting, the foyer and common areas on the main floor were found to be spacious and bright with large oversized windows allowing a vast amount of natural light through. There were many people mingling about yet the facility did not appear crowded. Staff, older adults and visitors appeared congenial and were conversing with others. There was a lot of activity. The grounds were on the smaller side with a few benches along the front walkway and parking in the front for visitors. The staff were observed being friendly and helpful to older adults and visitors.

Calvary Place PCH is located next to a residential neighbourhood and an industrial park. When visited, Calvary Place PCH had a quiet atmosphere with soft sounds of people having conversations. The foyer of Calvary PCH had the appearance of a small, upscale hotel lobby; the atmosphere was elegant yet not intimidating. There were people sitting in the lobby conversing and others playing card games. There were a few people coming and going with ease and they appeared to know their way around well. The facility did not seem crowded. The grounds were on the smaller side with parking in the front of the building for visitors.

The Convalescent Home of Winnipeg is located in a residential neighbourhood a few blocks off the main street of a well-known retail area. The foyer of the Convalescent Home was quiet with soft sounds of conversation. The appearance was of an older well-kept apartment building with a common area for older adults to gather casually. Both older adults and visitors appeared to know the place well. There were a few people coming and going at a relaxed comfortable pace as well as people sitting in the foyer conversing. The facility did not appear crowded. The staff at the front desk were friendly and helpful. The staff at the front desk knew the older adults as demonstrated by the positive personal comments that they made about them. The grounds were on the smaller side with parking to the side of the building for visitors.

### Study Sample

According to the Transition Manager of LTC and Community Housing (J. DiNicola, personal communication, February 13, 2009) in 2008 there were 720 community clients placed in a LTC setting within the WRHA compared to 1,212 hospital clients. Based on the estimate that the population of the LTC setting would have approximately 30 percent cognitively well older adults (based on available statistics) the investigator expected that this would be an ample population to select from in order to meet the inclusion criteria for sampling purposes.

A convenience sample of eleven female older adults was selected. Gubrium (1993) has suggested that men depict ‘home’ differently than women. For this study, the sample was homogeneous to control for gender differences in the perception of ‘home’. Sampling from four LTC settings was undertaken to ensure the likelihood of recruiting 11 cognitively well female older adults and to increase the potential of variations in perception. Inclusion criteria were: older adults who moved from a private home (condominium, apartment, independent dwelling, elderly person’s housing, or assisted living, and not from hospital or supportive housing); who had lived in the LTC setting for at least six months (to allow for “settling-in” and to allow sufficient time to potentially make a new ‘home’ for themselves); who were female; who were cognitively well (as identified by staff who were knowledgeable of older adults cognitive functioning and confirmed by scoring on a cognitive performance scale (CPS); and who were able to speak English and respond to basic interview questions.

As previously discussed in Chapter Two cognitive impairment includes many disabilities that can affect many of the activities of daily living (ADL) such as, grooming, dressing, and mobility and instrumental activities of daily living (IADL) such as, meal preparation, shopping, and banking. The definition of cognitive impairment provided by the RAI-HC Manual Canadian version second edition (2002) and measured by the Cognitive Performance Scale (CPS) score was used in this study. Cognitively impaired older adults individuals were excluded from this study.

Cognitively well was defined as having no cognitive disabilities, intact memories for both recent and distant events, no confusion, able to articulate speech well, comprehend the meaning of verbal and or written information, and function appropriately in social circumstances. As well, cognitively well individuals are alert and oriented to person, place and time, able to express needs, have decision-making capacity about day-to-day life and activities, and have good insight and judgement. Only cognitively well older adults were included in this study.

According to Dr. Kelly Murphy, a leading psychologist at Baycrest, one of the world’s premier academic health sciences centers focused on aging, situated in Toronto, Canada, “individuals with mild cognitive impairment do have a decline in cognitive skills, particularly memory, but they’re able to carry out normal activities of daily living and remain independent.” (Baycrest, 2009). Thus for the purpose of this study, older adults who may have had mild cognitive impairment were included in the sample. Level of cognitive functioning was determined by the older adult’s CPS score and input from a knowledgeable staff member in the LTC setting. A CPS score of zero to two (indicating no impairment or mild impairment) was considered an acceptable cognitive performance score to be included in this study.

## Facility/Resident Access and Ethical Approvals

First, an application for ethical approval was submitted to the Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba. In addition, an application for access approval was submitted to the Winnipeg Regional Health Authority (WRHA) Research Review Committee (RCC). Subsequent to receiving both of these approvals, access to older adults was requested and granted through the Directors of Care at each of the four LTC settings.

There were three primary concerns identified by the ENREB. First, the ENREB inquired if the participants had the right to have a guardian or an advocate attend the interview with them. The investigator responded that participants have a right to have a guardian, advocate, and/or family member attend the interview and this information was included in the Nurse Manager’s Script (Appendix B) and the Participant Consent Form (Appendix C). One woman chose to have her daughter present for the interview.

Second, the ENREB inquired about the location of the interview which should be selected by the participant to facilitate privacy. The investigator responded that the instructions to the participant had been revised to indicate that they select a location that will allow for privacy and confidentiality. All participants lived in private rooms. Two chose to have the interview in a private meeting room and nine chose to have the interview in their private rooms providing for privacy and confidentiality.

Third, the ENREB inquired about the storage and security of the raw data tapes at the investigator’s residence. The investigator responded that the raw data tapes would be stored in a locked filing cabinet, that there would be no names on the raw data and after successfully defending the study the tapes would be erased. The ENREB accepted these responses and approval was granted.

The WRHA RRC had two primary concerns. The first was privacy of the individual women in the study and the second was storage of the audio tapes in the investigator’s home. Although not a concern, the WRHA RCC requested that the investigator submit an executive summary of the final results of this study to the WRHA and provide a copy of any publications arising from the study.

The investigator agreed with the WRHA RRC that at least four settings would be used in this study and acquired support from Kildonan PCC, Lion’s PCC, Calvary Place PCH and The Convalescent Home of Winnipeg thereby facilitating privacy of the individual women in this study. In fact, in describing the women and providing direct quotations of what they said, care was taken to use pseudonyms and change some incidental information that might identify an individual participant.

The investigator assured the WRHA RRC that the audio taped recordings would be kept in a locked filing cabinet at the investigator’s home allowing the investigator access to the tapes as needed. This met the WRHA RRC’s expectations and approval for the study was granted.

Following access approval the investigator arranged for meetings with the Directors of Care from each of the LTC settings to provide them with the list of inclusion criteria (Appendix A) and the managers’ script (Appendix B) with which to introduce older adults to the study, as well as a copy of the consent form (Appendix C) to allow the older adults a preview of what to consider for decision making purposes. The investigator then contacted the older adults who were interested in participating and who agreed to have their names forwarded to the investigator by the Nurse Manager. The investigator then provided additional information on the study and obtained written consent (Appendix C) accordingly. The interviews were scheduled at a mutually agreed upon date and time. The investigator conducted all of the interviews. None of the women requested a second interview and there was insufficient time for the investigator to request a second interview.

Ethical approval and access was in place prior to the investigator contacting the Directors of Care at each of the four LTC settings regarding potential participants for the study. Ethical approval policy and protocols at the University of Manitoba are governed by the Tri-Council Policy on Research on Human Subjects (2001). The faculty affiliation (Faculty of Nursing) of the investigator determined which of the five Research Ethics Boards would review the application for ethical approval. The investigator’s advisor determined that ENREB was the appropriate ethics review board. Ethical approval was obtained from ENREB on July 9, 2009 and from The WRHA Research Review Committee on November 4, 2009 (Appendix D and Appendix J).

### Measurement

Measurement for the study consisted of three parts: socio-demographic questions; health related questions; and the interview script focusing on the research objectives. Socio-demographic questions included: In which year were you born (age)?, What is your marital status (never married, married, divorced, widowed)?, Do you have children?, Do you consider yourself to be a member of an ethnic group?, If so, which group?, Do you consider yourself to be a member of a church or religious group?, If so, which group?, In which year (or month) did you arrive to the personal care home?, Did you move from your own private home to personal care home (not supportive housing or hospital)?, What kind of work have you done for most of your life?

The health related questions included: Do you have any chronic illnesses? If so, what are they?, Are you able to do most things for yourself, do you need a little help, or a lot of help with: Grooming, Bathing/Washing, Dressing, Walking/Getting around, Eating., How would you rate your health? (Excellent, Very good, Good, Fair, Poor), Do you often feel sad or depressed?, How would you rate your quality of life? (Excellent, Very good, Good, Fair, Poor). The one-item self-rated depression question has been shown to be a reliable depression screening question by Mahoney, Drinka, Abler, Gunter-Hunt, Matthews, Gravenstein and Carnes (1994) and became a standard in surveys of older adults.

The interview script consisted of thirteen open-ended questions. Each question reflected one of the four research objectives as indicated in Table 3.0. The interview questions were pre-tested, and then revised based on the pre-test outcomes. This was accomplished by having two peers (nurses who work or have worked in the LTC setting) read the questionnaire and provide feedback on comprehension and ease of responding to the questions from the perspective of the LTC residents. As well, the investigator conducted the first two interviews and then met with the advisor to review the interview questions and the women’s responses. No changes were made at that time.

Table 3.0

*Interview Script Questions*

| Research Objective | Questions |
|---|---|
| To examine the perspective of the meaning of home prior to and after admission to the LTC setting amongst cognitively well female older adults | 1. Everyone has a different way of describing what home is. Could you please tell me what home means to you?<br>2. Now that you’re living in (_ _ _ _ _ _), has the meaning of home changed for you?<br>3. Do you consider (_ _ _ _ _ _ ) home? |
| To explore the lived experience of cognitively well female older adults in the LTC setting. | 4. How happy would you say you are living here?<br>5. How unhappy would you say you are living here? |
| To explore how living with cognitively impaired older adults affects day-to-day life of cognitively well female older adults. | 6. How does living with confused people affect your day-to-day life?<br>7. I would like to ask you about the good times and the bad times you have experienced living with confused people. Could you tell me about some of the good times? Could you tell me about some of the bad times?<br>8. What has it been like to share common areas with confused people?<br>9. Is there anything else you would like to tell me about what it has been like to live with confused people? |
| To explore how living with cognitively impaired older adults affects the meaning of home for cognitively well female older adults. | 10. How does this affect your feelings of home?<br>11. Does (_ _ _ _ _ _) feel like home to you?<br>Probe: If yes, what makes it feel like home?<br>12. What prevents you from feeling like (_ _ _ _ _ _) is home?<br>13. If everyone were like you, able to think clearly, would that make it easier to feel like (_ _ _ _ _) is home? |

Probes based on the Six Domains of ‘Home’ framework were used as needed during the interview and are listed in Table 3.1. One follow- up question was posed as a general closing question with the intent to end the interview on a positive note. The last question asked these women about their advice for others who might be moving into the LTC setting.

Table 3.1

*Probes Developed Related to the Domains of ‘Home’*

| Domain | Probes |
|---|---|
| Physical | 1. Is there any part or place in the PCH that you consider home?<br>2. Do you feel safe and secure here? |
| Social | 1. What are some of the activities that you participate in?<br>2. What are some of the activities that you do not participate in?<br>3. Can you describe some of the activities that you plan? |
| Spiritual | 1. Can you describe how you practice your religious practices or spirituality?<br>2. Do you feel like you fit in? Like you are part of the community here? |
| Spatial | 1. Tell me about your daily routine?<br>2. When you go out does it feel like you’re coming home? |
| Temporal | 1. Tell me about some of the possessions you brought with you when you moved?<br>2. What have you collected since you arrived? |
| Emotional | 1. Tell me about the friends you have made?<br>2. What kind of things do you do with your friends and family? |

### Data Collection

Initially twelve names of female older adults were provided by the four Directors of Care. However, before the interviews were scheduled, one of the women changed her mind and declined to participate and so the final sample size was eleven women. After the women agreed that the investigator could contact them, the investigator made initial contact by telephone to provide more information on the study, and to arrange the dates and times of their interviews. All eleven of the women had their own telephones in their rooms.

The investigator attended each of the LTC settings in person. Nine of the women chose to have their interviews conducted in their private rooms. Two women from the Convalescent Home of Winnipeg chose to have their interviews conducted in a private meeting room on the main floor of the facility. All interviews were conducted in either a single room or private meeting room so privacy was ensured for all of the women participants.

Prior to the formal segment of the interview, the investigator introduced herself as a part-time nursing student in the process of completing her Masters of Nursing degree. The investigator presented her University of Manitoba student card, which includes a photo for identification purposes. Then the investigator checked with the women concerning their wishes to continue or withdraw from the study. The investigator inquired if the women felt well on the day of the interview, which they all did. If they had not felt well, then another interview time would have been scheduled.

Next, the investigator discussed the use of the audiotape machine and carried on informal conversation to build rapport and establish some level of comfort and trust. The women understood and accepted the need to audiotape the interviews and none of them refused to be audiotaped. The interviewer explained to the women participants that once the investigator successfully defended her thesis, the audiotapes would be destroyed. The investigator also used field notes that were written after the interviews as a means of recalling details of the settings and the investigator’s feelings surrounding the events at the time of each interview.

Prior to beginning the interviews, the investigator reminded the women that they could decline participation at any time or decline answering any questions that they chose to. Interviews were conducted over a four-week period during the month of December 2009. On average the interviews took 40 minutes to conduct. None of the women required a rest period or needed to cease the interview due to fatigue, emotional distress or for any other reasons necessitating a second interview.

It should be noted that the members of this sample were selected and initially contacted by the Nurse Manager in the LTC settings prior to the Director of Care providing the women’s names to the investigator. It seems likely that the Nurse Manager would be drawn to recruit cognitively well older adults who were articulate, outgoing and interested in the topic. In addition to being relatively sociable, it may well be that those who then chose to participate felt comfortable with, and desired to, talk about their life and ‘home’ in the LTC setting.

### Data Analysis

All interviews were audiotaped and later transcribed into text by the investigator. The investigator reviewed each transcript while simultaneously listening to each audiotaped interview. The investigator then read each transcript to ensure the accuracy of each transcribed interview. A number was assigned to identify each interview and each line of the text for each interview was numbered to facilitate analysis. The length of the transcripts, which ranged between seven to eleven double-spaced pages of text, did not warrant qualitative analysis software for data management. Part of the process of analyzing the data was to list each interview question at the top of a page, write out all of the responses under each question, read and re-read the responses on that page, then highlighting the words that repeated and search for common responses.

The study objectives and the conceptual framework of the Domains of ‘Home’ which was gleaned from the literature guided the development and ordering of the interview questions. The investigator had identified six domains that describe the meaning of ‘home’. The physical, social, spiritual, spatial, temporal, and emotional domains of ‘home’ were used to develop probing questions. The six domains of ‘home’ facilitated the analysis of the data taken from the narratives captured through the interview process.

The investigator and her advisor separately organized the narrative data around the set of interview questions that addressed each research objective. Clearly, the women did not always adhere to each question in the order that it was asked and the women might, for example, talk about something related to objective #4 when responding to questions about objective #1. This occurred most often in relation to objective #2 and #3 where it seemed that for these women to describe their everyday life (objective #2), it invariably included talking about incidents with other older adults who were cognitively impaired (objective #3). Because the questions were closely linked to the objectives, the separate analysis by the investigator and advisor was easily compared for agreement on which statements by the women participants corresponded to the research questions (and thus, the research objectives). The analysis that is presented in Chapter Four is similarly organized around the objectives and interview questions.

The method of analysis was constant comparison as developed in sociology and anthropology (Glaser & Strauss, 1967). This strategy involved comparing the women’s responses to the questions (posed in relation to the objectives) in order to discern common patterns of responses across all of the women in the study. The investigator and advisor each brought their analysis together on two occasions of intensive comparison work and found little disagreement. The investigator, by virtue of being the interviewer, simply knew more about the verbal nuances and non-verbal communication that took place during the interview. The advisor by virtue of not coming into contact with the women provided a more substantive approach to the data without the personal attachment that sometimes occurs during the interview process. The addition of field notes also provided a context for the interviews. The process of reviewing each woman’s responses by question/objective was time-consuming but because it was done separately by the investigator and the advisor it meant that the comparison stage of analysis although intense was time efficient.

The final question on the advice that the women would give to others who might be coming to live in a LTC setting also was analyzed separately and then compared. The theme, “women who made it ‘home’” was discussed in detail by the investigator and the advisor and during that process, there was agreement that this theme was part of every question and objective and was best described as the “overarching” theme.

### Trustworthiness of the Data

The qualitative data was evaluated based on four characteristics in order to ensure trustworthiness. The four characteristics were credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985).

*Credibility.* There were three components of credibility used in this study. The first was prolonged engagement, which included sufficient time to perform interviews as well as learning about the setting and the culture of the sample (Lincoln & Guba, 1985;

Polit & Beck, 2004). The second was ‘member checking’ which included feedback from the women on content. The third was monitoring for saturation of findings.

First, prolonged engagement was achieved by the investigator scheduling interviews at times that best suited the women to allow them as much time as they needed to be comfortable with the idea of participating and to complete the interview. There was ample time to conduct the interviews and allow feedback from the women, however there was insufficient time within the overall project timelines for the investigator to request and arrange second interviews.

Prolonged engagement also pertains to an understanding of the setting and the characteristics of the sample. The women in this study seemed to exhibit a strong sense of identity and self-worth. Their responses to questions seemed sincere and sometimes insightful. They expressed positive feelings about connecting with people and participating in life’s activities with people. The women emulated similar behaviour to the culture of the staff appearing compassionate in their descriptions of others. These women more often presented optimism as they spoke. They spoke as though they belonged to the community not a LTC setting, and spoke positively about the LTC setting in which they were living.

Second, member checking with the women occurred at the time that data were being collected. During the interviews the investigator checked frequently with the women to ensure the meaning of their responses. Third, the investigator checked for similar responses recurring and patterns developing lead to the achievement of monitoring for saturation of findings.

*Dependability*. Dependability is described as stability of the data over time, consistency (Lincoln & Guba, 1985; Polit & Beck, 2004), predictability, and accuracy (Lincoln & Guba, 1985). One technique used to reach dependability was to pre-test the interview questions and then revise them as necessary. This was accomplished by having two peers (nurses who work or have worked in a LTC setting) read the questionnaire and provide feedback on comprehension and ease of responding to the questions from the perspective of the LTC setting residents. Also, the investigator conducted the first two interviews and then met with the advisor to review and revise the interview questions. There were no changes made at that time. Another way of achieving dependability is to create a paper trail beginning with the raw data, otherwise known as the interviews and field notes. The investigator kept field notes on each interview questionnaire to use as a source to describe the setting and characteristics of the LTC setting. The investigator also summarized feelings and impressions about each interview prior to and immediately following the conclusion of each interview in the style of a journal. The journal entries provided study context and kept the investigator’s biases in check; however they were not part of the data analysis.

*Confirmability*. Confirmability relates to independent subjective agreement (Lincoln & Guba 1985). Polit and Beck (2004) describe confirmability as the objectivity or neutrality of the data where two or more independent people concur about the data’s accuracy, relevance, or meaning. According to Lincoln and Guba (1985) this may be achieved through multiple independent observers agreeing upon the analysis of the phenomenon. This is also known as collective judgement, which is considered to be objective (Lincoln & Guba 1985). The investigator and the advisor analyzed the data separately for all interviews. The advisor and the investigator then met to discuss and analyze the data collectively. Meetings for this purpose were scheduled on a regular basis at a mutually agreed upon time.

*Transferability*. Transferability, the first component of trustworthiness, is also known as ‘naturalistic generalizability’ and may be achieved through the use of ‘thick description’ (Lincoln & Guba 1985). According to Polit and Beck (2004:436) ‘thick description’ “refers to a rich and thorough description of the research setting or context and of the transactions and processes observed during the inquiry.”. The investigator attempted to provide sufficient description of the data, including attentive analysis of social and cultural relationships as well as setting details, to allow one to conclude that the findings are transferable (Lincoln & Guba 1985). As previously discussed in the section describing the intended study sample, the purpose of sampling from four LTC settings was to attempt to increase the potential for variation in responses and to ensure the highest probability of meeting inclusion criteria and thus achieving a reasonable sample size.

## Summary

This chapter outlined the research design and provided descriptions of the research settings. The sample and inclusion criteria were described. One older adult who initially agreed to participate declined at point of telephone contact with the investigator. Otherwise there were no further barriers and eleven female older adults participated in this study. Protocol for access and ethical approval were discussed and the questions posed by the WRHA Access Committee and university Research Ethics Board were highlighted. Data collection and analysis procedures were described. Chapter Four, which follows, presents the results of data analysis and the findings from the study.

# Chapter Four: Findings

This chapter provides an overview of socio-demographic and health related characteristics of the women in this study. It also provides the constructs that emerged in relation to the four research objectives and the questions that were asked to address the objectives. The constructs emerging from the study are explored and related to previous research on the lived experience and the meaning of ‘home’ in the long-term care (LTC) setting under the following headings: (a) the meaning of ‘home’, (b) the lived experience, (c) does living with cognitively impaired older adults affect day-to-day life, (d) how living with cognitively impaired older adults affects the meaning of ‘home’, and (e) responses to the question about advice. The overarching theme for this sample of women seemed to be “women who made it ‘home’” and this is discussed. This chapter concludes with a summary.

## Sociodemographic Characteristics

Data on the socio-demographic characteristics of the sample was collected in order to provide a profile of the sample rather than for analytical purposes. The average age of the women was 86.6 years with the range being 55-99 years. There was one younger woman who was 55 years of age. This woman was in the LTC setting with severe physical limitations due to a degenerative neurological disease. A review of this woman’s level of function demonstrated few differences with her activities of daily living (ADLs) and instrumental activities of daily living (IADLs) compared to the other women in the sample; therefore, the investigator and advisor chose to keep this woman in the study. In short, her chronological age was different but her functional age was similar to the other women participants. The average age of this sample of women, excluding the youngest was 89.8 years and the age range was 81 to 99 years.

Marital status varied amongst the women. One woman was married, seven were widowed, two were divorced, and one had never married. In Manitoba, 65.1 percent of individuals over the age of 85 are widowed (Profile of Manitoba’s Seniors, 2010). The husband of the one married woman resided in the same LTC setting. Eight women reported having children and three reported that they did not.

The type of work that women were involved in prior to retirement included white collar jobs, homemaker, and volunteering. Two women considered themselves to be from an ethnic background, five did not, and four did not answer the question. Nine women acknowledged an affiliation with a church or religious group and two did not. The average length of stay in the LTC setting was 23 months with a range of six months to 4 years. This compares to 2.7 years average length of residence for the province of Manitoba in 2007 (Profile of Manitoba Seniors, 2010). So, as a group, these women had spent less time on average in the LTC setting when compared to the population average.

### Health Related Characteristics

Table 4.0 summarizes the women’s health related characteristics. Eight of the eleven women reported chronic conditions. Two women reported living with rheumatoid arthritis, three women reported living with heart disease, and two reported living with a degenerative neurological disease. One woman reported that she had many chronic conditions but did not state what they were. Three women reported that they had no chronic conditions which seem unlikely given the age of the women and their presence in a LTC setting but this report may speak more to the health optimism that became evident in the interviews and is reported later in this section.

Table 4.0

*Self-Reported Chronic Conditions*

| Chronic condition | Number of participants (n = 11) |
|---|---|
| None | 3 |
| Rheumatoid Arthritis | 2 |
| Heart disease | 3 |
| Degenerative neurological disease | 2 |
| Non-specific | 1 |

Activities of Daily Living (ADL) include grooming, dressing, bathing, eating and mobility. The levels of assistance required for the performance of ADLs that were used for the interview questions were *“Independent, a little help, or lots of help”*. Table 4.1 presents the women participants’ physical level of functioning. Three women reported being independent with grooming, two required a little help and six required lots of help. Three women reported being independent with dressing, three required a little help, and five required lots of help. One woman reported being independent with bathing, four required a little help and six required lots of help. Seven women reported being independent with eating, three required a little help and one required lots of help. Eight women reported being independent with mobility, while seven used mobility aides such as walkers and wheelchairs, one required a little help and two required lots of help.

Table 4.1

*Levels of Independence in Activities of Daily Living*

| Activity | Participants’ Degree of Independence(n = 11) | | |
|---|---|---|---|
| | Independent | A Little help | Lots of help |
| Grooming | 3 | 2 | 6 |
| Dressing | 3 | 3 | 5 |
| Bathing | 1 | 4 | 6 |
| Eating | 7 | 3 | 1 |
| Mobility | 8 (7 mobility aides[a]) | 1 | 2 |

[a] Included canes, walkers, manual wheelchairs, and electric wheelchairs

Overall, these women were relatively independent in mobility and eating but most required help with grooming, dressing, and bathing.

The women participants were asked to rate their health and quality of life. The five category self-rating scale used for these questions in this study was *‘Excellent’ ‘very good’ ‘good’, ‘fair’, and ‘poor’*. One woman reported having excellent health. Four women reported having very good health. Two women reported having good health and four reported having fair health. None of the women reported having poor health. Approximately 45 percent of the women in this study reported excellent or very good self-rated health as compared to 30.7 percent of women in Manitoba aged 75 and over in 2007 (Profile of Manitoba’s Seniors, 2010). Approximately 18 percent of the women in this study reported good self-rated health as compared to 36.3 percent of women in MB age 75 and over in 2007(Profile of Manitoba’s Seniors, 2010). Approximately 36 percent of the women in this study reported fair health as compared to 32.9 percent of women in MB age 75 and over in 2007(Profile of Manitoba’s Seniors, 2010). The responses to this item seem to demonstrate confidence in health and optimistic attitudes. Thus this group of women displayed relatively more health optimism compared to the Manitoba population.

None of the women reported having excellent quality of life. Six women reported having very good quality of life. One woman reported having good quality of life. Four reported that they had fair quality of life. None of the women reported having poor quality of life. These responses are similar given to the item on self-rated health and again seem to suggest optimism.

In Manitoba, all applications to the LTC setting are presented at the Regional Health Authority (RHA) Panel Review Board[3] for review and consideration for admission to the LTC setting. For the Winnipeg Regional Health Authority (WRHA) Panel, these women would have been recommended as requiring 24-hour care and/or supervision in order to meet criteria for admission to the LTC setting. This need for 24 hour care and supervision likely reflects the ADL needs of the women and for some, a lack of family support in the community. Once again it is noted that given the level of personal care needs of these women, their optimism in rating their health and quality of life is noteworthy. Nevertheless, the majority of women reported having “good health” or

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[3] Paneling is the approval process for admission to the Long-term Care Program. The Panel Review Board includes a physician and managers from the Long Term Care Access Centre and Home Care. Their role is to review the application information to ensure the most appropriate care option has been determined. If the Panel determines the individual does not require a Long-term Care placement at that time, the application will be rejected. A decision may be deferred if additional information is required.

better and “good quality of life” or better, thus demonstrating confidence in their health and a positive life view (Table 4.2 and Table 4.3).

Table 4.2

*Self-Rated Health*

| *Self-Rated Health* Participants’ degree of health (n = 11) | | | | |
|---|---|---|---|---|
| Excellent | Very Good | Good | Fair | Poor |
| 1 | 4 | 2 | 4 | 0 |

Table 4.3

*Self-Rated Quality of Life (QOL)*

| Participants’ degree of QOL (n = 11) | | | | |
|---|---|---|---|---|
| Excellent | Very Good | Good | Fair | Poor |
| 0 | 6 | 1 | 4 | 0 |

Self-reported levels of depression among the women were considered by using an open-ended question, *“Do you often feel sad or depressed?”* The responses varied from “No”, and “Not hardly ever, no”, to “Oh sometimes yeah but I don’t show it” and “Ah not too often but I do have times when I think back, I get a little depressed but I mean it passes”. None of the women admitted to often feeling sad or depressed. The investigator missed asking this question to one woman. This woman’s posture, facial expressions, and vocal tone were positive. She was socially engaged, had an expressive affect, and spoke verbosely throughout the interview. None of the women exhibited overt signs that they may be suffering from a chronic depression. As well, none of the women disclosed depression as a chronic condition (Table 4.0) earlier in the interview. Once again these women exhibited healthy optimism suggesting that these women possess a strong sense of identity and self-worth (Table 4.4).

Table 4.4

*Self-Reported Depression* (n = 11)

| Participants’ reports of depression (n = 11) | | |
|---|---|---|
| Yes | No | No Answer |
| 0 | 10 | 1 |

Research Objective # One: The Meaning of ‘Home’

The first research objective was, *“To examine the perspective of the meaning of ‘home’ prior to and after admission to the LTC setting amongst cognitively well female older adults.”* To explore the meaning of ‘home’ prior to and after admission to the LTC setting three questions were posed.

1. Everyone has a different way of describing what home is. Could you please tell me what home means to you?
2. Now that you’re living in (_ _ _ _ _ _), has the meaning of home changed for you?
3. Do you consider (_ _ _ _ _ _) home?

In exploring the meaning of ‘home’ prior to admission to the LTC setting the topic was introduced to the women by way of explanation that everyone has a different way of describing ‘home’. The women were then asked to convey what ‘home’ meant to them. Of the eleven women, ten included people, or activities associated with people, in their meaning of ‘home’. Specifically, six spoke of people and five spoke of activities associated with people. Five of the women used the word ‘independence’ or terms describing independence. Three spoke of personal belongings, three described décor and aesthetics, and three included the concept of space in their meaning of ‘home’. The terms used by these women are consistent with the six domains (physical, social, spiritual, spatial, temporal, and emotional) used in the working definition of ‘home’ constructed for the purpose of this study. The one domain of ‘home’ not commented on by the women participants was the “spiritual” domain (the notion of solitude, reflection, unwanted intrusion, boundaries and a place to retreat as a safe haven). Possibly the women felt safe and secure in their environment and thus gave this specific domain of ‘home’ little consideration or they may not have held this feeling of ‘home’ as being of a spiritual nature.

It seems likely that the two most important domains of ‘home’ for this group of women would have been first the physical domain and subsequently the social domain. As discussed earlier in this chapter most of the women in this study required assistance with meeting some of their most basic physical needs and many required mobility aides to mobilize. For this reason attempting to establish one’s place in the physical layout of the LTC setting seems an important component of developing a sense of ‘home’. Once an individual determines where and how they fit physically into a new environment and they perceive that their basic physical needs are being met consistently and reliably then it seems natural that having their social needs met would follow. The majority of women in this study certainly presented as being gregarious and it seems likely that they would quickly reach out to people in the LTC setting to meet their need for socialization.

There were three constructs that emerged from the meaning of ‘home’. The identified constructs, explored in this section are ‘people’, ‘activities associated with people’, and ‘independence’.

The first construct that emerged from womens’ descriptions of ‘home’ prior to admission to the LTC setting was ‘people’. The ‘people’ attached to the meaning of ‘home’ were family and friends. Six women used the word ‘family’. Three women used the word ‘friend(s)’. Two women used the word “someone”. Several women used all the terms, “parents”, “husband”, “son”, “people”, and “good neighbours” once. In the research by Gubrium (1993), Fiveash (1998) and Hammer (1999) older adults who were able to obtain a sense of ‘home’ appreciated people in general and held people in high regard. Brummett (1997), Hammer (1999), Dovey (1985), and Werner, Altman, and Oxley (1985) stressed the importance of people, relationships with people, interactions with people, and identifying with people in describing the notion of ‘home’. Hammer (1999:12) examined the lived experience of being at ‘home’ in assisted living centres and found, “that in some situations, the loss of a loved one was equated with losing one’s emotional ‘home’”. The women in this study verbalized that the most significant component of ‘home’ is ‘people’. This finding fits well within the findings of the current literature.

The second construct that was revealed from the interviews was ‘activities associated with people’. Phrases used that related to ‘activities associated with people’ were, ‘getting along’, ’good times’, ’not being alone’, ’church life’, ‘entertaining’, ‘conversation’, ‘social interaction’, ‘interpersonal relationships’, and ‘dining’.

This construct ‘activities associated with people’ can also be found in the literature where older adults reported living active social lives with people inside and outside the LTC setting (Gubrium, 1993; Fiveash, 1998; Hammer, 1999). The social encounters reported from this study were somewhat different from those noted by

Gubrium (1993). In Gubrium’s (1993) study, older adults actively sought out opportunities to interact with others such as being friendly greeters and visitors for new residents. As well, Brummett (1997) and Dovey (1985) included activities associated with people in their concept of ‘home’ suggesting that ‘home’ is a place where we connect with peers and friends and interact with people of one’s choosing. Werner, Altman, and Oxley (1985) emphasized the notion that activities associated with ‘home’ may recur on a daily, weekly, monthly, annually, or some regularly expected frequency creating a rhythm of repetitive events, especially the regular movement of people, places, and processes. ‘Activities associated with people’ is an important component of ‘home’ for individuals while in their ‘homes’ in the community and in their ‘homes’ that they establish in the LTC setting.

A third construct emerged from the transcripts, which was the notion that ‘home’ means ‘independence’. Interestingly, one woman who was in a wheelchair and physically dependent requiring the highest level of assistance with ADLs still described herself as, “… so independent”. Two other women referred to how they try to be independent, “I do as much for myself as I can for myself.” and “Well I’m getting some help now but I do most of it by myself because I have to look after myself.” Four other women described independence in unique ways, “Looking after myself.” and “I was 27 years by myself. I travelled. It was lonely sometimes but I entertained people. I guess I’m kind of a friendly person.” as well as, “I had the stroke nine years ago… I was sort of rehabilitated so I was doing pretty good. I could go out on my own and things like that.” and “We were independent….” One woman used the word “independence” by itself when describing ‘home’ prior to residing in the LTC setting. Other women expressed the notion of a loss of independence after moving to the LTC setting, which is summarized in Table 4.5. Although the investigator did not ask the women to compare their LTC setting life with their previous ‘home’ life, during this part of the interview most of the women made comparisons in relation to independence.

The women in this study may have raised the topic of independence in the LTC setting because they felt comfortable with the level of independence they exercised through making choices, expressing self-determination and preferences, and demonstrating autonomy while living in the LTC setting even though they were not as physically independent as in the past and required personal care support. Similarly in Hammer (1999) older adults expressed that ‘home’ has a sense of independence attached to it in that ‘at home’ an individual is his or her own boss or that one is in charge of oneself. Participants in Kahn’s (1999) study conveyed that when one resides in the LTC setting an individual is not on his or her own schedule for meals and bedtime, inferring that at ‘home’ an individual is on their own schedule and independent to make their own decisions. Dovey (1985), Brummett (1997), Hammer (1999) Hepworth (1999), Angus, Kontos, Dyck, Mckeever, and Poland (2005), and Dyck, Kontos, Angus, and McKeever (2005) speak of independence in the sense that at ‘home’ one has control over access as well as control over one’s environment. There are several similarities between the descriptions from women in this study and the literature in relation to independence.

Table 4.5

*Loss of Independence in the LTC Setting*

| Resident[a] | Comments |
|---|---|
| Betty | “The fact that I haven’t got a car and I can’t drive. You know if you are more independent you know then you are happier, eh.” |
| Madge | “You know you get use to doing things for yourself and you become very independent… I wished I lived in my own apartment again….” |
| Joan | “I came here with the idea knowing that I couldn’t take care of myself …” |
| Dorothy | “Oh no. This is entirely different dear. I’m being looked after.” |
| Ruth | “I’ve lost the use of my legs. …I have to use the wheelchair van because I can’t get myself from the ground into the vehicle.” |
| Virginia | “... That’s why we’re here. We need help. …The thing is that you recognize the need and accept your own.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

Next, the women participants were questioned as to whether or not the meaning of ‘home’ had changed now that they are living in the LTC setting. Six of the eleven women reported that the meaning of ‘home’ had not changed for them, three reported that it had, and two did not answer the question. Five of the six women that replied “No” provided additional comments within their answers (see Table 4.6). Phyllis simply stated, “No” without elaborating. The women who answered, “Yes”, to the meaning of ‘home’ changing also provided explanation. Lois expressed, “Oh of course it has to somewhat. But this is home, it’s decorated how I like it. No I’m very comfortable here.” Joan explained, “I guess I can’t participate in those things as much as I use to” referring to the things she use to do in her ‘home’. Alice identified that the reason the meaning of ‘home’ had changed for her was that, “Yeah I’m by myself. Well there’s another person. She’s a Catholic, too. She’s upstairs.” referring to her religious affiliation.

Table 4.6

*Comments on ‘Home’ had not changed since moving to the LTC Setting*

| Resident [a] | Comments |
|---|---|
| Betty | “No I really didn’t think about it.” |
| Madge | “No, but it hasn’t changed the fact that I would love to have been back in my home the way it was.” |
| Dorothy | “This is entirely different dear. I’m being looked after.” |
| Ruth | “No. As long as I have my own little space and lots of things to do.” |
| Virginia | “The point is its adjustment.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

Lastly, women were asked, *“Do you consider ‘this’ LTC setting to be your ‘home’ now?”* Eight women responded, “Yes” and three of the women responded, “No.” Four of the eight women that replied in the affirmative provided the following terms as part of their responses which suggests an underlying attitude within their answer, “Basically, yeah”, “I guess I haven’t got much choice”, “I have to now”, and “I have no place else to go”. These four women agreed that the LTC setting is ‘home’ but seemed to say so with a sense of resignation.

This sense of resignation was also observed in Kahn’s (1999) study whereby older adults were found to be “making the best of it”. Kahn (1999) described, “making the best of it” as a coping mechanism that allowed older adults a means of transitioning into the LTC setting. The participants in Kahn’s study verbalized the “pros” and “cons” of living at ‘home’ and of living in the LTC setting but were willing to accept the tradeoffs in order to make the transition and attain a sense of ‘home’ in the LTC setting. The four women in this study who used similar coping strategies as, “making the best of it” did not report being unhappy in their environment, thus supporting the notion that, even though they had resigned themselves to the LTC setting being ‘home’, they had adjusted reasonably well in their new surroundings.

In contrast to Kahn’s theme of “making the best of it”, one of Gubrium’s themes “making a new ‘home’” focused on the positive, where participants had a strong zest for life and love of humankind. Within the concept of “making a new ‘home’”, positive memories of earlier life influenced how participants viewed their current situation and future events, which helped participants in establishing a sense of ‘home’ in the LTC setting (Gubrium, 1993).

It should be noted that by the end of the interviews two of the three women who initially responded, “No” to the question, *“If they consider the LTC setting that they are currently living in to be ‘home’”* displayed ambivalence on the matter and suggested that the LTC setting does in fact feel like ‘home’. A summary of their comments can be found in Table 4.7.

Table 4.7

*Comments on ‘Home’*

| Resident[a] | Comments about the LTC setting not being ‘home’ (beginning of interview) | Comments about the LTC setting being ‘home’ (end of interview) |
|---|---|---|
| Doris | “This is not home. But uh, you know in my mind I’ll be here for the rest of my life I guess.”<br>“No not my home. It’s not as spacious as I’m used to but I understand.” | “Yeah. But this is home. I have to, you know get along the best I can.”<br>“I don’t know. Forget about home. This is home.” |

| | | |
|---|---|---|
| Ruth | “No not really because I still own a home in Rural Manitoba.”<br>“And that’s really really my home and how long that’s gonna stay I don’t know. But this is a good stopover place, you know.” | “Yeah but not. I don’t know. I don’t know what to say.”<br>”It’s not really home. It’s almost like. You know what it’s almost like. After my husband returned we went to South United States of America (USA) every winter. We’d leave in October and come back in April and we had a mobile home down there. And we loved it….”<br>”It’s uh, sort of like there’s always another place to go. When we were down there we were looking forward to coming home. And when it came time to go back down we were looking forward to going there. So no it was two homes really. And I would feel like this place kinda fits like that.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

A possible explanation for the ambivalence experienced by these two women is that, given the opportunity to reflect and explore the concept of ‘home’ and their feelings associated with ‘home’, they may have begun a journey to discovering ‘home’ in the LTC setting. The third woman who responded “No” this LTC setting is not ‘home’ made the following comments, “No. It’s my room. This is just my room. And some of this stuff is my furniture like….” There were no reports of feeling powerlessness, subservient, imprisoned, or frightened as found in the literature (Gubrium, 1993; Teresi, Holmes, & Monaco, 1993; Gorman, 1996; Fiveash, 1998; Hammer, 1999; Oh, 2006).

Conversely, all women reported either compassion, understanding, or respect for fellow older adults with cognitive impairment. Women who had required intervention by a staff member to assist with another older adults’ disruptive behaviour described feeling confident and comfortable that staff would respond promptly and intervene effectively.

The most disruptive behaviours most often reported were confused speech, taking other’s belongings (“stealing”), yelling/screaming, wandering into another’s room, wandering around the dining room at meal times, and resting in another’s bed. At no point in the interview did any women report fear or concern for their safety or well-being. These behaviours were not disturbing to all women but simply not tolerated as well by some women. Doris, who did not tolerate disruptive behaviour as well as some of the other women, reported, “ I ignore them you know” but then went on to describe multiple positive interactions with confused people where she handled the situation very well and at one point sought out assistance from a confused person,

> “There’s one woman sits out here in her chair so I can see her from here. She’s very, very confused. One day I was getting dressed and I had a button I couldn’t do up. On my sleeve I couldn’t do up this button. So I asked her if she could button this blouse for me. And she was pleased you know. I’m her friend ever since you know. Twice I’ve asked her to button it up for me. And she thinks she’s doing something to help you know. I like her but you can’t talk to her at all. But she likes to think that she’s doing something to help.”

Other women did not tolerate disruptive behaviour. Joan said, “Well I must say I’m not always too tolerant about it you know. I try to be but ah, sometimes I just walk out”. Francis said, “Wellll. Some, some are very frustrating… it’s annoying sometimes”. Lois said, “Oh sometimes I get PO’d about some of these residents, but they can’t help it.” Some of the women participants who were more accepting of the circumstances. Alice said, “It’s not bad. But it’s something you don’t know what to talk to them about. It’s a little bit hard….” Phyllis said, “Well the confused people don’t affect me at all”.

Madge said, “… but you know who is confused and you talk to them and whatever funny kind of an answer you get that’s what you get but you understand where it’s coming from you know”. Dorothy said, “Oh I don’t mind it”. Ruth said, “It has no affect on me at all” “Not bad. There’s a woman that screams a little bit at night but she doesn’t bother me”. Virginia displayed extreme understanding and sensitivity towards confused people in expressing the following,

> “Well you see with the confused people it’s very depressing. I look on it as I still have my mind. But it’s very depressing at times. You try to help them but you can’t”, “They send them all to my table and the people can’t tolerate some. The nurse asks me, ‘Do you mind?’ and she knows I don’t. I’m tolerant. And they do kooky things”, “Oh yeah. They don’t know what they’re doing. That’s why we’re here. We need help”, “Very sad. If somebody dies it’s like family. And since I’m here twenty-two have passed on. And we all suffer. It’s a family. You see them every day.” “I have no remorse at all. This room is like a meeting place. They come and go. One will sit down. Some can’t speak but they rest. It’s nice. I have an open door.”

This tolerance for those who could be difficult and sometimes highly disruptive or distressing was also found in Lapuk’s (2007) study of male veterans living in the LTC setting. One male veteran in that study summed up a quite compassionate description of an aggressive resident by saying, “He [aggressive resident] is not a desperate man, or a cruel or hard man. He is just confused. Confusion, loneliness, sadness, aggression comes into the picture”. It is possible that the women in this study were also compassionate and empathetic because they lived by “The Golden Rule” of treating people the way they would want to be treated. Or they might have treated difficult and disruptive resident people in a gracious fashion for the reward of the benevolent feelings that it brings.

In the literature, the percentages of participants that perceived the LTC setting to be ‘home’ varied significantly (Gubrium, 1993; Hammer, 1999; Lapuk, 2007). As shown in Table 4.8 Hammer (1999) found that 30 percent of the participants accepted the LTC setting to be ‘home’, Gubrium (1993) discovered that 50 percent of participants in his study perceived the LTC setting to be ‘home’, whereas Lapuk (2007) reported that 75 percent of older adults considered the LTC setting to be ‘home’. In this study 72.7 percent of the women considered the LTC setting that they now reside in to be ‘home’. As well, similarly to Lapuk (2007) the participants in this study did not connect the disruptive behaviours of cognitively impaired older adults with their perception of ‘home’.

Table 4.8

*The LTC Setting as ‘Home’*

| Study | Older adults who perceive the LTC setting to be ‘home’ (%) |
|---|---|
| Hammer (1999) (n = 10) | 30 |
| Gubrium (1993) (n = 24) | 50 |
| Lapuk (2007) (n = 8) | 75 |
| Present study (n = 11) | 72.7 |

In Chapter Two, a framework of six domains and qualities of ‘home’ was developed. Based on that framework, the following comparisons can be made between the components of ‘home’ and these women’s experiences in the LTC setting. ‘Home’ can allow for freedom of expression and development of one’s identity including perception of self and others. Most of the women in this study were able to report examples of this based on their routine practice of making choices regarding activities of daily living. As well, they chose whom to associate with, what activities to participate in, and when they wanted time alone. These women easily identified characteristics of themselves and others with self-descriptions of being a happy person, ‘laughing stuff off’, and not holding grudges. Examples of women getting to know other people are provided by the following two statements by Phyllis, “I know I just hear someone yelling and think oh that’s just Gladys, eh, eh, eh.” and Madge, “They become more or less something like your family too.”

Individuals attach aesthetic value to the meaning of ‘home’ and by collecting meaningful possessions develop place attachment and identity. This facilitates the bonding of people to their environment. These women displayed pride in the way they decorated their ‘home’ (rooms) and in the possessions that they either brought with them or had collected while living in their new setting. Many of the women talked about “my room”, “my space”, or “my stuff”. This demonstrates that they have been able to make a connection with their environment.

At ‘home’, engaging and interacting with others is a choice including the coordination of social activities. The women in this study offered many examples of self-determination with these tasks while living in the LTC setting. ‘Home’ encompasses such concepts, as solitude, reflection, lack of unwanted intrusion, boundaries and retreat. When combined they create a haven. Women reported that they always have the choice to spend time in their room away from the daily routine of the LTC setting and away from the disturbing behaviours of other older adults. Though, it should be noted that in common areas such as the dining room there is little chance of avoiding intrusion from disruptive behaviours. This is related to the structure in LTC settings where there is one main dining room for all older adults who are able to feed themselves or require minimal intervention to consume their meals. This allows older adults who wander to come and go from the table multiple times during a meal, which some women found difficult to tolerate. Common areas in the LTC setting appear to be similar to public places wherein one interacts with the general population in society.

‘Home’ solicits an understanding and a sense of place while living with rhythmic patterns of activities and traditions. The overall impression that the women studied made was that they know their ‘home’ and the people in it very well. ‘Home’ is signified by predictability and stability that an individual finds with “feeling at ‘home’”.

A brief comparison between the meaning of ‘home’ changing and the LTC setting being ‘home’ was undertaken to determine if there was a relationship between them (Table 4.9). Four of the women reported that the meaning of ‘home’ had not changed and that the LTC setting that they reside in is ‘home’. Two of the women reported that the meaning of ‘home’ had not changed and that the facility that they reside in is not ‘home’. Three of the women reported that the meaning of ‘home’ had changed and the LTC setting that they reside in is ‘home’. There were two women that did not answer the question. One of these two women reported that the LTC setting that she resides in is ‘home’. The other woman reported part way through the interview that the LTC setting that she resides in is not ‘home’ however, by the end of the interview this woman stated that the LTC setting is ‘home’. There were no patterns identified in relation to the meaning of ‘home’ remaining the same or changing and the LTC setting being ‘home’.

Table 4.9

*Has the Meaning of ‘Home’ Changed?*

| Has the meaning of ‘home’ changed? | The LTC setting is ‘home’ [a] | The LTC setting is not ‘home’ [a] |
|---|---|---|
| Yes | 3 | 0 |
| No | 4 | 2 |
| No Answer | 1 | 1 |

[a] n = 11

The meaning of ‘home’ for these women appears to be what you do in your ‘home’ (activities) and whom you do it with (people), two of the constructs that have already been identified. Similarly, Gubrium (1993), Fiveash (1998), and Hammer (1999) found that older adults who held a worldview that was optimistic and hopeful focused on positive attributes of people in general and searched out opportunities to live active social lives with people inside and outside their environment. These older adults who had an optimistic worldview found the meaning of ‘home’ in the people around them and their daily activities (Gubrium, 1993; Fiveash, 1998; Hammer, 1999). The women in this study demonstrated some of these same characteristics of optimism and social engagement.

Research Objective # Two: The Lived Experience

The second research objective was, *“To explore the lived experience of cognitively well older female adults in the LTC setting.”* To do this and in an effort to determine if cognitively well female older adults are happy living in the LTC setting, even when they do not consider the LTC setting to be ‘home’, two questions were asked.

1. How happy would you say you are living here?
2. How unhappy would you say you are living here?

Most of the women reported feeling happy residing in the LTC setting (n = 8). The remainder of the women reported being fairly happy (n = 1), being content (n = 1), and having adjusted very well (n = 1). None of the women reported being unhappy living in the LTC setting. Three women reported being unhappy with three different issues. The first woman had an issue with the food. She reported that she was told that she would not like the food but decided to choose this particular LTC setting nonetheless. This woman had indicated that the LTC setting is not ‘home’ and related this to the lack of fellowship in this particular LTC setting, not the food. The second woman had an issue with not having her car and therefore not being able to drive. Earlier in the interview this woman had indicated that the LTC setting is ‘home’. And the third woman had an issue with how hard the staff members have to work at times of staffing shortages. This woman had specified that the LTC setting is ‘home’. The investigator inferred that older adults who do not perceive the LTC setting to be ‘home’ could still be happy within their environment while residing in the LTC setting. Although these women do not view the LTC setting as ‘home’ all of them reported being happy in their environment.

Teresi, Holmes, and Monaco (1993), Gorman (1996), Fiveash (1998), Hammer (1999), Ragneskog, Gerdner, and Hellstrom (2001), and Oh (2006) all found that older adults living with cognitively impaired older adults were dissatisfied with their living conditions and experienced many negative emotions related to negative incidents. Some of the descriptors used by cognitively well older adults in these circumstances were dissatisfied, demoralized, deeply disturbing, resignation, anger, powerless, demotivated, indifference, apathetic, acquiesce, anxious, irritated, and afraid. In this study, women reported some experiences with cognitively impaired older adults as “depressing, confusing, difficult, feeling sorry for them, and frustrating” however none of the women reported incidents or experiences as severe as those reported in the other studies.

One reason that the women in this study may have reported a more positive experience living with cognitively impaired older adults is that they all had private rooms. On several occasions, the women reported that they have their own space when they need privacy and solitude. The women in this study have a place they call their own to which they can retreat. Another reason why the women in this study seemed less affected is that there may not have been serious behavioural disturbances. It may be that in 2010, disruptive behaviour is prevented or better managed due to increased knowledge and established standards and protocols that were not in place for earlier studies. Finally, public awareness of Alzheimer’s and related dementias is much higher in 2010 than in the 1990’s due to public awareness campaigns focusing on increasing knowledge and reducing stigma related to these diseases. This might explain the open or accepting attitude that the women had towards cognitively impaired older adults. A third reason may have to do with this being a Canadian study and the others being primarily from the United States. This is speculation. However, The Canadian and American health care systems differ in the source of funding and likely there are differences between the two systems in relation to LTC settings.

When Gubrium (1993) explored the experience of everyday life in LTC setting he derived ten themes from the narratives of interviews with twenty-five older adults. The five themes of “worried to death, it’s come to this, lovin the lord, sisters, disabled, and vigilant” did not appear in this investigation. The other four themes such as “making a new home, traveller, couples, and knowledgeable” were revealed in this study. Activities associated with “making a new ‘home’” such as decorating, making new friends, establishing new routines, and attending new social activities were reported. One woman described herself as a “traveller” living in the LTC setting but having the feeling like she is waiting to go to her other ‘home’. This woman had spent a number of years living six months in Manitoba, Canada and six months in the southern United States. There was one “couple” living in the LTC setting although they did not reside in the same room. This married woman reported that she visited her husband every day and worried about him on a daily basis. One woman had personal experience working at a mental health hospital as a young woman. This woman would fall under the theme of “knowledgeable” and expressed, “I know a little bit about mental illnesses and that.” She reported, “I think it has helped me to cope with the people here you know.” Although several of the women in this study were either wheelchair dependent or required a high level of assistance with ADLs, they did not describe themselves as disabled and thus “disabled” did not emerge as a theme in this study.

## Research Objective # Three: The Impact of Living with Cognitively Impaired Older Adults on Day-to-Day Life

The third research objective was, *“To explore how living with cognitively impaired older adults affects day-to-day life for those who are cognitively well.”* To explore this there were four questions presented to the women participants in this study.

1. How does living with confused people affect your day-to-day life?
2. I would like to ask you about the good times and the bad times you have experienced living with confused people. Could you tell me about some of the good times? Could you tell me about some of the bad times?

3. What has it been like to share common areas with confused people?

4. Is there anything else you would like to tell me about what it has been like to live with confused people?

Terms and phrases used by the women to answer how living with confused people affected their day-to-day life demonstrated empathy and understanding. As set out in Table 4.10 the terms and phrases from ten of the eleven women in response to the first question demonstrate empathy, compassion, acceptance, or tolerance of cognitively impaired older adults that they reside with in the LTC setting. These women may be modelling their behaviour after observing staff members’ perspectives and approaches when responding to these behaviours in a climate of tolerant intervention. One woman, ‘Joan’ was alone in expressing her preference to avoid mingling with cognitively impaired older adults by stating, “Well it means I have to spend more time with myself. Because you always hear the same thing over and over again. I can’t be critical of it. But I don’t like to participate in it too much. I don’t really do much of that. Well I have my own little room…. I do an awful lot of reading. Well I must say I’m not always too tolerant of it you know. I try to be but ah, sometimes I just like to walk out.” Joan, now widowed, disclosed that at ‘home’ she had cared for her husband who had Alzheimer’s and that she found his behaviour quite challenging at times until the disease had progressed to a later stage.

Table 4.10

*Comments on “Day-to-Day Life” with Cognitively Impaired Older Adults*

| Resident[a] | Comments |
|---|---|
| Madge | “You talk to them and whatever funny kind of an answer you get that’s what you get but you understand where it’s coming from you know but like I say pretty well you know who you’re going to talk to and that. “Sometimes they maybe talk a little bit off subject or whatever you’re talking about so you think okay I won’t go there but I really haven’t met too many people I can’t carry on a conversation with. You get so that you accept the families that come in and they become more or less something like your family too. I don’t have much of a family so I generally go to and I visit with just about everybody unless somebody lets you know they don’t want you to. Oh. Well you know right away that they are confused eh, so if you’re going to visit with them or talk with them you kind of try and keep it on a level that they can accept and talk back to you on. So I don’t have too much problem with that. There’s a few people around here that I know what I’m going to get from them when I talk to them so that’s, that’s it you know.” |
| Francis | “Sometimes you try to be nice and then they give you some stupid answers. Not that they can help it I guess but you try to be nice to them.” |
| Alice | “It’s not bad. But it’s something you don’t know what to talk to them about. It’s a little bit hard and then if you tell to them they nod their head. And if I tell them, `Don’t do that, that’s not nice.’ then they start yelling. We have a person here she always yelling. Not always but a lot of time. She tell me to, `Go to hell.’ and all that. And I don’t like that. Then I turn around and go into my room. And I have my own and that’s how I like it.<br>“They should put her on one side or one end and put us on the other end. I mean I’m not mad at her or anything. I talk to her and she doesn’t want to stop. And her children she has two daughters but they have to go home. They can’t stay here. Then she’s mad too that they go home. She yells and yells. But she is confused and she can do nothing about it. I hope I’m not gonna be like that but you never know. Like I said maybe I’m gonna be that one day. I don’t know. Just the Lord knows.” |
| Betty | “Not bad. There’s a woman that screams a little bit at night but she doesn’t bother me. She just started to do that a little while ago. But it doesn’t really get to me you know. Well I feel pretty comfortable you know the way it is and I really don’t know of anybody that doesn’t fit in. You know that lady that yells every once in while well I just laugh at that you know. But uh, I don’t let it bother me. Well this is it. I don’t let anybody really bother me.” |

| | |
|---|---|
| Virginia | “Well you see with the confused people it’s very depressing. I look on it as I still have my mind. But it’s very depressing at times. You try to help them but you can’t. They send them all to my table and the people can’t tolerate some. The nurse asks me ‘Do you mind?’ and she knows I don’t. I’m tolerant. And they do kooky things.<br>Oh yeah. They don’t know what they’re doing. That’s why we’re here. We need help. Oh yeah. I have no remorse at all. This room is like a meeting place. They come and go. One will sit down. Some can’t speak but they rest. It’s nice. I have an open door.”, and<br>“It has, no, it has no affect on me at all. No affect at all. Well I sometimes go, it goes through my mind like am I ever going to get like that. But if I do I do. Somebody will always be there. I have wonderful children and somebody will always be there to see that I’m looked after that I’m not laying out on the street somewhere you know what I mean.”<br>“Oh it just gets me PO’d when people walk in here. This one resident comes in here and says, `This is my room get out of here blah, blah, blah.’ You know its things like that. It kind of ticks me off but I have to understand that it’s their condition and they can’t help it. You know. I also get so close to their families. The families like me because I can calm them down. The families will come get me when they come to visit. The one lady I told you about, I sit with her and her two daughters and we have a great time. She considers me her daughter. I joke and call her mom and she loves that…. But we all might be there some day so who knows. … No. The thing is that you recognize the need and accept your own. I’m needed and they are needed. And they were people who that lived in the community, raised their families, did things better for the future, they’re not just nothing. They’re people. Absolutely. I look around and see all the mother’s, and the dad’s, and they all had their life. Worked in the community, the church. And they’re wonderful.” |
| Dorothy | “Oh I don’t mind it. I come in here and close the door. And sometimes I leave it open and they come and the nurse grabs them and takes them out. No, no. I say to them, ‘Who are you?’ and if they don’t speak I say, ‘If you can’t talk to me get out.’ I don’t want them here. Yeah. No, no. And I don’t’ want to have bad times. I want to be kind to them. Cause they’re folks too and they’re lovely people.” |
| Phyllis | “Well the confused people don’t affect me at all. Like I sit at a table who are all clear in their mind and I don’t have much to do with the others. It’s all quite good. No it doesn’t bother me at all. No it doesn’t bother me at all. I know I just hear someone yelling and think oh that’s just (Kitty) eh, eh, eh. Oh yes I know them pretty well.” |

| | |
|---|---|
| Doris | “It’s um. It doesn’t. I ignore them you know. I realize that it’s not their fault. They can’t help it. One day I come in here, well I’d been out someplace, and I come in, my door was locked. And then I got the nurse to… my key was in here and I got the nurse to open the door, she opened the door and there was a woman right in my bed. Well she was harmless. They got her out you know. Well, I didn’t know what to feel about that. But she has come in on other occasions. I know one day my bed wasn’t made when I was out when I came back there was a bump on the bed. They hadn’t made the bed yet. I come a little closer and it was the same woman curled up in my bed ha, ha, ha. And I you know, I just laughed. I couldn’t help it. She was curled up there as cozy as could be. I leave the door open. I don’t lock it. They can open it and walk in. Yeah we didn’t lock doors when we were raised. There’s another woman that comes in here. I’ll be watching something on television very interested in something on television and she’ll come stand right in front of the television. I’ll say, Edith this is not your room. Edith would you stand over so I can see the television’. She’s stubborn. She won’t, and then she starts touching stuff you know. Then I call for somebody to take her out.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

The responses were mixed when these women were asked about good times and bad times involving cognitively impaired older adults. Four women reported specific events around good and bad times, two women reported specific incidents around just good times, one woman did not report a specific event around good times but stated, “Its all quite good”, one woman reported just bad times, and three women reported no good or bad times. As previously discussed, good times included such activities as being polite to cognitively impaired older adults, gaining assistance from a cognitively impaired woman to fasten buttons and through this activity making a connection with her, helping in situations when someone’s belongings have been taken, becoming close to family members of cognitively impaired older adults, or helping to calm agitated older adults, conversation. One woman reported having an open door policy which facilitated a “meeting place” for all older adults and staff to come and go as they please. Bad times included activities such as inappropriate behaviour at meal times, becoming tired of listening to a woman who was speaking incoherently and ending the conversation out of frustration, finding a woman in your bed, the yelling, and having stuff stolen.

The four LTC settings in this study did not segregate cognitively impaired older adults from cognitively well older adults. All but one of the women said that the “bad times” were minor disruptions and tolerable. As in previous research (Gubrium, 1993) four of the women wondered if they would become cognitively impaired one day. However unlike Gubrium’s (1993) findings, these women reassured themselves that if they did become impaired or confused that they would be well taken care of based on their observations from living in the LTC setting and the care given to residents who were cognitively impaired.

Gubrium (1993), Fiveash (1998), and Hammer (1999) found that older adults who lived with a worldview that was optimistic and hopeful also embraced living in the LTC setting with a purpose in life, not just tolerance, and connected with, and developed attachments to their environment and others. These older adults had made up their mind that this was ‘home’. Older adults actively engaged in life were able to express love for everyone (humankind) and wanted to help them (Gubrium, 1993). The women in this study conducted their lives in a similar fashion. They wanted to help others when they could, as its own reward. They interacted with others because it meant establishing and maintaining connections with people, including with family members of other residents. The women had positive outlooks on life and were authentic to their personalities. They reported that life was good at ‘home’ prior to the LTC setting and now life is good in the LTC setting. These are the women who found a way to make the LTC setting ‘home’.

This introduces the overarching theme of this study; that being “women who made it ‘home’.”

The women participants were asked what it is like to share common areas with cognitively impaired older adults to allow them the opportunity to expound on their experiences. Two women provided no answer. Two women found that sharing common areas can be upsetting and disruptive at times. The remaining women found sharing common areas to be generally comfortable and enjoyable.

Research Objective # Four: How Living with Cognitively Impaired Older Adults Affects the Meaning of ‘Home’

The final research objective was, *“To explore how living with cognitively impaired older adults affects the meaning of ‘home’ for cognitively well older adults.”* There were four questions designed to support exploring the fourth research question.

1. How does living with confused people affect the meaning of home?
2. Does (_ _ _ _ _ _) feel like home to you?
3. What prevents you from feeling like (_ __ _ _ _ _) is home?
4. If everyone were like you, able to think clearly, would that make it easier to feel like (_ _ _ _ _ _) is home?

When asked, *“How does living with confused people affect the meaning of ‘home’?”* nine of the eleven women responded, “No.” Madge responded, “Yes. I was alone on my own for a long time after my husband left and I became very independent.” Otherwise Madge did not say how living with confused people affected the meaning of ‘home’. Joan did not answer the question directly but stated, “Well it’s not something I would choose.” The answers to this question left the investigator with more questions such as, “Then what does affect the meaning of ‘home’?” and “How is a sense of ‘home’ established?” This is clearly something to be further pursued.

The next question asked of the women was, *“Does (name of the LTC setting) feel like ‘home’?”* Nine of the eleven women answered, “Yes.” Ruth was ambivalent and Dorothy did not answer the question. Ruth expressed ambivalence and recounted a story of when she use to travel between two ‘homes’, one in Manitoba and one in the southern United States. After telling her story she then commented, “I would feel that this place kinda fits like that.” This comment lead the investigator to suppose that Ruth did not feel settled in the LTC setting. The investigator asked Dorothy, *“What prevents you from feeling like (name of the LTC setting) is ‘home’?”* and she did not answer this question as well. When Dorothy was asked, *“If everyone were like you, able to think clearly, would that make it easier to feel like (name of the LTC setting) is ‘home’?”*, she replied, “Yes because then there would be fellowship.” Dorothy was legally blind which may have contributed to social isolation and may have interfered with attaining a sense of ‘home’. Regardless of the circumstances that created the situation Dorothy lead the investigator to believe that she felt isolated living in this particular LTC setting. Both Ruth and Dorothy had personal reasons for not feeling like the LTC setting is ‘home’ which were not related to the presence of cognitively impaired older adults or their behaviour(s).

### Responses to the Question on Advice

As a final question, the women were asked if they had anything else they would like to share with the investigator. In general, they did not have anything more to discuss. Two women provided additional information about confused people, with one woman sharing personal information about her situation at ‘home’ with her husband who had

Alzheimer’s. Another spoke of how she copes with having her own room, and one repeated a question that she had about why the really confused older adults can’t go to a different place in the LTC setting, such as a separate wing or facility.

Women were also asked if they had any advice to offer someone who that was getting ready to move into the LTC setting, what it would be? Their advice is presented in Table 4.11.

Table 4.11

*Advice on Preparing to Move to the LTC Setting*

| Resident[a] | Comments |
|---|---|
| Joan | “I guess it would be to accept it. Well and you have to if you can’t take care of yourself. What are you going to do?” |
| Madge | “Oh golly I don’t know. I don’t know what I would say to them. Maybe if they asked around or found someone like you that has been in several places and can tell you more about them. I guess it depends on the person.” |
| Francis | “Just grin and bear it ah, ah, ah.” |
| Betty | “No. I think I can say that everybody’s different you know. Everybody feels differently about things and that. Anybody that I’ve spoken to here is happy.” |
| Virginia | “They have to be ready. When you’re ready because you do give up everything, absolutely. And you only take a few things with you. Can’t clutter, well they cluttered me. I didn’t bring all that stuff ha, ha, ha.” |
| Ruth | “I would just tell them don’t push it when you come here. Don’t’ think it’s gonna happen overnight because it doesn’t. You know the first six weeks that I was here thank goodness for my daughter being so close by and she was in and out two to three times a day you know.” |
| Lois | “Oh gosh. Try to be as upbeat as possible. Think positive things.” |
| Alice | “I would tell people to make their own minds about where to go. I’m happy that I am here. I made my mind about this place.” |

| | |
|---|---|
| Dorothy | “Well. What would I say? You know I have friends now that are younger than me. I have one friend that is coming over tomorrow evening. I have a friend from where the neighbourhood I use to live in and she brings ladies to come visit with me.” |
| Phyllis | “If they think for themselves I have no advice. They should think for themselves.” |
| Doris | “I don’t know. Forget about home, this is home.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

Generally speaking, the advice from these women fell into three categories. The first was “accept it [the move]” and Joan, Francis and Doris all referred to accepting or becoming resigned to the move. Francis added humour with the phrase “grin and bear it”. The second category was “it depends on the person” and both Madge and Betty made reference to how different people respond to things. Ruth also alluded to the adjustment that is part of the move. The third category is “be ready [for the move]”. Virginia spoke most directly, saying “they have to be ready” while Alice suggested that people have to make up their minds, as she had done. The other women provided advice that did not fit into the other categories, for example, Lois suggested be upbeat and positive. Both Phyllis and Dorothy said that they did not have advice but then Phyllis added that “they should think for themselves”.

### Privacy

The construct of privacy was not addressed by the investigator during the interviews. Nonetheless, the women in this study made several references to privacy and control over access of, as Ruth put it “…my own little space…”, and Joan expressed, “Well I have my own little room…” and Madge described, “…my little room upstairs…” referring to private space and expressing ownership and control of territory.

There were different levels of comfort with privacy experienced in the LTC setting expressed by the women in this study. Virginia appeared to feel so comfortable with the level of privacy that she experienced in the LTC setting that she had an open-door policy, “And this room is like a meeting place. So the door is always open.” Virginia also commented on the notion of privacy in her home prior to living in the LTC setting advising that, “We had a hallway that we called North Vietnam and South Vietnam, ha, ha as a joke. But that separated us. We were independent and they were.” referring to living arrangements with her son’s family. Dorothy described the following, “I come in here and close the door. And sometimes I leave it open and they come in and the nurse grabs them and takes them out.” explaining that there are times when she had privacy and times when she did not however she received assistance in trying to maintain control over access. Dorothy also provided an example of maintaining control over access by inviting friends to visit, “I have one friend that is coming over tomorrow evening.” Alice described home as “You know home is yours” making reference to ownership and control of the physical, emotional, spiritual, temporal, spatial, and social territories of home. Alice is conveying the notion that a person’s home does not belong to everyone, it is not public domain, it is “ours” and we own it in its entirety. Just as Dorothy did, Alice also used her room as a safe haven, “Then I turn around and go into my room”.

Lois talked about the lack of privacy, “They wander into people’s rooms… She walks into rooms and steals stuff. So that’s kind of difficult.” There were also reports of intrusion on privacy of thoughts and solitude by overhearing unwanted communication. As an example, Joan described, “Because you always hear the same thing over and over again.” Doris described situations surrounding a lack of privacy as well, “One day I come in here… there was a woman right in my bed.” yet Doris did not appear to be disturbed by this incident as she later reported, “I leave the door open. I don’t lock it. They can open it and walk in… we didn’t lock doors when we were raised.” Finally Frances discussed the lack of privacy at meal times surrounding behaviour that she found disruptive, “Well I wish they would sit down and eat… They run around and then they come back to eat and their plate’s not there. Then they start complaining.”

All of these women attempted to control access and therefore privacy in their own way. Some women were comfortable with co-residents and staff coming and going as they pleased, while other women were more comfortable with the idea of controlling access by invitation, but could not always maintain this control in the LTC setting. In the literature (Gubrium, 1993; Brummett, 1997; Fiveash, 1998; Hammer 1999; deVeer & Kerkstra, 2001) discuss the importance of privacy in relation to the concept of home. Many of the participants in their studies did not have private rooms and therefore could not often escape the experiences that they described as disturbing. It is possible that because all of the women in this study had private rooms, and thus a safe haven to escape to if needed, that this afforded them the opportunity to be tolerant of the disruptive behaviour of cognitively impaired older adults. Additional questions during the interviews could have been asked to elicit richer information on the notion of privacy as well as the lack of it in the LTC setting in 2010.

### Women Who Made it ‘Home’

After the data analysis was completed for the four research objectives and the advice question, the investigator reviewed the transcript and field notes and reflected on the one-to-one experience of interviewing the eleven women. During this process, it became clear that “woman who made it ‘home’” was an overarching theme. Looking at these women through their descriptions and experiences of ‘home’ prior to and after admission into the LTC setting provided a view of them as genuine people who were engaged with others and who were participating in life’s activities much as they likely were before they moved from their ‘home’ in the community to their ‘home’ in the LTC setting.  Living in the LTC setting has not seemed to harden or disillusion them. When they need respite, they can retreat to the privacy of their rooms. While these women are institutionalized they are living real lives, maintaining their values and they are displaying tolerance and understanding towards their co-residents who are cognitively impaired. These women have made a ‘home’ for themselves by having respect and value for all people and enjoying active engaged lives. The overarching theme of “women who made it ‘home’” might be described as inspirational by the investigator.

This group of women spoke openly and honestly and graciously disclosed their experiences and feelings to the investigator. They spoke as if life in the LTC setting was “no big deal” and a commonality to all who lived there. These women perceived living in the LTC setting to be common ground for all older adults connecting them in this way. These women blended in with the setting, by demonstrating caring and acceptance of those who were cognitively impaired. They were resilient throughout their lifetime and had coped with various life events such as divorce (n = 2) and becoming widowed (n = 7), and now adapting in the LTC setting. The women offered many compliments about the quality of care and how committed and caring the staff members were. In the few opportunities that presented themselves, the investigator observed staff members who were respectful, considerate, kind, and caring to residents.

These optimistic women reported good health and good quality of life and most believed that they were in the best place possible (see Table 4.12). They seemed comfortable in their environment, spoke as though they belonged to the community not a LTC setting, and spoke positively about the LTC setting in which they were living. These women were authentic with no airs or pretences but rather they were each in their way the “genuine article”. They treated their fellow residents well and tried to help in their own way perhaps simply because it felt good to be helpful and kind to your neighbour.

Table 4.12

*Comments about the Best Place to be*

| Resident[a] | Comments |
|---|---|
| Virginia | “And this is number two. Really. You’ve got your own room. Sometimes others have two or three in a room. This is wonderful. … I’m here to die because this is the last place. And I’m ready and it’s a wonderful place to die from. … Very caring. Even in death. The families can be reassured that some bodies with them. …Well here there is a lot of dedication. The staff is excellent. I’m not kidding you. I’m sincere. Maybe in other places not but there is good staff. The nursing staff is fabulous and the people that work here are wonderful.” |
| Joan | “Well the people here are very nice and caring. So that was helpful. Any if I run across any problems you know there are people I can come to and talk to…. The staff is very good.” |
| Francis | “Oh yeah. I like it here.” Yeah well my kids picked this place for me. They went looking all over the place and they liked this one the best.” |
| Betty | “Anybody that I’ve spoken to here is happy.” |
| Ruth | “But this is a good stopover place, you know. Well for one thing the staff are wonderful, they really are.” so we looked around and found this place and I’m quite satisfied here.” |

| | |
|---|---|
| Phyllis | “It’s all quite good. Yeah I chum with people like myself. Like Ann or Jean down here is a good friend of mine.” |
| Alice | “I’m happy that I am here. I made my mind about this place. It’s good I have my own place.” |

[a] For the purpose of this study, pseudonyms have been given to the women in this study including any residents that they have called by name.

Summary

This chapter first presented description of the socio-demographic and health-related characteristics of the eleven women who participated in this study. Generally speaking, they are physically frail, cognitively well and optimistic about their health and quality of life. Most viewed their previous ‘homes’ in the community connecting them with people, activities with people, and independence. Most said that their perception of ‘home’ did not change because of their move to a LTC setting.

Since coming to the LTC setting, all of the women had experienced interaction with cognitively impaired residents. Sometimes these were more distant experience as when one of the women referred to hearing the sounds of a cognitively impaired resident and sometimes more personal, as when another woman described finding a cognitively impaired female resident sleeping in her bed. The responses overall were compassionate and understanding, but some of the women sometimes had to ignore or stay away from residents who were disruptive. Overall, the presence of cognitively impaired residents did not affect the women’s feeling of ‘home’ in the LTC setting.

The women’s advice to those who might be moving to the LTC setting emerged into mainly three themes: “accept it [the move]”, be ready [for the move]”; and “it depends on the person”. Finally, the overarching theme of “women who made it home”, is a phrase that seems to distil much of what the women said about themselves and the meaning of ‘home’. It may be too soon to say but it does seem that these women would have made a ‘home’ for themselves wherever they might be, including a LTC setting.

Chapter Five, which follows, provides further discussion and recommendations regarding policy, clinical practice and further research arising from this study.

# Chapter Five: Discussion and Recommendations

This study explored how living with cognitively impaired older adults affected the meaning of ‘home’ for cognitively well female older adults in the long-term care (LTC) setting. The study’s main conclusions are that: (a) the women in this study identified qualities of ‘home’; (b) living with cognitively impaired older adults had no effect on the meaning of ‘home’ for most of these cognitively well female older adults; (c) many of these cognitively well female older adults established a sense of ‘home’ in the LTC setting; (d) some of the women who were not able to establish a sense of ‘home’ still reported feeling happy living in the LTC setting;  and (e) the process by which some of these women established a sense of ‘home’ while others did not establish a sense of ‘home’ is not known.

This chapter briefly reviews the findings derived from investigating the four research objectives. Two other sections describe the limitations of the study and the strengths of the study. The following section focuses on recommendations for policy, practice and further research. This chapter closes with a conclusion.

## Research Objective # One

The first research objective was, *“To examine the perspective of the meaning of ‘home’ prior to and after LTC admission amongst cognitively well female older adults.”* The constructs that emerged early from the transcripts were “people”, “activities associated with people” and “independence”. From an observer’s perspective, one might conclude that it is possible for only the first two constructs (“people” and “activities with people”) to continue after moving to another ‘home’, the LTC setting. However, although some of the women reported that they were in the “best place” and that they needed more care, most of the women did not describe themselves as sick or disabled, as evidenced by their reports of few chronic illnesses, good health and quality of life, and no feelings of depression.

Three women reported that the meaning of ‘home’ had changed now that they resided in the LTC setting but did not provide examples or descriptions that detailed this change. One woman described how she could no longer participate in the same activities as she used to do, and another explained that she felt alone as she has become disconnected from her church members. There were no patterns identified in relation to the meaning of ‘home’ remaining the same or changing and the LTC setting being ‘home’. In this study eight women considered the LTC setting to be their ‘home’ now.

Their descriptions of their ‘home’ in the LTC setting reflected all but one of the six domains of ‘home’ that were established from the relevant literature as a framework for the meaning of ‘home’ for this study. The one domain that was not described was ’spiritual home’, meaning the notions of solitude, reflection, unwanted intrusion, boundaries and a place to retreat as a safe haven. In fact, later in the interviews when some of the women described the disturbances caused by cognitively impaired residents, they did speak of leaving the disturbing situation and going to their respective rooms. In fact, all of the eleven women had private rooms and so the spiritual domain in relation to unwanted intrusion, boundaries and a place to retreat as a safe haven might have been taken for granted by the women. Not all LTC settings have private rooms.

While thinking about the meaning of ‘home’ and changes in the meaning of ‘home’, the women participants often talked about other residents and in particular, residents with cognitive impairment. At this early stage in the interview, the women as a group seemed comfortable to discuss situations that others might find distressing. As indicated in Chapter Four, most of the women spoke relatively kindly about their interactions with cognitively impaired older adults. As Madge said, “They become more or less like your family, too.”

Research Objective # Two

The second research objective was, *“To explore the lived experience of cognitively well female older adults in the LTC setting.”* This objective explored whether or not these women were happy living in the LTC setting. Nine women reported being happy, one woman reported being content and one reported adjusting very well. When questioned about unhappiness none of the women reported being unhappy. These findings are not surprising, given the women’s optimism in reporting good health and quality of life, and no feelings of depression. As noted earlier, this reported optimism is greater than that reported in comparison to the community dwelling population (Profile of Manitoba’s Seniors, 2010).

It raises a question or two and that is, is this optimism sustainable and for those who have lived in LTC for several years, what keeps this optimism sustainable? The average length of stay in LTC amongst the women studied was one year plus eleven months with a range of six months to 48 months. This optimism may again relate to the overarching theme of “women who made it home”.

Research Objective # Three

The third research objective was, *“To explore how living with cognitively impaired older adults affects day-to-day life of cognitively well female older adults.”* Most of these women expressed empathy and acceptance of people with cognitive impairment however a few expressed some frustration and annoyance living with the behaviours exhibited by cognitively impaired older adults. There were no reports of fear or concern for personal safety or well-being and none of the women reported perceiving the behaviours as aggressive or disturbing.

These cognitively well women had opportunities to meet with some of the families of those who were cognitively impaired and learn more about them. This may have allowed the women to see the cognitively impaired older adult outside of the current situation, a glimpse of this person prior to the behavioural symptoms of Alzheimer’s disease or related dementia. As Virginia said, “And they were people who lived in the community, raised their families, did things better for the future, they’re not just nothing. They’re people.” Contact with families promoted a more sympathetic perspective that might be applied to all of the older adults who were cognitively impaired. A few of the women had done simple things that communicate caring to these residents, for example the woman who asked for help with her button and the other woman who allowed a resident with cognitive impairment to sit at her dining table.

### Research Objective # Four

The final research objective was, *“To explore how living with cognitively impaired older adults affects the meaning of ‘home’ for cognitively well female older adults.”* Nine of the eleven women interviewed indicated that living with confused people did not affect the meaning of ‘home’ for them. One woman (Madge) replied in the affirmative but related her response to becoming independent living on her own after her husband left her. Another woman (Joan) did not answer the question however specified that if she had other options, she would not choose to live with confused people. Neither of these two women described in more detail why living with cognitively impaired residents affected their meaning of ‘home’. It may be that because this question was asked near the end of the interview, the responses were relatively brief. It might also explain why the following question, that is, asking women if they had anything else that they would like to share with the investigator, also received few responses. Two women provided additional information about confused people, one woman shared personal information, one woman spoke of how she copes, and one repeated a question that she had asked earlier in the interview.

### Assumptions

Assumptions held by the investigator declared at the onset of this study were that cognitively well older adults experienced significant stress and dissatisfaction from living with cognitively impaired older adults, that cognitively well older adults might feel at ‘home’ and call the LTC setting ‘home’ provided all older adults living together were cognitively well, and that if given the choice between living in an integrated LTC setting or a segregated LTC setting that cognitively well older adults would choose segregation.

The findings in this study contrast with the investigator’s assumptions. The women in this study did not report that they experienced significant stress or dissatisfaction in the LTC settings that they lived in. In fact they reported the opposite. The majority of women conveyed that they were happy, that they perceived themselves to have good health and quality of life, that they were comfortable in their surroundings and that they had bonded with the people they lived with and felt at ‘home.’ A large majority of the women in this study reported that the LTC setting in which they lived is ‘home’ even though the majority of the population in LTC settings has some level of cognitive impairment. This also is in contrast to the investigator’s assumptions. In this study the third assumption regarding integration versus segregation was not explored however, this would be an excellent question to include in future research on cognitively well older adults in shared accommodations with cognitively impaired older adults.

### Question on Advice

As a final question, the women interviewed were asked if they had any advice to offer someone who was getting ready to move into the LTC setting and if so, what advice would they give. The responses were categorized into three themes: “accept it [the move]; “be ready [for the move]; and “it depends on the person”. There were other responses. Lois said “try to be upbeat” which in itself is instructive because it rests on the assumption that moving to a LTC setting is a negative experience. This is certainly the broader social perception of moving to a LTC setting. Ruth spoke of a difficult adjustment that occurs during the first six weeks and this was likely her experience. Two of the women had no advice.

In retrospect, it may be that the question could have been phrased differently and might have stimulated more detailed responses. For example, a question that asks at a more personal level, “What were some of the things that made it easier or harder for you to move into this LTC setting?” could be followed by “Given your experience, what would you say to someone who is getting ready to move into this LTC setting?”.

### The Overarching Theme: Women Who Made it ‘Home’

“Woman who made it ‘home’” is the overarching theme that emerged from this study. Based on their strength of character, including a great deal of resilience, these women have found their own individual means of coping positively in their environment, connecting with their community, and establishing a new ‘home’. Overall, living with cognitively impaired older adults in the LTC setting had little or no impact on the meaning of ‘home’ for these women or on their ability to establish a sense of ‘home’ in the LTC setting. Although this is not a replication study, there are similarities between this study and Lapuk’s (2007) work that examined cognitively well male older adults’ perceptions of aggression in their ‘home’ setting and how they relate aggression to their sense of ‘home’ in the LTC setting. The most notable similarity is that participants from both studies reported that the behaviours of cognitively impaired older adults did not affect their sense of ‘home’ in the LTC setting. As well, both groups demonstrated a level of acceptance and empathy towards cognitively impaired older adults that was remarkable. In contrast to the literature (Teresi, Holmes, & Monaco 1993; Gorman, 1996; Fiveash, 1998; Hammer, 1999; Oh, 2006), these two studies revealed caring and compassionate older adults.

## Limitations

This study applied an exploratory descriptive approach to the study of the impact of cognitively impaired older adults on the meaning of ‘home’ and everyday life for cognitively well female older adults. There are several limitations that must be identified that are related to the research objectives and questions, the self-selected sample, the timeline for data collection, and generalizability.

First, in terms of the research objectives and questions, there are more questions that could have been asked that were not asked. For example, we do not know how women establish a sense of ‘home’ and what impedes or prevents others from establishing this sense of ‘home’. It is likely that adhering to the framework of the domains of ‘home’ limited the scope of questions in the interview script and therefore the process of establishing a sense of ‘home’ was overlooked. As a second example, the question related to asking advice might have been made more personal and thus garnered more detailed responses

A second limitation was that the convenience sample was available first because Nurse Managers likely filtered their selection by choosing female residents who were highly engaging, verbal and interactive and second because the women who agreed to participate were likely interested in the topic or wanted to help with a research project or were generally “joiners”, people who were active and would join an activity, even as a research subject. This all female sample excluded the male perspective on establishing a sense of ‘home’. It is common knowledge that a large majority of older adults in the LTC setting are female yet there are cognitively well men residing in the LTC setting that also should have a voice on the subject.

A third limitation of this study relates to the timeline for data collection. Although there was sufficient time to obtain abundant information from the first set of interviews, the four-week period of data collection did not allow the investigator the opportunity to offer the women a second interview unless it was related to fatigue or a woman’s choice to have two shorter interviews instead of one longer one.

Care should be taken when generalizing the findings from this study. All the women who participated in this study resided in private rooms. The lived experience of ‘home’ for older adults in shared accommodations may be very different from that of the women in this study. Had some or all of the women resided in shared accommodations the data may have included diverse and or negative experiences involving cognitively impaired older adults. Research is needed in the area of cognitively well older adults who live in shared accommodations, which is two or more bed rooms, with cognitively impaired older adults.

Strengths

The three areas of strength in this study are the research design, the interview guide and the investigator. A fourth area that might be considered more of a contribution than a strength is the development of the framework of the domains of ‘home’.

First, using an exploratory descriptive method facilitated open and flexible dialogue between the investigator and these women. So little is known about the meaning of ‘home’ in LTC settings and everything that is learned from this study adds to that literature. The advantage of using an exploratory descriptive approach is that it clarifies assumptions about relationships between phenomenon and accurately describes the characteristics of persons, situations, or groups (Polit & Beck, 2004). The exploratory descriptive method assisted the investigator in comprehending the views, attitudes and values of the cognitively well female older adults in the LTC setting.

The semi-structured interview guide and the investigator were effective as tools in stimulating and facilitating responses from these women. Most of the questions elicited rich detailed information about the phenomenon under study. The investigator’s clinical experience with hundreds of Home Care clients permitted the investigator to feel comfortable with silence, probing, redirection, refocusing, summarizing and member checking for confirmation of the information presented. The goals of interviewing were accomplished through the use of a well-designed interview guide that connected with the four objectives and good interviewing technique.

Finally, a succinct and detailed definition of ‘home’ could not be found in the literature therefore the framework of the domains of ‘home’ was developed for the purpose of this study. This framework might be used or tested by other researchers conducting studies on similar or related topics.

## Recommendations

Recommendations presented here relate to policy, clinical practice, and future research. Policy recommendations centre on programs and education. Clinical practice recommendations focus on the following four areas: (a) nursing interventions that address social support, (b) LTC settings to host family activities, (c) LTC settings to establish support groups and (d) LTC settings to establish educational sessions. Future research suggestions deal with cognitively well older adults in shared accommodations and understanding how cognitively well older adults establish a sense of ‘home’ in the LTC setting.

*Policy*. The concept of a program that might be named “making it ‘home’” and includes the above recommendations under clinical practice, as a standard policy for all LTC settings at the regional health authority level would be beneficial for those older adults who are moving to a new ‘home’. The proposed program could involve a welcoming committee named something such as “The Welcome Wagon Crew” (which should include both women and men), regular meetings with a core group of staff, and a buddy system whereby an established older adult is assigned to a new older adult as a social support. If older adults are not available then possibly a staff member could be considered, and a questionnaire related to “What does Home Mean to You?” for new residents to complete close to time of admission to be used as a tool by the staff to encourage the process of establishing a sense of ‘home’. This program could be tailored to suit each facility provided it included the essential components of welcoming new older adults and assisting them to attain the sense of ‘home’. Establishing and maintaining a sense of ‘home’ is such an important factor in the overall health of individuals that the investigator strongly believes that this type of program should be policy at the regional health authority level and incorporated into accreditation standards.

Education and support group sessions should be developed as standards for accreditation as well. There were various degrees of emotion, both positive and negative, reported surrounding living with cognitively impaired older adults, therefore older adults should have the opportunity to have this explored, examined, and then support provided at a professional level.

Upon receiving ethical approval from the WRHA RRC, the committee requested that the investigator submit an executive summary of the final results of this study to the WRHA and provide a copy of any publications arising from the study. This provides a means to distribute the above recommendations offered at the regional health authority level.

*Clinical Practice.* Considering the emphasis these women placed on people within the meaning of ‘home’, nursing interventions that promote social support and encourage the development of new relationships/friendships may be beneficial to older adults in establishing a sense of ‘home’ in the LTC setting. As well, LTC settings could consider hosting family activities on a regular basis in order to assist older adults to maintain family relations because these relationships continue to be an essential component of what ‘home’ means to older adults following LTC admission. Resident support groups that allow individuals to explore the concept of ‘home’ and feelings associated with ‘home’ may lead to the establishment of a sense of ‘home’ within the LTC setting. Debriefing sessions for residents who witness disruptive events would be beneficial in assisting cognitively well older adults in dealing with the emotional aspects of such occurrences. Education sessions on cognitive impairment for new and existing older adults would allow individuals the opportunity to ask questions and have those questions answered by knowledgeable professionals. This could also include such topics as an introduction to cognitive impairment, what behaviours are commonly exhibited, teaching caring behaviours towards older adults with cognitive impairment, and to teach coping mechanisms for those who live with others who have Alzheimer’s disease or a related dementia. On an informal basis, nurses could monitor for opportunities for “teachable moments” throughout their shifts. These are unplanned opportunities that present themselves as staff and residents are going about their day when a nurse can facilitate knowledge translation.

*Research.* Previous research is limited on the perspective of those older adults who are cognitively well in the LTC setting. This could be a general area of focus for future research. More specifically research is needed in the area of cognitively well older adults residing in shared accommodations with cognitively impaired older adults in the LTC setting. Knowledge is lacking on the prevalence of male and female older adults in the LTC setting not able to attain a sense of ‘home’. Future research needs to investigate the extent of the problem.

Understanding how cognitively well older adults establish a sense of ‘home’ in the LTC setting would be beneficial information when creating programs to facilitate the process for all older adults in the LTC setting. Questions that need to be asked include, “How does a sense of ‘home’ evolve in an individual?” “Is there a process?” “If there is a process can it be conceptualized?” “If the process can be conceptualized can it be taught to others to facilitate a sense of ‘home’ for all older adults in the LTC setting?” This study has revealed that additional efforts are needed in assisting all older adults to make a ‘home’ for themselves in the LTC setting.

## Conclusion

This chapter provided an overview of the findings from the four research objectives as well as the question on advice and the overarching theme of “women who made it home’. Limitations and strengths of the study were described and discussed. Finally, recommendations for policy, clinical practice, and future research were provided, based on the findings and analysis of this study.

This study addressed the key question of, “How does living with cognitively impaired older adults affect the meaning of ‘home’ for cognitively well female older adults in the LTC setting?” Eleven cognitively well female older adults from four LTC settings were interviewed to elicit their perspectives on the meaning of ‘home’ in the LTC setting. In this study the data suggests that the meaning of ‘home’ for cognitively well female older adults is not greatly affected by the presence of cognitively impaired older adults, at least in a setting with privacy and social interaction/supports.

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# Appendix A: Resident Inclusion Criteria

For this project, a maximum of twelve residents from personal care homes are required for interviews. The interviews are expected to last about one hour, possibly longer. A second interview may be scheduled if residents are in agreement.

The residents *must*:

- have moved from a private home (condominium, apartment, independent dwelling, elderly person’s housing, or assisted living), not hospital or supportive housing,
- have lived on the unit for at least six months
- be female
- be cognitively well (chosen by staff who are knowledgeable of residents cognitive functioning and confirmed by their MDS cognitive performance score of 0-2)
- speak English and be able to converse with the interviewer

Mildly cognitive impaired residents will be interviewed however moderately to severely cognitively impaired residents will not be interviewed.

# Appendix B: Nurse Manager Script

Hello Ms./Mrs. _____________

A nursing student in a Master’s program from the University of Manitoba is doing a study on the meaning of home for residents before and after placement in personal care home. She is also interested in knowing what it is like to live day-to-day life in a personal care home.

The student’s name is Bonnie Keating and she would like to interview about 12 residents in personal care homes who are willing to talk about how living with confused individuals affects the meaning of home. The interview might take about 60 to 90 minutes, but it could take place at different times and whenever and wherever you choose. The interviews will be face-to-face. The questions ask about your background, your health, and your perspective on the meaning of home for you. A family member, guardian, or advocate is welcome to be present.

You do not have to agree to participate but if you are interested in hearing more about it, I will let Bonnie know and she will contact you with further information and then you can decide if you want to participate or not. Feel free to speak with a family member about your participation in the project. Would you like me to contact Bonnie on your behalf? Are there any questions?

# Appendix C: Resident Consent

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 details 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. If you wish to participate please feel free to speak with a family member about your involvement in the project. A family member, guardian, or advocate is welcome to be present during your interview with me.

I am a graduate student in the Master of Nursing program at the University of Manitoba. The purpose of this project is to provide a description of your meaning of home prior to and after personal care home admission, describe what life is like for you in the personal care home, describe what it is like for you to live with confused individuals on a day-to-day basis, and how that affects the meaning of home for you in personal care home. Your participation involves taking part in a face-to-face interview that asks about your background (such as your age and family status) and health characteristics (such as illnesses and how you see your health), and about your life experiences in personal care home. The interview might take about 60-90 minutes and we can break it into two or three meetings. In order to ensure privacy and confidentiality I would like to suggest we meet in an office here in the personal care home that will allow for this.

There are no known risks associated with participation in this project, however, this topic may cause you some discomfort. You may choose to answer some or all of the

Appendix C: Resident Consent (continued)

questions. If you find any of the questions about your experiences living with confused people in personal care home to be upsetting, we can stop the interview and you can decide whether or not you want to continue. The interview will be audiotaped and later transcribed so that I can read about what you said. Once I have had an opportunity to read what you have said, I would like to ask you if I correctly understand what you have said. When I report my findings from this project, I will be reporting on what a group of residents like you have said. If I quote what you say in my report, I will not identify you by name or by any other identifier. All of the information that I collect will be kept confidential except if I discover any incident of abuse. The Protection for Persons in Care Act requires that I report any incident of abuse that might come to my attention during this project.

I will not disclose your participation in the project. My advisor, Dr. Guse, will have access to the transcription of your interview and the information from the background and health questions but she will not know who you are. About two years after my project is completed when the findings have been reported, then I will destroy all of the tapes, transcriptions and questionnaires. In the meantime, I will keep all this material safely in my home and Dr. Guse will keep the transcriptions and questionnaires safely in a locked cabinet in her Deer Lodge Centre office.

If you are interested in receiving a summary of the findings from this project, please indicate so at the end of this consent form. I will send or deliver a summary of findings.

Your signature on this form indicates that you have understood to your satisfaction the

Appendix C: Resident Consent (continued)

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.

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

**Participant’s Signature** **Date**

**Researcher and/or Delegate’s Signature** **Date**

I would like to receive a summary of the findings. My name and contact information is given below:

## Appendix D: Ethics Approval Certificate

### APPROVAL CERTIFICATE

09 July 2009

**TO:** **Bonnie Keating** (Advisor L. Guse)
Principal Investigator

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

**Re:** **Protocol #E2009:060**
**"Cognitively Well Residents Cohabiting with Cognitively Impaired Residents: How does this impact the meaning of home for the cognitively well residents in personal care home?"**

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- **if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Eveline Saurette in the Office of Research Services, (e-mail eveline_saurette@umanitoba.ca, or fax 261-0325), including the Sponsor name, before your account can be opened.**

- **if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.**

**The Research Ethics Board requests a final report for your study (**available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html**) in order to be in compliance with Tri-Council Guidelines.**

# Appendix E: Sociodemographic Questions

Before we get started on the questions related to the meaning of home and living with confused individuals, I have some questions about your background and health. The answers to these questions will be grouped together to describe the group of people who participated in this research.

1. In which year were you born (age)?
2. What is your marital status (never married, married, divorced, widowed)?
3. Do you have children?
4. Do you consider yourself to be a member of an ethnic group? If so, which group?
5. Do you consider yourself to be a member of a church or religious group? If so, which group?
6. In which year (or month) did you arrive to the personal care home?
7. Did you move from your own private home to personal care home (not supportive housing or hospital)?
8. What kind of work have you done for most of your life?

# Appendix F: Health Questions

1. Do you have any chronic illnesses?  If so, what are they?
2. Are you able to do most things for yourself, do you need a little help, or a lot of help with:
3. Grooming
4. Bathing/washing
5. Dressing
6. Walking/Getting around
7. Eating
8. How would you rate your health? Excellent, Very good, Good, Fair, Poor?
9. Do you often feel sad or depressed?
10. How would you rate your quality of life? Excellent, Very good, Good, Fair, Poor?

## Appendix G: Sociodemographic Summary

Table G1: Sociodemographic Summary, n = 11

| | |
|---|---|
| Average age | 86.6 years (excluding the youngest 89.8) |
| Ages | 55 yrs, 81 yrs, 83 yrs, 87 yrs, 90 yrs (2), 91 yrs, 92 yrs (2), 93 yrs, 99 yrs |
| Range of Age | 55-99 years |
| Marital status | Married 1 = 9.1 %, widowed 7 = 63.6 %, divorced 2 = 18.2 %, never married 1 = 9.1 % |
| With children and without children | With children 8, without children 3 |
| Type of work | Teacher 2, secretary 1, clerk 3, print shop 1, stay at home mom 3, volunteer (church and “Home for the aged”) 1 |
| Ethnicity | Yes 2, no 5, did not say 4 |
| Church/religious affiliation | Yes 9, no 2 |
| Average length of stay | 1 year 11 months |
| Range: Average length of stay | 6 months to 4 years |

## Appendix H: Health Questions Summary

Table H1: Self-Reported Chronic Conditions, n = 11

| | |
|---|---|
| No chronic diseases | 3 |
| Rheumatoid arthritis | 2 |
| Heart disease | 3 |
| Degenerative Neurological disease | 2 |
| Yes but did not say what | 1 |

Table H2: Activities of Daily Living

| | Independent | A Little help | Lots of help |
|---|---|---|---|
| Grooming | 3 | 2 | 6 |
| Bathing | 1 | 4 | 6 |
| Dressing | 3 | 3 | 5 |
| Mobility | 8 (7 mobility aides) | 1 | 2 |
| Eating | 7 | 3 | 1 |

Table H3: Self-Rated Health

| Excellent | Very Good | Good | Fair | Poor |
|---|---|---|---|---|
| 1 | 4 | 2 | 4 | 0 |

Table H4: Self-Rated Quality of Life

| Excellent | Very Good | Good | Fair | Poor |
|---|---|---|---|---|
| 0 | 6 | 1 | 4 | 0 |

Table H5: Self-Rated Depression, n = 11

| Yes | No | No Answer |
|---|---|---|
| 0 | 10 | 1 |

## Appendix I: Research Questions

People talk about what it is like to live in a personal care home like (_ _ _ _ _ _ _ _ _ _ _). There is not a lot of talk about what it is like to live with confused people in a personal care home. Today I would like to ask you about what it has been like for you living with confused people in the personal care home. If you feel that answering these questions is upsetting and you would prefer not to answer them, please be assured that your preferences are important and will be respected. You do not have to answer any questions and you may stop the interview and change your mind about participating, if you wish. My intention is to learn more about your perspective, not upset you in any way.

Research Question #1:

I would like you to describe the meaning of home before you came to the personal care home. Then I would like you to describe the meaning of home since you have been living in the personal care home.

1. Everyone has a different way of describing what home is. Could you please tell me what home means to you?
2. Now that you’re living in (_ _ _ _ _ _ _ _ _ _ _), has the meaning of home changed for you?
3. Do you consider (_ _ _ _ _ _ _ _ _ _ _) home?

Probe: how does it compare to the meaning of home prior to moving here?

Research Question #2:

To explore the lived experience of the cognitively intact in personal care home.

4. How happy would you say you are living here?
5. How unhappy would you say you are living here?

Research Question #3:

To explore how living with cognitively impaired residents affects day-to-day life.

6. How does living with confused people affect your day-to-day life?
7. I would like to ask you about the good times and the bad times you have experienced living with confused people. Could you tell me about some of the good times? Could you tell me about some of the bad times?
8. What has it been like to share common areas with confused people?

Appendix I: Research Questions (continued)

9. Is there anything else you would like to tell me about what it has been like to live with confused people?

Research Question #4:

To explore how living with cognitively impaired residents affects the meaning of home.

10. How does this affect your feelings of home?

11. Does (_ _ _ _ _ _ _ _ _ _ _) feel like home to you?

Probe: If yes, what makes it feel like home?

12. What prevents you from feeling like (_ _ _ _ _ _ _ _ _ _ _) is home?

13. If everyone were like you, able to think clearly, would that make it easier to feel like (_ _ _ _ _ _ _ _ _ _ _) is home?

Lastly, if you could give any advice to people moving into a nursing home what would it be?

Thank you for speaking with me today. I hope that my asking you these questions has not caused you to feel anxious or sad. If you are feeling upset, I would like to stay and keep you company until you feel better. We can talk about some other things. Or, if you like, I can call someone that you would like to talk to – perhaps the nurse manager or the social worker or a pastoral care worker or someone else that you might identify. Please let me now what I can do for you.

## Appendix J: Research and Ethical Approval

Winnipeg Regional
Health Authority
*Caring for Health*

Office regional de la
santé de Winnipeg
*A l’eroute de notre sante*

200 -1155 Concordia Avenue
Winnipeg, Manitoba
R2K 2M9 CANADA

November 4, 2009

Ms. Bonnie Keating
Community Case Coordinator
Home Care -Assiniboine South
Winnipeg Regional Health Authority
3401 Roblin Boulevard Winnipeg, MB R3R OC6

Dear Ms. Keating:

**Re: "Cognitively Well Residents Cohabiting with Cognitively Impaired Residents: How does this impact the meaning of home for the cognitively well residents in personal home care?"**

**WRHA Reference No: 2009-011**

The WRHA will approve the study on the condition that the participating sites not be identified unless at least 4 sites are involved. The rationale behind this is that privacy of individual women included could be compromised. Our strong preference is that you would expand the study to include at least two more personal care homes, but we realize that as a student project and essentially a pilot project, your ability to do so may be limited. Expanding to more sites would have the additional benefit of having your subjects come from a variety of environments, a factor that could conceivably affect the way they respond to the study question.

Other points that came up in the discussion include:

- Our comments about the socio-demographic information were based on concern for protecting privacy. We understand that there is a need to have some aggregate information to describe the context, but it needs to be kept to the minimum required. Adding more sites to the study would help prevent individual identification.
- Our comments about the consent form template do reflect our feeling that the Bannatyne HREB checklist gives a wider range of elements to include. However, we will not require you to change the form since it has been approved by ENREB

We will accept your justification for keeping the tapes in your home.

Your research access request for the above-named study has been approved by the Winnipeg Regional Health Authority (WRHA) Research Review Committee pending confirmation that the following conditions are met or agreed to:

- You, your co-investigators, and your research assistants comply with the relevant privacy legislation as indicated below.
  ☒*The Personal Health Information Act*
  ☐*The Freedom of Information and Protection of Privacy Act*
  ☐*The Personal Health Information Act* and *The Freedom of Information and Protection* of *Privacy Act*

## Appendix J: Research and Ethical Approval (continued)

- You complete and return the attached Confidentiality Agreement(s) to Judy Li, Concordia Hip & Knee Institute, WRHA, 200 -1155 Concordia Avenue, Winnipeg, MB R2K 2M9;
- You submit to our attention any significant changes in your proposal prior to implementation or any significant changes during the course of the study;
- You submit a summary of the final results of the study to the WRHA and provide us with a copy of any publications arising from the study;
- It is an expected courtesy that WRHA will be given a minimum of five working days advance notice of publication or presentation of results with policy implications, in order to be prepared for public response;
- You agree to be accountable for appropriate storage and elimination of material.

Thank you for selecting the Winnipeg Regional Health Authority as the site to conduct your research. Please let us know should you encounter any site-related difficulties during the course of your study.

We extend best wishes for successful completion of your study.

Yours Sincerely,

Dr. Michael Moffatt, M.D. MSc., FRCPC
Executive Director, Division of Research and Applied Learning
Chair, Research Review Committee
Winnipeg Regional Health Authority

cc. Dr. Brian Postl, WRHA
Dr. John Arnett, Chair, HREB

Encl: ***PHIA Agreement***