

**Understanding the Quality of Life of Personal Care Home
Residents with Alzheimer's Disease and Related Dementias:
Family Caregivers' Perspectives**

by

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ABSTRACT

Manitoba's population is aging. Trends in personal care home (PCH) use have also changed so that residents today have more cognitive impairments including Alzheimer's disease and related dementias (ADRD). While quality of life (QoL) has emerged as an important PCH research outcome, this literature is relatively sparse for residents with versus without ADRD. This study was conducted to examine the QoL of PCH residents with ADRD, using a recently developed but as of yet untested framework by Kane and colleagues (1999, as cited in Frytak; Kane 2001, 2003). The specific aims of this study were to gather family caregivers' perspectives on: (a) the meaning of the six domains that constitute Kane et al.'s ADRD-specific PCH-QoL framework; (b) domains they considered to be more important or lacking from this framework; and, (c) general PCH policies, practices, and activities that currently (or could better) facilitate positive QoL experiences for their loved ones. Seventeen family caregivers from five not-for-profit PCHs in Winnipeg, Manitoba participated in a one-to-one semi-structured interview. Participants agreed with the meaning and importance of Kane and colleagues' original ADRD-specific domains (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence), however emphasized that the meaning of each was influenced by their loved one's level of illness, values, PCH experience, and life history. Participants also indicated that dignity was an additional essential QoL domain for PCH residents with ADRD, and identified select PCH practices that could more positively influence their loved one's QoL. These include: (a) encouraging family involvement in resident care and daily activities, (b) promoting a sense of community and belonging

within the PCH; and, (c) allowing for innovative programming to help fulfill family expectations. Staff attentiveness and family presence were recognized as key players for optimizing PCH-QoL. Participants acknowledged several challenges in this area such as inadequate staff levels and the need for some staff to become more ADRD sensitive. Overall, the knowledge gained in this research is essential for understanding the unique QoL perceptions of PCH residents with ADRD and for developing strategies aimed at optimizing their QoL.

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To Bertie, Millie, and Albina,

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*“A single conversation across a table with a wise man
is worth a month's study of books;
A single moment of understanding
can flood a whole life with meaning” (Chinese proverb).*

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CHAPTER 1 – INTRODUCTION AND RESEARCH OBJECTIVES

1.1 Introduction

Older adults are defined as people 65 years and older and for demographic purposes, are often grouped into young-old (65 to 74), middle-old (75 to 84), and old-old (85 and older) age categories (Chappell, Gee, McDonald, & Stones, 2003; Health Canada, 2002; Kinsella & Velkoff, 2001). Manitoba is currently undergoing a population aging phenomenon characterized by an increase in both the number and proportion of older adults (Chappell et al.; Health Canada; McPherson, 2004). In 1956, there were 76,567 older adults living in Manitoba comprising 9.0% of the population. This number increased to 161,885 older Manitobans (14.1% of our population) by 2006 (Statistics Canada, 2009) and is expected to reach 261,200 people (17.2 % of our population) by 2028 (Manitoba Bureau of Statistics, 2008c).

Within the province of Manitoba, 94.4% of all older adults and 76.1% of old-old adults continue to live in the community (Menec, MacWilliam, Sooden, & Mitchell, 2002). The vast majority of the remaining older adults live in nursing homes which are referred to as personal care homes (PCHs) in Manitoba. Regardless of the definition, these institutions provide long-term care to individuals who can no longer be safely or prudently cared for in the community (National Advisory Council on Aging [NACA], 2004).

Older adults have historically been, and currently still are, the predominant users of PCHs in Canada and Manitoba (Forbes, Jackson, & Kraus, 1987; Menec et al., 2002). Compared to the past, however, residents presently are admitted to PCHs much later in life with more physical and cognitive impairments including

Alzheimer's disease and related dementias (ADRD) (Martens, Fransoo, McKeen, The Need to Know Team, Burland, Jebamani, et al., 2004; Menec et al.). Collectively, ADRD is a term used to summarize a group of progressive cognitive disorders with a spectrum of illnesses that range between purely neurologic (loss of recall, communication, and information processing abilities), psychiatric (withdrawal, depression, anxiety, delusions, uninhibited behaviour) and physical (visual spatial problems, changes in appetite and sleep patterns, loss of mobility, bladder and bowel incontinence) signs and symptoms (Alzheimer Society of Canada, 2009; NACA, 2004). ADRD-related illnesses are therefore very debilitating and have become a prominent cause of mortality amongst older adults in general (Alzheimer's Association, 2009), and especially in PCHs where many residents live with advanced stages of ADRD (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005). In Manitoba, at least half of PCH residents have been diagnosed as living with ADRD (Martens et al., 2004).

Quality of life (QoL) has evolved as an important research outcome in health services research and within the context of PCHs, strategies to conceptualize and measure QoL are continually being developed. While several QoL frameworks have been developed for use in PCHs, the framework as developed by Lawton is thought to be the most comprehensive thus far (Frytak, 2000; Ready & Ott, 2003; Selai & Trimble, 1999). Lawton (1991, 1994, 1997) defined QoL as a multidimensional construct with four overarching dimensions including: (a) psychological well-being, (b) behavioural competence, (c) objective environment, and (d) self-perceived QoL. These four dimensions can be grouped into either subjective (psychological well-

being and perceived QoL) or objective (behavioural competence and objective environment) components, and each component is assessed using more tangible measures, termed domains. For example, measureable aspects of the objective environment QoL component may include such domains as physical safety, the presence of amenities, and a person's privacy (Lawton, 1997).

Consistent with the general PCH literature, several QoL scales have also been developed specifically to measure QoL for PCH residents with ADRD. To date however, the majority of this research has assessed the objective QoL components, partly due to unique methodological and ethical challenges faced when conducting research with residents (Hubbard, Downs, & Tester, 2003; Tester, Hubbard, Downs, MacDonald, & Murphy, 2004; Zimmerman et al., 2005). Recently, in an attempt to elucidate the subjective experience of PCH residents with ADRD, Kane and colleagues (1999, as cited in Frytak, 2000; Kane, 2001, 2003) documented six psychosocial QoL domains for PCH residents with ADRD, including enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence. The relevance and relative importance of these domains however, have not been empirically tested and will only be used for the first time in this research.

1.2 Research Objectives

This research was conducted to examine the QoL experience of PCH residents with ADRD as perceived by family caregivers, using Kane et al.'s (Kane, 2001, 2003) ADRD-specific PCH-QoL framework as a guide. Specifically this research sought to gather family caregivers' perspectives on:

1. The meaning of the six domains that constitute Kane et al.'s ADRD-specific PCH-QoL framework;
2. Domains they considered to be more important as well as domain(s) deemed lacking from Kane et al.'s framework; and,
3. General PCH policies, practices, and activities that currently (or could better) facilitate positive QoL experiences for their loved ones.

This study sought to capture the experiences of residents with ADRD who are unable to articulate their own QoL experiences. A qualitative approach was employed, whereby one-to-one interviews were conducted with family members of PCH residents with ADRD. The knowledge gleaned from this research helps to validate Kane et al.'s PCH-QoL framework, specifically as it applies to PCH residents with ADRD. The meaning, breadth, and scope of each domain has been investigated from the perspective of family caregivers, with the intent of helping care providers, program planners, and policy makers to further understand approaches to optimize QoL for PCH residents with ADRD.

1.3 Overview of Thesis Organization

The remaining chapters in this thesis document the process and results of this research. The information provided in Chapter 2 of this document reviews past and projected population aging trends and PCH use patterns in Manitoba, and also provides an introduction to ADRD. Chapter 3 discusses different strategies and frameworks that have been developed to measure QoL in PCHs and provides some highlights of the ADRD-specific literature. Kane et al.'s (Kane, 2001, 2003)

framework for measuring QoL in PCHs, from which this research is based, is also introduced.

The study design and methodology used to conduct this research is provided in Chapter 4 of this document. Detailed results from this research are provided in Chapter 5, and a discussion of how these findings compare to the literature, along with the theoretical, policy, and practice implications of this research are provided in Chapter 6. Study contribution, limitations, and directions for future research are summarized in Chapter 7 of this document.

CHAPTER 2 – BACKGROUND INFORMATION

2.1 Chapter Highlights

This chapter presents background information essential for understanding the results of this research within a larger context. Past, present, and projected population aging demographics in Manitoba are first discussed, followed by past and present trends in PCH use. This chapter also defines ADRD and discusses the prevalence and impact of this disease. Highlights of this chapter are summarized as follows:

1. Consistent with most developed countries, the population of Manitoba is rapidly aging, and growth in the number of older adults is expected to exceed overall population growth for at least another 20 years. Within the older adult population, the old-old (85+ years old) are expected to grow in number at a faster rate than either of the middle-old (75-84 years old) or young-old (65-74 years old) subpopulations.
2. As compared to the past, people entering PCHs today are much older and are more physically frail.
3. In general, ADRD is prevalent in both community-dwelling and institutionalized older adults, and many PCH residents have advanced ADRD. The impact of this disease is profound and may be partly responsible for higher levels of care required in PCHs today than in the recent past.

2.2 Past, Present and Projected Population Aging Patterns in Manitoba

2.2.1 Population Demographics in Canada and Manitoba

As of June 1st, 2008, 13.8% (n=164,882) of Manitoba's population was 65 years and older. The majority (49.4%) of these older adults are 65-74 years old with fewer individuals belonging to the middle-old (35.0%) and old-old (15.6%) age categories (Manitoba Health & Healthy Living, 2008).

In 2006, Manitoba was ranked seventh oldest amongst all Canadian provinces and territories in terms of population aging. At this time, 14.1% of the Manitoba population was 65 years or older, compared to for example, 2.7% of the population of Nunavut and 15.4% of the population in Saskatchewan (Table 2.1) (Statistics Canada, 2009).

Table 2.1

Number and Proportion (%) of the Canadian Population 65+ Years Old, Overall and by Provinces and Territories, 2006

Province/Territory	Number of older adults By Province/Territory	Proportion (%) of Population 65+
Saskatchewan	149,300	15.4
Nova Scotia	138,220	15.1
Prince Edward Island	20,185	14.9
New Brunswick	107,635	14.7
British Columbia	599,815	14.6
Quebec	1,080,295	14.3
Manitoba	161,885	14.1
Newfoundland/Labrador	70,260	13.9
Ontario	1,649,180	13.6
Alberta	353,420	10.7
Yukon	2,290	7.5
Northwest Territories	1,980	4.8
Nunavut	805	2.7
CANADA	4,335,245	13.7

Source. Statistics Canada, 2009

2.2.2 Past Population Aging Trends in Manitoba

Population aging occurs when the number of older adults increases at a faster rate than the population 0 to 64 years old, and one indicator of population aging is an increase in population median age (Chappell et al., 2003; Health Canada, 2002; Kinsella & Velkoff, 2001). Using this metric, population aging has already occurred substantially in Manitoba, and for example, the median population age in this province was 29.0 years in 1951 versus 38.1 years in 2006 (Manitoba Bureau of Statistics, 2008b). Additionally, the Manitoba older adult population itself has also aged, with the highest rate of growth occurring in old-old individuals. Between 1956 and 2006, growth in population size increased by a factor of 6.3 as compared to a factor of 2.1 for older adults in general and 1.4 for the entire Manitoba population (Table 2.2) (Statistics Canada, 2009).

Table 2.2

Rate of Population Increase in Manitoba by Specific Age Groups, 1956 to 2006*

Age group	Population 2006	Population 1956	Rate of increase
85+ only	23,910	3,801	6.3
65+	161,885	76,567	2.1
Entire population	1,148,400	850,040	1.4

*Rate of increase = Population 2006/Population 1956.

Source. Statistics Canada, 2009

2.2.3 Population Projections in Manitoba

Population projections for the next twenty years predict that growth in the number of older Manitobans will surpass that in all other age categories (Manitoba Bureau of Statistics, 2008c). Between 2008 and 2018, Manitoba's population is expected to increase in size by 10.6% (from 1,208,000 to 1,336,000 people), whereas the older adult population will grow by 21.7% (from 163,700 to 199,300 people). Similarly, between 2018 and 2028 the entire Manitoba population is projected to increase in size by 25.7% (from 1,336,000 to 1,518,100 people) while the number of older adults during this time will increase by nearly 60% (from 199,300 to 261,200 people) (Manitoba Bureau of Statistics).

2.3 Patterns of Personal Care Home Use in Manitoba

2.3.1 Defining Personal Care Homes in Manitoba

Nursing homes throughout Canada are uniquely referred to as personal care homes (PCHs) in Manitoba, and provide: (a) room and board with meals, laundry, and housekeeping; (b) 24-hour nursing support for medication administration, wound management, and coordination of health services; (c) personal care or assistance with grooming, bathing, and other activities of daily living (ADLs); and, (d) access to a multidisciplinary health care team comprised of a general practitioner or geriatrician, physical therapist, occupational therapist, and dietician (Manitoba Seniors and Healthy Aging Secretariat, 2005).

PCH admission in Manitoba occurs in a coordinated, standardized fashion, and is usually initiated when one's care needs in the community can no longer be

provided safely or cost-effectively (Manitoba Seniors and Healthy Aging Secretariat, 2005). In order to be considered as eligible for admission, prospective residents are allocated to 1 of 4 levels of care, as a strategy to help estimate hours of nursing care that residents will need on a daily basis. Level 1 care residents are thought to require minimal assistance from nursing staff to perform ADLs such as bathing and dressing, feeding, compliance with medication regimen and other treatments, ambulation, and elimination. By contrast, Level 4 care residents are thought to require the greatest amount of nursing care, as these residents are often completely dependent in their ability to perform ADLs (Menec et al., 2002).

In Manitoba, PCHs can be categorized into either for-profit or not-for-profit facilities, and are regulated by regional health authorities via the Personal Care Homes Standards Regulation and Personal Care Services Insurance and Administration statutes (Canadian Healthcare Association, 2004; Health Canada, 1996; Government of Manitoba, 2006). As of March 31st, 2008, the Winnipeg Regional Health Authority (WRHA) housed 5,515 PCH beds or 57.7% of all PCH beds in Manitoba, and two-thirds of the 37 PCHs in the WRHA were defined as not-for-profit (Manitoba Health & Healthy Living, 2009).

2.3.2 Personal Care Home Use Patterns

Older adults have historically and continue to be the predominant users of PCHs in Manitoba (Forbes et al., 1987; Menec et al., 2002), where, for example, the average age of admission to a PCH is 83 years (Manitoba Health & Healthy Living, 2009). It is important to note however, that the majority of older Manitobans continue to live in the community. In 2002, only 5.6% of all older Manitobans and

less than 25% of the old-old subpopulation resided in PCHs. These proportions translate into a total of 8,849 older adults who resided in a PCH, of whom 63.3% were 85 years and older (Manitoba Health, 2002b). The age and sex distribution of Manitoba PCH residents is provided in Table 2.3

Table 2.3

Number and Proportion (%) of PCH Residents in Manitoba by Age and Sex, 2002

Age group	Total	Male	Female
85+	5064 (54%)	1111 (12%)	3953 (42%)
75-84	2949 (32%)	949 (10%)	2000 (22%)
65-74	836 (9%)	392 (4%)	444 (5%)
< 65	442 (5%)	217 (2%)	225 (3%)
Total	9291 (100%)	2669 (28%)	6622 (72%)

Source. Manitoba Health, 2002b

Functional dependency when performing ADLs is the most important factor precipitating PCH admission in Manitoba, followed closely by cognitive impairment (McPherson, 2004; Menec et al., 2002). Recent trends in PCH use patterns reveal an increasing median age and also a higher level of care for PCH residents, demonstrating that PCH residents today are generally older and frailer as compared to the past (Menec et al.).

2.4 An Introduction to Alzheimer's Disease and Related Dementias (ADRDs)

ADRD is a collective term for dementia disorders, which includes Alzheimer's disease, vascular dementia, Pick's disease, Lewy body dementia, and Creutzfeldt-Jakob disease (Manitoba Health, 2002; NACA, 2004). Dementia is a strong predictor of PCH admission (Menec et al., 2002; O'Brien & Caro, 2001) and is the only mental health disorder that is more common in older adults than in any other age group (McPherson, 2004).

Alzheimer's disease (AD) is the most common of all dementias, constituting 75% of all provincial and 65% of all national cases of dementia (Manitoba Health, 2002; NACA, 2004). Today, there are 500,000 Canadians with AD. Of all AD-diagnosed individuals, 62% are women and 86% are 65+ years old (Alzheimer Society of Canada, 2005). AD is also the fifth leading cause of mortality for older adults in the United States (Alzheimer's Association, 2009). Typical early symptoms of AD include mild forgetfulness and in later or advanced stages, symptoms often include severe disorientation, loss of functional and information processing abilities. People in the latest stages of AD also typically lose their ability to verbally communicate, to be mobile, and to be bladder/bowel continent (Alzheimer Society of Canada, 2009; NACA). This global decline between early and late stages is depicted in Table 2.4.

2.4.1 Prevalence of Alzheimer's Disease and Related Dementia in Personal Care Homes

In 2002/03, 46% of residents 75+ years old were diagnosed with ADRD at the time of admission to a PCH in Manitoba, and between 1997 and 2002, 67% of all

Table 2.4

Progression of Illness in Alzheimer's Disease (AD)

Stages of AD	Typical symptoms
Early stage	Mild forgetfulness and communication problems; difficulties with orientation, learning new things and concentration; mood changes; passiveness, withdrawal, and depression; mild coordination problems.
Middle stage	Forgetfulness about personal history; personality changes; increased confusion, anxiety and restlessness; delusions and uninhibited behaviour; increased needs for ADL assistance; changes in appetite and sleep patterns; language difficulties; visual spatial problems.
Late stage	Loss of recall, communication, functional, and information processing abilities; severe disorientation; possible withdrawal; increased use of non-verbal methods of communication; loss of mobility; loss of bladder and bowel control; 24-hour supervision required.

Source. Alzheimer Society of Canada, 2009; NACA, 2004

PCH residents 75+ years old were diagnosed with ADRD (Martens et al., 2004).

Similar data are reported elsewhere; for example, Zimmerman et al. (2008) reported that 50% of all PCH residents in the United States have ADRD. The majority of these residents have more advanced ADRD as defined by severe cognitive impairment (Zimmerman et al., 2005) and are more susceptible to respiratory infections, accidental falls, and fractures as compared to residents without ADRD (Doupe, Brownell, Kozyrskyj, Dik, Burchill, Dahl, et al., 2006). This and other evidence supports the assertions of O'Brien et al. (2001) who claim that PCHs are the new care-settings for older adults with ADRD, and that these residents have significantly greater care needs versus their counterparts without ADRD.

CHAPTER 3 – A REVIEW OF THE RELATED QUALITY OF LIFE LITERATURE

3.1 Chapter Highlights

Care guidelines for PCH residents with ADRD promote optimizing quality of life (QoL) (Ettema, Drees, de Lange, Mellenbergh, & Ribbe, 2005; Selai & Trimble, 1999). QoL has evolved as an ubiquitous term in health research to summarize all important aspects of life and health outcomes, while health-related QoL (HRQoL) typically defines how a person's life is affected by illness and/or medical treatment (Kane, 2003).

This chapter contains four sections. A general overview of QoL literature is first provided followed by a review of the PCH-related QoL literature for residents with and without ADRD. Lastly, this chapter provides an introduction to the Kane et al. framework (1999, as cited in Frytak, 2000; Kane 2001, 2003) which has guided this thesis research. Highlights of this chapter are as follows:

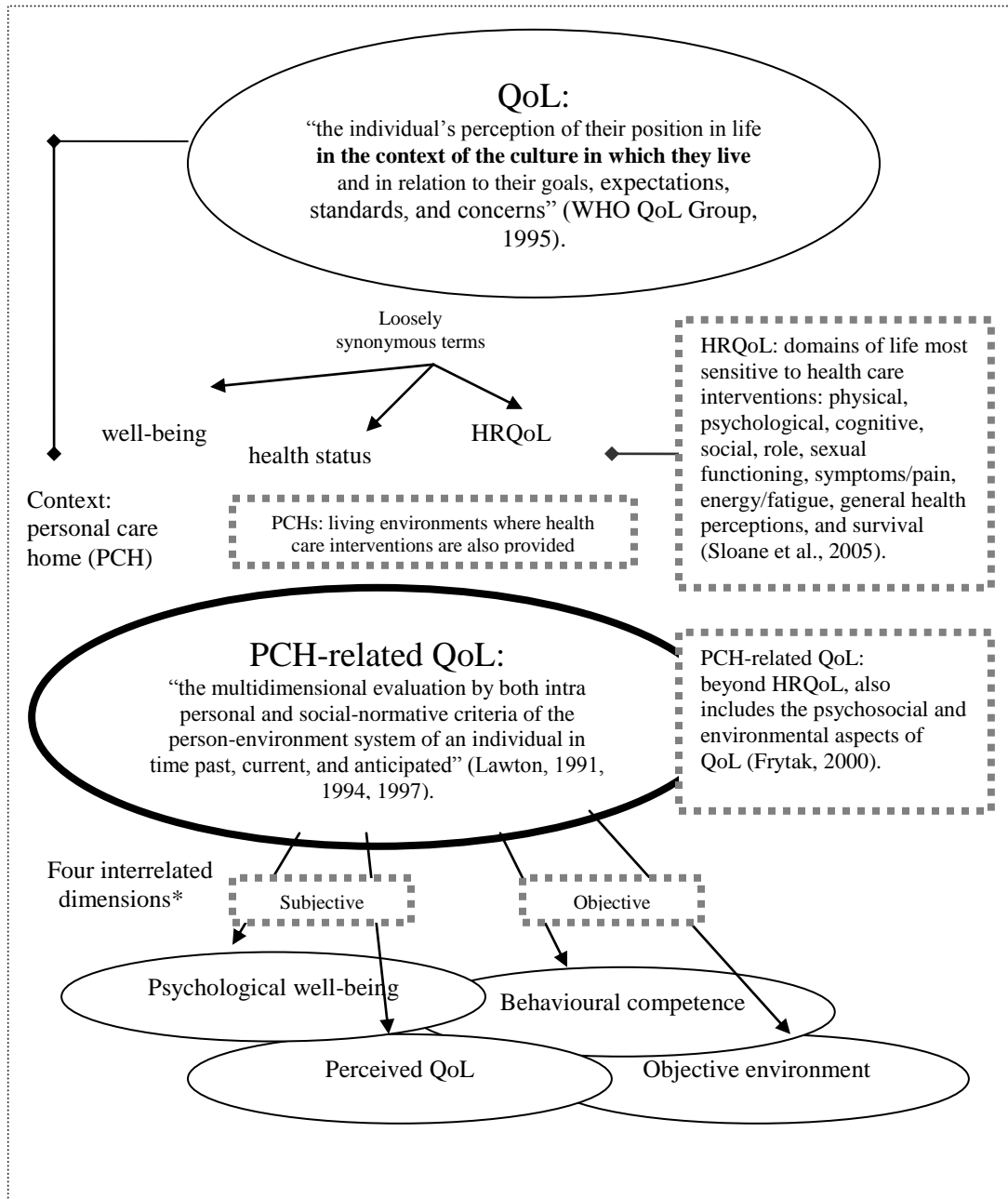
1. Lawton's (1991, 1994, 1997) framework is one of several PCH-QoL frameworks and is acknowledged to be the most comprehensive to date. This framework posits that QoL has four interrelated dimensions including psychological well-being, perceived QoL (referred to as subjective), behavioural competence, and objective environment (objective).
2. Several scales have been developed to measure QoL with domains (subdimensions) that vary between researchers and studies. Effort to develop a gold standard in PCH settings, especially one that measures QoL of the frail elderly who cannot communicate, is ongoing.

3. QoL research in the generic PCH literature has been conducted using a combination of subjective and objective domains. This literature generally describes the meaning of QoL from the perspective of these residents, and also describes factors that add to or detract from a positive QoL experience.
4. Knowledge pertaining to the subjective QoL domains is lacking for PCH residents with ADRD (Frytak, 2000; Kane, 2001, 2003). Due to methodological and/or ethical challenges, QoL knowledge about these residents has been generally obtained by observing behaviour via structured interviews or observation checklists.
5. Kane and colleagues have proposed a framework for measuring QoL for PCH residents with ADRD, consisting of six ‘psychosocial’ domains of enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence. While this framework was designed to further understand QoL for PCH residents with ADRD, at present the validity of these domains has not been empirically tested.

3.2 Definitions of Quality of Life

QoL, along with quasi-synonymous terms ‘HRQoL’, ‘health status’, and ‘well-being’ (Selai & Trimble, 1999), have been embedded in health, PCH, and ADRD discourse for at least 30 years. The World Health Organization (WHO) defines QoL as an “individual’s perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns” (WHO QoL Group, 1995). Figure 3.1 illustrates the intersection between this and various related definitions including PCH-related QoL.

Figure 3.1. A conceptual guide for Quality of Life.



*Dimensions can be further stratified into ‘domains’ to describe scope, and facilitate measurement, of selected QoL dimensions. QoL measures can be dimension-specific and reflect a wide range of domains that vary between studies and researchers.

3.2.1 Personal Care Home-Quality of Life Frameworks

PCHs in Canada are permanent living environments when the health care needs of older adults exceed that which can be provided safely in the community. For this reason, PCH-QoL frameworks generally subscribe to a broader view of QoL, versus HRQoL (Kane, 2003; Sloane et al., 2005), the latter which is limited to domains sensitive to health care interventions (e.g., physical, psychological, cognitive, social, role, sexual functioning, symptoms/pain, energy/fatigue, general health perceptions, and survival) (Sloane et al.). Overall QoL also encompasses the psychosocial and environmental aspects of QoL (Frytak, 2000) as reflected in frameworks that include: (a) survival, security/safety, purpose, and independence (Jones, Robinson, & Golightley, 1986); (b) quality of care, physical environment, social-emotional environment, ability, autonomy, and morale (Cohn & Sugar, 1991); (c) physical functioning, daily activities (recreational, instrumental, work), mobility, social functioning and well-being, positive and negative affect states, aesthetics, self-concept, and overall life satisfaction (Brod, Stewart, & Sands, 1994); and, (d) social interaction, appearance of resident to others, and nutrition (Deletter, Tully, Wilson, & Rich, 1995), among others. Within the PCH environment, Lawton's (1991, 1994, 1997) QoL framework is generally acknowledged to most systematically conceptualize PCH-QoL (Frytak, 2000; Ready & Ott, 2003; Selai & Trimble, 1999).

3.2.2 Lawton's Personal Care Home—Quality of Life Framework

Lawton (1991, 1994, 1997) conceptualized QoL as the “multidimensional evaluation by both intra personal and social-normative criteria of the person-

environment system of an individual in time past, current, and anticipated”. His QoL is a construct of four overlapping subjective (psychological well-being and perceived QoL) and objective (behavioural competence and objective environment) dimensions which can be further stratified into ‘domains’ which are used to describe the scope and facilitate measurement of selected QoL dimensions. Considered to be the central dimension of QoL, psychological well-being is defined as “how good a person feels” (Jonker, Gerritsen, Bosboom, & Van der Steen, 2004) or “the weighted evaluated level of a person’s competence and perceived quality in all domains of contemporary life” such as affect state, happiness, morale, life satisfaction, and self-esteem (Lawton, 1997). Conversely, perceived QoL reflects a person’s degree of satisfaction with life in general (Jonker et al.), and domains from this dimension typically include spirituality, satisfaction with health care, the presence of family and friends, and having spare time as well as an adequate living environment (Lawton, 1997). Behavioural competence is the QoL dimension most affected by disease, encompassing cognitive and functional abilities as well as social behaviour (Jonker et al.). The typical domains from this dimension include meaningful time use, social engagement and emotional expression (Lawton, 1997). Lastly, the dimension of objective environment typically focuses on a person’s living situation, including domains such as physical safety, presence of amenities, freedom from barriers, legibility of the environment, privacy, stimulating or aesthetic quality, and choice (Lawton, 1997).

Though Lawton’s comprehensive framework is acknowledged by many PCH-QoL researchers, most have used study-specific domains pending their research goals

and target population (Frytak, 2000; Lawton, 1997), which in turn has led to a lack of consistency in the more general PCH QoL literature. Despite 30 years of discourse in the literature, multiple PCH-QoL frameworks are still being used without any gold standard of QoL measurement (Ettema et al., 2005; Kane, 2003; Ready & Ott, 2000; Sloane et al., 2005).

3.3 A Summary of Personal Care Home-related Quality of Life Research

PCH-QoL research has been conducted using structured or semi-structured/open-ended resident interviews, interview by proxy and observation by trained observers (Ettema et al., 2005; Gerritsen et al., 2007; Kane, 2003; Ready & Ott, 2003; Sloane et al., 2005). Examples of established QoL measures with tested psychometric properties include the Philadelphia Geriatric Centre Morale Scale (PGCMS) (Lawton, 1975), Positive and Negative Affect Scales (PANAS) (Watson, Clark, & Tellegen, 1988), the Schedule for the Evaluation of Individual QoL Direct-Weighting Version (SeiQoL-DW) (Browne, O'Boyle, McGee, McDonald, & Joyce, 1997), and the WHO-QoL Brief Questionnaire (WHOQOL-BREF) (The WHOQOL Group, 1998). Table 3.1 outlines the domains and methods of data collection for these measures.

Several researchers have argued that self-report is superior to other methods of QoL measurement (Gerritsen et al., 2007; Kane, 2003; Ontario Association of Non-Profit Homes and Services for Seniors [OANHSS], 1996). Some researchers further maintain that QoL is really the individual's own unique construct and thus have employed semi-structured or open-ended interviews versus structured questionnaires (Aller & Van Ess Coeling, 1995; Echteld, Deliens, Ooms, Ribbe, &

Table 3.1

Selected Personal Care Home-Quality of Life Measures

Measure	Domains	Method
Philadelphia Geriatric Centre Morale Scale (PGCMS)	Agitation, attitude toward own aging, and lonely dissatisfaction	Self-report; structured
Positive & Negative Affect Scales (PANAS)	Positive-, negative affect	Observation
Schedule for the Evaluation of Individual QoL – Direct Weighting Version (SeiQoL-DW)	Subject-nominated five areas of life considered central to their individual QoL	Self-report; semi-structured
WHO-QoL Brief Questionnaire WHOQOL-BREF	Physical, psychological, social relationships, and environment	Self-report; structured
Minimum Data Set – Health Status Index (MDS-HSI)	MDS-NH (functional- health status, social environment, and service items) and HUI2* domains (sensation, mobility, emotion, charts, resident cognition, self care, pain)	Clinical assessment (observed function, medical and family report)

*The HUI2 is a generic HRQoL measure commonly used in community-based samples. ‘Fertility’, another domain of the HUI2, was excluded from the MDS-HSI scale development.

Source. Browne et al., 1997; Lawton, 1975; Torrance, et al., 1996); Watson et al., 1988; WHOQOL Group, 1998; Wodchis et al., 2003.

van der Wal, 2005; OANHSS, 1996). These studies collectively emphasize the subjective psychological well-being (Gerritsen et al.) and perceived QoL dimensions of Lawton's framework. Conversely, Wodchis et al.'s (2003) Minimum Data Set-Health Status Index (MDS-HSI) and Lai et al.'s (2005) WHOQOL-BREF framework emphasize the more objective dimensions of Lawton's framework. While outcomes from these frameworks may be less comprehensive, their relative brevity makes them easier to administer with more directly applicable results.

Based on evidence from several frameworks, PCH residents have generally defined their QoL as relatively 'good' or 'beyond good' (Echteld et al., 2005; Guse & Masesar, 1999). Particularly important QoL aspects include maintaining good contacts with friends/others and maintaining good health (Echteld et al.; Lai, Tzeng, Wang, Lee, Amidon, & Kao, 2005), and constructs such as people, personal characteristics, room and board, well-being, nature and being helpful are also associated with QoL (Guse & Masesar). People's ability to communicate with and help others and also to care for themselves has also been shown to enrich QoL (Aller & Van Ess Coeling, 1995). Some evidence also suggests that community- versus PCH-dwelling individuals generally report a better QoL (Wodchis, Hirdes, & Feeny, 2003), potentially highlighting the important influence of health and disability on QoL (Lai et al., 2005). Lastly, the vast majority of this evidence has been obtained from 'interviewable' PCH residents, and cannot necessarily be extrapolated to those with ADRD.

3.4 Alzheimer's Disease and Related Dementia-Specific Personal Care Home-Quality of Life Literature

Considerably more QoL research has been conducted on PCH residents without versus with ADRD. Between 2000 and 2010, the literature retrieved 76 articles of which only 23 were ADRD-specific. The vast majority of this literature has been conducted in the United States or Europe. While three Canadian studies were found investigating QoL for non-ADRD residents (Guse & Masesar, 1999; OANHSS, 1996; Wodchis et al., 2003), no equivalent QoL Canadian literature was found for PCH residents with ADRD. Lastly, most of this literature focuses on the objective QoL domains. More pronounced limitations in verbal communication, memory, decision-making capacity, and emotional disposition among ADRD residents (Hubbard et al., 2003) add to the methodological and ethical challenges of this literature area (Tester et al., 2004; Zimmerman et al., 2005).

This review introduces six ADRD-QoL scales that have been used in North American or European PCHs including: (a) Dementia Care Mapping (DCM) (Kitwood & Bredin, 1992); (b) Philadelphia Geriatric Centre Affect Rating Scale (PGC-ARS) (Lawton, 1994; Lawton, van Haitsma, & Klapper, 1996); (c) QoL in Dementia (QoL-D) (Albert, Del Castillo-Castaneda, Jacobs, Marder, Bell, et al., 1996); (d) Alzheimer's Disease Related QoL (ADRQL) (Rabins, Kasper, Kleinman, Black, & Patrick, 1999); (e) QoL in Late-Stage Dementia (QUALID) (Weiner, Martin-Cook, Svetlik, Saine, Foster, & Fontaine, 2000); and, (f) the QUALIDEM (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2007b). The QoL domains and methods of data collection employed by each of these scales are outlined in Table 3.2.

Table 3.2

Alzheimer's Disease and Related Dementia-Specific Quality of Life Measures for Personal Care Homes

Measure	Domains	Method
Dementia Care Mapping (DCM)	Well-/ill-being, social withdrawal, and activity	Observation
Philadelphia Geriatric Centre Affect Rating Scale (PGC-ARS)	Positive-, negative affect	Observation
QoL in Dementia (QoL-D)	PGC-ARS and Terri & Logsdon's Pleasant Events AD Schedule Domains (passive-active and social-nonsocial activities)	Proxy interview; structured
Alzheimer's Disease Related QoL (ADRQL)	Social interaction, awareness of self enjoyment of activities, feelings and mood, and response to surroundings	Proxy interview; structured
QoL in Late Stage Dementia (QUALID)	QoL-D domains	Proxy interview; structured
QUALIDEM	Care relationship, positive-, negative affect, restless behaviour, positive self-image, social relations, social isolation, feeling at home, and having something to do	Proxy interview; structured

Source. Albert et al., 1996; Kitwood & Bredin, 1992; Lawton, 1994; Lawton et al., 1996; Logsdon & Terri, 1997; Rabins et al., 1999; Terri & Logsdon, 1991; Weiner et al., 2000.

All scales listed in Table 3.2 gather data using either observational or proxy respondent techniques. Observation tools include the DCM and the PGC-ARS. The DCM (Kitwood & Bredin, 1992) was originally conceived as an audit tool to evaluate care in PCH residents unable to report on their experiences (Brooker, Foster, Banner, Payne, & Jackson, 1998). It assesses three domains of QoL: well-ill being, social withdrawal, and activity. The PGC-ARS (Lawton, 1994; Lawton et al., 1996) was originally developed to assess positive-negative affect in residents of special care units (SCUs). SCUs are areas within PCHs specifically designed for residents with ADRD, many of whom are in advanced stages of this disease with limited ability to verbally communicate. This strategy employs systematic observation of resident facial expression, body movement, and other communication cues which trained observers correlate to a predominant state such as mild pleasure, high pleasure, anger, anxiety or fear, sadness, general alertness, or sleeping/dozing.

Proxy tools include the QoL-D, the ADRQL, the QUALID, and the QUALIDEM. The QoL-D (Albert et al., 1996) was developed on the premise that “the experience of living was the key component of QoL and that readily observable behaviours would offer insight into the experiential world of persons with dementia” (Sloane et al., 2005). It assesses two QoL domains (positive-negative affect and activity), measured through family caregiver and/or staff reports. The ADRQL (Rabins et al., 1999) was developed from consultations with family caregivers and AD experts. It assesses five domains of QoL: social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surroundings. The revised version of this scale (Kasper et al., 2009) maintains all five of these original

domains, however makes some minor additions and deletions to subdomains. The QUALID (Weiner et al., 2000) is the modified QoL-D scale (Albert et al., 1996) and was developed specifically for use in late-stage dementia residents in SCUs. Like the QoL-D, QUALID assesses affect and activity through interviews with health care staff. The QUALIDEM (Ettema et al., 2007b), the newest of ADRD-specific QoL measures, was originally framed from Droes and Van Tilburg's (1996) Adaptation-Coping Model, and was refined through focus groups of individuals suffering from ADRD and expert panels. Rated by health care staff, it assesses nine QoL domains: care relationship, positive affect, negative affect, restless tense behavior, positive self image, social relations, social isolation, feeling at home, and having something to do.

While factors contributing to good QoL for non-ADRD residents is well understood, the analogous evidence for residents with ADRD is less well developed (Aller & Van Ess Coeling, 1995; Echteld et al., 2005; Guse & Masesar, 1999). Some authors, however, have documented a positive relation between resident activity and well-being or QoL (Albert et al., 1996; Fossey, Lee, & Ballard, 2002), while others (Ettema et al., 2007) reported that positive self-image, feeling at home and having something to do had no real impact on QoL for PCH residents with severe dementia. Lastly, some evidence reports that community-dwelling older adults with ADRD have a better QoL versus their PCH resident counterparts (Kasper, Black, Shore, & Rabins, 2009).

3.5 An Introduction to the Kane et al. Framework: A Novel Framework for Measuring Quality of Life in Personal Care Home Residents with Alzheimer's Disease and Related Dementias

As stated previously, ADRD-QoL measures have been assessed using a variety of domains. However, QoL knowledge about PCH residents with ADRD is still fairly fragmented, as most of these domains represent objective QoL dimensions, and are based on frequencies of counts using observational or proxy respondent interview techniques. For PCH residents with ADRD, knowledge about the subjective QoL domains is virtually non-existent. Kane et al.'s framework (1999, as cited in Frytak, 2000; Kane, 2001, 2003) was developed to provide some additional insight into these domains.

The Kane et al. framework features 11 domains of QoL currently absent from the repertoire of most PCH-QoL assessment tools, most notably the Minimum Data Set for Nursing Homes (MDS-NH) (Kane, 2003), including autonomy, individuality, dignity, privacy, enjoyment, meaningful activity, relationships, security/safety, comfort, spiritual well-being, and functional competence. These domains were intended to represent the psychosocial or subjective QoL dimensions, with more information provided in Table 3.3.

Within their original framework, Kane et al. (2003) posited that only six domains (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence) were relevant across the full spectrum of PCH residents with ADRD. Conversely, Kane et al. (2003) posited that the domains of autonomy, individuality, dignity, privacy, and spiritual well-being each required some degree of cognitive functioning that may be difficult to assess in ADRD residents, and should therefore be excluded with assessing QoL for these residents. Lastly, as a part of their framework, Kane et al. (2003) also emphasized that: (a) considerable overlap or

Table 3.3

*The Kane et al. Personal Care Home (PCH)-Quality of Life (QoL) Framework:
Domains and Definitions*

Domain	Definition
Autonomy	Residents take initiative and make choices for their lives and care.
Individuality	Residents express their preferences and pursue their past and current interests while living at the nursing home, maintaining a sense of their own personal identity and continuity with their past.
Dignity	Residents perceive that their dignity is intact and respected and do not experience feelings of being belittled, devalued, or humiliated.
Privacy	Residents experience a sense of bodily privacy, have the ability to keep personal information confidential, and have sufficient opportunities to be alone and to communicate and interact with others in private.
Enjoyment	Residents express or exhibit pleasure and enjoyment, verbally and nonverbally. Conversely, they do not express or exhibit unhappiness, distress, and lack of enjoyment.

Source. Kane et al., 1999, as cited in Frytak, 2000, pp. 204-205

Table 3.3, continued

Domain	Definition
Meaningful activity	Residents engage in discretionary behaviour, either active activity or passive observation, that they find interesting, stimulating, worthwhile. Conversely, they tend not to be bored with their lives.
Relationships	Residents engage in meaningful person-to-person interchange where the purpose is social.
Security/safety	Residents feel secure and confident about their personal safety and security of their possessions and have clarity about rules and practices.
Comfort	Residents experience minimal physical discomfort, including symptoms such as pain, aches, nausea, dizziness, constipation, and itching, and no discomfort from being cold, hot, thirsty, or in an uncomfortable position. They perceive that staff notice and attend to their physical comfort.
Spiritual well-being	Residents perceive that their needs and concerns for religion, prayer, meditation, moral values, and meaning in life are met.
Functional competence	Residents function independently in the nursing home in keeping with their abilities and preferences.

Source. Kane et al., 1999, as cited in Frytak, 2000, pp. 204-205

interrelations would exist across domains; (b) residents may attach different levels of importance to the six domains and would likely interpret each domain differently pending their level of illness; and, (c) resident experiences in these domains would also depend on their health status, social situation, personality, and care environment.

Kane et al.'s work is thus far in the conceptual stage without empirical evidence available to validate the six domains of QoL for PCH residents with ADRD (Frytak, 2000; Kane, 2001, 2003). However, this framework offers a fresh perspective to study PCH-QoL for residents with ADRD, specifically by complementing QoL knowledge in the more objective dimensions. The present research is the first known application of Kane et al.'s framework designed to provide some validation of the meaning and importance of the six domains of QoL for PCH residents with ADRD.

CHAPTER 4 – METHODS

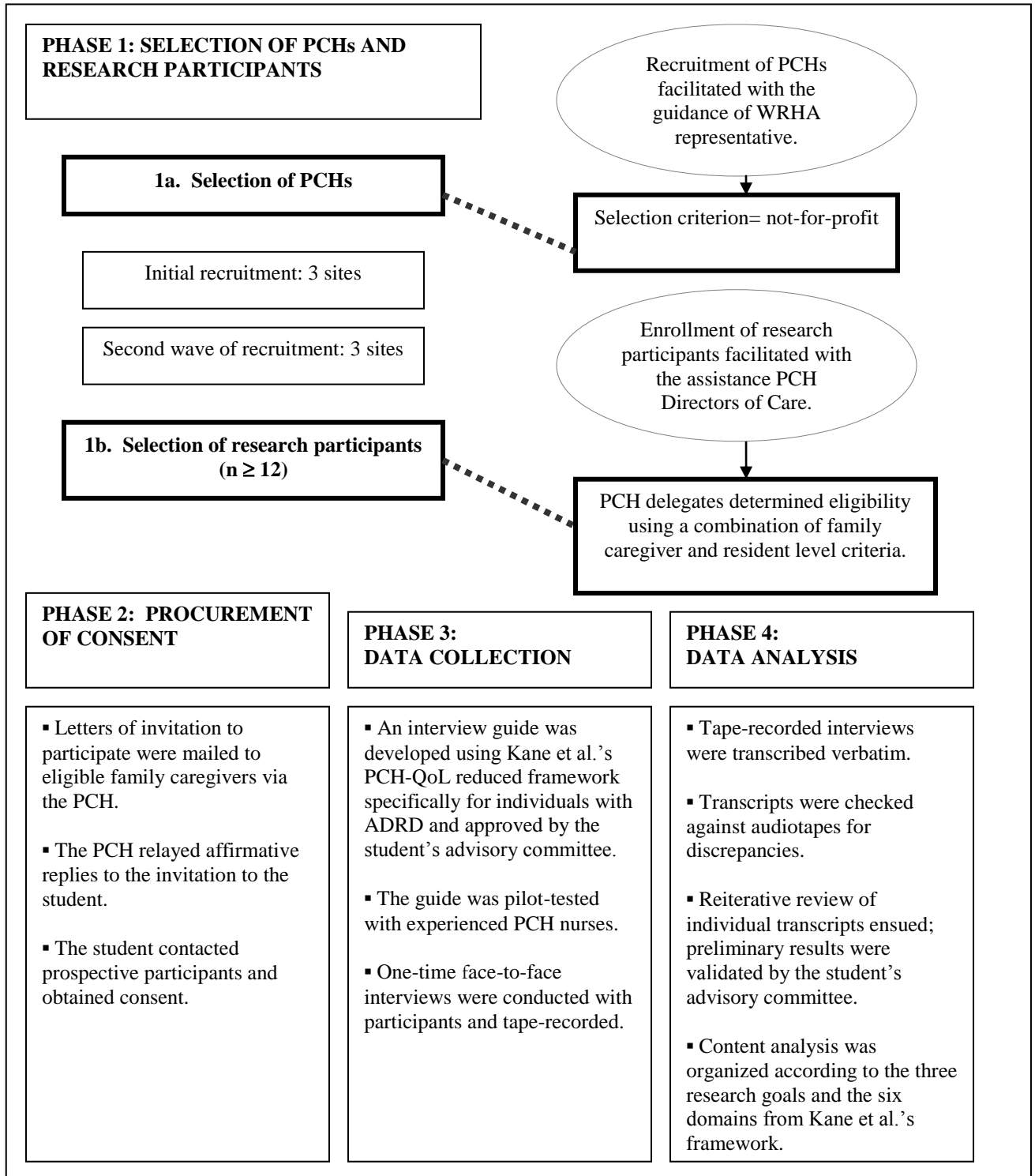
This study was conducted to examine the QoL of PCH residents with ADRD, using Kane et al.'s (1999, as cited in Frytak, 2000; Kane 2001, 2003) framework as a guide. A qualitative methodology was employed through semi-structured interviews with family caregivers to address three research objectives:

1. To gather family caregivers' perspectives on the meaning of the six domains that constitute Kane et al.'s ADRD-specific PCH-QoL framework;
2. To gather family caregivers' perspectives on the domains they consider more important as well as domain(s) deemed lacking from Kane et al.'s framework; and,
3. To gather family caregivers' perspectives on general PCH policies, practices, and activities that currently (or could better) facilitate positive QoL experiences for their loved ones.

Seventeen face-to-face interviews were tape-recorded and later transcribed, from five PCHs in Winnipeg. Data were analyzed with reiterative perusals of individual transcripts to extract recurrent themes and other issues of relevance to PCH-QoL. Ethics approval to conduct this research was provided by the University of Manitoba Health Research Ethics Board (Appendix A) and the WRHA Research Review Committee (Appendix B).

This research was conducted in four phases as illustrated in Figure 4.1. Phase 1 involves the selection and recruitment of PCHs and research participants. Participant consent was obtained during Phase 2. Data were collected in Phase 3 of this research and analyzed in Phase 4.

Figure 4.1. A schematic of the research methodology.



4.1 Phase 1: Selection and Recruitment of Personal Care Homes and Research Participants

4.1.1 Personal Care Homes

Invitation to participate in the study was open to all not-for-profit PCHs in the WRHA (see Appendix C) which comprise two-thirds of all PCHs in this health region. PCH recruitment was facilitated with the guidance of the WRHA PCH Program Director.

The PCH recruitment period spanned six months, between June and November of 2008. Through the WRHA PCH Program Director, the proposed study was introduced at regular meetings and reinforced by e-mails. As of September 2008 three PCHs agreed to help recruit study participants, and following a second recruitment attempt in November 2008, three additional PCHs agreed to take part in this study.

Once PCHs had agreed to take part in this study, the following steps were taken:

1. The WRHA PCH Program Director notified the student of interested PCHs, and provided the student with contact information for the PCH delegate (usually the PCH Director of Care).
2. The student contacted respective PCH delegates to confirm interest, address initial questions, and arrange a face-to-face meeting to discuss the study further.
3. The student e-mailed copies of the letter of invitation to participate

(Appendix D) and letter of support from the WRHA PCH Program Director (Appendix E) to the PCH delegate following their initial telephone conversation.

4. During the face-to-face meeting, the student and PCH delegate reviewed the three-fold role of site participants in the study. PCH delegates were asked to: (a) determine prospective participants who satisfied a combination of family caregiver and resident criteria, (b) mail the student-prepared invitation packages to family caregivers who met both PCH resident and caregiver criteria, and (c) forward the contact information of interested family caregivers to the student who was solely responsible for obtaining consents and conducting the interviews.

4.1.2 Research Participants

Research participants in this study were defined as the family caregivers of PCH residents. They also must have satisfied each of the following criteria:

1. *Be the spouse, sibling, or child of a PCH resident.* Immediate family members are likely to have the most valid responses as it pertains to their loved one (Kane, 2003). These family members typically have detailed knowledge of the resident before he/she were admitted to a PCH, and are more likely to interact with the resident on a meaningful level than staff or any other visitor. Family members' perception of their loved one's QoL may be the most precise as they can ever be.
2. *Be fluent in English.* Participants' fluency in English may help facilitate in-depth responses from a small number of interviews.

3. *Been regular weekly visitors at the PCH in the past three months.* Eligible family caregivers must have visited their loved one at least once weekly in the past three months. This criterion helps ensure that participants were able to provide as precise and as accurate responses to interview questions regarding their loved one's QoL.

Study participants' loved ones, the PCH residents, must also have satisfied each of the following criteria:

4. *Been diagnosed with ADRD at or prior to admission to the facility.*
5. *Be 65 years old or older.*
6. *Must have lived in the same PCH in the last three months, without having been hospitalized for greater than one month during this time.* A minimum residency requirement of three months will allow residents to have attained some sense of normalcy in their new environment. Less than three months' residency has been previously defined as short-stay for PCH residents (Guse & Masesar, 1999).
7. *Have had no known diagnosis of schizophrenia, bipolar disorder, mental retardation, or acquired brain injury.* Residents with these mental health disorders may display behavioural problems that could adversely affect QoL. This exclusion criterion has been applied most notably in Zimmerman et al.'s Collaborative Studies in Long Term Care (2005).
8. *Not be placed currently in a dementia-designated area or special care unit (SCU) in the PCH.* SCUs are smaller and provide special interventions for residents who may require them (Manitoba Health, 2002).

9. *Not be receiving palliative care or be expected to die in the next month.* This criterion prevented grieving family caregivers from being interviewed.

Irreversible illness or imminent death may likewise have some effect on residents' QoL.

Collectively, these criteria guided the selection of research participants by PCH delegates. Eligible family caregivers meeting these criteria received a package directly from the PCH delegate consisting of: (a) a cover letter by the PCH Director (Appendix F), (b) a student's letter of introduction and invitation to participate (Appendix G); and, (c) a self-addressed stamped return envelope to be returned directly to the PCH. Only interested family caregivers were asked to return the completed reply forms.

The original protocol stipulated that if it was not possible to recruit at least 12 family caregivers from the first three PCHs, recruitment may continue with a fourth PCH, following the same recruiting procedures. Recruitment continued until delegates from six PCHs agreed to participate. A sample size of no less than 12 participants was proposed and approved by the student's advisory committee to address the goals of the research and achieve data saturation. Additionally, criterion sampling was employed to facilitate the recruitment of a relatively homogeneous sample that reflects the profile of PCH residents with ADRD. Other qualitative studies in PCHs have used between 12 and 26 respondents (Bergland & Kirkevold, 2005; Monaghan, 2002).

4.2 Phase 2: Procurement of Consent

The student researcher contacted family caregivers once their contact information was forwarded by respective PCH delegates. The student was solely responsible for obtaining consent and conducting the interviews. Verbal consent was first obtained during the initial student/family caregiver conversation. During this conversation the student confirmed that participants were willing and able to participate in this study, addressed initial caregiver questions about the study, and arranged a mutually convenient meeting time and place for the interview. Written consent (Appendix H) was obtained on the day of the interview.

4.3 Phase 3: Data Collection

Face-to-face semi-structured interviews were used as the sole method of data collection. An interview guide (Appendix G) was developed using Kane et al.'s PCH-QoL reduced framework (2001, 2003) specifically for individuals with ADRD and approved in advance by the student's advisory committee. This guide was pilot-tested with four nurses working at four different PCHs. Each nurse had worked in a WRHA PCH for at least three years and was selected with the guidance of the student's nurse colleagues. Changes were made to the interview guide as suggested by the pilot-testers, one of whom likewise had a parent with ADRD in a PCH.

The interview guide consists of four parts and questions were asked in the following order:

1. Introductory questions were first asked about the family caregiver, to obtain basic demographic information about the interviewee and to provide some background about his/her level of familiarity with the resident;
2. Basic demographic questions were then asked about the PCH resident, to provide further background information and to refocus the interview back to the resident;
3. Specific questions were asked about the resident's QoL in the PCH, to gather the family caregiver's perspectives on the meaning and general importance of Kane et al.'s (2001, 2003) domains, and also understand how facility policies, practices, and activities facilitated positive QoL experiences for residents with ADRD; and,
4. A final set of questions was asked about the resident's health status, mental and physical functioning, to provide some reference for the family caregiver's responses.

The interview initially developed to last between 45 to 90 minutes, in actuality ranged between 60 and 120 minutes. The majority of these interviews were conducted in a private room within the PCH while a few were held in participants' homes. In both settings, only two people were present during the interview: the interviewee and the interviewer. Interviews were tape-recorded and later transcribed, supplemented by field notes taken during and immediately following the interview to facilitate analysis.

4.4 Phase 4: Data Analysis

Interview data were perused for descriptive information about the family caregiver and resident, as well as family caregiver appraisals about their loved one's QoL. Interviews from the sixth PCH were excluded from analysis as all residents were determined to be residents of SCUs within the PCH during the interview with their family caregivers.

4.4.1 Family Caregiver and Resident Characteristics

Information on family caregivers' sex, type of relationship with resident, frequency and duration of weekly visits at the PCH; residents' sex, age, pre-PCH living arrangement, length of stay at the PCH, type of ADRD diagnosis, and presence of other family visitors and/or private help were extracted from transcripts to describe the population represented in the study.

4.4.2 Participants' Perspectives on their Loved Ones' Quality of Life

Interview transcripts were read repeatedly to identify recurrent themes and resounding issues pertinent to PCH-QoL. Organizational categories for analysis were the three research goals and the six domains from Kane et al.'s (2001, 2003) framework. The steps undertaken to interpret interview data are outlined below:

1. Transcripts were first checked against audiotapes for discrepancies. Field notes taken during and immediately after the interview were clarified or supplemented.
2. Corrected transcripts were read individually and a preliminary results summary was developed from transcripts and field notes. This summary

listed in point form components of Kane et al.'s six domains as well as other possible domains identified by participants. These were supported by quotes extracted from two representative transcripts. This output was submitted to the student's advisory committee for review and was revised as necessary.

3. Transcripts were read a second time to solidify and supplement the preliminary results summary. The domains were defined and relevant quotes were extracted from all 17 transcripts.
4. Output in #2 and #3 were amalgamated. Domain definitions were refined, quotes were rearranged according to the refined definitions, and less compelling quotes were removed from the document.
5. Output in #4 was reiteratively reviewed to respond conclusively to the three research objectives. This output was submitted to the student's advisor for review and was revised as necessary.

CHAPTER 5 – STUDY RESULTS

This chapter describes study participants and highlights participants' perspectives about their loved one's QoL, organized as per the three study objectives of this thesis research.

5.1 Research Participants: A Profile

The five PCHs involved in this study represented 16% of the 3,555 not-for-profit beds in Winnipeg, each representing a different area of the WRHA's 12 communities (WRHA, 2007).

An overview of PCH resident characteristics are provided in Table 5.1. These residents were predominantly 85+ year old women who had lived at home prior to PCH admission. The majority of these residents were diagnosed with non-specific dementia, had been a PCH resident for a year or more, and in addition to having visits from study participants, had other regularly visiting family members (e.g., spouses, children, in-laws, and nieces) and/or privately hired help. Privately hired help, listed in order of most to least common, include companion services, music therapists, massage therapists, and retentive cognitive therapists. Some residents had companion services around the clock, while others who used this service received at minimum two hours daily.

An overview of family caregiver (participant) characteristics is provided in Table 5.2. These individuals were predominantly the daughters of PCH residents. Participants visited their loved ones between one to seven times a week, and

Table 5.1

Characteristics of Personal Care Home Residents with Alzheimer's Disease and Related Dementias (Loved Ones of Study Participants)

Strata	Categories	Distribution
Sex	Female	14 (82%)
	Male	3 (18%)
	Total	17(100%)
Age	Old-old	12 (70%)
	Middle-old	3 (18%)
	Unknown	2 (12%)
Pre-PCH living arrangement	Directly from home	8 (47%)
	Interim*	5 (29%)
	Assisted living	3 (18%)
	Unknown	1 (6%)
Length of stay in PCH	≥ 1 year	13(76%)
	< 1 year	4 (24%)
ADRD diagnosis	Unspecified dementia	8 (47%)
	Other than AD	5 (29%)
	AD	4 (24%)
Had other regular visitors (≥1x/week)	Received other visitors	15 (88%)
	Did not receive other visitors	2 (12%)
Companion/other service use (≥1x/week)	Received companion and/or other services	9 (53%)
	Did not use service	8 (47%)

*Transitional PCH while awaiting placement in PCH of choice.

individual visits ranged from half an hour to eight hours in length. Participants most commonly cited (see ‘mode’ in Table 5.2) visiting their loved ones about three to four times a week, for about an hour and a half per visit, at various times throughout the day.

Table 5.2

Characteristics of Study Participants (Family Caregivers)

Strata	Categories	Distribution
Sex	Female	13 (76%)
	Male	4 (24%)
	Total	17 (100%)
Relationship with resident	Daughter	11 (64%)
	Wife	2 (12%)
	Husband	2 (12%)
	Son	2 (12%)
Weekly visitation frequency	Minimum	1x/week
	Mode	3-4x/week
	Maximum	7x/week
Duration of visit (hours)	Minimum	0.5
	Mode	1.5
	Maximum	8.0

5.2 Participants’ Perspectives on Their Loved Ones’ Quality of Life:

Highlights of Findings

This thesis was developed to address three important questions about the QoL of PCH residents with ADRD. Specifically as it relates to the Kane et al. framework (Kane 2001, 2003), this research sought to determine: (1) family caregivers’

perspectives on the meaning of the six ADRD-specific domains (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence); (2a) what domains, if any, are missing from this reduced/ADRD-specific framework; (2b) which domains are most important; and, (3) which PCH facility policies, practices, and activities in general, currently facilitate or potentially could facilitate improved QoL. Highlights of research findings are summarized as follows:

1. Participants generally concurred with Kane et al.'s definitions of the six ADRD-specific PCH-QoL domains. At the individual level, the breadth and scope of each domain were further defined by resident level of illness (e.g., the severity of ADRD and comorbidities), values, expectations, and life (including PCH) experiences to date. Residents' experiences and/or achievements on the six domains varied in intensity as shaped by these and other individual circumstances.
2. While all domains were recognized as singular entities by study participants, their responses reflected intersections or overlap: their loved ones' experiences were not always distinct for a given domain. For instance, cited examples of residents' experience of enjoyment can also have been cited under 'comfort' (passive enjoyment) or 'meaningful activity' (active enjoyment). Other similar analogies include the achievement of 'meaningful activity', as a spectrum between 'enjoyment' and 'functional competence' experiences; and 'security/safety', as a spectrum between 'comfort' and 'relationships' experiences.

3. While the ADRD schematic as proposed by Kane et al. does not include autonomy, individuality, dignity, privacy, and spiritual well-being from the generic PCH-QoL framework (Frytak, 2000; Kane 2003), participants in the current research did mention ‘dignity’ as an important QoL domain for their loved ones.
4. Dignity, defined by participants as encompassing respect, acknowledgement of the person, the preservation of modesty, and facilitating pride in oneself, was also considered amongst one of the most important domains for residents with ADRD, along with security/safety, comfort, and enjoyment.
5. Study participants cited several PCH facility policies, practices, and activities facilitated positive QoL experiences for their loved ones. These included select physical attributes of the PCH including its actual location, and facility policies/activities that: (a) encouraged family involvement in resident care and daily activities; (b) promoted a sense of community and belonging within the PCH; and, (c) allowed for innovative programming to help fulfill family expectations.
6. Participants also acknowledged their own presence and staff attentiveness as QoL-enhancing for their loved ones; however, they called for better dementia care, more skilled care, and better staff to resident ratios.

5.2.1 Study Objective #1: What are Family Caregivers' Perspectives on the Meaning of the Six Domains that Constitute Kane et al.'s Alzheimer's Disease and Related Dementia-Specific Personal Care Home-Quality of Life Framework

Early in the interview process, participants were asked if they agreed with the verbatim definitions of the six QoL domains as provided by Kane et al. As a part of their response, participants provided examples of how their loved ones experienced each of these six domains. If participants felt their loved one's experience was suboptimal in any one domain, they also discussed how their loved one's experience could be further enhanced.

Overall, study participants agreed with Kane et al.'s definition of each QoL domain (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence), although participants often used different terms to describe each domain. In short, enjoyment was vernacularly termed 'happiness', 'contentment', and 'satisfaction'; meaningful activity as synonymous with anything that provided (or may provide) stimulation, a detractor from boredom, a functional or creative outlet, and means of socialization; relationships with 'interactions'; security/safety with physical safety, companionship, and emotional well-being; comfort with physical/medical care; and functional competence with choice/autonomy.

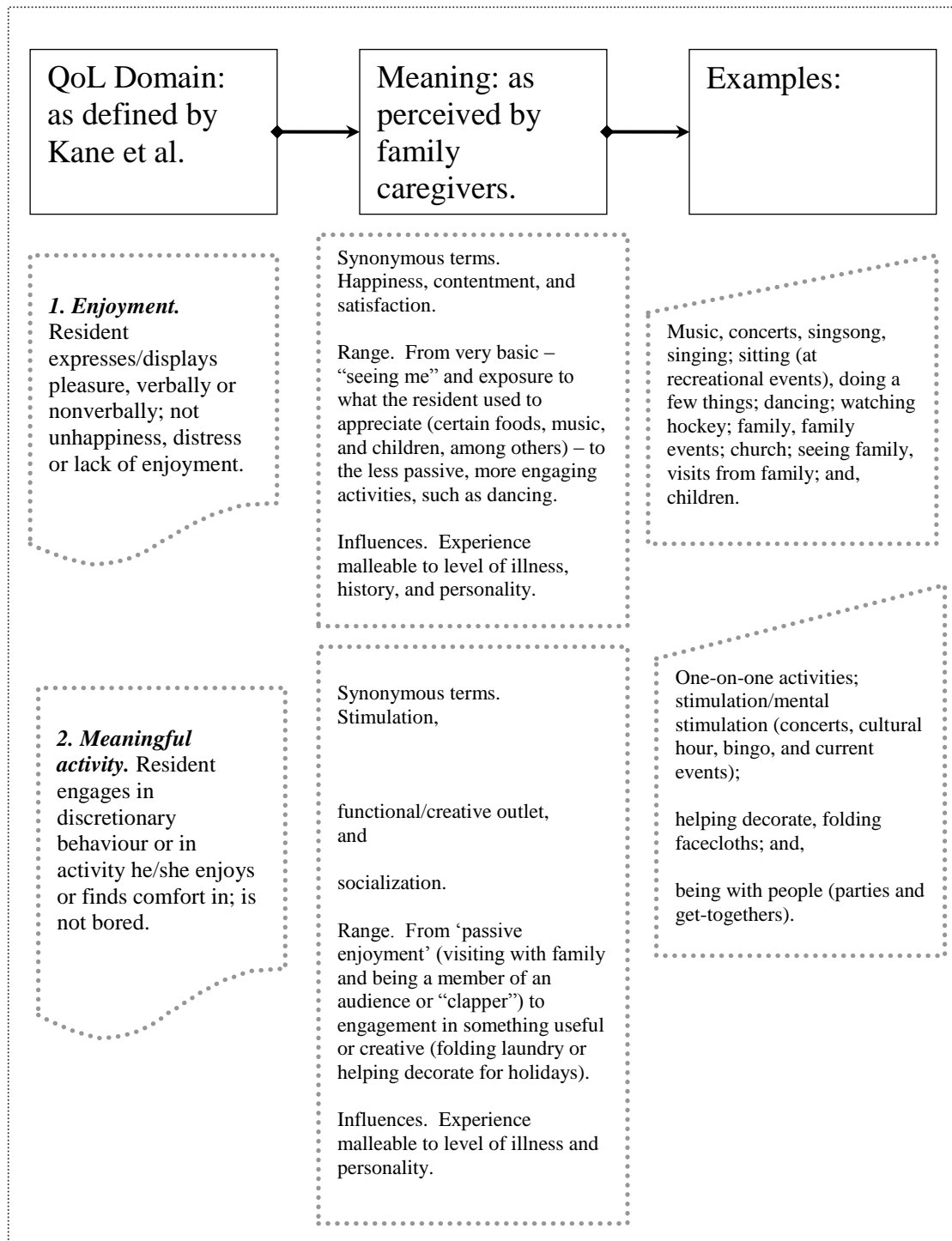
The range of examples provided on their loved one's QoL experiences on each of the six domains illustrated how family perspectives, despite subscription to some standard/ideal or a common understanding of what is important, are highly subjective and individualistic.

Likewise noteworthy is the overlap between domains. Examples of respective experiences on several domains were not always exclusive to those domains. Specifically, cited examples of residents' achievement of 'enjoyment' ranged between passive enjoyment (comfort) and active enjoyment (meaningful activity). Residents' achievement of 'meaningful activity' ranged between simple enjoyment and more complex meaningful activity (functional competence). Residents' achievement of 'security/safety' ranged between examples of 'comfort' and 'relationships' experiences. Additionally, residents' achievement of 'dignity' included examples of higher levels of 'comfort'. Regardless, all domains were considered relevant as individual entities. Figure 5.1 summarizes PCH-QoL within the context of the Kane et al. framework as perceived by participants.

Detailed results are provided in the remainder of this section separately for each of Kane et al.'s QoL domains. Text within each domain begins with Kane et al.'s definition followed by participants' respective understandings of the domain, possible influences on these perspectives, and selected excerpts from the interviews. To help provide additional context for interpreting results (e.g., to show how findings were generalized across respondents including different sexes), pseudonyms have been attached to select excerpts.

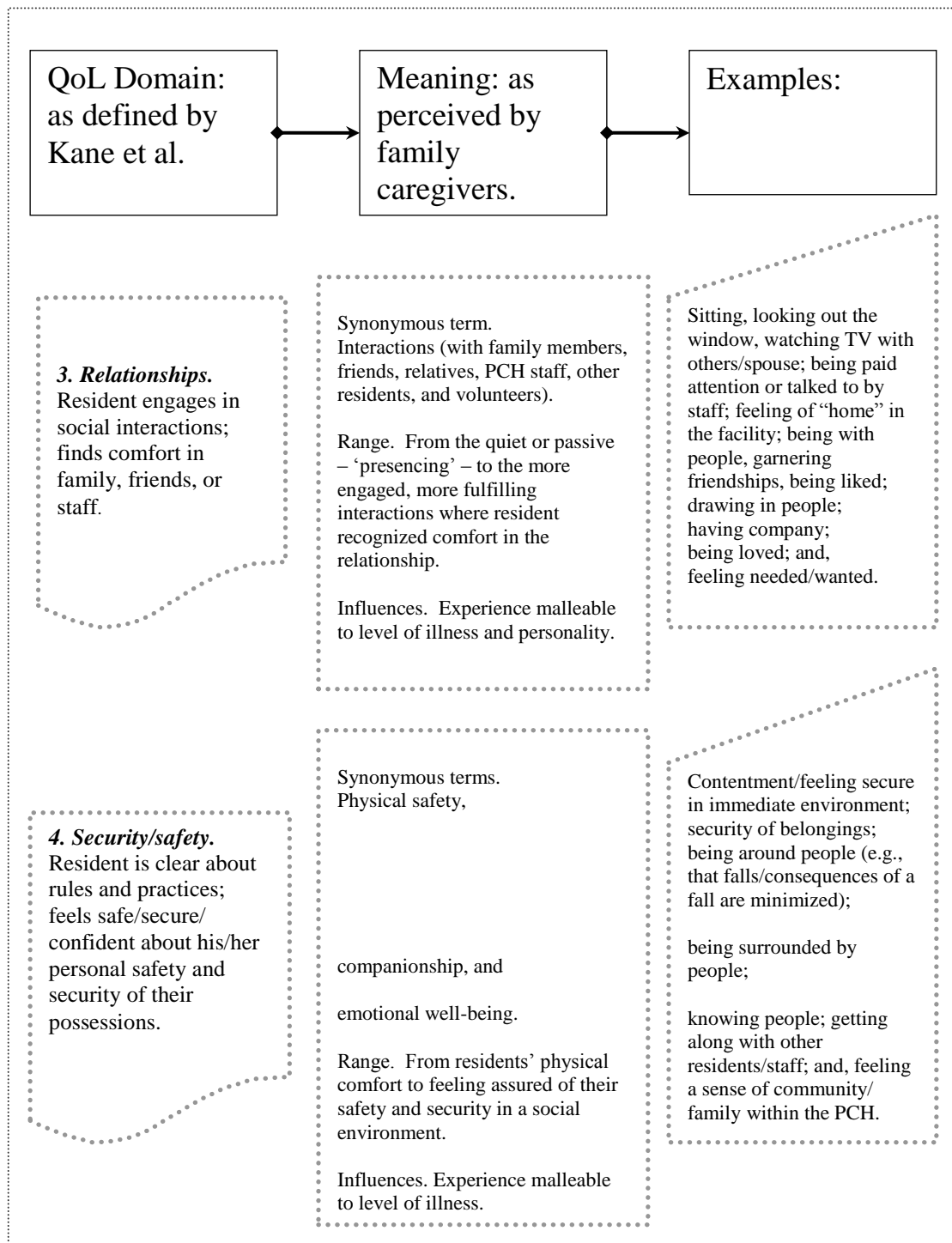
5.2.1.1 Enjoyment: Resident expresses/displays pleasure, verbally or nonverbally; not unhappiness, distress or lack of enjoyment. Enjoyment was synonymous with the words 'happiness', 'contentment', and 'satisfaction' as used by participants. Their responses often reflected the influence of level of illness on their loved ones' achievement of the domain. For example, residents with more advanced

Figure 5.1. The Kane et al. Framework and participants' perspectives on meaning.



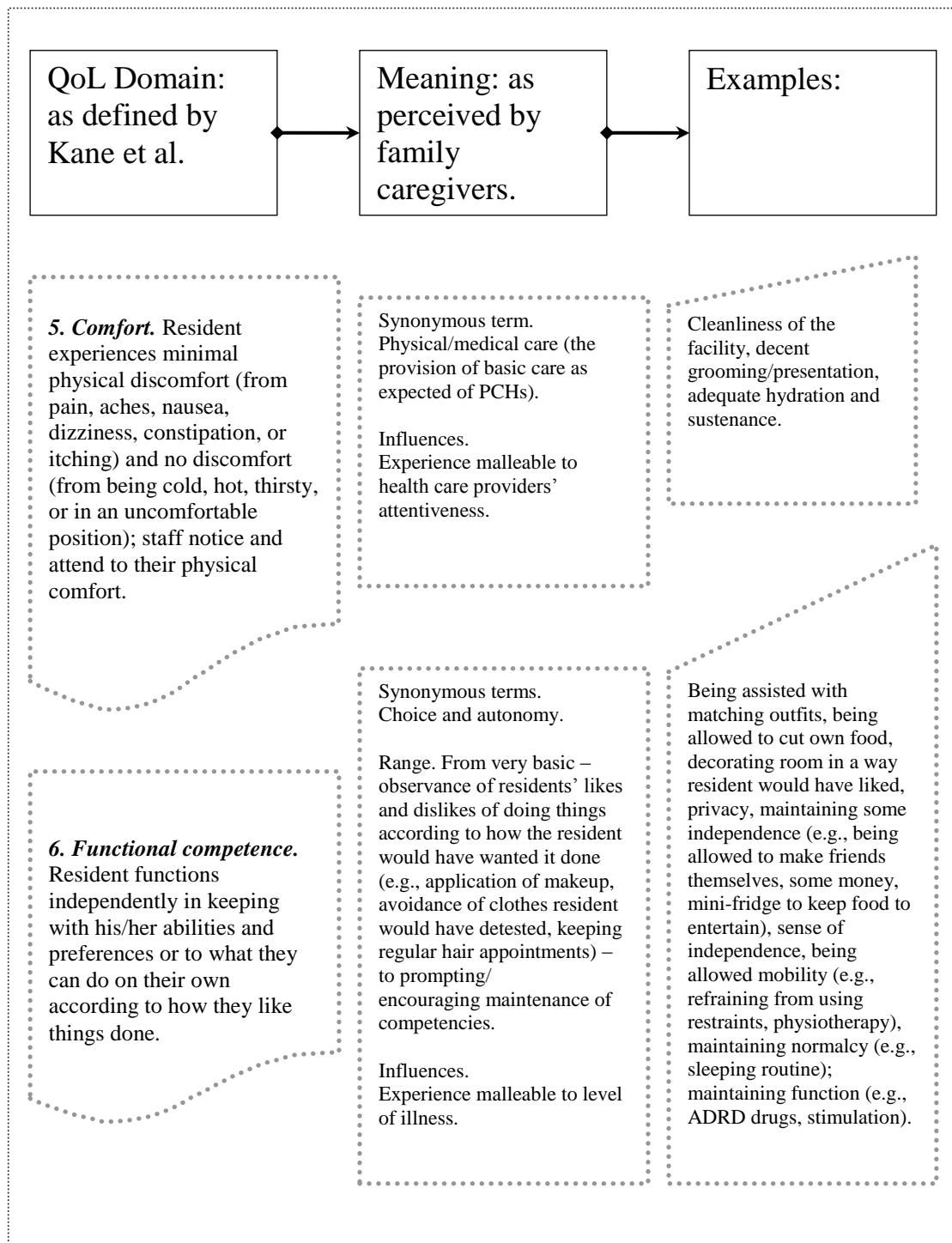
Source. Frytak, 2000; Kane, 2001, 2003

Figure 5.1, continued.



Source. Frytak, 2000; Kane, 2001, 2003

Figure 5.1, continued.



Source. Frytak, 2000; Kane, 2001, 2003

ADRD were interpreted to experience some enjoyment if they did not exhibit what would be perceived as uncomfortable facial features and/or body posturing. Whereas with residents with less advanced ADRD, participants took their loved ones' verbal expression of pleasure or contentment to mean they experienced enjoyment.

Examples of enjoyment ranged from the very basic – “seeing me” (family) and exposure to what the resident used to appreciate (certain foods, music, and children, among others) – to the less passive, more engaging activities, such as dancing.

Enjoyments were likewise personality-dependent and typically, though not always, the same enjoyments the resident had prior to his/her admission to the PCH.

The following excerpts illustrate the range of resident enjoyment experiences as a function of level of illness, history (the familiar), and personality:

1. Enjoyment as a function of level of illness;

DEBBIE: I guess there's not many [enjoyments] ... She's finding it really hard to enjoy things now.

LORI: Would she be happy if she could do some of the things she can't do anymore? I don't know. She doesn't like TV anymore. She used to watch TV ... She doesn't want to read or, I don't know if she can read anymore.

CHRIS: Sometimes after an outing she's more mixed up totally, they say, and agitated. So sometimes it's not a good thing ... An hour is probably all she can sit and stay focused. She gets agitated and is very concerned about time. And keeps looking at her watch. “What time is it? I need to get going. I need to go home.”

LORI: The BBQs and that, they have them in the summer, are great. But she's kind of lost ... If the benefit is that we come and we do it with her, that's probably ...

TAMMY: She is passive but she enjoys things ... she smiles.

JANE: With dementia, some things are gone but music really comes forward ... When they'll have a sing song ... she will sing up.

FRAN: The idea about the experience [of enjoyment] ... When we go there, we're sitting and even if we're dancing, for sure. But now he still enjoys when he's sitting doing a few things. And when he starts to sing with me. And he's going a little bit. It doesn't last too long but while it's lasting, I get him to sing and I see that he's enjoying that.

2. Enjoyment as a function of 'the familiar';

SUSAN: She does like to watch the hockey games. Even though she doesn't comprehend the whole thing anymore, she still gets that little bit of excitement and stuff in her.

FRAN: The other thing that I noticed, he loves music. We used to have every Friday night, our whole family would get together and close friends sometimes. And my parents and his parents and some of the sisters and brothers and nieces and nephews. And we'd sing all these songs.

FRAN: We did a lot of things together as a family and so on and he's very family-oriented. Show him pictures of the kids and what they're doing and stuff. And he definitely enjoys that.

MARY-ANNE: I know she goes to church ... She's enjoying it. But I think it's familiar to her.

3. Enjoyment as a function of personality; and, general appraisals.

BARRY: If there was a group of people sitting together who all like listening to Mozart operas, would that make her QoL better? I don't know. Maybe. She was always a person who did so many things by herself. We're very similar in that regard ... person who doesn't need somebody else to create my entertainment.

BARRY: But there just weren't very many people who read the way my mother read. Who traveled the way my mother traveled. Who led that kind of life ... The kind of things they organize are not necessarily ... I think she would love to travel ... We're looking at somebody whose walking is not good, who has basically got incontinence.

DEBBIE: What makes them the happiest too is when they see their own family. It really, really brightens their day ... Seeing me, I know that.

MARY-ANNE: She really loves family things. They had hot dog day ... My two daughters and their families all came and, of course she really enjoys things like that.

MARY-ANNE: She loves when children come. And they do come from the schools around here.

SUSAN: On the whole, things are not too bad. They really couldn't improve her way of life because a lot of the residents here, for example, they like to play bingo, things like that. And games and things. But she's not into that. So what she's doing right now, she's happy with my visits. She's happy with family visits. She enjoys the music when there are these concerts here. She likes to go to that. Basically that's what it is ... She is a very, very private person. She's been like that all her life. She's not changing now.

CHRIS: Friends have asked her how she was doing. She said, "I'm content." She's always very relaxed.

5.2.1.2 Meaningful activity: Resident engages in discretionary behaviour or in activity he/she enjoys or finds comfort in; is not bored. Meaningful activity was synonymous with anything that provided (or may provide) stimulation, a detractor from boredom; a functional or creative outlet; and means of socialization.

‘Meaningful’ was a relative term, varying between degrees of illness and personalities. Residents who used to be homemakers found baking, for example, meaningful; whereas, someone who frequented operas in the past derived greater comfort in listening to classical radio instead. On the illness continuum, this domain progressed from ‘passive enjoyment’ with such examples as visiting with family and being a member of an audience, “a clapper”; to residents actually engaging, be it out of their own volition or encouraged, in something where they felt useful or creative like folding the laundry or decorating the PCH for the holidays like Christmas or Thanksgiving.

The following excerpts illustrate the broad scope of meaningful activity, from stimulation, functional or creative outlet, to socialization:

1. Meaningful activity as stimulation;

JANE: Time is really heavy on your hands ... To have some sort of recreational, socialization, occupational therapy kinds of things [is important].

RM: The last two years in the apartment alone she became very bored ... She’d sit in her chair by the hour. And I think that’s why, when she came here, she settled in so well. Because there was something to see. There was something to do.

MARY-ANNE: I said to her one day, “Mom, does it bother you to be sitting here?” She said, “No, it’s interesting. Some days it’s really interesting.” I think the recreation here has been wonderful to her.

JOHN: When I come here, I devote all my time to her. I just don’t sit with her and look at her as she looks at me. I try to make her as active as possible ... I try to exercise her mind by talking to her, keeping her busy ... by reminding her about things, by asking her a lot of questions.

HELEN: I tried to get them to do as much as I could ... The recreational director here on this floor is very good. She does some one-on-one stuff with him ... I think she wheels him around. She told me she was doing some game with him and some other man, just some sort of mental stimulation stuff. And I have somebody come in privately.

FRAN: He needs a lot of stimulation. And you can’t give it to them at home. They have staff, a lot of staff and different help, nurses; concerts, cultural hour, bingo; for the mind, current events ... And it’s encouraging that even if they don’t give an answer, they’re involved, they’re connecting.

2. Meaningful activity as functional or creative outlet; and,

SUSAN: Her first reaction is always to say, "No." All I do is, "Oh mom, come on, I want to go see your ...". Stuff like that ... And she does end up having a good time. You take her back to her room and she said, "Oh I'm so glad I went. Thank you," and stuff like this. And so you know that she enjoyed it.

FRAN: And every holiday that comes, they have the residents sit down and do decorations ... beautiful stuff that's significant of what the holiday stands for. So it's giving them a little bit, I don't know how much they understand. But it's like connecting. With Alzheimer's, all those things are connections. It's connecting with something.

MARY-ANNE: She said to me, they asked her to help. She had to help, she said ... I see them so, some of the ladies having to fold facecloths and that and I think it's a great activity. It's something that even if they are very demented, they remember how to do ... And I think she likes to be still useful in some ways.

3. Meaningful activity as socialization.

TAMMY: They need things, they need a happening all the time ... I think socialization ... to have parties and get-togethers ... What's life all about for them ... If you have a party to go to, aren't you excited? I am. It's the same with them, there's no difference.

TAMMY: She was always a social person. And if someone said, you see now I find her sleeping all the time. But it's boredom ... A lot of times we come and she's always like with her head down. And just because there's nothing, and no one to talk to. So a lot of times after she eats, I bring her to where there's some people talking.

5.2.1.3 Relationships: Resident engages in social interactions; finds comfort in family, friends, or staff. Relationships were synonymous with 'interactions': with family members, friends, relatives, PCH staff, other residents, and volunteers. Interactions ranged from the quiet or passive -- for example, simply 'presencing' -- to the more engaged, more fulfilling interactions where the resident recognized some comfort in the relationship. Level of illness and personality were again determinants of the diversity of these interactions as illustrated in the following excerpts:

1. Relationships as a function of level of illness;

BILL: As a rule, we sit there and look out the window. But lately we've been sitting there watching TV ... I don't think she can participate in very much here. She hasn't got that capacity.

DAVE: She doesn't really relate with the other residents much because she cannot communicate and they generally can't either.

JOHN: I would have liked her to participate more with the residents, but she won't say a word. She'll just sit there ... because of her hearing problem too, you have to talk to her right to her face. You gotta be close. But if I was away like this and I talk to her, she won't hear me, even with a hearing aid. Therefore you would think that she didn't listen. She's trying to listen but she can't. So because of the eyesight, and her hearing ...

HELEN: It's [experience of relationships] diminished. And he likes to, some of the staff here, like if they stop and, pay attention to him and talk. The women who are more skilled or bright and cheery, he really likes that. His face lights up and looks up and smiles.

2. Relationships as a function of personality; and,

JOHN: My position on our relationship is a little bit different than what's a lot of these other people. We've been married for 62 years. We've never been apart in 62 years ... What I regret mostly, in a way, is the closeness that we are ... She depends solely on me ... She or I don't mingle too much with the other residents. We keep to ourselves.

CATHY: Mother seems to garner friendships ... Mom has these people that want to be with her all the time ... Mom has people drawn to her.

TAMMY: She's a wonderful lady ... She'll never do anything, not right. That's the kind of person she is ... She's always got company coming ... Everybody loves her.

FRAN: I think also that the person that's going in, somebody like my husband is very sociable. He loves people. He loves to be with people even if he's just sitting with them. And so he's actually very happy there ... I think the same doesn't apply to everybody ... Person that's not sociable, who doesn't like people. You know, depends what age they are.

MARY-ANNE: But you know, they say that she's so easy to look after because she's very easygoing. And was, always even in her apartment when I was caring for her ... She's always been very grateful for what you do.

3. General appraisals: diversity of the relationship experience.

CATHY: One of mom's friends ... we know that she needs to feel needed, to feel wanted, to know that she's important.

TAMMY: Socialization is important. And to her it was really important. She loves people. She always went to things.

MARY-ANNE: There's far more social interaction here. And I think, as a family member, that's part of, for me, I haven't felt the need to be here all day either ... I think she's very comforted by the number of people around her.

CATHY: There's a lady... and they were very, very strong friends. A deep-seated relationship in terms of their enjoyment of each other.

MARY-ANNE: She really likes to bake because she likes sitting around the table with the other ladies. And they all have some difficulties conversing but they seem to have a friendship.

MARY-ANNE: One of the recreational people that was here said, we took her upstairs and asked where she wanted to sit. She said, "I want to sit there beside my friend." There are names on the floor that she does feel are her friends.

LIZ: There's two ladies that have taken to him ... I'm so pleased that he's got a friend ... She talks to him and I see her, when they walk by and if I'm wheeling him by and he saw her, he'll give her a smile.

MARY-ANNE: When my brother was here a few weeks ago, he was quite amazed. As he said, we brought her back at night and she was quite tired. We had her out all day. And [name] was on the floor. And my mom put her arms up to greet her. You know, like I'm home and give me a hug. She really seems to enjoy the affection that they give her. I think it feels like a family.

SUSAN: I just about started crying just before Christmas, the group of people from the seniors' block that she was in before she came. And they were just sweethearts. There were three of them. And it brightened her day. You could just tell. And mom's got this wicked smile. Mischievous little smile and stuff. And then her eyes twinkle. She was really, really happy.

JOHN: When I come there, usually she's lying in bed and she's sleeping. And I don't bother her. In about fifteen, twenty minutes later, she wakes up. She hears somebody moving around. So she would say, "Who is it?" So I come up to her bed and I tell her who it is. And a big smile comes to her face.

5.2.1.4 Security/safety: Resident is clear about rules and practices; feels

safe/secure/confident about his/her personal safety and security of their possessions.

Security/safety was synonymous with physical safety, companionship, and emotional well-being as a result of interactions with staff and other residents. In most, if not all cases, this domain was a compelling reason for PCH placement. Along the illness continuum, the achievement of this domain ranged from residents' physical comfort to feeling assured of their safety and security in a social environment.

The following excerpts illustrate the degree of illness as a determinant of the security/safety experience; the scope -- from physical safety, companionship, to emotional well-being; and, other examples of what this domain meant to participants (under "general appraisals"):

1. Security/safety as a function of degree of illness;

MARY-ANNE: I don't know so far that she's uncomfortable. She's very content here and has been from the very beginning.

HELEN: I think he's secure. But when I leave he checks. Especially now that he's improved. I have to keep reminding him that things are OK.

DEBBIE: She's very unhappy ... One lady will insult my mother so now my mother thinks that's the way to behave here. She thinks it's part of the culture ... she was never negative ... And she yells at staff too. Because if they yell at her, she won't take it. She'll give it right back.

2. Security/safety as physical safety;

MARY-ANNE: It was definitely a relief for me to know that she was safe. I mean the last while at home, every night I would wonder if I ever call, I'm almost afraid to call her in the morning, and I did call and she was on the floor, things like that. So since she's been here, those concerns are gone.

DEBBIE: I find it harder now that she's in here than when she lived at home. But I know it's better for her because I know that there's people that are around here should anything happen.

JANE: Doors are monitored ... residents can't just sort of walk out or whatever.

SUSAN: My mom gets her plate, and that the people around her are as aware as she is that it is her plate, this is her food. And she won't reach into yours and you don't reach into hers.

JANE: You know like people being able to either harm one another. That's never a good thing. Like you don't want those kinds of things. Or even you wouldn't want a lot of verbal kinds of things.

BARRY: She was so isolated before she went in the home. The last couple of years, people came to the house. They rang the doorbell. She didn't hear it. They'd phone. She didn't hear the phone. People were wondering, well where is she, you know. She was very, very isolated. I would go over and find her in bed. She'd been sleeping, whatever. So she has a lot of contact with people now.

3. Security/safety as companionship;

CHRIS: Basically my main goal is that she's not left alone. And just sitting on her own in her own little world ... Most of the time I know when she's alone, she's agitated ... she's constantly asking for me ... And time is hard for her ... My goal is to make her happy. And let her be content in a social situation.

LORI: I think that's QoL if there's people around. There's some security of other people being there, even if they don't talk to her.

MARY-ANNE: She's been better here. And I've often thought that I should have paneled her earlier. But you think you're doing the right thing to keep her as long as you can ... But I think the isolation's hard. And she certainly is not isolated here.

MARY-ANNE: She doesn't ever seem to be frightened ... And I think the part about the four-bed ward has not bothered her. I think she actually feels comfortable that somebody's there.

SHELLIE: She doesn't like to stay in her room alone. She's very much a people person because she's used to being with people. Like even though she's not active as far as sports, crafts, activities, reading, whatever, exercise, she likes to be with people.

MARY-ANNE: Two years ago I would have just thought that was absolutely the most important thing that my mom has a private room. But, now I've come to realize that's not what

is good for her or what she wants. I think she'd be almost frightened in a private room now. She feels the comfort of the other ladies and we have not had any issues with any of them either.

LORI: I don't think she's unhappy with being there. She has people around. She is well looked after and [they are] terribly good to her. She eats well. She likes everything she eats ... I think she's just happy having people around.

4. Security/safety as emotional well-being; and,

SUSAN: Very important ... that she's comfortable living where she's living. That she can sleep at night. That she doesn't fear the staff around her. I want her to be comfortable as possible. I want her to have all the comforts. I don't want her to have fear. I want her to feel safe. I want her to feel very comfortable.

SUSAN: I don't know everybody but I can say hi to anybody. It doesn't hurt. And the staff is pretty regular. The people who work on the main floor, work on the main floor so it's not very hard to get to know them after a year of coming in and out and stuff. It's a good place. I thank God quite often that mom is here. So do other members of my family.

SUSAN: She came from the hospital to here ... who could ask for better. I've seen what being placed does ... or some place temporary can do to some people ... I feel that the best thing that ever happened to her was to come here in one stop. And not having to move around again and get adjusted ... She knows a lot of people here.

SHELLIE: They [staff] all kind of like her. You know, "Your mom's so cute. She makes us laugh." And I think she likes that. She seems to be very, oh, she's very secure here. Very secure. And comfortable. You can tell it's a community and that's very important for them.

MARY-ANNE: They spend the day like a family. I watched them bake one day. They have a bowl of spoons and one breaks the egg. And one puts the egg in, one would butter the cookie sheets. And I felt like I wanted to help. But they just seemed to enjoy doing that together. Just the same as my mom and I had always baked together. And I think that's, she feels that companionship.

5. General appraisals.

CHRIS: She needed somebody 24/7 ... The best solution for her was a nursing home.

BARRY: If I could live with her, I probably would. I don't think it's doable in the condition she's in ... Sure it's hard when you go and you see she's just sitting there. But on the other hand, her energy is so much decreased. What would she actually have energy to do? When she was in her house that last year and a half, she was getting a lot of time in bed. Now at least there are people around interacting with her.

SUSAN: The staff. The residents. The environment. My mom's got a great big beautiful window there that she looks out to. Those things are important.

5.2.1.5 Comfort: Resident experiences minimal physical discomfort (from pain, aches, nausea, dizziness, constipation, or itching) and no discomfort (from being cold, hot, thirsty, or in an uncomfortable position); staff notice and attend to their

physical comfort. Comfort was synonymous with physical/medical care. The achievement of this domain was an expectation and considered a reflection of the facility and its staff. Prime examples included cleanliness of the facility, decent grooming or presentation of their loved ones, and that residents received adequate hydration and sustenance.

The following excerpts illustrate this domain's scope as physical/medical care as well as product of health care providers' attentiveness:

1. Comfort as physical/medical care; and,

TAMMY: I just hope that when I walk away that mother has good care ... Our main goal is to have her pain free and happy, at this point.

TAMMY: I want to know that if I'm not there, someone's feeding her ... Of course, but that comes with the territory here. There is safety ... In here, there's everything.

JANE: Having somebody help her to be comfortable ... attentive to what her needs are.

LIZ: He's not suffering. He's getting good care.

SHELLIE: I think the first thing of course is the medical. Of course, it's always the medical attention. The medical care that she needs. But, which is, of course, very important.

FRAN: The women that are there, all of them took over for me. They're all telling him what to do and he's doing it. Like remind him to take his medicine and all the different things that I would do.

MARY-ANNE: I was a nurse many years ago myself. The cleanliness for an old building is, you know ... So my mom first came here too how clean she always was ... But I mean they all get one bath a week ... You know they go to the bathroom, they don't clean themselves as well ... But they're all washed here and they're not smelly. And you don't smell it when you walk in the doors ... And it's an old building of [number] old people.

MARY-ANNE: It's always spotless and she is too. She's kept clean. I mean it's such an important thing.

MARY-ANNE: She's always clean. Always clean. I mean her hair may not look perfect, I understand. Her clothes are always clean. She looks well cared for.

LORI: I don't see that anything really distresses her ... It's not the number of roommates, it's nursing care.

BILL: I'm quite pleased with the care that she gets here. Well fed. And her room is tidy and one thing and another ... She's getting better care than I would be able to give her at home.

2. Comfort as a product of health care providers' attentiveness.

HELEN: He does have this discomfort problem in his bottom sometimes. And I think some of it's from sitting all the time. I really wish there was more, means of moving them. Even if he sat, I've got a nice chair in his room. And I haven't dealt with this yet. Could they not just move him in and let him sit in the room. There's a problem with leaving him alone. But if I were here. But I don't think they'll take the time to do it. And then, we've got this problem with sliding down in his chair all the time. Well they aren't, they aren't dealing with that.

BARRY: I think the home is doing an OK job. I think, when you talk about staff, it's so personal. There are two people doing the same job and one of them I could just kiss because she's so wonderful and one of them you just wish you'd never ever saw again ... There are people who are great and there are people who aren't. And that is just a function of the individual. And how do you, it's the luck of the draw.

DEBBIE: There's voices that are raised by so called professionals that work here and they need to be a little more understanding ... It doesn't seem like the staff on the floor know how to calm the residents down I should say so they don't feel so bad.

5.2.1.6 Functional competence: Resident functions independently in keeping with his/her abilities and preferences or to what they can do on their own according to how they like things done. Functional competence was synonymous with choice and autonomy. At the very basic, it was the observance of residents' likes and dislikes and of doing things according to how the resident would have wanted it done; for example, daily application of makeup, avoidance of clothes the resident would have detested, and keeping regular hairdresser appointments. At the other end of the continuum, it involved staff encouraging the maintenance of competencies, particularly mobility and grooming.

The following excerpts illustrate the scope of this domain as influenced by illness, from facilitating choice/autonomy to maintaining competencies:

1. Functional competence as influenced by level of illness;

HELEN: A lot of that's gone. The QoL ... well I wouldn't say that that was super high ... He's not very competent any more and stuff he does when he was highly intelligent, highly confident man.

2. Functional competence as facilitating choice/autonomy; and,

MARY-ANNE: She likes matching outfits. That was just in her personality. I think she misses not being able to do things herself ... We were just at my apartment. I'd made

poached eggs on toast for lunch which is one of her favourites. And when I took hers to the table, she said, "Don't cut it."

SUSAN: And, we decorate her room in a way, in a fashion that makes it her own. It makes her environment and everything else. So that's important.

SUSAN: The one thing that was really important to me, and I think to my mom, was a lot of nursing homes have two to a room ... My mom is not the social butterfly. And we know that. So it's easier for her. And I think she would, she prefers to be in a room by herself. I think she would have found it very hard being with somebody else permanently. She could live for a long, long time ... These people are getting older. And they get set in their ways. And they have different levels of dementia or different health problems or different needs. So how do you decide that is how it's going to be with?

SHELLIE: She likes to have her own little money there. She still likes to have that independence ... And she still washes all her underwear ... because this is the old, old habit of washing clothes. So we come see her and they're hanging all over the place ... And I think they just let her.

SUSAN: She uses her wheelchair. She still cheats and gets around on her own in the bed, in the room to go to the bathroom and stuff. And we're aware of it. And there's nothing that we can do about it. We're not going to have her restrained or anything.

JANE: Another one of the challenging things is about the sleep routines. When you're in a facility you just sort of fit in with the routine ... And she liked to be up really late. She's never gone to bed early in years and years. And then you come to a facility ... So it's suddenly like, they're having to change patterns of a lifetime kind of thing.

DEBBIE: I had to get an attendant for the evening because otherwise my mother would be in bed at 6:30. It doesn't fit everybody's needs ... The caregivers cost just as much as the rent for the month to stay here. But at least I know that I don't have to worry because it's like an assembly line here in the mornings.

CHRIS: One of her best activities is going for groceries. She has a little fridge and at the beginning, it was insane because she was buying onions, lettuce for in case the kids come and she'd have something to make a salad ... We would buy groceries even though I knew that the next week I would come and throw them all out because she's never going to make a salad here, right.

CHRIS: But she still does go with [caregiver] and they buy fruit. Tea and coffee if people come. Cookies. She likes to entertain. But nobody really comes but she likes to entertain or even the women from across the hall ... [Caregiver] will organize like a tea time. So that's nice and that's what she would like.

3. Functional competence as maintaining competencies.

HELEN: I had gone to a public lecture for this [doctor] and he had mentioned there was some new drug for advanced Alzheimer's. So the nurse practitioner tried to find out the name and I finally contacted him ... I wanted to try the new drug. So the nurse practitioner was very good. So that's what we did. I had contacted this [doctor] again. And he, maybe it was because he'd seen my dad in the hospital. He came ... and he agreed that he should try this new medication ... And so he was put on it. On the other stuff, before, he was kind of just lethargic and kind of in a daze ... But he's become much more physically alert and, he's more aware of what's going on around ... So he's improved quite a bit.

JANE: The medical nursing staff ... tried to come up with a combination of medications that worked so that she's able to be responsive. Because there was a point in time ... where she was almost, I want to say, so zonked on medication. Her head would be down, her eyes would be staring at the floor. And she was just like, you couldn't get any communication out of her ... And then you thought, there isn't much QoL in that either.

TAMMY: They recently moved her and we're not happy where they moved her at all. They moved her with people who are very low. And she was sitting with a friend that she knew from years ago. And she was much happier in the other area ... The people she's with are just non-stimulating. One lady makes a lot of noises and yells. One, there's no communication. And the other one, almost nothing.

SUSAN: The staff here, the physio staff, they work with her for about ten minutes, maybe twice a week or something. Which I didn't call that much physio. So I hired the other one. She was a bit more active.

BARRY: She's still walking. But she spends a lot of time in the wheelchair. Whenever I go, she walks. I get her to walk.

SUSAN: The activities to me are, they're not just to spend an hour and half, here with my mom and not having to be just by her side all the time. To me it's to get her, to keep that bit of independence that she still has left.

5.2.2 Study Objective #2a: What Domains, if any, Are Missing from Kane et al.'s Alzheimer's Disease and Related Dementia-Specific Framework

Dignity was mentioned verbatim by participants as likewise important to their loved one's QoL without prompting. They were blind to this domain, along with autonomy, individuality, privacy, and spiritual well-being which were original components of Kane et al.'s generic PCH-QoL framework, but omitted from their ADRD schematic (Frytak, 2000; Kane, 2003).

Originally defined by Kane et al. (Frytak, 2000; Kane, 2000, 2003) as "residents perceive that their dignity is intact and respected and do not experience feelings of being belittled, devalued, or humiliated," participants' version of dignity encompassed respect, acknowledgment of the person, the preservation of modesty, and facilitating pride in oneself. The achievement of dignity signified a more humane

way of doing things and an environment where staff cared and exercised sensitivity in their conduct towards residents and families.

The following excerpts illustrate the importance of dignity as well as its scope within PCH-QoL: facilitating pride in oneself (ones' appearance), the preservation of modesty, and acknowledgement of the person/individual:

1. Dignity: A likewise important domain;

CHRIS: I think the dignity of the patient is very important ... Seeing them clean and presentable. And treated like people.

LIZ: That he's respected. I think that is a key word.

CHRIS: To be treated with respect. And to have her needs taken care of.

CHRIS: You do have to be a certain personality to be able to deal with that I think. But that's important to me, family, to treat them, to treat her with dignity and have her look presentable. And not to be talked about in front of them.

2. Dignity as facilitating pride in ones appearance;

SUSAN: Some might think it's crazy but it means something to us ... her appearance. We feel that your appearance sometimes reflects how you feel about yourself that particular day or whatever ... It's still important to, that there's cleanliness.

TAMMY: She always liked to keep herself nice ... her hair. And she has beautiful hair, when she gets it done. We put a colour in it because it's so grey. She was always so beautiful blonde. We put a colour in here. I take her to the hairdresser. And her hair's usually beautiful.

MARY-ANNE: My mother was always perfectly groomed. Her hair will be done. Her makeup will be on. She'll have lipstick on. You know to her that would have been an important thing. I suppose it still is to me because I walk in and she looks, you know.

JANE: She was the kind of person, if you got dressed up, you wanted to look nice. She actually had to reconcile herself when she came to the facility, she'd wear shoes that were kind of clunky ... Her sense was that, you want to look good and don't want to look sort of thrown together with some obscure things.

JANE: So that you can still have that bit of a sense of pride in how they look. That kind of thing ... the family and I had sort of long decided like it's not important if any of this costume jewelry gets lost.

3. Dignity as the preservation of modesty; and,

SUSAN: She won't wear pants. She's very old fashioned. She's got very crooked legs. She still has pride.

SHELLIE: She didn't want to go out anymore. So they started to give her that [Imodium] ...

JANE: I think it's hard for a lot of older people. And including the ones with dementia. And you need to go to the bathrooms. You have the urge, some sense that you want to go to the bathroom. And meanwhile, well they can't. She can and she does. But people are trying to say if you've got an incontinence product on, it's OK, you don't need to go there.

JANE: One of those humiliating experiences for a lot of people to have an incontinent product on ... In some cases, a dehumanizing kind of thing to some person while since early childhood was very conscious, you know, that people do not soil themselves, that do not void, they make every effort to go to the bathroom.

JANE: Some of things that she doesn't like is bath time ... She said, it's really embarrassing, everybody knows where you're going ... She sort of thought, it just seems like so immodest kind of thing almost ... I guess as a lady you just wouldn't announce to all your company and everybody around like I'm heading for a bath.

4. Dignity as acknowledgement of the individual.

LIZ: He tries to converse with me. But he's in his own world. So I listen and respond what I feel is appropriate as to him that dignity.

MARY-ANNE: In the afternoon now she doesn't seem to want to go down ... She can make that choice. If she doesn't want to go and she wants to have a nap, she's in her bed, right.

TAMMY: They don't always take her when she has the urge. They don't take her when she, you know. If they're busy or it's lunch time. It's terrible because my mother has a lot of dignity which I'm sure has been changed since.

JANE: They were trying to say because they thought she had dementia, they would just put her in with three others. Deaf and demented people.

DEBBIE: When her back was really sore, she rang the bell because she couldn't reach the Kleenex box ... And the nurse came and she said, "That's all you're ringing me for?" So she said, "I can't reach the Kleenex," and then she said, "Well since you're here and if that's not enough, take me to the bathroom." And like she couldn't really walk that well. So she says, "You have a diaper on, you can pee in the diaper."

DEBBIE: My mother had a bad go of it. They phoned me and said, your mother used the b word. I said, "My mother's not five years old," you know. "It's not a big deal ... If she swore and said something really gross, I could see it offending people. But I mean like that's almost an everyday word. It's on television." But I figured, like this is ridiculous. Don't treat her like she's five years old. She's a full grown woman.

DEBBIE: You don't pee on command. I says, "Tell them to hold their bladder for two hours." It's not going to happen. So that went on for four months. And my mother's in these huge crazy diapers and very undignified. So she'd throw them on the floor. And the lady would scream at my mother and say, "Oh she's crazy, look at her, she's got those diapers on the floor."

JANE: I think that's such an important thing. And when you sort of think, to sort of honour the person, they're whole personhood kind of thing ... that we don't ever want to be speaking down to them or just they're you know, like not capable or that kind of thing. Trying to give them, the regard for their age and their personhood. Or sometimes even when she's not too communicative, just sort of very much try maybe even anticipate what she might want to know about or, and help her to be a bit prepared for some of the other things that might be

happening. Or to try to have maybe a bit of insight into, you know, why some things are likely to be happening.

5.2.3 Study Objective #2b: Which of the Framework's Domains Are Most Important

Participants considered dignity and all six domains of Kane et al.'s ADRD schematic as important to their loved one's QoL. Determining the most important domains was achieved by noting the emphases placed on certain domains via multiple citations of achievement or lack of achievement on those domains.

In response to the most important QoL domain, participants were unable to identify a sole domain; rather, **security/safety, comfort, enjoyment, and dignity** were considered the most important domains. The collective achievement of these domains was repeatedly mentioned by participants as a goal to strive for. They desired to maintain their loved ones' comfort and safety, facilitate whatever pleasure is attainable, and uphold dignity. The following excerpts illustrate the importance attached to these domains:

CATHY: On a personal basis is to be safe. And to receive the very basics ... the very basics of care. And that is to be safe, to be hydrated, that she is kept clean ...

MARY-ANNE: It was definitely a relief for me to know that she was safe ... And she's always clean. Always clean ... She looks well cared for. And she's content, you know, she doesn't make a fuss when I leave. She just looks healthy ... she seems happy ... she's just she's happy to be here.

TAMMY: We just kind of hope that, you know, she has good pain control. And we just want her to be happy and pain free. That's our goal for her now.

LORI: I figure 24 hours a day if she'd be happy ... comfort ... no pain ... I think she's reasonably happy.

JANE: In some ways, it's sad to say, but it's almost more a bit like just existing. And we try to think of some things that might bring a little bit of pleasure and enjoyment to her days.

JANE: When you think of all the losses the person's had, there really isn't much to look forward to with happy anticipation. But it is nice to get small pleasures out of people ... I guess we'd probably have to think in terms of the perspective of most people her age. It's, I guess, maybe what's to be expected, sort of on the type of resignation to these are the

realities. And that for her to be home or cared by any one family member would not be a practical alternative either.

CATHY: I think that if our residents here experience the very basics so that they are clean. They have food. They are fed, etc. Those are expectations, or those are things that are necessary to maintain life. So that I would like to see for the residents is more of a personalized, very personalized experience for them.

CHRIS: It's my pleasure to see my mother happy and having a nice life. I mean these are her last years, I want them to be pleasant ... From a daughter's point of view, you want your mother to be cared for and you want to know that she's going to be cared for ... I really feel sorry for the other residents who have no family here. They have nobody to advocate for them. There's nobody to even visit. Like shop for clothes. They're dressed horribly and it's not very dignified to see some of the people. I've seen some this afternoon who are all mismatched in old clothes that all balled up and out of style.

BARRY: I give her a lot. I give her as much as I can. As for the rest, pretty good. Food is, I think, good. The care, I think, is pretty good.

SUSAN: But I think of QoL for her to feel happy. For her to feel secure. There's a reason for her to be alive. She's just not wilting away ... And safe, like she feels secure. But to be happy to be here.

DAVE: The thing is not to make the client feel that this is the end of their time, and try to make everyday a pleasant one ... by having a lot of activity, music, sunlight, and happiness in their environment.

5.2.4 Study Objective #3: Which Personal Care Home Facility Policies, Practices, and Activities in general, Currently Facilitate or Could Potentially Facilitate Improved Quality of Life

Participant perspectives on current facilitators of positive QoL were deduced from their loved one's achievement of each of the seven domains. This section examines PCH-QoL enhancing practices (including policies and/or activities) in the context of the seven domains. The proceeding excerpts illustrate the unique strengths of the three groups of facilitators of QoL: the facility, direct care providers/staff, and family caregivers. While participants (family caregivers) may be more successful in enhancing their loved one's achievement of enjoyment, meaningful activity, relationships, and dignity; the facility and its staff, due to their 24-hour guardianship

of PCH residents, may be better able to promote security/safety, comfort, and functional competence.

Cited potential detractors of optimal QoL which also arose from this inquiry are documented separately in Section 5.2.5. In general, there were calls for better dementia care, more skilled care, and better staff to resident ratios. As with facilitators of QoL, detractors also included external influences beyond the PCH's control which may adversely affect respective residents' QoL. Figure 5.2 summarizes the current facilitators and further strategies by domain to optimize QoL for PCH residents with ADRD.

5.2.4.1 Personal care home-related facilitators. PCH-related facilitators of positive QoL encompassed the facility's physical attributes including its location, and also the extent to which the PCH: (a) accommodated and encouraged family involvement; (b) fostered a sense of belonging or a 'home'; (c) implemented innovative programs that helped to fulfill family expectations; and, (d) developed community partnerships. The following excerpts highlight these QoL enhancers and the domains they help achieve:

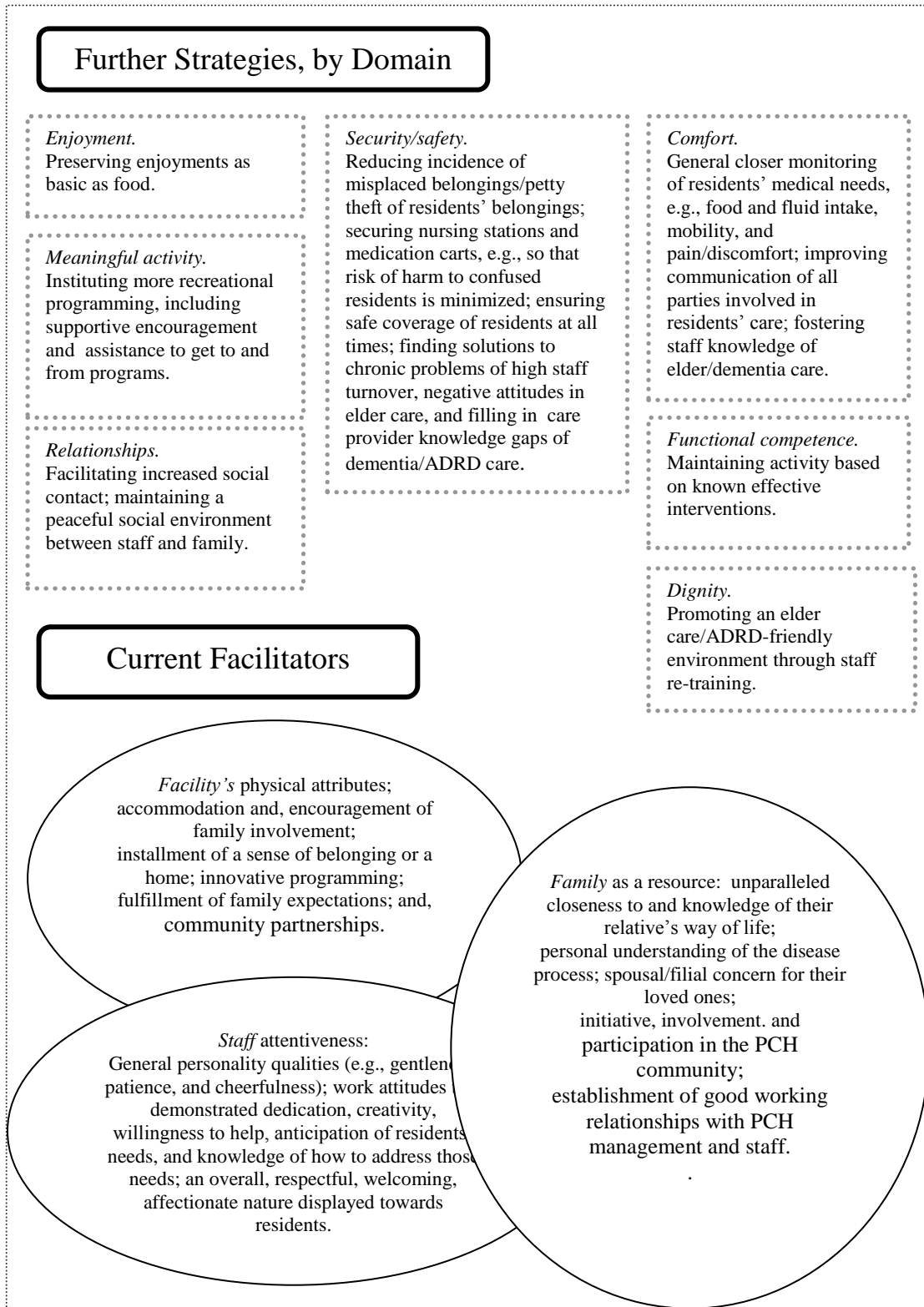
1. Physical attributes;

JANE: (Enjoyment) What are nice, and a lot of the rooms here do it, at least have some big windows ... which is nice both for the light to come in and also to be able to see outside. To see daylight. To see trees. To see houses.

SUSAN: (Enjoyment) In the summer, they have that gazebo at the back ... and we'd sit in the swing out front. And she'd just say to me, OK, just sit there, you close your eyes ... So it became a habit that my mom and I ... And we didn't always have to talk. But we were still together. And she really loved it. And she'd never want to come in ... And she'd say, do you hear the birds and ... oh, the breeze was just you know and stuff like that.

JANE: (Enjoyment) I think really here it is very nice in terms of the outdoor spaces and things in the immediate neighbourhood ... It also seems to look more like a regular neighbourhood.

Figure 5.2. Current facilitators and further strategies to enhance quality of life for residents with Alzheimer’s disease and related dementias.



MARY-ANNE: (Enjoyment) If it's nice we go for a walk. There's a lovely garden here in the summer. She's always loved flowers and there's always lots of flowers and some vegetables growing there. We go out a lot in the summertime. They do their activities outside in the morning. But it's a nice neighbourhood too. There's always somewhere to walk ... And there's a little park right across the street, there's a little fountain there. So we would often sit there and just chat.

2. PCH accommodation and encouragement of family involvement;

MARY-ANNE: (Enjoyment) [Family access] is very easy and very much encouraged. They did a lot of things this summer ... I mean they had Mother's Day tea and it was lovely. I mean they did it all up. They made scones and home made jam and it was beautiful. And they did a summer BBQ. They invited all families to come ... They really do encourage families with children to come.

MARY-ANNE: (Enjoyment) They had the petting zoo here this summer, and she quite enjoyed, you know, holding a rabbit ... I brought my six youngest grandchildren so she really enjoyed just watching them in there with the goats and the chickens.

MARY-ANNE: (Comfort) I find them very receptive here as far as administration, you know, if you bring concerns ... you can always have someone to talk to ... I wanted to bring my mom's chair ... I spoke to the director of the nursing. She said, I don't know where we'll put it but, she said, just bring it. So I had it delivered ... When I first brought it here this summer, it was funny. She looked at it, she sat in it and she said, Oh, an old friend.

3. Installment of a sense of belonging or a home;

FRAN: (Meaningful activity) It [Christmas] was just so beautiful. The decorations, everything. It was really, you know...

MARY-ANNE: (Security/safety) I love the atmosphere in this place. It feels like home and for a family member here, you're very much included. And because it's small, so many of us know each other now. You get to know everybody else's families too. And we often sit down in the lounge in the front, you know, all of us together. So we chat like a family. We get to know each other.

4. Innovative programming;

FRAN: (Meaningful activity) They have very good programs for both physical and mental. A lot of them. Everyday there's a whole list of programs every hour practically. They do exercises three times a week. They do current events three times a week. They do music or some sort of entertainment sometimes twice a day. What else? I got the extra stuff here. But they really seem to me to sound like they really know a little bit about what good QoL is. And not to say that they can't look for more because there's always more. But, you know, such a little thing on their door, they have something. They have their name and if they're hard to recognize their own name, they have something there that they like. On our door is a couple dancing. I think it's very thoughtful, you know, so that the patients can maybe recognize their own room.

FRAN: (Meaningful activity) But don't you think that's quite a good list of stuff that would really help them to a better QoL. I'm very impressed actually.

MARY-ANNE: (Relationships) For the Grandparents' Day it was kind of cute ... They just had pie and ice cream and tea and coffee and lemonade for the kids. And, they asked the children ... if they had a song or a little poem. And they had some poems there for them to

read, and then we had a little sing song with the old songs. It was nice for the family to ... I think it's extremely important, especially the children. Because, you know, that's part of life isn't it?

5. Fulfillment of family expectations; and,

LIZ: (Security/safety) Once, funny thing. He gets his bath Thursday mornings there. So he'd had his bath. I arrived there at eleven o'clock in the morning and he was laying. Like the bed's this way and he was laying across his bed that way. And I went, touch him to get him up and just wasn't moving. So I called one of the staff. They came in and looked at him. And they went and got a fan, got a basin with ice cubes and water, got the blood pressure machine. And I had three nurses in there. So the head nurse came to me and said, do we want him to go to the hospital? And I said, no. I don't want him waking up and being alarmed, because he's been in there three months. I could see I was in the way, so I said, I will leave and I'll come in a couple of hours. So I came back, this was about two o'clock. And, he'd already been diagnosed. He's had an x-ray. And he was already put on an antibiotic. So on the bedside table, the blood pressure machine. And I could see that they had come in and had checked him twice since I had been there.

MARY-ANNE: (Security/safety) The staff has been fabulous as far as I'm concerned.

DAVE: (Security/safety) This place has just been wonderful to my mom.

DAVE: (Security/safety) I don't think you'll find a better place.

SUSAN: (Security/safety) It is a great place. The people understand that she's very shy. The residents understand that she's very shy. But they still communicate with her and stuff. The staff sometimes, like after lunch or breakfast, they have her sit in the front in the wheelchair where there's a group of women that sit there. So they get to visit. And even the residents tell me like, oh your mom's such a nice lady and stuff.

LIZ: (Security/safety) There's going to be times where the staff is there and, all of a sudden, there's an emergency. They've got to go to the emergency. So, you know, it's give and take. I can't ... I'm very happy with the facility.

SUSAN: (Comfort) They certainly can't complain about this place. I dare them to say anything ... Everybody says like this place is just, you know, my family thinks the people who have visited think this place is just absolutely wonderful for mom. They're really happy that she's in a place that's clean. She's well cared where she's safe.

LIZ: (Comfort) I honoured their position because I appreciate that they're concerned about what they're doing with their patients.

SUSAN: (Comfort) I find that this place, they have a mission statement. And that the patient comes first. And I truly believe that the staff that I know really live up to that mission statement. I'm amazed sometimes at how great they are. I can honestly say that there is not one thing that I have seen any staff member say or do that would affect the QoL for the residents here. And I do spend time here. They're really, they have patience, they're understanding. They're understanding of family as well. They're kind. If they have a minute, like today, I had bought my mom some new clothes. And it's hard for me to do it on my own now. One of the girls said to me, I'll come with you and we'll try it on together and stuff. So she volunteered her time and came with me. But it's OK, she's never going to get in trouble for that, because that is part of their mission statement is to accommodate the patient's needs. And it is a need.

SUSAN: (Comfort) It's definitely not that she lacks some care here. As far as being here, it's really good.

LIZ: (Dignity) Very rarely do you see anyone that's sitting in dirty clothes.

6. Community partnerships.

MARY-ANNE: (Enjoyment) There's a piano teacher and he does his recital here. That's a great idea because it's a nice space and there's lots of pianos here. And they all enjoyed that. About 30 or 40 of them came down for that.

MARY-ANNE: (Enjoyment) The children always make them light up eh ... The schools are quite good. There's a daycare. And they've come quite a few times in the winter. Especially around Christmastime ... and St. Patrick's Day they had Irish dancers come, you know, so there's lots of activity.

5.2.4.2 Staff attentiveness. Participants often commented that staff attributes positively affected their loved one's quality of life. These staff attributes included: (a) general personality qualities such as gentleness, patience, and cheerfulness; (b) work attitudes which demonstrated dedication, creativity, willingness to help, anticipation of residents' needs, and knowledge of how to address those needs; and, (c) an overall respectful, welcoming, and affectionate nature displayed towards residents as illustrated in excerpts below:

LIZ: (Meaningful activity) They try to keep him involved in the things that are going on.

MARY-ANNE: (Relationships) I think her QoL is as good as it could be. I really do. She really cares a lot for some of the staff ... She doesn't ever complain about anybody ... And she seems so content when I come, she always seems to be happy. And when I bring her back, if I've had her out for a day, she's happy to come home.

LORI: (Relationships) I think the people at the nursing home are probably more of a family than I am which in some ways isn't a bad thing. And they know her probably better than I do at this point ... She taught one of the Filipino health care aides to speak Icelandic. Really quite interesting. I mean there's obviously a bond there that's pretty special.

MARY-ANNE: (Relationships) The other night I brought her back late. And there were two of the young aides that were there waiting for her. Nannie, we're glad you're home ... her arms out. And I thought, it must be so nice to be greeted like that, when she feels welcome.

CHRIS: (Security/safety) I must say that most of the care that I've seen here has been positive, as far as interaction with the residents. They're very loving. They're kind, they are. I don't know that I could do it, work with some of these people. Some of the elderly are very stubborn in their ways and they want things certain way ... If you're here at dinner time, that is the most demanding crowd you've ever seen.

TAMMY: (Security/safety) The nurses are wonderful. I really like them all. Even the health care aides, I really like them. Everybody. There isn't a person that I don't like, I don't think. No, they're very nice. I feel they just need more of them.

DAVE: (Security/safety) It's been a good experience and it is a great place. The staff is all around always, happy and helpful and very cheerful with the residents.

MARY-ANNE: (Security/safety) The minute I get the wheelchair up, somebody runs to help me. I don't have to ask. They're so aware of where everybody is. They watch and they're so good, running right there.

DEBBIE: (Comfort) The person that does the recreation is amazing ... You can tell when someone genuinely cares about what they're doing. How they treat people. She gives them 120% every single time.

DAVE: (Comfort) I think the care workers do very well in providing the best QoL they can for the client.

LORI: (Comfort) They're very good. They know exactly what to do with her.

SUSAN: (Comfort) The care is very important. And I have to say that we are very fortunate that the care here is very good ... It's important for her to associate with other people. Interact in any way with other people be it the staff or the residents. So the staff comes in, they do take the time to talk to her. And I think that's great. I don't think they do it just for my benefit when I'm here ... The care is the primary, the priority. And it's here.

HELEN: (Comfort). They've been very good here. They got, they tried to get right on top of it. And they saw it right away and tried to get on top of it.

LIZ: (Dignity) And I feel that the care he's getting there, the staff do give their residents respect ... It's not just with him but I could watch what they did with the other ones. I've seen the progression of other residents. If it's a problem, all they do is take the resident and they take them somewhere else, distract them. And they say, come on we'll do such and such with you or, if they're going into somebody else's room, you know, this is not your room, come on, you know. But they do not do anything to. As I said, I am very impressed, just by their attitude and how they handle things here.

LIZ: (Dignity) They don't give up on them, that's what I find.

DAVE: (Dignity) The care providers are very good. It is a difficult job which requires patience, temper control, care skills, strength and imagination. They keep the client clean, well fed, entertained where possible and most do their best to make the client really feel at home ... they are like an extended family to the client. Their hard work and dedication is quite noticeable and enhances the QoL of the client. They try their best to individualize each client and entertain each different personality to their utmost and a lot of love is extended from themselves to the client as if they were their own family members.

DAVE: (Dignity) They seem to treat everyone equally and respectfully; the best they can do considering their heavy workload and sometimes I think the system could possibly make things better by having more staff on hand to handle the clients.

5.2.4.3 *Family presence.* Families, as resource and resident advocates,

helped enhance their loved one's QoL in the PCH. Their unparalleled closeness to

and intimate knowledge of their relative's way of life made them most able to instill some normalcy in their loved ones' PCH lives. Spousal or filial concern, as well as personal understanding of the disease process, made them best advocates for their loved ones. Additionally for some, initiative, their own involvement and participation in the PCH community, and establishment of good working relationships with the health care team further enabled them in their capacity as resource and advocate. The following excerpts illustrate the value, roles, and unique contributions of families in their loved one's QoL:

1. Family as a resource;

TAMMY: Family is really important. But you can't tell other people how to live or what's important.

BARRY: She's tremendously appreciative. I mean she said to me on many occasions, you know, you make my life much richer or whatever.

BARRY: I'll tell you what I honestly believe is that a lot of people are missing something very, very special in their life. Now I don't have children. It's easy for me. But they are missing a very special relationship that they could have with somebody. Even with the losses. But I think they don't see that. And that is, I think, rather unfortunate. But there's often a lot of baggage, from the relationship between the children and the parents. And I think people have trouble seeing beyond the losses. My mother's demented now, there's not interaction. But that's not true. A person is still there. Although we're lucky because my mother is still very much there. Sometimes you have to make an effort. You have to make choices.

CATHY: If mom needs a new pair of slacks, mom gets seven pairs of slacks. New blouse, mom will get seven blouses ... So I think if the family takes care of their resident, so she looks good, smells good and feels good, etc. the staff also want to come in and there's, when the staff talk to my mom, they're always touching her ... But we ensure that mom is that way because that's who she was at home. Mom was always impeccable ... So we continue that to this day because that's mom's comfort level.

SHELLIE: She's called the spoiled one around here ... I don't know if there's a day in the week that she doesn't get either one of us ... We all work, therefore we come at night. We might stay an hour, an hour and a half. Saturdays, her two sisters come. My other sister brings [them]. They're here all afternoon and a little bit in the evening. And on Sundays, it's usually that I bring her to my house or my other sister.

DEBBIE: And then after I take her back to her room and ask her if she has to go to the bathroom. And I pull her pants down. She sits on the toilet and I stay in the other room. And then I'll go back and I'll wipe her and pull her pants up and direct her to the sink so she can wash her hands and everything. And then I'll put the TV on and then I'll take her to the room across the nursing station and we'll play the card game or we'll just sit there and try and get a group of ladies to sit together and try to have a little conversation.

JOHN: There's two or three people there who are, I would call again 'with it' and I usually go up to them and I talk to them and they give me a kiss on my hand. And they expect me every time I'm there to come up and talk for a few minutes. And I do that. And when I do that, a big smile comes to their face ... I'm not related to them. And like I say, I'm part of the staff down there. But, I try to help out as much as I can. And then I keep the nurses on their toes.

DAVE: Visiting often, she will not forget who I am, and try to bring a little comfort and light into her life.

SUSAN: I think everything that can be done for her is being done for her as far as the personal care home is concerned. The family, we try to make it special when we visit. And we try to make it a quality visit.

SUSAN: I don't ever want to lose her. I'd like her to be around forever ... I think they provided us with a very good life. I appreciate everything they did for us. So therefore I don't mind right now doing that and helping her.

2. Closeness/intimate knowledge of resident's way of life and unparalleled ability to instill some normalcy in loved one's PCH life;

CATHY: We are so in tune with mom's likes and dislikes ... We, as mom's children, know certain things ... Mom's QoL in my opinion comes from her family ... And it's a pleasure to spend the time and it's a pleasure to do what we do with mom.

TAMMY: He's [son] always doing something, you know, because he used to tease her incessantly, and she loves it. She's used to lots of jokes.

FRAN: I try to understand as much as I can what my husband's going through in order to try to help him.

FRAN: Because it's short term memory, when I go there, I try to think of things that will bring us closer and so I look through picture albums of different times that we've had and sit and discuss how much fun and different things that we've done together.

BARRY: Absolutely fantastic to spend time with her, if you engage her. The problem is that you have to engage her. I have a very close relationship with her. And I tell her basically everything about my life.

3. Understanding of the disease process;

LIZ: The support group was something I didn't know whether I wanted to go to. But I thought, you do everything that you can to learn and make yourself aware.

FRAN: I joined an Alzheimer support group where the people understood what I'm going through and we are able to give each other advice ... I find it very helpful to be involved.

FRAN: But I think it's [support group] very important. I think that I've gone there. I had excellent advice from somebody there. You go to people who all are in the same boat and all understand each other a little bit. Because we're all having to do with many of the same complaint.

FRAN: They keep telling me he doesn't understand you. He tells everybody I never come. I'm there, I know he's connecting. But I understand that he doesn't remember the minute I leave. But that's where I think the understanding comes in.

FRAN: We have to remember that, yes, Alzheimer's affects the brain and everything else ... But it doesn't mean that, I don't think it's all gone. I truly believe that way deep down inside there's still something in there ... I don't believe everything is dead inside. Maybe your brain doesn't function the normal to get conversation out or, to react to things or to do activities or whatever. But I still think there's something there. I truly believe that it's important that, you still talk to them. That you still care about them. That you still try to do things that, anything to keep up the QoL as long as possible.

4. Advocacy;

SUSAN: As far as I'm concerned, as a family member to her, I feel responsible as her daughter. She has a large family. But I personally feel responsible in making sure that, she's getting the best care. That we are still continuing to have conversations and we still try to go to activities. I'm still not ready just to say, sit in your room all day and just sit there.

DAVE: I try to ensure that the environment is suitable for her and that the care she is given is adequate.

TAMMY: She's really gone down. But, we try our best. I do whatever I can ... I can't imagine how people live without an advocate. They fall between the cracks. That's exactly what happens. I've watched it. You know. I see other people being with her, how terrible it is to have no one, or children that live out of town or children that don't bother. I don't feel that way. I have one mother and we plan on keeping her as long as she ... That's exactly how we feel about her.

BARRY: Even when somebody moves into a home, you have to still be very active because the situation changes. Should she get a wheelchair now? Should we change the walker? You have to be on top. And I'm a proactive person but you have to be.

SUSAN: I've noticed in her personal care, her self care. We have to do that when we come in. Like we notice that she can't, she doesn't clean her dentures because we know right away that is not. She forgets. She doesn't do it. And she doesn't wash her mouth. So that's bad. We tell the nurse to kind of cue her that way.

5. Initiative;

CATHY: (Enjoyment) Mom enjoys our music. So we have a music therapist that comes in once a week.

CATHY: (Enjoyment) Mom responds very, very much to any family interactions. If we talk about the kids, the grandkids or things that we used to do at home ... I would probably talk more about cooking and recipes. My other sister is very spiritual, so they would sing songs from church and pray. And my other sister is very much hands-on, so she would talk about the kids, etc ... And there's an awful lot of laughter.

MARY-ANNE: (Enjoyment) I started to read to her. And I read her Anne of Green Gables ... but she seemed to know enough about what I was reading ... she laughed in the right places and then she was quite excited for me to come again. Did you bring the book, you know.

CATHY: (Meaningful activity) We provide most of the stimulus for my mom. Meaning my sisters and I are here everyday ... And what we do is, each sister brings a different QoL to my mom's existence at this point. One sister does an awful lot of physical kinds of things, like hand massages, nails, facials. I do my mom's hair once a week so I do head massages and curling of the hair, etc. An awful lot of music. We play music for mom. The third, one of

the sisters does all my mom's laundry. So there's an awful lot of interaction between mom picking out what outfits that she would want ... We do an awful lot of walks in the summertime ... we ourselves, meaning the family, do most of what is required for my mom outside of the medical care.

JANE: (Meaningful activity) Usually try take her off her home unit ... go look at something different ... try to have a little bit of some stimulation beyond the same usual walls.

MARY-ANNE: (Meaningful activity) We did try to involve her for a while, getting her, say, fold face clothes and, some of the towels and things to have a sense of doing something ... So that you're not just sort of totally just sitting in a chair doing absolutely nothing. And just sort of maybe get her interacting a bit with other people, that kind of thing.

SUSAN: (Meaningful activity) I find that because of the activities, like I come in earlier and I visit with her and then we can go to the activities together. And then I can help as well over here with the activities which I really like to do. I find it's important for my mom to interact with somebody else. Therefore I feel that it's good for her to get out and be participating in activities.

JANE: (Meaningful activity) We've hired some companions to be with her. Because there isn't a whole lot of people that are going to be available to visit, we wanted to make sure she had some stimulation and things ... Or if they needed a little something, then somebody could maybe get that for them because we know the staff have, you know, a lot of residents to care for.

SUSAN: (Relationships) As a daughter and caregiver, I like her to remember my name. It's one way of knowing that we're still connected. And it's important to me. So I really put a lot of effort into it. Now I have the time to do this. Some other people don't. So maybe it's not fair ... But to me, yes, I need to talk to my mom. I need to have conversations with her. Just her and I. But I also need her interact with other people. I need to see her try. Today was not successful. That's OK. I'll try again tomorrow if I'm here or when the next day I come. I don't give up very easily. And I think sometimes people give up too easily and that doesn't help them.

BARRY: (Relationships) One of the reasons we had the party is that I hoped that some people who would come to the party would then start coming and visiting her a little bit more regularly. Some who maybe hadn't seen her since she moved into the home or were a little bit apprehensive. Will she remember me, you know. Is she still with it, blah, blah, blah. And then thinking, OK, if they come and see her at the party and see that she is really very with it, that they would come other times. Whether they will or not, I don't know. You know, I hope so but I've been very concerned to try in whatever way I can to make her life good.

BARRY: (Relationships) People don't interact a lot. I try to engage her with this man [boyfriend]. For example, there's a woman who she never knew before she came to the home. But we always stop at her room if the door's open and talk to her for a few minutes. There's a man who she did know, not well, but she knew. Whenever we see him ... So I try very much. I don't necessarily go these people's rooms. But whenever we see them, we stop and we talk to them and we interact with them. And she does that herself.

DEBBIE: (Relationships) I've cultivated friendships for her ... I go in everybody's room and stick my head in and say, hello, how are you and stuff like that.

CHRIS: (Relationships) I think what happens is they [hired companion] become attached and really do care, she really does love my mother and care about her I think.

CHRIS: (Functional competence) I hired a caregiver who is still with us for part of the time, who now takes her out to the community ... She likes being out. To the community things.

JOHN: (Functional competence) We are trying with physio to get her to stand and to walk. The problem is, the physiotherapists who work here, because they have so many patients, only give her maybe ten, fifteen minutes of their time, maybe once a week. That's about it. So I went ahead and I hired private physiotherapist to come here once a week for 40 or 45 minutes.

HELEN: (Functional competence) ... a relatively new private care company. They had somebody called a cognitively retentive therapy doing this program ... I started him on it with her twice a week. It's supposed to try to retrieve memory. They weren't sure if it was too, a little far gone. I don't know whether it worked or not but I have retained her because it's one on one. It does provide mental stimulation. She tries really hard. She plays some music, church music, different songs and stuff he recognizes. And she's just a lovely person and she really, is interested in my dad, pays attention to him. He doesn't remember who she is but I can tell on a certain level that he responds to her.

6. Involvement, participation in loved one's PCH community; and,

MARY-ANNE: (Enjoyment) Halloween ... we brought the children ... I take them upstairs in their costumes for the other ladies to see. And we walked by and there was one lady there in the chair and I've never seen her respond to anything. The minute she saw them get off the elevator, her eyes just lit up. Oh, she said, look at them. And I've never heard her say a word.

SUSAN: (Enjoyment) I picked them up at the dollar store ... it's a little congratulations card. And she [recreation staff] hands them out for second and third or something. So the residents actually get a little something which makes them feel good.

SUSAN: (Enjoyment) A lot of family members believe in bringing her lots of treats ... The chocolates, it got to the point that I started giving them to the activity director. So she could use it as treats for the residents who don't get anything at all or for games or activities or the way she wanted to.

DEBBIE: (Meaningful activity) I play card game with them that I learned from the recreation director and they love it. And we play it like everyday. Card bingo. They absolutely love it. And everyday we play, it's like the first day that we've played it. And it's repetitive. And I'm trying, as well by being repetitive, teaching one of them, the one that has the best memory, to be able to do it when I'm not there. And that's happening now ... and if people would learn how to play that game, it's engaging for a lot of people. And it helps the time go by because there's really nothing to do.

SUSAN: (Relationships) I'm quite willing to work here and stuff and help out.

SUSAN: (Relationships) One day my husband and I were here and this woman has really no family left whatsoever. We had talked to her a couple of times and stuff. And they love to tell you their stories. But she said, you know what I want? I said, OK, what do you want? She said to me, I would like a nonalcoholic beer. So I said, well, are you trying to tell me that you want somebody to go get you some non alcoholic beer? And she says, oh would you? So we asked the nurses. And they said it's no problem. So he went out and he was going to get her a six-pack. And she said, no make that two. So she gave him the money. He ran out and got it for and brought it back. And it doesn't hurt to do that. Other people would say, why would you do that? Well why not? Did it hurt us? No. Did it cost us a whole lot in gas? No.

SUSAN: (Security/safety) And they talk to me. And I know some of them forget who I am. But that's OK. I don't care. If I put a smile on their face for two seconds. If I can put a smile

on mom's face, it's all worthwhile. So I do walk in here and my family says, like well, you should just be taking care of mom. I am taking care of mom. They all know who my mother is. I feel that that's part of it. Because if she's going to be sitting up front, let her know that these people. If she sees me interacting with them that way, then I think it gives her a bit more peace of mind ... that everybody's in the same boat. Everybody has their lonely times. Everybody has their happy times. Everybody has their good days. Everybody has their bad days ... It's only I know how to keep her comfortable. To keep her safe. To keep her, I don't want her to be afraid. I don't want her to be frightened. I want her to treat these people like. And they're really respectful.

SUSAN: (Comfort) They do a lot. I make a point too for me, because I appreciate everything the staff does here, that I give back. If I see somebody with a need, the wheelchair needs to be pushed or whatever, then there's nothing wrong with me pushing somebody or see somebody that I know that's supposed to be with their walker and they're not using the walker. And I'll say, like OK (name), your family's going to be very upset if you don't get your walker. Or to help the girls with the activities by going door to door, do the main floor for them and encourage people to come to the activities and stuff. Doesn't hurt me to listen to somebody else who has something to say either another resident who might have something to say.

7. Enabling working relationship with the PCH.

LIZ: I'm still learning there too. I don't go in and say this is wrong or that's wrong. I ask why it's this way. They obviously have a reason for doing it ... I have a very good, I could speak to any of the staff there. And I mean I learn from them and they learn from me.

JOHN: Anything that has to be done I usually get in touch with the staff and they do it for me. I phone every morning. Every morning I call. They know who I am and I demand certain things. And I get it. I'm very close with the physician here ... I know exactly what I want and I want to discuss it verbally with the doctor. I don't want to tell the nurses to tell the doctor. I want direct contact. That is very, very important to me

JOHN: There's certain foods that she doesn't like. And I've already spoken to the dietician. So they try to avoid giving her that type of food that she doesn't like. The gal who brings in the food usually has something alternative for her if she doesn't like what everybody else eats.

JOHN: I talk to them [staff]. Actually work with them ... If I found something wrong, I'm right at it immediately. But so far, oh I found the odd thing that isn't right. But nothing really, really serious. And after I speak to the nurses, it's usually corrected very quickly.

5.2.5 A Summary of Potential Detractors of Optimal Quality of Life by Domain

Participants also observed impediments to their loved ones' experience of a generally positive QoL. This section emphasizes general problems in need of attention. Overall, residents may benefit collectively from better dementia care, better staff to resident ratios (including a better gender mix of male and female direct care providers), and more skilled care (combined with good personality qualities) in

these health care settings. These needs are highlighted in the proceeding excerpts, followed by itemized recommendations per domain. Bold-faced text represents the main thrust of their assertions.

JANE: Perhaps if we had **facilities maybe specifically committed to people with dementia** ... because that is their prime need ... Because sometimes in that way things are set up to be a bit more easy for everybody. For staff and for the residents. And so there is that safety, security thing. And then to be able to have staff that can commit to some of those more socialization kinds of things or the recreational things.

HELEN: **There are certain things that are missing that you would prefer him to have. But there's not enough staffing, there's not enough skilled care.** I think there's programming here that they could do for dementia people that isn't done. I'm sure there's way more advanced stuff going on I understand in some other jurisdictions. And I think there's **an attitude towards dementia people that is detectable. Sort of a dismissiveness** and stuff like that sometimes.

DEBBIE: **The staff needs to be more understanding.** I think that's really important. And I think they should be smiling. And I think that they should not raise their voices. I think that the staff should be mature enough to know when somebody says something that's not positive to them, they should not take it personally ... And I mean that's really, I'd say, I figured how immature are these people that work here. They shouldn't be working with elderly people if they don't realize that they can't control sometimes what they say. And they're not even going to know five minutes later they even said it. So why hold a grudge against them and then not want to do things for them and punish them because they said something that was offensive at the time. I mean it's part of their dementia. And they're either not trained right or they're working in the wrong field. There has to be some better understanding of the type of people that live here and how to deal with them. Because a lot of times they make the situation worse by how they behave. They don't diffuse the situation, they inflame it. And it really makes me angry because there's no need for that. So I just think that if the staff were a lot kinder and patient and smiled and more positive, that would reflect in the way the residents feel.

DEBBIE: I don't like what I see. A lot of times it shouldn't be that way. Whether they need to have training sessions, yea, they do. **They need a lot of training sessions. They have handwashing seminars. I think they could do something a little more cerebral than that.** So I mean they do have to take the time I think to really train the people in all aspects. I mean it's a service industry too.

HELEN: The QoL I would say is that it's **there's some limitations there because, you're in a setting and you've got institutional care** and family comes in and the rest of the time people do what they can but there's chunks of time when you're just sitting there ... and you got no mobility.

HELEN: It's not bad here. And **part of it is lack of staffing. Not enough staffing** Period. And that's money and provincial standards and so on and so forth. But, I think there could be more training of the hands-on staff.

DEBBIE: Fifteen residents to one health care aide. And they have to get them up in an hour, put them on the toilet, so it's like an assembly line. **There's no real care involved** ... I remember at the beginning, someone put her on the toilet and then she'd gone to the next room. And my mother said, where is she, like what's going on. And they rush. And then they have to come get them off. And I felt really sorry for them. And they have to grab the

first thing that's there to put on them. And a lot of work for those two women, you know, to get done in a short period of time.

DEBBIE: **It's a lot of stress. And some of them can handle it with a smile and others get nervous and they scream, because they have so much to do and they don't handle the stress well** ... In the summertime, they're short staffed. Some days in the past few weeks they had one health care aide for 30 people. It's not fair to the residents.

DEBBIE: Seems like they're desperate for staff ... And **nobody wants to, I don't know, do these jobs.**

FRAN: I sometimes worry when these young nurses, and you know, he likes to flirt with them. And they don't realize that he's just kidding ... I'm not even certain at this point whether he would even know what's right to do or wrong to do. I used to tell him, look, you've got to know the person before you joke with them ... **There's not too many men that do that work that I see.** And so I'm a little worried that he might get himself into trouble. Some people have good sense of humor and they can take it but others take it seriously.

5.2.5.1 Enjoyment. Residents may benefit from a unified effort from the facility to preserve those enjoyments as basic as food.

DEBBIE: Food is probably one of her only enjoyments ... That's mostly what people this age have to look forward to is a good meal ... The food's dry or burnt or undercooked or overcooked. It's not tasty. And that's just care. Because anybody that can read a recipe can cook. So if you follow the directions it comes out right. It's very simple so **it boils down to care.** If you're going to rush, that's what you're going to land up with.

5.2.5.2 Meaningful activity. Residents may benefit from more recreational programming, including supportive encouragement and assistance to get to and from programs.

SHELLIE: She seems to participate in their activities. She enjoys them and sometimes she tells me no. But I think **they have to go motivate her** to get out sometimes. And then once she's there, she's fine.

DEBBIE: There's really nothing to do when the activities finish at three ... Maybe twice a week there's something on Tuesday and Thursday evening. But that's only if you have a **way of getting there.** Which means you have the wherewithal to get out of your room, find your way to the elevator, find your way to where the program is.

FRAN: Boredom's a big issue because there's nothing to do, between 3:30 and 5 ... And then after supper ... The recreation's excellent, it's really good. But **could be more** maybe.

5.2.5.3 Relationships. Residents, especially those without regularly visiting family or friends, may benefit from increased social contact through a visiting

program, for example, with local communities and schools. Care must likewise be taken in planning compatible roommates or safe room assignments at minimum.

DEBBIE: The **woman they placed her with has really bad dementia**. And she wanted the door closed all the time. She didn't want the TV on and she wanted the lights out all the time ... She always used to tell me, get your mother's things and I want to throw them out. So I'd have to appease her all the time.

SHELLIE: Some of them are **very lonely**. But, you know, the staff have work to do too that can't be sitting beside them all the time. And then, they're always wanting volunteers to come to do that kind of work too, but it's not always an easy thing, to get the volunteers in to help.

HELEN: I guess, what I find a little difficult and a little distressing is, and I guess I can't blame people, I think there could be more visitors. I think people find it difficult and it just dies out. And I also, you know, churches used to do more visitation. They had people who were visiting, visiting committees. I guess lifestyles of people, women are working and that just doesn't happen any more. Yea, I think **there could be more that kind of thing. You know the community keeping up**.

LORI: Like my mother's friend, like she doesn't like to go on the outings and that. She says, I don't know if I have any money. I say, yes, your money's managed by the public trustee. You're looked after. You have a pension. **Like they need someone to tell them these things, even though they may think that they're not important**. They are important to them. They need to stay in touch with reality as much as possible and they need contact with people from the outside. Because you lose that when you become institutionalized because it's a different, a whole different environment. And just to remind people of what it is. Like I come in and I tell them, like I went shopping and bought that or whether I did or not ... just to remind them of, how it was, you know. I'm going home and cook a meal and this is what I'm going to prepare ... I'm going to take my daughter here and we're going to go get a haircut. Just things to remind of the real world. Because you lose touch with the real world when you leave it.

CATHY: I think there's a part of us humans that when we are **in the presence of that gentleness and caring, residents respond to that**.

CATHY: There's one woman, a friend of my mother's, she had her purse held together with paper clips. Terrible. It was falling apart. She has no family that really comes to see her, maybe once a year. And she walks around with this purse. So I gave her one of mine. She's so happy, you know ... I bought her a little diary because I said, you know, if you want to know something and you ask somebody a question, you can write the answer down. Because she says, I don't even know if I have a doctor here. I said, everybody has a doctor here. If you want to know who your doctor is, speak to the nurse behind the desk and you write it down in the little book I got you. So that's when you're not sure if you remember you have a doctor or not, you can look. You know, just things, **supports to anchor people** because they lose their touch with reality and they get scared. And I think makes the dementia worse when they don't have people that come visit them, and engage them in conversation.

5.2.5.4 Security/safety. Residents may benefit from increased accountability

from the PCH to reduce the incidence of misplaced belongings and petty theft of

residents' belongings; to secure nursing stations and medication carts, among others, so that the risk of harm to confused residents is minimized; to have safe coverage at all times, including during shift report and baths that residents are always supervised; and, to have long-term solutions to chronic problems of high staff turnover, negative attitudes in elder care, as well as knowledge gaps in dementia/ADRD care.

CHRIS: I don't know what can be done about it, but **clothes disappear, things disappear** ... I mean everybody is functioning from some degree of dementia ... Things get mixed up and things get lost. You can't have valuables.

DEBBIE: Another thing I worry about, there is a man. He rummages through the nursing station. There's scissors there. There's no door. The door's open. So he walks right in. And there are times, they're distributing medication so the nurse is with the wagon and the health care aides are answering the lights. They're in rooms helping patients. And then there's [resident's name], he becomes a nurse. He's in the nursing station looking for the fuse box. And he goes through all the drawers, and there's scissors in there ... He's **an accident waiting to happen**. He could hurt himself or he could hurt other people ... He was in my mother's room one day looking for the fuse box. So she just screamed and he ran out.

JOHN: I don't like when they change nurses who have never been on the floor, never been on the ward ... When they bring a brand **new girl in, who doesn't know the patients**. Which is very, very important ... A mistake can happen very easily.

SUSAN: So in the care, that they're **kind and gentle and stuff like that and that they're understanding. And, they have a sense of humor**. It's very important to her. It's important for her to laugh sometimes. Or to smile and twinkle. So the care is very important. The care as well of her room.

DEBBIE: There's a lot of **preconceived notions** that some of the staff members have. Sometimes there's people that are really hard of hearing ... and sometimes they hear what's being said ... I don't think they have enough patience and I don't think that they should be raising their voices to these people. **They can't help the way they have become** ... they're not intentionally trying to annoy them.

DEBBIE: So we're playing our card game ... And one of the workers came over. I would say the card. And then she would point out quickly before the person had a chance to realize that it was the card. Let's say I said four spades. And then you had the four spades. But you weren't quick enough to turn it over. She would say, [knock on table] point to it and say four of spades. So of course the other lady got offended. She says, I wish you would go away. So I giggled. She says, she insult me ... So she went away and she was mad. I went to her and says, come on Mrs., you're not going to hold a grudge are you. She goes, no. I says, come on, you know these people **don't mean anything by it. It's just how they're feeling. It's really nothing against you**. Don't take it personally. She said, OK. And then the next day we're playing and she says, oh I hope your mother wins. I don't want that one to win.

DEBBIE: If the nurse would come in and be positive and the health care aides too, I think if they just had a more positive attitude it would make the stay here more bearable ... I want a positive environment for her. I guess that's the main thing. And **people to be a little more mature, not to take seriously everything, not to hang on to every word** that's said here. And to understand that people don't remember what they said. And some people with certain

types of dementia say things that we consider inappropriate which they don't realize it's inappropriate any more, and to just let it go and start fresh with the next day.

DEBBIE: She's very unhappy ... And when she voices that she's unhappy, some of the staff get offended by it ... She needs **positive environment**, caring, kind staff that are positive. That's I think the most important thing. **So that she feels welcome here.**

DEBBIE: A lot of residents too don't have any support from the outside world. They're very frightened because they don't understand what's going on ... They **need some kind of liaison person that could sit down with them and talk to them and reassure them**, that everything is ok and that they're fine. And that they don't have to worry. And that's a big problem here because a lot of people they sit here, and they say, take me, I want God to take me. I have nobody that comes to visit me. I'm scared ... They become worried and fearful. And it's not the way that they should be living their last years.

DEBBIE: Just having someone that you can trust and that's there on a regular basis... Some type of **psychiatric nurse or something that understands what these people are going through.**

DEBBIE: It's **responsibility of the institution to correct the behaviour ... But there were a lot of times like my mother also got penalized because she has a companion.** Like when you're elderly, even when you get past 50, when you have to go to the bathroom, you have to go. You can't wait. So they wouldn't take her to the bathroom until ... They say to you, your lady's going to come in like two hours.

DEBBIE: I brought her here for peace of mind that I know that she's got 24-hour care. **Not to have to worry that the staff are inept and don't do what they should be doing.** I don't think anybody, like even if she an accident and she was wet, she should be changed. You can get a rash too and can get an infection, you know. She could have really been scalded. Thank goodness it wasn't bad. That the outcome was OK. But I mean it's the point. It **wasn't handled correctly at all by anybody** ... This is not what I had in mind for my mother. She deserves better than that.

DEBBIE: And then the lady my mother shared the bed with ... She went and used my mother's toilet and left the place like you wouldn't believe. So I went to the nurse. And, she says, well do you need someone to clean it? So I said, no, my mother's companion cleaned it and she shouldn't have had to. That's not her job. And she says, well we don't know how to handle things like that here. I says, OK, I just wanted to let you know. Maybe you could keep an eye on her, so she doesn't wander into my mother's room anymore, so. She always gives me jab. She says to me, you know, we have to raise our voice sometimes ... Like she was implying that she knows that I tell [name] on her when she misbehaves. So she's not too pleased with me. But **I have to be the policeman.**

5.2.5.5 Comfort. Residents may benefit from general closer monitoring of residents' medical needs; for example, of their food and fluid intake through such measures as implementing regular hydration times between meals, one-to-one feeding; of their mobility, through physiotherapy; of pain, through increased staff sensitivity to residents' non-verbal cues of discomfort. Residents may also benefit in

general from better communication of all parties involved in their care especially between shift changes or facility transfers. As already noted, residents may also benefit from more informed staff on elder and dementia care.

CATHY: **The other thing, like even to drink.** Because sometimes I think you'll find she won't ask people for something to drink. She has to be, I think, really, really thirsty before she would even think to ask for something ... It's important to have those opportunities for like the midmorning snack or the mid-afternoon break, you know, somebody brings some things.

CATHY: **Mom was allowed to be dehydrated** ... We were told that end of life was imminent ... and she was completely unresponsive ... And the doctors said that there was nothing wrong with mom other than she was dehydrated.

HELEN: He does have this discomfort problem in his bottom sometimes. And I think some of it's from sitting all the time. **I really wish there was more, means of moving them.**

DAVE: From the viewpoint of the caregivers, if you have a **better understanding of what they want**, I think they might be able to make it even better.

JOHN: **You really can't judge a person in a personal care home that has dementia, or does have Alzheimer's to tell you honestly ... unless when you're inquiring or when you're taking to them, that particular moment there, then they can answer you truthfully.** Otherwise, you're not going to get a true answer. No way, it's impossible.

FRAN: Maybe from a nurse's viewpoint too is to understand that they really don't have very much idea ... **and that they can have these two things happening at one time to contradict each other.**

HELEN: He's half-laying and half-sitting on the floor. He doesn't realize it. I think it's really **important that people ask** him, does it hurt? No, nothing hurts. Touches him in the spot, in a spot and he screams out because he doesn't know what hurts.

JANE: And I think it's hard, and once in a while they have had her on **diuretics** ... which can be a bit challenging because I think, you do need to go. And yet, you know, it might not be part of the routine whatever.

JANE: If you go to bed at 6:30 pm ... chances are they're going to wake up at one and two in the morning or certainly before 6:00 am kind of thing. And I can see where the night staff are going to think, how come the person's awake or calling out or something. I think some of that is you need to go to the bathroom. Because I think when you pass that length of time ... you have a sense of needing to get up to the bathroom. Or **getting a bit slept in** at some point.

CHRIS: **I'm still not working so that I can be with her** the days that the caregiver is not with her ... She [caregiver] is here quite a bit ... **To be honest, the reason I was doing that, I thought that if she was less demanding on the staff, that they would not move her over to the other side.**

CHRIS: **If I knew she was being cared for in a better way, I wouldn't feel the need to maybe spend as much time here to be honest.** The physical, taking her to the washroom, getting, being dressed properly. I don't think if I didn't have somebody private that that would be happening. I know it wouldn't be happening because I saw before I had help. So I

think the bottom line for nursing homes in any of the different sections is having more nursing help. They don't have enough help. They don't have enough nurses.

CATHY: To **feed her one-on-one** to her face so that she would see. And to tell her what foods she's eating.

SHELLIE: Of course there's always negative anywhere you go ... but I think it's maybe due to short staff. Like sometimes **I find they could be there more often to help, to cue her and do this and that** ... But they just don't have the time. I don't know if it's the time or short staffed or what it is ... For some people, I can see they need that extra time for either companionship. Somebody to sit by you...

TAMMY: She only gets a bath once a week which we don't like very much. It's not very good. Twice would be better. **I don't think someone that's in a diaper should wait once a week for a bath** ... I was totally stunned. That really grossed me out totally. I mean most people take a shower everyday or twice whatever. To me, that could be an area if they had more staff they could do more of that thing. So I have my caregiver because my mother when she was with it, told me so ... So she gets twice a week.

SHELLIE: The only thing is to do with the doctor. When they come here, they lose their personal doctor ... and she adored [doctor]. So when she left, she lost him. That was hard for her and for us. Because then it's like, we never, **unless we ask and unless we're aggressive and we ask and we ask and we ask, we don't know what's going on** ... And we never hear anything about when the doctor comes. Like that's one thing I would like as a family member when a doctor comes, I would like to know. Be informed and maybe find out what's happening. Because I go ask my mom, she knows nothing.

SHELLIE: It would frustrate us because all her records ... they have nothing here. Some of the nurses even said, we didn't know that your mom had ... **We would tell the nurse something, then you'd have to go tell the other nurse. You come in on another shift, nobody knows anything.**

5.2.5.6 Functional competence. Residents may benefit from collective efforts to maintain activity via known effective interventions.

JANE: Sometimes by having a companion or somebody even sort of like bringing up, it's lunchtime. And, oh look what we've got for lunch ... giving her cues to get started. Sort of like, oh, that soup looks really good. How about pick up the, lift my spoon ... And then sometimes, like once she gets going, but there's been sometimes it's almost that, to **get somebody started** at sort of like what to do with utensils or food in front of you.

JANE: For quite a while she was quiet ... depends too what medication they've got her on as well. Because **they have this thing about people not calling out and wanting things.**

TAMMY: I really was very, very upset that they did that ... When we come in, they give us a bunch of papers to sign and a bunch of papers to read that we should know what we're doing. And explains exactly what's our responsibility, what's their responsibility. **I think there should be a form made up that when a person with Alzheimer's comes in ... They should have this form. When you come in for three months, we'll be giving you the Aricept.** After three months, we're going to take it off for a month to see how it's working on you. We're going to take it off gradually, 5g at a time for the month. And after the month, if it doesn't seem to have any effect, we'll stop giving it to you. And after the month, if it's harming you, we don't know what it's going to be ... The family has to be consulted

and that you have to follow what the family has agreed upon ... I think it's important for us to know if they're going to take a pill off ... That they might not be taken off when they could possibly have another couple of years of enjoyment at this time in their life. Taken off unnecessarily.

CATHY: She was not in the wheelchair. But it was more for the **convenience of the staff that mom was put into a wheelchair** ... When she first came, she was able to walk with a walker but I guess the staff shortages, etc, it became such that mom lost the ability to walk.

HELEN: I've got a rehab aide working here with range of motion. I mean, I think, he just sits all day. I think they should be, I think that he should be able to, **they should be trying to walk him but they aren't**. I don't think they have the staffing here. So, I've been thinking of trying private physio again.

LORI: QoL, I sometimes I think of function. I think she'd be happy if she could walk ... It's a real shame. But, you know, **you don't get physio in nursing homes**.

DEBBIE: **People like to make choices**. And a lot of it's like common sense when you really think about it. Like a lot of them I think they don't want to take a bath. They just don't want to have staff taking their clothes off and that. Like a pain in the ass. **But sometimes to have some control over your life like where you can say no, I don't want to do this**. But it's easy to turn it around too. You ask them, do you want to take a bubble bath or do you want to try this new shampoo. Like give them a choice so you'll get them to take a bath but they'll have some say in it. What kind of soap you're going to use or, just something so that they do have some control over their lives.

JANE: When you're in a triple, like a four-bedroom that looks like a hospital thing with curtains and things, **I don't think to most people that speaks home** ... Because I think it makes you think more like you're in a hospital room or somewhere different ... When was the last time most of the older people that were sharing with anybody. Some of them maybe never went to camp or when was the last time someone had cohabited with two or three strangers.

JANE: For the most part you don't have a lot of **privacy and comfort** of your own space ... or to even have certain things or activities.

JANE: Likewise you sometimes wonder about the quality of sleep. **What if you were having a good sleep and then if one of these other three people in your room needs something or is restless or something or confused** ... Or things that maybe could set off a little bit of a chain reaction.

5.2.5. 7 *Dignity*. Residents may benefit from more attentive staff, versed in residents' likes and dislikes; and better informed of dementia-/elder-care sensitive practice.

MARY-ANNE: **She knows when things are put together**. I came a couple of weeks ago, she had blue pants on a black and white stripe top and I could just see the look on her face, eh ...

CHRIS: **You need to have a caregiver to have a person looking, dressed in the proper clothes and looking well**. I mean, today, when I came, her hair was like she had put her finger in an electric socket and was all over the place. Nobody had done her hair in the

morning. It doesn't seem that there's enough staff ... depending on what shift it is ... And they're running.

CHRIS: **She needs to be taken care of.** And sometimes they just don't have time to. They would put her in, I mean I come in the winter and would be wearing a summer outfit. So you have to organize all the clothes and put them away. I take out the outfit for the next day or the caregiver does, otherwise they're not dressed properly ... **They grabbed the first thing because they're in a hurry I guess or slap, bang, bang.** And they put it on. They don't care what they look like.

DEBBIE: I think **how you treat them is the most important thing.** They need to be treated a lot nicer. It's got to be a positive environment if you hope to keep on going. And better food. Or better food preparation.

DEBBIE: So she says, you have a diaper on, you can pee in the diaper ... **It's not appropriate behaviour for any nursing home.**

DEBBIE: Funding has increased I hear so it would be nice if it was used to enhance the lives of the people that live here rather than being used like for building, for equipment and things ... **Their emotional needs are more important.**

Participant interviews also highlighted non-PCH-related QoL detractors such as resident's personality, level of illness, the family/social network, and resources as illustrated in the following excerpts:

1. Personality;

BARRY: (Enjoyment) I think she has a good QoL. She's never been a person who was difficult ... Basically you put food down in front of her she eats it. It's great. It's fine. She's not a fussy person ... She's not a complainer. I think she has a good QoL. Sure, there were things I would change on, I would surround her with people like herself. But there aren't very many of them.

BARRY: (Meaningful activity) It would be wonderful if there was a group of people who she could have an intellectual relationship with ... It's difficult because there just aren't very many people in that category.

LORI: (Relationships) She doesn't like to share people. She likes to be one-on-one.

FRAN: (Relationships) He's sort of being looked after and not objecting to it ... I'm very blessed that my husband is very pliable.

JOHN: (Relationships) Each one's different. It depends where they're from, it depends how close.

2. Level of illness;

CHRIS: (Enjoyment) But now, in a way, it's [dementia] a blessing in disguise because she thinks that's her apartment and she could be anywhere ... doesn't really make any difference with her at this point.

CHRIS: (Enjoyment) [Happy]... When I'm here. I'm sure she's not happy when I'm not here. She does not like being alone. Are all of her physical needs cared for? Yes. But as far as happy. No ... I think it's more related to her illness.

LORI: (Enjoyment) There's no point taking her out. It's more disturbing for her ... We took her out for her birthday and she was just miserable. I think it's just she's not in her familiar surroundings. The more her mind goes, the better it is that she's in familiar surroundings.

TAMMY: (Enjoyment) I just wish I could take her out. But it's impossible. I can't take her in the car and I can't do any of that.

LORI: (Meaningful activity) I don't know what she does during the day, what outings she does. Or what they do with her. I think she's so physically and mentally limited to what she can do.

BILL: (Meaningful activity) I don't think she can participate in very much here. She hasn't got that capacity ... She doesn't comprehend what's going on.

LORI: (Meaningful activity) She's a hairdresser. And you can't get her down to the beauty shop to get her hair done. And here's a woman who always had her hair done perfect.

DEBBIE: (Relationships) She can't understand why these other people aren't [communicative]. And she gets frustrated, she says, you know me. She says, what's wrong with you. Why don't you know me because I know you ... But I think a lot of it too is they forget a lot. Like what happens in the morning is forgotten in the afternoon. And so she's frustrated ... She says, why don't you remember me? I remember them? What's wrong with them? That's because she's functioning a little better.

SUSAN: (Relationships) There are stages, like this lady that I know that's here. And I really feel sorry for her family because she's a human vegetable. I've gone up there and I sometimes wish it was way back when and we can talk and stuff but she would never remember anything. And her family finds it hard to come here because she can't communicate at all.

3. Family/social network; and,

MARY-ANNE: (Relationships) Sometimes I feel embarrassed. I need a whole table of ten usually. I feel badly for the ones that don't have [family].

JOHN: (Relationships) I'm more involved with my wife now than I was with my mother ... Although I used to visit her, not everyday because I was working.

HELEN: (Relationships) I could get a companion for him. I've thought of that. But I come in everyday. You know if I were working, so see I'm retired so it makes that possible. Otherwise I think I'd probably hire a companion to come in.

JOHN: (Relationships) My wife is 84 years old. So she had a lot of friends but they're not around any more. So therefore as far as friends are concerned, it's very minimal right now. She does have a sister who visited her once a week. And that is the, and then I have a brother and sister-in-law who are both not well.

CATHY: (Relationships) We know through human frailties that if you want to deal if, as a health care person, you have to deal with each resident. If that particular resident, and I'm going to say my mom, if she always looks very well dressed ... smells always very, very good ... and mom's room, looks like a mom's room. Pictures of kids on the wall ... It's always very, very pleasant ... She's very, very clean because each one of us as we come in, we wash

mom up, you know, two or three times a day ... Her clothes are only worn once ... So mom always looks good. Smells good. And pleasant to be around. The caregivers are more apt to want to do something for that person. So mom, besides getting good care from her family, also gets very good care ... Mom's touched an awful lot. Mom is talked to an awful lot. And it's because mom is not, she's never nasty. She never yells or has bad words for any of the staff ... mom acts socially, you know, in an acceptable behaviour.

4. Resources.

BARRY: (Comfort) She's kind of a special case. Judging from what I've seen. But she has tremendous resources. And I think one of the reasons that she's done so well is that she has resources that a lot of other people don't have. Because of that independence. Because of that not really needing her creature comforts because of that not being a complainer.

CHRIS: (Comfort) It's very expensive to have somebody in a home like this. Your per diem, as you know, is costly to live in a nursing home. And then you have to pay almost as much for a private caregiver ... You want your mother to live forever 'til she's ready to go type of thing, ripe old age. I want her to have the best. And it's a very costly endeavour.

CHRIS: (Comfort) She's lucky to have the money. Because, I don't know what she would do without it.

While the facility can modify several practices to facilitate better QoL for residents under its care, the promotion of QoL relies on all stakeholders working collaboratively to achieve that end, from the PCH, people under its employ, to residents and their families. As the preceding excerpts have shown, not all detractors from achieving optimal QoL are facility- or health care team-dependent; however, the PCH can begin addressing shortcomings within its control.

CHAPTER 6 – DISCUSSION

This chapter summarizes the findings of this research as per the original research objectives stated in Chapter 1 of this thesis, compares these findings to the generic and ADRD-specific PCH-QoL literature, and discusses the theoretical, policy, and practice implications of this research.

6.1 Summary of Findings

Study participants generally agreed with the six domain definitions as proposed by Kane et al., providing more commonly used terms for these and examples of how their loved ones achieved enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence.

1. Enjoyment was synonymous with happiness, contentment, and satisfaction. Achievement of this domain ranged from the very basic – “seeing me” and exposure to what the resident used to appreciate (e.g., certain foods, music, and children) – to the less passive, more engaging activities (e.g., dancing).
2. Meaningful activity was synonymous with stimulation, a functional or creative outlet, and socialization. Achievement of this domain ranged from ‘passive enjoyment’ (e.g., visiting with family and participating in programs as an audience member or “clapper”) to engagement in something useful or creative (e.g., folding facecloths and helping with holiday decorations).
3. Relationships was synonymous with interactions (e.g., with family members, friends, relatives, PCH staff, other residents, and volunteers). Achievement of this domain ranged from the quiet or passive – ‘presencing’ – to the more

engaged, more fulfilling interactions where the resident recognized comfort in the relationship.

4. Security/safety was synonymous with physical safety, companionship, and emotional well-being. Achievement of this domain ranged from residents' physical comfort to feeling assured of their safety and security in a social environment.
5. Comfort was synonymous with physical/medical care. This domain represented the provision of basic care which families expected from a PCH environment. Study participants responses suggest that the achievement of comfort was most dependent on staff attentiveness.
6. Functional competence was synonymous with choice and autonomy. The achievement of this domain ranged from the very basic – the observance of residents' preferences, customs, or routines (e.g., in grooming, dressing, other beauty regimens such as, maintaining regular hair appointments) – to prompting/encouraging maintenance of competencies.

Dignity, while not a part of Kane et al.'s six domain framework for residents specifically with ADRD, was also considered important by participants to their loved ones' QoL. They defined dignity as synonymous with respect, the scope of which encompasses facilitating pride in ones' appearance, the preservation of modesty, and acknowledgement of the person/individual. Of the seven domains (dignity and all six domains of Kane et al.'s ADRD schematic) considered to be relevant to their loved ones' QoL, dignity, security/safety, comfort, and enjoyment were collectively the most important domains.

Participants were able to identify several PCH policies, practices, and activities that currently or could better facilitate positive QoL experiences for residents with ADRD. Participants stated that positive QoL experiences for their loved ones were facilitated by factors such as: (a) the facility's physical attributes including location; (b) staff members' accommodation of family and encouragement of family involvement; (c) installment of a sense of belonging or a sense of 'home'; (d) the inclusion of innovative programming; (e) staff attentiveness and fulfillment of family expectations; and, (f) the development of community partnerships. Conversely, participants also cited high staff turnover, inadequate staffing, and some negative elder care attitudes as detriments to high QoL. They further stressed that PCHs could use more skilled care and resident-centered staff, and environments where dementia-/elder-care sensitive practices are implemented and also exercised.

6.2 Comparisons to the Broader Literature

While the broader literature stipulates that PCH residents' QoL is 'good' (Echteld et al., 2005; Guse & Masesar, 1999), that of community-dwelling older adults' is thought to be better (Kasper et al., 2009; Wodchis et al., 2003). While there are no comparable data for residents with ADRD, within generic PCH populations, relationships (people, personal characteristics, maintaining contacts with friends/others), functional competence (maintaining health, well-being), security/safety (room and board), meaningful activity (being helpful), enjoyment (nature) are most important among other constituents of QoL (Echteld et al.; Guse & Masesar; Lai et al., 2005). Functional competence and meaningful activity (ability to communicate with others, ability to care for self, and ability to help others) enhance

the QoL experience for interviewable PCH residents (Aller & Van Ess Coeling, 1995). Specific to PCH residents with ADRD, increased enjoyment (pleasure) (Lawton et al., 1996) and meaningful activity (activity or any recreational outlet) may facilitate better QoL (Albert et al., 1996; Fossey et al., 2002).

This thesis study suggests that the experience of all domains, and not just enjoyment and meaningful activity, may yet be heightened through the collective efforts of the PCH, direct care providers/staff, and family caregivers. A plausible reason why the generic literature has found enjoyment and meaningful activity as domains that can be intensified (so as to facilitate better QoL) may be due to relatively easier strategies to implement versus more complex solutions related to other domains. For example, increasing hours of recreational programming to facilitate enjoyment and meaningful activity will be less challenging than changing care providers' attitudes to promote comfort and dignity.

Comfort and dignity are two of the most important domains for residents with ADRD, but less important for the generic PCH population (Echteld et al, 2005.; Guse & Masesar, 1999; Lai et al., 2005). A possible explanation for this difference may be greater relevance attributed to other domains by residents with higher levels of cognitive and physical functioning. For these residents, maintaining their health and some level of productivity (functional competence and meaningful activity) may be more pertinent than merely being free from discomfort or dressed in clean clothes (comfort and dignity).

While overall QoL was not graded, results of this study suggest that the QoL of PCH residents with ADRD is at least satisfactory. Results indicate that these

residents are able to achieve enjoyment, meaningful activity, relationships, security/safety, comfort, functional competence, and dignity, albeit at different degrees. Participants also indicated how QoL could be further improved in each of these areas, by developing for example, a better understanding of their past experiences and individual circumstances. Participants also provided several successful PCH facility policies, practices, and activities that currently facilitate their loved ones' QoL, however also identified key potential detractors.

6.3 Theoretical Implications and Future Research Directions Specific to the Kane et al. Framework

This study validates Kane et al.'s framework as a potentially useful QoL tool to use in PCH residents with ADRD, at minimal by identifying the relative importance of these various domains in the overall PCH-QoL picture. The six domains (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence) as defined by Kane et al., resonate with family caregivers' understanding of QoL and remain relevant to their loved ones' QoL. However, while not identified in the original framework, this research demonstrates that dignity is one of the most important QoL domains for PCH residents with ADRD, and strategies have been suggested for enhancing QoL in this particular domain. Also, as per the original assumptions of Kane et al. (2003), this research demonstrates degrees of importance attached to QoL domains often vary, pending unique circumstances such as severity of illness and different personalities modified by his/her own set of values, expectations and life (including PCH) experiences to date. This study additionally lends support to Kane's (2003) argument that care delivery can affect the experience

of domains: the attentiveness of staff was especially singled out as QoL-enhancing for residents.

This research is the first to gather empirical data that supports Kane et al.'s novel framework for measuring QoL in PCH residents with ADRD. While dignity was not originally proposed as a part of the six-domain framework, family caregivers considered this domain to be as important, as compared to other domains such as enjoyment, meaningful activity, relationships, security/safety, comfort and functional competence. This study proposes a modified version of the Kane et al. ADRD schematic where dignity will constitute the seventh domain.

Further research is needed to compare the importance of QoL domains as discussed in this research: (a) both to non-ADRD PCH residents and to people with ADRD living in a community setting and (b) family caregivers' versus PCH staff perspectives.

6.4 Policy and Practice Implications

Findings from this study suggest that the Kane et al. framework may be pragmatically employed by policymakers and service providers. An enriched understanding of these residents' QoL can be used to develop or bolster already existing strategies to optimize QoL achievement. Moreover, where fiscal and human resources are limited, the achievement of security/safety, comfort, enjoyment, and dignity supersede that of other domains.

Inquiry into how residents achieved QoL on specific domains have provided insight on the range of QoL-enhancing experiences that PCHs, staff, and family caregivers can help facilitate. Two practical applications of knowledge gained from

this research include: (a) gradual implementation of strategies and recommendations to optimize QoL achievement within the context of the seven domains and (b) early integration of the Kane et al. framework in the admission interview. For example, the questions below may be asked of residents and their family caregivers upon entry to the facility:

1. What are some examples of your loved one's enjoyments, such as entertainment and food preferences?
2. What hobbies did your loved one keep? Did your loved one prefer one-to-one activities over group activities, or equally? What kind of activities did your loved one used to engage in?
3. Who comprises your loved one's support network such as family, friends, pets? Would he/she be interested in visitors from the community?
4. What security/safety issues are you most concerned of for your loved one?
5. What are normally your loved one's cues of discomfort? What kind of things would help facilitate their comfort?
6. What special routines in grooming and dressing, for example, would be helpful to know?
7. What would dignified care mean to your loved one?

Similarly, a non-exhaustive list of strategies and recommendations to help facilitate QoL is as follows:

1. Preserving **enjoyments** as basic as food; for example, maintaining updated individual resident inventories of food, grooming, and other preferences; relaying this information to other members of the health care team; and

observing these preferences that includes allowing the family to facilitate their maintenance as long as they do not affect the resident or the immediate social environment adversely.

2. Instituting more recreational programming to facilitate **meaningful activity** via taking individualized inventories of residents' pre-PCH admission activities, encouraging participation in events or programs residents may enjoy and providing assistance to get to those programs, assessing residents' continued interest in their previous enjoyments, and introducing new meaningful activities when indicated.
3. Maintaining a peaceful and stronger social environment to promote **relationships**. For example, mobilizing family and community presence in the PCH; establishing a visiting program for residents without regularly visiting family or friends; and, exercising as judiciously as possible residents' room and seating arrangements.
4. Finding solutions to chronic problems of high staff turnover, negative attitudes in elder care, and knowledge gaps in dementia/ADRD care to generally enhance residents' achievement of **security/safety**. More specifically, ensuring safe coverage of residents at all times, securing nursing stations and medication carts; securing nursing stations and medication carts; and instituting measures to reduce the incidence of misplaced or unintentionally stolen belongings such as comprehensive labeling of residents' belongings upon admission and applying markers to residents' rooms that would deter wandering residents from entering those rooms.

5. Fostering staff knowledge of elder/dementia care and reinforcing staff accountability to residents' health care needs to facilitate residents' **comfort**.
For example, exercising vigilance in knowing changes in residents' health status, such as changes in appetite and level of discomfort; being attentive to residents' needs through nonverbal cues; and, ensuring continuity of care between shifts.
6. Providing more recreation, more physiotherapy, and better communication with families on residents' care regimens to facilitate **functional competence**.
7. Providing more adequately staffed PCHs with reinforced dementia-/elder-care sensitive practice to facilitate **dignity**.

Figure 6.1 synthesizes the findings of this research into a quick-reference model that may be used towards QoL enhancement of PCH residents with ADRD.

Figure 6.1. Enhancing the quality of life of personal care home residents with Alzheimer’s disease and related dementias: A model.

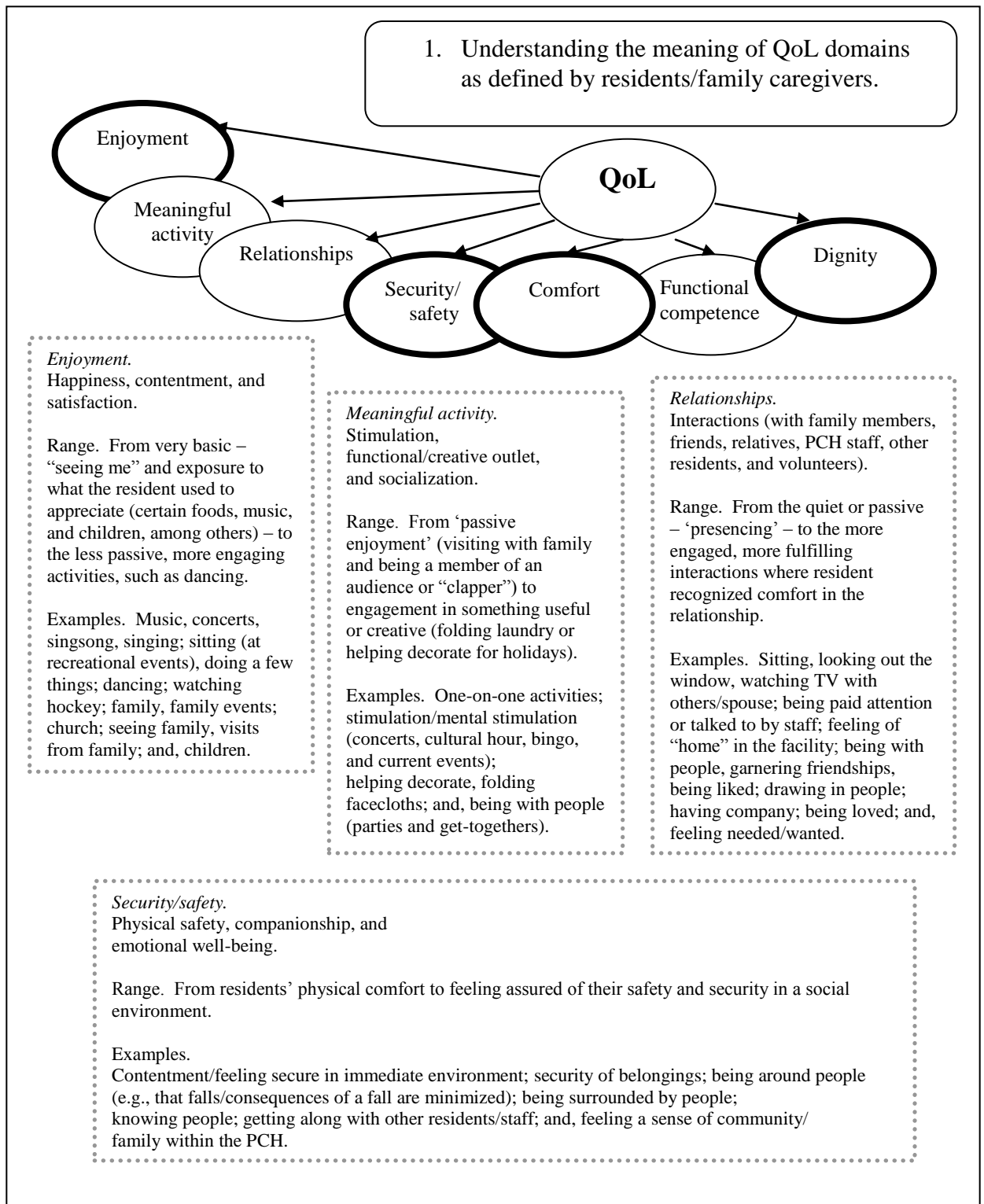


Figure 6.1, continued.

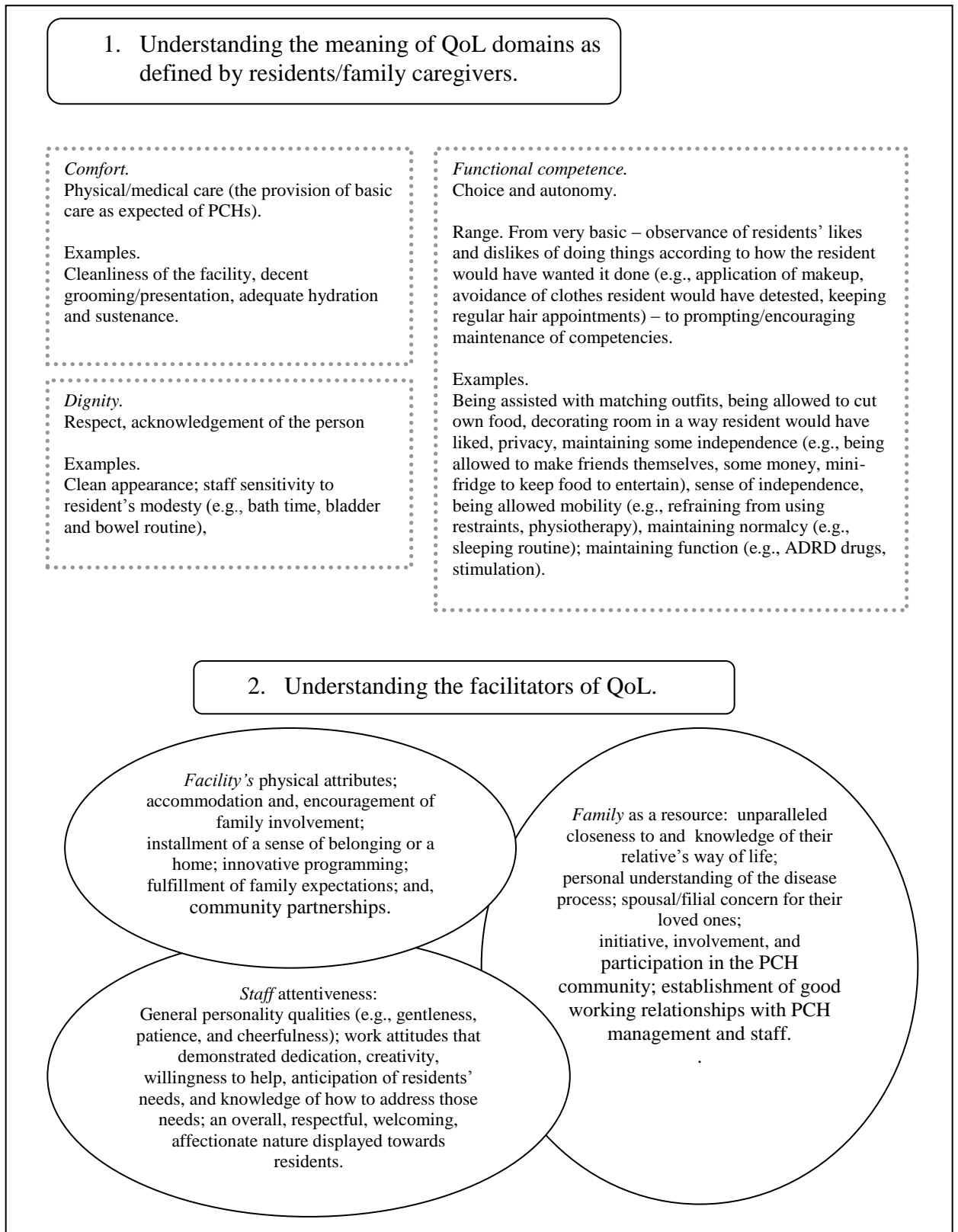
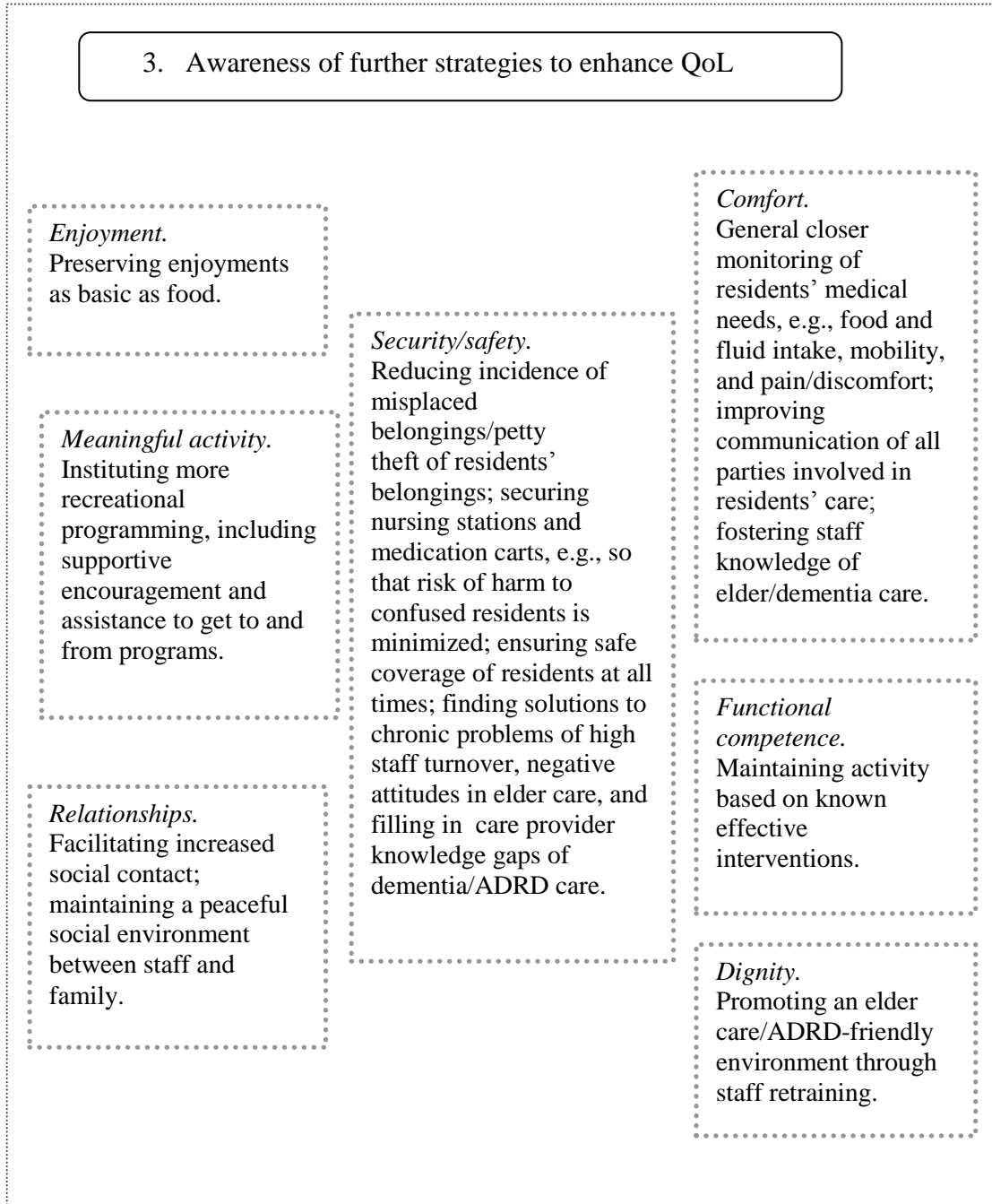


Figure 6.1, continued.



CHAPTER 7 – CONCLUSIONS

This chapter summarizes the contribution of this research to existing knowledge, the limitations of this study, and directions for future scientific inquiry.

7.1 Contribution to Existing Knowledge

Findings of this study reinforce the importance of psychosocial domains (enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence) to the QoL of residents with ADRD, as per the Kane et al. ADRD schematic. However, while Kane et al. did not include dignity in their six domain framework, dignity was disputed to remain as relevant as enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence.

The influence of individual circumstances on perspectives of QoL meaning and on level of achievement of these domains; and the interrelationships between them were emphasized in participants' responses. Most importantly, findings from this study validate the utility of the Kane et al. framework, as a tool that may provide a more complete understanding of QoL.

7.2 Study Limitations and Directions for Future Research

The results of this research were based on one-time interviews with family caregivers of residents with ADRD, in not-for-profit PCHs in the WRHA. Readers are cautioned of several methodological and analytical shortcomings that may limit generalizability of findings.

One method of data collection from a single source did not allow for triangulation of study findings. Cross-sectional data may have been easily tampered with by a recent negative experience, or extrapolated beyond recognition due to a recent laudable deed performed by staff. While criterion sampling was employed, it was basic given historically low participation rates (Aller & Van Ess Coeling, 1995; Guse & Masesar, 1999). Stratification of PCHs, family caregivers, and PCH residents was kept simple. Facility size, age of the facility, or degree of stability were not considered. Family caregiver burden was not assessed; and, possible differences attributed to age, sex, length of stay, or levels of care (ADL function, level of cognitive impairment, and comorbidities) were not reflected in the inclusion/exclusion criteria or analysis.

Moreover, transcripts were not compared between PCH sites, between family caregiver characteristics (sex and type of relationship with resident), or between resident characteristics (age, sex, length of stay, and social support) given the small convenience sample. Possible influences on proxy responses were not also probed further such as the degree of translucency in interviews, degree of relationship with resident, and their own health status, personality, and social situation.

Future scientific inquiry may be directed towards dispelling uncertainties due to the identified methodological and analytical challenges of this research. Additionally, comparisons of QoL perspectives between not-for-profit and proprietary PCHs and between generic wards and ADRD-designated units may be informative on which to develop further strategies to optimize QoL in these health care settings, especially for residents with ADRD.

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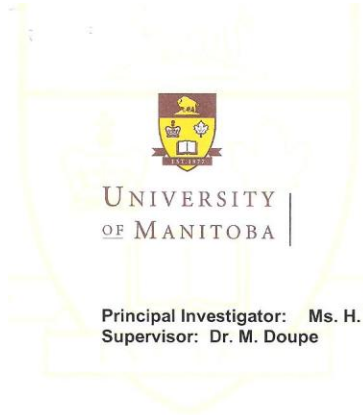
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APPENDICES

Appendix A: University of Manitoba Health Research Ethics Board

Approval of Research Study



BANNATYNE CAMPUS
Research Ethics Boards

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APPROVAL FORM

Principal Investigator: Ms. H. Rona
Supervisor: Dr. M. Doupe

Protocol Reference Number: H2007:108
Date of REB Meeting: May 28, 2007
Date of Approval: June 12, 2007
Date of Expiry: May 28, 2008

Protocol Title: "Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease: Family Caregivers' Perspectives"

The following is/are approved for use:

- Protocol dated May 7, 2007 Revised June 8, 2007 (Version 2)
- Research Participant Information and Consent Form Version 2 dated June 8, 2007
- Letter of Invitation to PCH Version 2 dated June 8, 2007
- Statement of Interest to Participate Version 2 dated June 8, 2007
- Letter of Invitation to Eligible Family Caregivers Version 2 dated June 8, 2007
- Draft Letters of Support from WRHA PCH Directors and PCH Directors dated June 8, 2007
- Handout for Research Participants Version 2 dated June 8, 2007
- Interview Guide Version 2 dated June 8, 2007

The above was approved by Dr. John Arnett, Ph.D., C. Psych., Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated June 8, 2007. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations*.

This approval is valid for one year from the date of the REB meeting at which the study was reviewed. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought from the relevant institution, if required.

Sincerely yours,

A handwritten signature in blue ink, appearing to read "John Arnett".

John Arnett, Ph.D., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above protocol reference number on all correspondence.

Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414

www.umanitoba.ca/faculties/medicine/research/ethics



UNIVERSITY
OF MANITOBA

BANNATYNE CAMPUS
Research Ethics Boards

P126-770 Bannatyne Avenue
Winnipeg, Manitoba
Canada R3E 0W3
Tel: (204) 789-3255
Fax: (204) 789-3414

APPROVAL FORM

Principal Investigator: Ms. H. Rona
Supervisor: Dr. M. Doupe

Protocol Reference Number: H2007:108
Date of Approval: November 2, 2007

Protocol Title: "Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease: Family Caregivers' Perspectives"

The following is/are approved for use:

- Protocol Version 3 dated October 24, 2007
- Research Participant Information and Consent Form, Version 3.0 dated October 24, 2007
- Letter to Invitation to PCH Directors Version 3 dated October 24, 2007
- Draft Letter of Support from the WRHA PCH Program Director Version 3.0 dated October 24, 2007
- Draft Letter of Support from the PCH Director Version 3.0 dated October 24, 2007
- Letter of Invitation to Eligible Family Caregivers Version 3.0 dated October 24, 2007
- Interview Guide Version 3.0 dated October 24, 2007
- Handout for Research Participants Version 3.0 dated October 24, 2007

The above was approved by Dr. John Arnett, Ph.D., C. Psych, Chair, Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your letter dated October 24, 2007. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations*.

A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought from the relevant institution, if required.

Sincerely yours,

John Arnett, Ph.D. C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above protocol reference number on all correspondence.

Inquiries should be directed to the REB Secretary Telephone: (204) 789-3255 / Fax: (204) 789-3414

Appendix B: Winnipeg Regional Health Authority Research Review Committee


Approval of Research Study

MSN Hotmail - Message


Page 1 of 3

Home | My Page | Hotmail | Spaces | Video  Web Search: Go

 Today | Mail | Calendar | Contacts

hazel_annr@hotmail.com 

 Reply |  Reply All |  Forward |  Delete |  Junk |  Put in Folder |  Print View |  Save Address

From : David Hultin <dhultin@wrha.mb.ca> 
Sent : November 6, 2007 5:33:20 PM
To : "Hazel Ann Rona" <hazel_annr@hotmail.com>
Subject : RE: Proposal -Understanding the Quality of Life of PersonalCareHome Residents with Alzheimer's Dise

Good morning Hazel

Thank you for your correspondence regarding amendments to your proposal, WRHA Ref. 2007-032. The Research Review Committee recently met to discuss your request, and I am pleased to report that you have approval to proceed with your study and the amendments noted.

Continued best wishes for successful completion of your project.

Regards
David

David A. Hultin, MA
Project Coordinator
Research and Evaluation Unit
Division of Research and Applied Learning
Winnipeg Regional Health Authority
1900-155 Carlton St.
Winnipeg, MB. R3C 4Y1

(Phone) 204.926.7034
(Fax) 204.947.9970

>>> "Hazel Ann Rona" <hazel_annr@hotmail.com> 10/25/2007 10:32 AM >>>

RE: Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease: Family Caregivers' Perspectives (WRHA Reference No: 2007-032)
Dear Mr. Hultin,
As per our phone conversation, please find attached the necessary documents for expedited review of proposed amendments to my original protocol approved May 31st, 2007 by the WRHA Research Review Committee.
Thank you.
Respectfully submitted,
Hazel Rona

From: "David Hultin" <dhultin@wrha.mb.ca>
To: <umrona@cc.umanitoba.ca>
Subject: Proposal -Understanding the Quality of Life of Personal CareHome Residents with Alzheimer's Disease

<http://by115fd.bay115.hotmail.msn.com/cgi-bin/getmsg?msg=611C5CE8-0415-475A-A72...> 11/7/2007



Winnipeg Regional Health Authority
Office régional de la santé de Winnipeg
Caring for Health À l'écoute de notre santé

1800 - 155 Carlton St.
Winnipeg, Manitoba
R3C 4Y1 CANADA

155, rue Carlton, suite 1800
Winnipeg, Manitoba
R3C 4Y1 CANADA

TEL: 204 / 926.7000
FAX: 204 / 926.7007
www.wrha.mb.ca

TÉL: 204 / 926.7000
TÉLÉC: 204 / 926.7007
www.wrha.mb.ca

May 31, 2007

Hazel Ann Rona / Malcolm Doupe
Department of Community Health Sciences
University of Manitoba
750 Bannatyne Avenue
Winnipeg MB R3E 0W3

Dear Ms Rona and Mr. Doupe:

Re: Proposal "**Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease: Family Caregivers' Perspectives**"
WRHA Reference No: 2007-032

We are pleased to inform you that 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:


- Access to patients in each Personal Care Home to be negotiated individually;
- Ask for volunteers instead of having relatives respond if they are not interested in participating;
- 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*
- You complete and return the attached Confidentiality Agreement(s) to Eleanor Hennessey, WRHA, 1800 - 155 Carlton Street, Winnipeg, MB R3C 4Y1;
- 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.

.../2

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,

A handwritten signature in blue ink, appearing to read "Michael Moffatt", with a stylized flourish at the end.

Michael Moffatt, MSc., M.D., FRCPC
Executive Director
Division of Research and Applied Learning

cc: Dr. B. Postl
Ms L. Esposito
Chair, HREB
Real Cloutier
Lori Lamont

Encl: **PHIA Agreement**

Appendix C: Not-for-profit PCHs in the WRHA

Calvary Place PCH	Calvary Place is a 100-bed PCH and is operated under the sponsorship of the Heritage Benevolent Association of Manitoba, Inc. Its mission is to provide the highest quality of care to the residents in a Christian environment as a genuine expression of Christ's heart and ministry. To accomplish this goal, Calvary Place has embraced a mandate to focus on Christ-like care.
Misericordia Place	Located in the heart of Winnipeg, Misericordia Place PCH opened in February of 2000 and is a fully accredited Faith-based home providing quality care in a home-like environment. Opened in February 2000, the interdisciplinary team incorporates a holistic approach to care based on Misericordia's core values of caring, respect and trust.
Concordia Place	Concordia Place is an accredited 140-bed PCH owned and operated by the Concordia Hospital. Concordia Place is guided by Christian values and strives to provide compassionate, person-oriented care through an interdisciplinary approach.
*Riverview Health Centre	Riverview Health Centre is a 388-bed long-term care facility providing services to the aging and chronically ill. The chronic care and rehabilitative components comprise 160 beds. Two hundred twenty-eight beds are available for PCH residents, including 60 beds dedicated for Alzheimer and other dementia care.
West Park Manor PCH	West Park Manor is an accredited 150 bed PCH in southwest Winnipeg. Being a not-for-profit home, it is run under the sponsorship of the Seventh-day Adventist Church. Its mission is to provide holistic long term in a Christ-like manner as a service to residents.
Bethania Mennonite PCH Inc	Bethania is a 147-bed faith-based PCH. It also houses a highly specialized nine-bed assessment and treatment unit for behaviorally challenged clients. Bethania values creativity and innovation in continuously seeking better ways to enhance the quality of life for elderly persons. The inter-disciplinary team uses a holistic approach to deliver services based on the home's corporate values of trust, respect, integrity and hope.
The Saul and Claribel Simkin Centre	The Simkin Centre, located in Lindenridge, is an accredited faith-based 72-bed PCH dedicated to providing resident focused quality care and support services to the elders of the Jewish Community. The Home provides Kosher meals, cultural programming and spiritual care in a homelike environment according to core Judaic values. An Adult Day Program is also offered.
Convalescent Home of Winnipeg	The Convalescent Home is an accredited PCH for 84 residents. The Home provides a home-like atmosphere and responds to the individual needs of the residents, offering the personal care necessary to enhance and enrich their lives. The Board and Staff are dedicated to a standard of excellence for long-term care and related health services and committed to 'performing small wonders' whenever possible.
Donwood Manor PCH Inc	Donwood Manor is a 121-bed accredited PCH in northeast Winnipeg. Its mission statement is "to uphold the personal dignity through compassionate service and Christian love," which is demonstrated through its focused approach to individual care.
**Foyer Valade Inc	Foyer Valade is a 115-bed accredited Catholic PCH owned by the Catholic Health Corporation of Manitoba (formerly the Grey Nuns). Officially designated as a Francophone

	facility, it offers programs to adults suffering from dementia as well as adults with significant losses of autonomy.
*Fred Douglas Lodge	The Fred Douglas Lodge PCH is part of the faith-based, non-profit Fred Douglas Society. It has life lease units, 28 supportive housing apartments, 15 assisted living units, 38 fixed income-housing units, respite to the community and an Adult Day Program for 18 participants daily. Accredited since 1980, the Lodge is home for 136 residents including eleven beds dedicated to the behaviorally challenged elderly. The Art of Caring™ is embraced through an interdisciplinary team that embraces the values of caring, mutual respect, dignity, and innovation to deliver services in a home-like environment. The Lodge is committed to the spiritual care of residents through on-site Pastoral and Palliative Care Programs.
*Golden West Centennial Lodge	Golden West Centennial Lodge is a 116-bed PCH, located in west Winnipeg. The Lodge offers a variety of programs for its residents including outings, recreation, rehabilitation and music therapy. The philosophy is resident-focused and encourages family and volunteer involvement. The Lodge offers an Adult Day Program for 65 participants.
Holy Family Nursing Home	Holy Family Nursing Home is an accredited 276-bed PCH, dedicated to the practice of Christian values working in harmony with an interdisciplinary team promoting professional excellence. The Home is owned and operated by the Sisters Servants of Mary Immaculate, a Ukrainian Catholic Congregation. Programs and services are designed to meet the needs of the individuals of Ukrainian and Slavic heritage. Holy Family works with the community to meet health care needs, participates in health care programs and promotes research for the improvement of resident care. An Adult Day Program and a Respite Program are also offered.
Pembina Mennonite PCH	Newly renovated, this 57-bed PCH offers specialized services to deaf residents residing in a dedicated unit, in addition to traditional long term care services. Staff are encouraged to develop American Sign Language skills, and participate in courses offered throughout the year. The Home values a holistic approach and addresses physical, emotional and spiritual needs. It is sponsored by the Bethania Mennonite PCH.
Lions Personal Care Centre	The Lions Personal Care Centre is a 116 room PCH, which is one part of the larger complex comprised of Assisted Living, Supportive Housing and Adult Day Clubs. It is Manitoba's first registered Eden facility, focusing on a social (versus medical) approach to care to curb the three common ailments of the elderly - loneliness, helplessness and boredom.
Meadowood Manor	Meadowood Manor is an 88-bed accredited non-profit PCH and 90-suite elderly persons housing complex, committed to "being a Christian community exhibiting the compassion of Jesus Christ". An in-house chaplain provides and co-ordinates spiritual care. One bed is dedicated to respite care.
Luther Home	Luther Home is an 80-bed accredited PCH located in North Winnipeg. Sponsored by the Christ Lutheran Church, the Home provides care to residents of all denominations. Within the Home, there is one designated respite bed available, and an Adult Day Program. The complex includes two Elderly Persons Housing units (total of 89 suites) and a group home for adults with Mental Health disabilities.

*The Middlechurch Home of Winnipeg	Incorporated in 1884, The Middlechurch Home of Winnipeg is an accredited 197 bed PCH, including a life-lease senior's condominium complex. Staff are dedicated to the care and nurture of people in need of physical, psychological, social and spiritual support.
*Park Manor PCH	Park Manor is the only PCH serving Transcona and its surrounding communities. Park Manor is an accredited 100-bed non-profit Home sponsored by the Seventh-day Adventist Church. The interdisciplinary team uses a holistic approach to provide care for residents based on the mission statement of "Offering love, peace, compassion, hope and empowerment...to care as Christ did". The Transcona community responds with significant involvement in programming and volunteer support. An Adult Day Program and Meals on Wheels are also provided to the community.
St. Josephs Residence Inc	St. Joseph's Residence is a 100-bed PCH owned by the Sisters of St. Benedict. This fully accredited residence is located in northwest Winnipeg. The mission of St. Joseph's Residence is "to show forth the God's love in an environment of respect, reverence and hospitality in the spirit of St. Benedict, by fostering compassionate care to the elderly."
*The Sharon Home Inc	The Kanee Centre, located in the North-end, is 157-bed accredited PCH dedicated to providing resident focused quality care and support services to elders of the Jewish Community. Guided by the core Jewish values; Kedushah (sanctity); Derech erets (respect); and Kavod (honor), the organization, in close collaboration with the community, strives to improve the quality of life for all who use its services. Kosher meals and programming is designed to meet cultural needs of our community. An adult Day Program and respite Program are also offered.
*Golden Links PCH	Golden Links Lodge is an 88-bed accredited not-for-profit PCH in the St. Vital area of Winnipeg. It is committed to providing excellence in care in response to the needs of their residents, their families and the community and in keeping with the Odd Fellows' and Rebekahs motto of "Friendship, Love and Truth." Golden Links Lodge also offers an Adult Day Program (24 spaces), respite care (2 beds) and a non-insured in-house foot care program.
*Taché Centre	Taché Centre is a 314-bed accredited Catholic PCH owned by the Catholic Health Corporation of Manitoba (previously the Grey Nuns). Officially designated a bilingual facility, it offers programs to young adults with physical challenges, adults suffering from dementia as well as adults with significant losses of autonomy. Taché also offers a Respite Program, a Day Centre and a Shared Living program.
*Deer Lodge Centre	Deer Lodge Centre is the province's largest rehabilitation and long term care facility with 487 beds. The Centre operates a wide variety of inpatient and community based programs, such as Assessment and Rehabilitation, PCH, Chronic Care, Respiratory Chronic Care, and Psychogeriatrics. One hundred fifty-five of the beds are dedicated to the care of veterans. Deer Lodge Centre works with residents and their families to achieve the mission of "Making lives better."

*Special Needs Unit within the facility.

**Francophone facility with a Special Needs Unit.

Source. Doupe et al., 2006; WRHA, 2006

Appendix D: Student's Letter of Invitation to PCH Directors



The University of Manitoba

Project Title: Understanding the quality of life of personal care home residents with Alzheimer's disease and related dementias: Family caregivers' perspectives.

Researcher: Hazel Ann Rona, RN, BScN [REDACTED]

Advisor: Dr. Malcolm Doupe; [REDACTED]

Date

Ms. Jane Doe
Director, Better Care PCH
1234 First Street
Winnipeg, MB A1C 2B3

Dear

I am a Master's student in the Department of Community Health Sciences at the University of Manitoba currently working on my thesis entitled, "Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease and Related Dementias: Family Caregivers' Perspectives". **The purpose of this research is to gain a better understanding of what quality of life means for residents in a PCH with Alzheimer's disease and related dementias (ADRD).** It is my hope that findings from this research will begin to form a basis for developing strategies to optimize the quality of life for these individuals.

As an established PCH in the WRHA, your facility has been suggested as one of three sites most ideal to conduct this study. **I would like to conduct individual interviews with family caregivers of residents with ADRD who live in your PCH. If interested, your role in this research would be two-fold:**

i) Help select about 6 informal caregivers of residents with AD from your PCH, and send letters (prepared by myself) to these participants inviting them to participate in this research. Please note that caregivers must be the spouse, sibling, or child of a resident in your PCH; be fluent in English; and have visited their loved one in your PCH at least once / week during the past three months. The loved ones of these caregivers must be diagnosed with ADRD (e.g., Alzheimer's disease, vascular dementia, Pick's disease, Lewy body dementia, and Creutzfeldt-Jakob disease) or simply "dementia", be 65 years old or older, have lived in your PCH for the last three months (without being in the hospital for more than one month during this time), have no known diagnosis of schizophrenia, bipolar disorder, mental retardation, or acquired brain injury, not be placed currently in a special care unit or dementia-designated area within your PCH, and not be receiving palliative care or be expected to die in the next month.

ii) Receive the return correspondence from these participants, and forward the names of willing caregivers to me so that I can provide them with more information about this research.

Pending your interest, I have prepared a mail-out package that you can use to help contact caregivers. Please note that I will only contact individuals who have expressed an interest in this research.

This study has received approval from the University of Manitoba Health Research Ethics Board. Ms Lori Lamont is aware of this research and is actually a member of my graduate advisory committee. Please also note that staff or PCH residents will not be involved in the study, there will be no analytic comparisons between participating facilities. Please also be assured that I will take every measure not to pose an inconvenience to your facility. Enrollment is voluntary and a copy of the summary of the findings will be provided to you at the conclusion of the study.

Thank you in advance for your kind consideration. Within a week's time, I will follow up with a phone call to entertain any questions you might have about this research, and if you may be interested in participating. Again, thank you.

Sincerely,

Hazel Ann Rona

Appendix E: Template Letter of Support from the WRHA PCH Program Director

WRHA Logo

Date

Ms. Jane Doe
Director, Better Care PCH
1234 First Street
Winnipeg, MB A1C 2B3

Dear

I have been approached by Hazel Rona regarding her proposed study entitled, “Understanding the Quality of Life of Personal Care Home Residents with Alzheimer’s Disease and Related Dementias: Family Caregivers’ Perspectives”. Hazel is a Master’s Student in the Department of Community Health Sciences at the University of Manitoba. In reviewing the goals of her research and the participant and resident selection criteria, I have suggested your facility as a possible site from which to recruit participants. Enclosed is her letter of introduction outlining the purpose and details of her research. Your participation in this research is voluntary.

Sincerely,

Lori Lamont
PCH Program Director
WRHA
Phone:
E-mail:

Appendix F: Template Letter of Support from the PCH Director

Individual PCH Logo

Date

Ms. Jane Doe
1234 First Street
Winnipeg, MB A1C 2B3

Dear

I have been approached by Hazel Rona regarding her proposed study entitled, “Understanding the Quality of Life of Personal Care Home Residents with Alzheimer’s Disease and Related Dementias: Family Caregivers’ Perspectives”.

Hazel is a Master’s Student in the Department of Community Health Sciences at the University of Manitoba. She has asked if I would help her recruit people to be involved in her study. A letter from Hazel is attached that describes her research in more detail, and also provides directions should you wish to be involved in this research.

Please note that your name will only be passed on to Hazel if/once you provide permission for me to do so. Please also note that your decision to be involved in Hazel’s research will in no way affect the care of your loved one at our PCH.

Thank you in advance for considering this request and please feel free to contact me (XXX-XXXX) if you have any further questions.

Sincerely,

Florence Nightingale
Director, PCH
567 Second Street
Phone:
E-mail:



The University of Manitoba

Project Title: Understanding the quality of life of personal care home residents with Alzheimer's disease and related dementias: Family caregivers' perspectives.

Researcher: Hazel Ann Rona, RN, BScN [REDACTED]

Advisor: Dr. Malcolm Doupe [REDACTED]

Dear Caregiver,

I am a Master's student in the Department of Community Health Sciences at the University of Manitoba, and am currently working on my thesis entitled, "Understanding the Quality of Life of Personal Care Home Residents with Alzheimer's Disease and Related Dementias: Family Caregivers' Perspectives."

The purpose of this research is to gain a better understanding of what quality of life means for residents with Alzheimer's disease and related dementias (ADRD) (e.g., Alzheimer's disease, vascular dementia, Pick's disease, Lewy body dementia, Creutzfeldt-Jakob disease or simply "dementia") **who live in a PCH.** It is my hope that findings from this research will help to develop strategies to optimize the quality of life for these individuals.

As a caregiver of a PCH resident with ADRD, **I am writing this letter to ask if you would participate in my research.** If so, you will be asked to take part in an audio-taped face-to-face interview (just you and I) that will take between 45 and 90 minutes of your time, conducted at a place and time of your convenience. During this interview I will be asking three types of questions, to: (1) describe yourself as caregiver and the health of your loved one in a PCH; (2) gain your perspectives about the quality of life that your loved one experiences in a PCH (e.g., if and how she/he experiences things like enjoyment and relationships); and, (3) understand things that PCH care providers could do to increase your loved one's quality of life.

This study has received approval from the University of Manitoba Health Research Ethics Board. Your loved one or staff members involved in his/her care will not be involved in the study. Your name will only be known to me, and any information you provide will be completely anonymous. Enrollment is voluntary and I will provide you with a summary of my findings at the conclusion of the research.

A self-addressed stamped envelope is provided with this invitation; please indicate if you would like to participate at your earliest convenience. This will help us to determine whether we should approach more individuals. A second letter will be mailed within two weeks if we have not yet heard from you. Thank you for your kind consideration.

Sincerely,

Hazel Ann Rona

STATEMENT OF INTEREST TO PARTICIPATE

I have read the accompanying letter.

PRINT NAME

I am interested in hearing more about this research. I can be contacted at _____ and the best time to call me is _____.

Please return using the self-addressed envelope at your earliest convenience. Thank you.



The University of Manitoba

Project Title: Understanding the quality of life of personal care home residents with Alzheimer's disease and related dementias: Family caregivers' perspectives.

Researcher: Hazel Ann Rona, RN, BScN [REDACTED]

Advisor: Dr. Malcolm Doupe [REDACTED]

RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have about the study or any part of the document that is unclear.

Purpose of Study

This research study is being conducted to gain a better understanding of what quality of life means for residents in a personal care home with Alzheimer's disease and related dementias (e.g., Alzheimer's disease, vascular dementia, Pick's disease, Lewy body dementia, Creutzfeldt-Jakob disease or simply "dementia").

Study Procedures

If you take part in this study, you will be asked to participate in an audio-taped face-to-face interview that will take between 45 and 90 minutes of your time, conducted at a place and time of your convenience. During this interview I will be asking three types of questions, to: (1) describe yourself as caregiver and the health of your loved one in a PCH; (2) gain your perspectives about the quality of life that your loved one experiences in a PCH (e.g., if and how she/he experienced things like enjoyment and relationships); and, (3) understand things that PCH care providers could do to increase your loved one's quality of life. Every effort will be made to complete the interview within the allotted time frame. At the conclusion of the interview, you will be asked for your permission by the research student if she can contact you at a later time to clarify some of your responses.

Risks and Discomforts

This research is not expected to pose much risk to you; however, since the questions may relate to a sensitive topic it is possible that some questions may upset you. You are free to refrain from answering any questions you prefer to omit, without prejudice or consequence.

Benefits

There may or may not be direct benefit to you from participating in this study. We hope the information learned from this study will benefit health care providers in the development of strategies and interventions to help enhance the quality of life of individuals with Alzheimer's disease and related dementias in personal care homes in the future.

Acknowledgment of Participation

Unfortunately, we cannot offer you more than our thanks for taking part in this research. A copy of the summary of our findings will be mailed to you at the conclusion of the study.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however, your name and other identifying information will not be used or revealed. All study related documents will bear only your assigned study number. Signed consent forms will be scanned and stored electronically in a password-protected file in a secure computer. Digital recordings of the interviews will likewise be stored in a password-protected file in a secure computer. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All records will be kept in a locked secure area and only those persons identified will have access to these records. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate

or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your loved one's care at his/her personal care home.

We will tell you about any new information that may influence your willingness to stay in this study.

Questions

If any questions come up during or after the study, please contact the undersigned at ([REDACTED])
This is a part of my research and my advisor, Dr. Malcolm Doupe can be alternately contacted at [REDACTED]

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study with Hazel Rona. I have had my questions answered by her in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by her to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

Participant signature _____

Date _____
(day/month/year)

Participant printed name: _____

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: _____

Date _____
(day/month/year)

Signature: _____

Role in the study: _____

Appendix I: Interview Guide

[Before meeting the participant, will record date and agreed meeting time, as well as with whom the interview is with.]

[Start recording.]

Our interview begins with introductory questions about yourself and your loved one – for example, how you are related and how long he/she has been living at the personal care home -- to help us understand where you are coming from; followed by specific questions about your perception of their quality of life in the personal care home in the last three months. Lastly, we will conclude our interview with a basic description of your loved one's health status, mental and physical functioning.

PART I-A: Introductory questions about the participant.

1. You have a loved one who lives in a personal care home. How are you related?
 - a. (Spouse) How long have you been married? Do you have children?
 - b. (Child) How many siblings do you have?
 - i. (Has siblings) Where are they living? Where do you fit in?
[probe: oldest/youngest, only daughter]
 - c. (Sibling) Your brother/sister has no children? He/she has never married?
2. How long has it been since you have acted as the primary caregiver for your husband/wife/brother/sister/father/mother?
3. How did you become the primary caregiver?
4. Are there others involved in his/her care?
 - a. (Yes) Who and how are they involved?
5. How was your relationship with your husband/wife/brother/sister/father/mother before his/her admission to the personal care home? What kind of things did you do for him/her?
6. How often do you see your husband/wife/brother/sister/father/mother now at the personal care home? Do you come at a particular time (morning/afternoon/evening) or it varies?

PART I-B: Introductory questions about the resident.

1. How long has it been since your husband/wife/brother/sister/father/mother resided at this personal care home?
2. Is this the first personal care home your husband/wife/brother/sister/father/mother has been admitted to?
 - a. (No) How long was his/her stay at the previous personal care home?
 - i. Why did he/she move?
 - ii. Were there other personal care homes before that?

3. Does he/she live in a single room?
 - a. (No) How many roommate(s) does he/she have?
 - i. Does he/she get along well with the roommate(s)?
 - ii. Have there been problems with the roommate(s) in the past?
 1. (Yes) What kind of problems?
4. How old is your husband/wife/brother/sister/father/mother?
5. When did he/she retire? Retire from? How did he/she spend his/her retirement years? [probe: volunteer work, clubs/organizations he/she was affiliated with, hobbies, interests, daily routine]
6. Are there any other things you like to mention, to help me understand more about your loved one?

PART II. Specific questions about the resident's quality of life in the personal care home using Kane et al.'s framework as a guide.

In discussing quality of life, we will use the last three months as our time reference. I have adopted the work of some researchers who feel that enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence as important domains/components of quality of life in personal care homes. To describe their quality of life, we will examine each of those domains in detail, again, using the last three months in the personal care home. [provide handout: Appendix J]

1. Enjoyment is defined as resident expresses or displays pleasure, verbally or nonverbally; not unhappiness, distress or lack of enjoyment
 - i. Does this definition make sense to you?
 1. (Yes) Anything to add to this definition?
 2. (No) Why? Would you have defined it differently?
 - a. (Yes) How would you define enjoyment?
 - ii. Do you think enjoyment is important to your loved one?
 1. (Yes) Why?
 - a. Do you think your husband/wife/brother/sister/father/mother experiences this?
 - i. (Yes) Can you think of some examples of how enjoyment is experienced?
- [Probe: What does the resident enjoy presently? What did he/she use to enjoy? What among those examples can he/she still enjoy in a personal care home at their present health status, mental and physical functioning? How do you know they enjoy?]
1. Are there some things the personal care home can do differently to maximize your loved one's experience of enjoyment?
 - ii. (No) Why? What could be done differently so that your loved one experiences enjoyment?

2. (No) Why not?

2. Meaningful activity is defined as resident engages in discretionary behaviour or in activity he/she enjoys or finds comfort in; is not bored

i. Does this definition make sense to you?

1. (Yes) Anything to add to this definition?

2. (No) Why? Would you have defined it differently?

a. (Yes) How would you define meaningful activity?

ii. Do you think meaningful activity is important to your loved one?

1. (Yes) Why?

a. Do you think your husband/wife/brother/sister/father/mother experiences this?

i. (Yes) Can you think of some examples of how meaningful activity is experienced?

[Probe: What kind of activities does the resident engage in or find comfort in presently?]

1. Are there some things the personal care home can do differently to maximize your loved one's experience of meaningful activity?

ii. (No) Why? What could be done differently so that your loved one experiences meaningful activity?

2. (No) Why not?

3. Relationships is defined as resident engages in social interactions; finds comfort in family, friends, or staff

i. Does this definition make sense to you?

1. (Yes) Anything to add to this definition?

2. (No) Why? Would you have defined it differently?

a. (Yes) How would you define relationships?

ii. Do you think relationships are important to your loved one?

1. (Yes) Why?

a. Do you think your husband/wife/brother/sister/father/mother experiences this?

i. (Yes) Can you think of some examples?

[Probe: Who compose the resident's social network? Whose company/presence does the resident enjoy?]

1. Are there some things the personal care home can do

differently to maximize your loved one's experience of this domain?

- ii. (No) Why? What could be done differently so that your loved one experiences meaningful relationships?

2. (No) Why not?

4. Security/safety is defined as resident is clear about rules and practices; feels safe/secure/confident about his/her personal safety and security of their possessions

i. Does this definition make sense to you?

1. (Yes) Anything to add to this definition?

2. (No) Why? Would you have defined it differently?

a. (Yes) How would you define security/safety?

ii. Do you think security/safety is important to your loved one?

1. (Yes) Why?

a. Do you think your husband/wife/brother/sister/father/mother experiences this?

i. (Yes) Can you think of some examples of how security/safety is experienced?

[Probe: What does feeling secure and safe to the resident mean at his/her current health status, mental and physical functioning?]

1. Are there some things the personal care home can do differently to maximize your loved one's experience of security/safety?

ii. (No) Why? What could be done differently so that your loved one experiences security/safety?

2. (No) Why not?

5. Comfort is defined as resident experiences minimal physical discomfort (from pain, aches, nausea, dizziness, constipation, or itching) and no discomfort (from being cold, hot, thirsty, or in an uncomfortable position); staff notice and attend to their physical comfort

i. Does this definition make sense to you?

1. (Yes) Anything to add to this definition?

2. (No) Why? Would you have defined it differently?

a. (Yes) How would you define comfort?

ii. Do you think comfort important to your loved one?

1. (Yes) Why?

- a. Do you think your husband/wife/brother/sister/father/mother experiences this?
 - i. (Yes) Can you think of some examples of how comfort is experienced?

[Probe: Can the resident relay his/her needs? Is staff perceptive and responsive to those needs? What cues should staff be perceptive of? What is comforting/what settles them down?]

- 1. Are there some things the personal care home can do differently to maximize your loved one's experience of comfort?
 - ii. (No) Why? What could be done differently so that your loved one experiences comfort?
- 2. (No) Why not?

6. Functional competence is defined as resident functions independently in keeping with his/her abilities and preferences or to what they can do on their own according to how they like things done

- i. Does this definition make sense to you?
 - 1. (Yes) Anything to add to this definition?
 - 2. (No) Why? Would you have defined it differently?
 - a. (Yes) How would you define functional competence?

ii. Do you think this important to your loved one?

- 1. (Yes) Why?
 - a. Do you think your husband/wife/brother/sister/father/mother experiences this?
 - i. (Yes) Can you think of some examples of how functional competence is experienced?

[Probe: What can the resident do/cannot do? What are his/her preferences? What among his/her capabilities are encouraged? Preferences followed?]

- 1. Are there some things the personal care home can do differently to maximize your loved one's experience of this domain?
 - ii. (No) Why? What could be done differently so that your loved one experiences functional competence?
- 2. (No) Why not?

7. Enjoyment, meaningful activity, relationships, security/safety, comfort, and functional competence, as listed on your handout have been mentioned. Do you think they embody quality of life in a personal care home completely? [allow interviewee to consider this question]
 - a. (No) What else is important? Why? Can you provide examples to help me understand what you mean?
8. How would you rank all domains, including those you've added, in order of importance?

PART III. Questions related to the resident's health status, mental and physical functioning.

We have talked about your loved one's quality of life in a personal care home, but we haven't yet discussed his/her health status or mental and physical functioning in the last three months.

1. What medical conditions has he/she been diagnosed with?
 - a. How long has it been since the diagnosis of dementia?
 - b. What signs and symptoms of dementia have been prominent in the last three months? [probe: see symptoms below]

Early Stage	Middle Stage	Late Stage
<ul style="list-style-type: none"> • mild forgetfulness and communication problems • difficulties with orientation, learning new things, and concentration • mood changes • passiveness, withdrawal, and, depression • mild coordination problems 	<ul style="list-style-type: none"> • forgetfulness about personal history • personality changes • increased confusion, anxiety, and restlessness • delusions and uninhibited behaviour • increased needs for ADL assistance • changes in appetite and sleep patterns • language difficulties • visual spatial problems 	<ul style="list-style-type: none"> • loss of recall, communication, functional, and information processing abilities • severe disorientation • possible withdrawal • increased use of non-verbal methods of communication • loss of mobility • loss of bladder and bowel control • 24-hour supervision required

2. Are there other health issues? For example, does he/she presently experience frequent headaches and dizziness, shortness of breath, nausea and vomiting, upset stomach or cramps, decreased appetite, diarrhea, constipation, new bladder/bowel incontinence (that is, bedwetting or is unable to anticipate going to the bathroom), pain not relieved by medication, tiredness, bedsore, recent fall in the past three months, appointment with a specialist in the past three months, hospital stay in the past three months?

- a. (Yes – fall) How was he/she affected by the fall?
 - b. (Yes – appointment with a specialist) The appointment with a specialist was in regards to?
 - c. (Yes – hospital stay in the past three months) The hospital stay was in regards to? How long did he/she stay in hospital?
3. How would you describe your husband/wife/brother/sister/father/mother today mentally and physically?
- a. How would you describe a typical visit?
 - b. A typical day?
 - c. Is there anything else you'd like to talk about that I haven't thought to ask?

I shouldn't encroach on your time any longer. Thank you very much. Once all interviews are completed, you will receive a copy of my findings in a year or two from now. May I contact you at a later time if I need to clarify some of your responses?

[Stop recording.]

[Note total duration of the interview.]

Appendix J: Handout for Research Participants

Quality of life. "... the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual." It includes psychological well-being, behavioural competence, objective environment, and perceived quality of life.

Enjoyment. Expresses or displays pleasure, verbally or nonverbally; not unhappiness, distress or lack of enjoyment.

Meaningful activity. Engages in discretionary behaviour or in activity he/she enjoys or finds comfort in; is not bored.

Relationships. Engages in social interactions; finds comfort in family, friends, or staff.

Security/safety. Is clear about rules and practices; feels safe/secure/confident about his/her personal safety and security of their possessions.

Comfort. Experiences minimal discomfort (from pain, aches, nausea, dizziness, constipation, or itching) and no discomfort (from being cold, hot, thirsty, or in an uncomfortable position); staff notice and attend to their physical comfort.

Functional competence. Functions independently in keeping with his/her abilities and preferences, or to what they can do on their own according to how they like things done.