Mount Saint Vincent University
Department of Family Studies and Gerontology

Silent partner in care: Impact of physical environment on quality of life for residents with cognitive impairment in long-term care

by

Stephanie A. Chamberlain

A Thesis

submitted in partial fulfillment

of the requirements for the degree of

Master of Arts in Family Studies and Gerontology

June, 2014

Halifax, Nova Scotia

Mount Saint Vincent University

Department of Family Studies and Gerontology

Silent partner in care: Impact of physical environment on quality of life for residents with cognitive impairment in long-term care

by

Stephanie A. Chamberlain

Approved:

Janice M. Keefe, Ph.D. Professor, Family Studies and Gerontology Director, Nova Scotia Centre on Aging and Lena Isabel Jodrey Chair in Gerontology Mount Saint Vincent University Thesis Advisor	Date
Pamela Fancey, M.A Associate Director, Nova Scotia Centre on Aging Nova Scotia Centre on Aging Member, Thesis Committee	Date
Robin Stadnyk, Ph.D, OT(Reg) NS Assistant Professor and Post-Professional Coordinator School of Occupational Therapy Dalhousie University Member, Thesis Committee	Date

Dedication

For Myrtle, Hazel, and Kay, my role models and the great loves of my life.

Abstract

The increase in older adults in the Maritime provinces signifies the need to focus on the suitability of current continuing care services, and plan for the expected increase in prevalence of Alzheimer's and related dementias. Nursing homes have an increasing need to offer spaces that are consistent with the changing health needs of older adults with cognitive impairments, and support family and community engagement in the home. Family members of residents with cognitive impairments provide a unique opportunity to examine the perspective of family, who are often an under examined partner in the care team.

This study examines family member survey and case study data collected by the Care and Construction project. Using the Person-Environment Fit Model, the aim of the project is to explore the impact of facility features and design elements on quality of life for residents with cognitive impairment from the family perspective. The research seeks to better understand how residents and family members use the available space and if the environment supports their interactions in the home.

Analysis of the survey data revealed a relationship between the homelikeness, square footage, and size of neighborhood on resident quality of life. Family members have positive perceptions of the nursing home environment when there is an opportunity to personalize private space, and there are communal areas that support social engagement and individual resident activity needs. The analysis suggests that facility features and design elements can positively impact family member perceptions of cognitively impaired resident quality of life.

Acknowledgements

This thesis could not have been completed without the assistance and dedication of many individuals. I would first like to thank Janice Keefe, my supervisor, for her mentorship, both in this Master's program and towards my future career goals. I was exceptionally fortunate to have Pamela Fancey and Robin Stadnyk as my committee members. Their insight and encouragement throughout the entire process was invaluable. I would like to thank the Nova Scotia Centre on Aging for allowing me access to the data, without which this entire project would not have been possible.

I would like to thank Judith Godin for her assistance with statistical analysis. Her knowledge and enduring positive attitude were, at times, the only light at the end of the analysis tunnel. I am so lucky to have found both a colleague, and a friend in Christy Nickerson-Rak, her positivity and good humour were a necessity throughout the thesis process. Thank you to Rachel Ogilvie for her careful editing and formatting skills.

I would like to recognize my fellow graduate students for their support. In particular, Sacha Nadeau, who acted as a willing sounding board and gerontology partner-in-crime.

Finally, I would like to thank my Mom and Dad for their continued emotional and financial support. They have set an unbelievable example of how with hard work and perseverance you can achieve your goals.

Table of Contents

List of Figures

List of Tables

Chapter 1: Introduction and Research Questions

Introduction

Canada is undergoing a demographic shift, which will see a larger proportion of the population made up of older adults. The increase in older adult population is expected to require over 10,000 new long-term care beds every year for the next 35 years (Canadian Medical Association, 2013). The Maritime provinces will feel the weight of demographic change given that they are home to the highest proportion of elderly population, with 16.5% of the Nova Scotia population over the age of 65 (Statistics Canada, 2011). In response to the increase in older adults, the Nova Scotia government was tasked with refocusing policy to address the needs of this growing segment of the population. In 2006, the Department of Health and Wellness released their Continuing Care Strategy (CCS), which committed to funding the addition of new long-term care beds, with 832 to be created in 2010, increasing to a total of 1,320 over eight years (Department of Health and Wellness, 2006). The CCS proposed new models of care and marked a new era of long-term care facilities that reflect attention to staffing approach, physical design, and homelikeness of long-term care homes.

Nova Scotia is not alone in developing homes with new physical design and homelikeness. Scandinavian countries, such as Sweden, operate nursing homes known as group living homes, developed as the social alternative to traditional medical designs and approaches (Annerstedt, 1993; Kihlgren et al., 1993; Malmbery & Zarit, 1993). A close comparator to Scandanavian models of group living is the Green House® model, which was created out of the Eden Alternative philosophy in the United States and consists of a single home with six to twelve residents (Kane, Lum, Cutler, Degenholtz, & Yu, 2007;

Rabig & Rabig, 2008). In addition Prince Edward Island (PEI) has recently announced its plans for developing smaller neighbourhood type long term care facilities with five replacement facilities feature neighbourhood style living arrangements with communal living space, courtyard access and private bedrooms (PEI Department of Health and Wellness, 2012).

Initiatives to identify those aspects of nursing homes promoting respect for resident desires and opinions are not new, but the focus on both environmental and personnel changes are described as the culture change movement (White et al., 2012). Mission statements and organizational approaches to care identify as practicing resident-centered, resident-directed or person-centered care; all approaches are focused on resident well-being (Brune, 2011; Chapin, 2010; Rahman & Schnelle, 2008). Architectural and environmental change is a key component within the culture change movement, which includes design to enhance homelikeness of the facilities and represent a focus on smaller homes with "neighbourhood" or "cottage" style configurations (Rabig & Rabig, 2008; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). The cottages include a smaller number of residents with private bedrooms surrounding a centralized living space.

As existing homes are being renovated and new ones built, both in Nova Scotia and across the country, it is important to keep in mind the future demographic landscape of long-term care. The Alzheimer's Society of Canada estimates that by 2038 nearly 3% of the Canadian population will have dementia, an increase of 2.3 times the current number (Rising Tide Report, 2010, p.7). Presence of a cognitive impairment is the "most common reason for entry into a nursing home" (Zimmerman et al., 2013, p. 1399).

Approximately three out of five residents in long-term care, nearly 60%, have a diagnosis of dementia (Canadian Institute for Health Information, 2009).

In addition, due to gender differences in life expectancy, rates of dementia are higher for women than men and "of the years senior women live with dementia, 1.4 years on average are spent in facility based long-term care, as compared to 0.6 years for men" (Canadian Healthcare Association, 2009, p.62). Nursing homes must be designed for the anticipated resident population that has a greater likelihood of cognitive impairment (Lawton, 2001). There has been an increase in homes built within the context of the "culture-change movement", but the extent of their impact on quality of life for residents with cognitive impairments is unknown (Rahman & Schnelle, 2008). The presence of cognitive impairment means that residents may be unable to participate in research, and family members of residents in long-term care offer a unique perspective with which to examine resident quality of life and foreshadow future needs.

Research Questions

This research seeks to better understand the impact of physical design on residents with cognitive impairment from the family perspective. A secondary data analysis of survey and interview data was conducted to explore the impact of varied physical designs on resident quality of life with the objective of better understanding:

1. From the family perspective, to what extent do facility characteristics impact resident quality of life for those with cognitive impairment?
2. In what way does the physical environment impact family and resident use of space?

Chapter 2: Theoretical Framework

To achieve the research objectives, Lawton and Nahemow's (1973) Person Environment Fit Model (PEFM) was used to analyze both environmental and individual characteristics and their impact on quality of life. The PEFM is a foundational theoretical framework within environmental gerontology and describes the balance between individual capacity and the environment's ability to support or hinder behavioural outcomes (Figure 1). The model is framed as a delicate balance between competence and press. Competence is the functional capacity of an individual, namely physical, psychological and intellectual capacity (Lawton, 1977). Press is the effect of environment on the individual.

The interaction of competence-press results in behavioural outcomes based on the achievement of equilibrium between individual and environmental factors, known as the adaptation level (Sheidt & Norris-Baker, 2003). Inconsistencies between individual functional capacity and environmental stressors result in negative emotional states and maladaptive behaviours. At the model's conception, Lawton and Nahemow described its intended population as the vulnerable elderly. Given that persons with cognitive impairment have lowered thresholds for physiological and psychological stress, they are more vulnerable to maladaptive environmental stimuli (Grant, 1996).

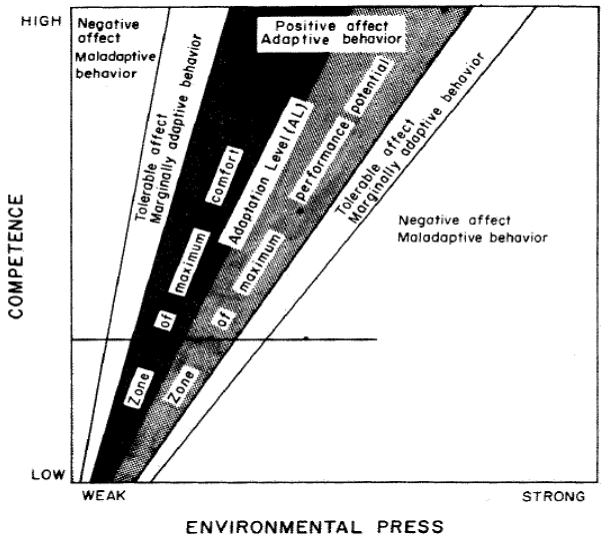

Figure 1. Lawton and Nahemov (1973) Person Environment Fit Model

For this research project, Lawton and Nahemov's model was used to examine competence as it relates to cognitive capacity, and the impact of physical environment on resident quality of life within nursing homes. Given that the model reflects both relational and environmental contexts, it is appropriate for this research project because it "provides insight into resident-level variables that may interact with facility-level variables to affect the provision of high quality care" (Bravo, De Wals, Dubois & Charpentier, 1999, p.180). Residents in long-term care with cognitive impairment have reduced capacity, and the concept of environmental docility proposed by Lawton suggests that reduced capacity could result in a "greater likelihood that one's behaviour or subjective state would be controlled by environmental factors" (Lawton, 1990, p. 345 as cited in Sheidt & Norris-Baker, 2003, p. 36).

It must be noted that the model has been criticized within gerontological research as only describing the characteristics of the individual and the environment, with limited analysis focused on a measurable outcome of the person and environment interaction

(Scheidt & Norris-Baker, 2003). The focus on resident quality of life as the outcome moves beyond previous criticism of the model to examine the transactional relationship between individual and environment. The PEFM model has been used to inform the literature review with a focus on the intersection of environmental components of nursing homes, resident capacity and their resultant impact on perceived resident quality of life.

Chapter 3: Review of the Literature

Chapter Overview

Resident quality of life is a multifaceted concept, and can be explored through the lenses of cognition, perspective, and facility characteristics and design. Individual level cognitive characteristics will be explored to address the potential for functional challenges and opportunities for larger scale environmental intervention. Family member as respondent will be explored as a unique perspective, to understand residents who may be unable to provide consent and as an observer to assess quality of life of the resident within the physical environment of the nursing home. This literature review will examine the intertwining relationship between cognition and environment on quality of life from a family perspective.

Quality of Life

Quality of life is increasingly used as an outcome measure in nursing home research because it recognizes that well-being is a complex system of interacting personal and contextual components. Although the term is used frequently within research, there are many interpretations of what components are included in its definition. An overview of global and disease specific quality of life definitions is useful in examining those elements which are universal across measures.

Global measures of quality of life have been developed by organizations including the World Health Organization, which employs a definition referencing personal characteristics as well as environmental and social features of the individual's life (WHO, 1997). Quality of life is understood from a single individual's perspective,

and can be understood in relation to the larger societal context in which they live. The assessment of quality includes the interactions of personal beliefs and expectations. Powell Lawton's (1997) definition is perhaps the foundational understanding of quality of life, which consists of four domains including psychological well-being, individual perceptions of quality of life, behavioural competence and environment influence. Articulations of quality of life offered by Stewart and King (1991) include domains that measure internal satisfaction with life, self-esteem, autonomy, and heath including physical and cognitive ability and ability to perform self-care, focusing on internal competencies and broadening the understanding of psychological and behavioural needs from Lawton's more basic four domain descriptions (p. 28-29).

Frameworks designed specifically for residents within nursing homes identify domains including "autonomy, privacy, dignity, meaningful activity, relationships, food enjoyment, security, functional competence and spiritual well-being" as primary areas of interest (Kane, 2003, p. 31). Kane's measurement tool recognizes that domains are not static, but interact and are impacted on by other factors. For example, food and the experience of dining also influence autonomy and competence.

The range of cognitive impairments and their resulting health and behavioural challenges necessitates alternative measures to better understand the quality of life of persons with cognitive impairment. The onset of illness or disease does not alone define quality of life, nor relegate persons to negative experience, but the understanding of quality of life benefits from disease specific lens to assess those aspects of quality of life that are impacted by illness (Rabins, Kasper, Kleinman, Black & Patrick, 1999). The Dementia Quality of Life Instrument (DQLI) offers a disease specific lens and identified

two unique variables: sense of aesthetics-- the appreciation of surroundings and stimulation of sensory capacity; and interaction capacity-- the relationship between individual cognitive and communication challenges and relationship building (Brod, Stewart, Sands, & Walton, 1999). Dementia-specific quality of life instruments highlight the potential differences across perspectives. When the DQL domains are examined between resident and family, residents cited opportunities for attachment and social contact as important, whereas family identified aesthetics of the home frequently as positively influencing quality of life (Dröes et al., 2006).

Similar to the DQLI, the Alzheimer Disease Related Quality of Life (ADRQL) focuses on quality of life for persons with Alzheimer's and has five domains which include social interaction, awareness of self, feelings and mood, enjoyment of activities and response to surroundings (Rabins et al., 1999). When comparing disease specific instruments such as the DQLI and ADRQL both have items focused on the physical environment, which has not been demonstrated in other non-disease specific instruments. The inclusion of environmental impact on resident quality of life within the instruments highlights the potential importance of design elements on residents with cognitive challenges.

Quality of life is an interaction of individual and contextual factors, which allows for a description of experience beyond purely clinical indicators (Barnes, 2002; Degenholtz, Kane, Kane, Bershadsky & Kling, 2006; Lawton, Winter, Kleban & Ruckdeschel, 1999;). While there are a variety of models available, quality of life scales provide a useful objective measure of a subjective phenomenon. Disease specific quality of life measures informs my literature review by revealing environmental context and

design elements, such as response to surroundings and sense of aesthetics as important, in particular from the family's perspective.

Cognitive Impairment and Physical Design

The expected increase in older adult population with cognitive impairments creates a need to further examine their interactions with healthcare institutions. The physiological indicators of dementia can vary by individual, but typically include gradual reductions in memory, executive functioning, spatial perception, behavioural disturbances, stress thresholds and mood (Alzheimer's Australia, 2004; Burgener, Twigg, & Popovich, 2005). A large body of research focuses on how physical environment can induce or mediate behaviours related to cognitive impairment, such as pacing and disruptive behaviours, with a particular focus on residents in special dementia units (see Cohen-Mansfield & Werner, 1998; Low, Draper, & Brodaty, 2004; Morgan & Stewart, 1998; Zeisel et al., 2003). This provides an opportunity to further explore the environment as it relates to residents with cognitive impairment, but move beyond responsive behaviours and focus on overall quality of life.

Morgan and Stewart (1998) examined the movement of residents from a high-density unit to low-density unit and found overall improvement in non-disruptive behaviour in the lower density units. Rather than design to limit and constrain behaviours, it is possible to move "beyond designing in order to control, affect or diminish 'problem behaviour,' and instead improve overall resident quality of life" (Chalfont & Rodiek, 2005, p. 347).

In addition to behaviour disturbances, cognitive impairment can lead to reduced visuospatial orientation, leading to challenges navigating a nursing home. Wayfinding

can be assisted by “eliminating any unnecessary alcoves and wall recesses within the corridor walls” (Marquardt & Schmieg, 2009, p.335). After examining wayfinding behaviours of residents in Montreal, Passini et al. (2000) found that monotonous design elements and limited visual access to main living areas introduced more wayfinding challenges. Residents with cognitive impairment have challenges orienting within large, multi-purpose rooms with indistinguishable activity areas, spaces that have a clearly recognizable purpose assist in orientation and wayfinding (Alzheimer’s Society Australia, 2004). Residents with cognitive impairments benefit from “a continuous wandering loop and fewer residents than in a traditional unit” as these provide greater opportunity for social interaction as well as direction (Chappell & Reid, 2000, p. S236). Homes can compensate for cognitive losses by providing decorative cues and personalized room entrances to assist residents in identifying their location within the unit and home (Davis et al., 2009).

The relationship between cognition, outcomes and environment is often compared between special care units and traditional homes (Chappell & Reid, 2000; Falk, Wijk, & Persson, 2009; Kutner, Mistretta, Barnhart, & Beldoff, 1999). The new neighbourhood configurations, which include circular areas for wayfinding, clustering of private and interactional areas, are indicative of special care facility design principles; therefore many of the dementia friendly design principles are embedded within the small homes design (Kovach, Weisman, Chaudhury, & Calkins, 1997). Verbeek et al. (2009) completed a literature review regarding the presence of homelike nursing home arrangements and found only two peer-reviewed papers from the Canadian context, both of which concerned special care facilities (see Reimer, Slaughter, Donaldson, Currie, & Eliasziw,

2004; Slaughter, Calkins, Eliasziw, & Reimer, 2006). The emergence of small homes with integrated units including residents with and without cognitive impairment provides an alternative design from that of primarily special care units as the sole environment for residents with cognitive impairment.

Environmental features have more impact on residents in early stages of impairment than for those with more severe symptomology. The higher the degree of impairment, the greater emphasis is placed on personal care than physical design, as the environment is unlikely to significantly impact behaviour (Cohen-Mansfield & Werner, 1998; Cutler, Kane, Degenholtz, Miller, & Grant, 2006). Residents who are less impaired may be more capable of participating in social activities; therefore designs that enhance social interaction may have a greater impact on residents with less cognitive impairment (Edelman, Fulton, Kuhn, & Chang, 2005). Family members of residents with severe cognitive impairment placed less importance in the physical design and aesthetics given the increased care needs, finding that privacy was not a significant concern (Cooney & McClintock, 2008). Lawton (2001) reminds us that nursing homes must be designed with the anticipated population in mind. Given the capacity and needs of residents in nursing homes, environmental modifications must be tailored towards these varying levels of impairment (Teresi, Holmes, & Ory, 2000).

Family Perspective

Examining the perspective of family members of residents in long-term care necessitates a discussion of the applicability of external persons to describe the subjective phenomenon of quality of life. The use of proxies as respondents to assess quality of life is challenged throughout gerontological literature because when comparing proxy and

informant reports of quality of life there is relatively poor response agreement, with family reporting quality of life as lower than the resident (Conde-Sala et al., 2009; Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011; Novella et al., 2001; Ready, Ott, & Grace, 2004). It must be acknowledged that there are clear limitations to assessing quality of life from a perspective other than the subject of interest.

Nevertheless, the family remains an integral part of the resident's life and contributes to positive psychosocial well-being (Naleppa, 1997). Their perception of the resident's quality of life is an important perspective to assess– particularly for people who have dementia-as they often provide information about the residents' previous life and monitor resident care (Bowers, 1988; Dupuis & Norris, 2001). When describing the source of important social and emotional relationships, residents will most often identify a family member, giving the home an increasing responsibility to provide a supportive environment for both residents and their family (Moyle, McAllister, Venturato, & Adams, 2007). Family members often have had a long career having provided both technical care and emotional support for residents in nursing homes (Dupuis & Norris, 2001; Gaugler, 2005; Keefe & Fancey, 2000).

An environment that supports resident needs will likely have a positive influence on family satisfaction (Calkins, 2005; Lum, Kane, Cutler, & Yu, 2008). Family members identify homes as being more "family-oriented if they offered private spaces for families and residents to meet" (Gaugler, 2006, p.93). Environmental features have the capacity to enhance family involvement and provide opportunities for residents to take pride in their surroundings (Gaugler, Andersen, & Leach, 2004, p. 778). Features within the physical design that facilitate interaction, such as designing rooms for family events and private

meeting areas, create opportunities for social interaction. Families report that their visits are more enjoyable when they are given a variety of options of space and can interact in spaces that are reminiscent of home (Angelilli, 2006). Neighbourhood or cottage dining arrangements, in comparison to large facility dining rooms, offer more opportunities for personal, intimate communication between residents and their family members (Davis et al., 2009). Communal areas create a more inviting space to visit grandchildren who otherwise may be uncomfortable in an institutional environment (Cioffi, Fleming, Wilkes, Sinfield, & Le Miere, 2007). Designated areas for informal socializing can discourage isolation, as well as provide seating for residents who have mobility and ambulation challenges (McAllister & Silverman, 1999).

Physical Environment

Physical environment characteristics range from building and unit size, to design elements within various areas of the home. Although the importance of identifying quality of life from a family perspective was previously stated, the following research was not completed from a family perspective unless otherwise stated, demonstrating a distinct lack of available research. The physical environment has not been considered at the forefront of quality of life, rather a silent partner in care (Cohen-Mansfield & Werner, 1998). Although the culture change movement includes both the physical and social dimensions of care, philosophical and staffing modifications are most often described in relation to resident outcomes with little examination of physical environment (Chapin, 2010; Rahman & Schnelle, 2008).

Persons with dementia can benefit from both social and environmental prompts to assist in reorientation. The neighbourhood organization can act as an architectural cue to

reinforce the facility as a home and assist in reliving experiential memories (Chaudhury, 2003; Rabig, 2009). A home is more than just a “place”, it is the combination of social, psychological, historical, cultural, and physical design components that collaboratively encompass an individuals’ life (Cutchin, 2005). Physical space, whether it is a house or an apartment “is the physical context that holds together diverse events that occur over time in one’s life but are related to that place” and is powerful because of its meaning to the unique individual (Chaudbury, 2003, p. 93).

Chapin (2010) describes one’s identification with their surroundings as “placemaking”, and when one is able to positively identify with their environment results in residents’ enhanced comfort and security. Nursing homes were created with medical care as the primary focus and were designed with similar architecture to hospitals, with long corridors containing bedrooms on either side of the hallway to maximize space and efficient use of staff time (Cutler, Kane, Degenholtz, Miller, & Grant, 2006). These homes function like an acute care setting with nursing stations and medical equipment as the focal point, which is a powerful reminder of the institutional environment (Schwarz, Chaudhury, & Tofle, 2004). Culture change models are designed in neighbourhood configurations and advocate for the elimination of long hallways, visible nurses stations, medical activities and prominent personal care equipment (Crews, 2005; Rabig et al., 2006). The movement away from nursing stations, their replacement with lounge areas and open kitchens suggest that the homelike activities are the focus, rather than medical care (Innes, Kelly, & Dincarslan, 2011).

Residents need to be able to see themselves reflected in the building; a facility based on the medical model does not provide a tangible connection to their life or respect

their life experiences (Edvardsson, Sandman, & Rasmussen, 2005). The transition experience of residents to newly created dementia cottages in British Columbia, family remarked that an accessible kitchen and attached living areas recreate the "'the hustle bustle' of normal family life" and reflect a continuation of valued lived experiences (Robinson, Reid & Cook, 2010). The neighbourhood design, with communal dining and exposed kitchens connected to living areas, stimulates multiple senses. An environment that acts through multiple sensory structures can impact resident psychosocial status (Davis, 2009; Dijkstra, Pieterse, & Pruyn, 2006).

Homelikeness

The term homelikeness or a "homey" atmosphere is identified within the literature as positively associated to quality of life, but it is a contentious concept because of the lack of an operational definition (Robinson, Reid, & Cooke, 2010). Results from the quality of life survey of cognitively intact residents from the 23 study sites in Care and Construction suggested that as perception of homelikeness increased, so did resident perception of quality of life (Earl et al., 2013). Much like placemaking, identifying an atmosphere that is homelike is subjective. Qualitative data describe neighbourhood designs as "more like home", "homey", with little follow up as to specific components that create a homelike atmosphere (Lum, Kane, Cutler, & Yu, 2008). In order to describe the impact of neighbourhood design, it is useful to compare traditional homes to the smaller designs to identify specific areas of dissent. Although removing large medical reminders of institution is positive, it is not enough to create a homelike environment. Shields and Norton (2006) provide insight into the importance of authenticity when delineating between home and institution:

> It's one thing to have finger paintings grandchildren gave Grandma displayed on the kitchen fridge. That's home. It's quite another to have finger paintings from a visiting classroom lining the corridor walls and integrated with seasonal borders carefully displayed by an activity director. That's institution (p. 9).

Although culture change emphasizes the movement away from the medical to a more holistic organizational context the realities of providing appropriate personal care to older adults requires consideration of safety needs. Call systems within resident rooms and mobility aids attached to walls create limits to resident freedom when personalizing their space (Torrington, 2006). Attempting to create a homelike atmosphere in a physical space designed to house dozens or potentially hundreds of residents is problematic because the "furniture and fittings chosen for their homeliness may look inappropriate and incongruous in a larger space and increase confusion rather than make people feel 'at home'" (Torrington, 2006, p. 47).

Davis et al. (2009) identify a dementia friendly environment as one that is a "cohesive system of support that recognizes the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way." Social connection is particularly important for residents in nursing homes and it has been found that residents with moderate to severe cognitive impairment suffer from a significant loss of social connectivity and generalized feelings of loneliness (Cahill & Diaz-Ponc, 2011).

As health capacity decreases, it is necessary for the environment to provide more support to compensate for the loss, and "familiar surroundings ought to give 'support and benefit' for demented persons and to a certain extent stimulate and encourage social

action" (Kihlgren et al., 1992, p.348). Positive response to the physical features is enhanced when residents and family have the opportunity to change environmental features, such as moving furniture and artwork, both in the resident room and in the neighbourhood (McAllister & Silverman, 1999). Providing residents and family with the opportunity to add personal items both in the resident room and outside the resident room have practical considerations as they assist in wayfinding for residents with cognitive impairment (Kovach, Weisman, Chaudhury, & Calkins, 1997). Giving residents and family members the opportunity to provide input on decorations and personalize their individual space can enhance attachment to the space and overall feelings of satisfaction.

An ethnographic study completed by McAllister and Silverman (1999) examined the capacity for community building in two long-term care homes, one traditional and one specialized for dementia patients. The results from their observations suggest that a lack of space for small informal groups discouraged opportunities for social interaction between residents and others in the home. Facility level design characteristics that are associated with resident quality of life are those that enable activities and relationships by having varied spaces throughout the building to interact (Torrington, 2006). Cooney, Murphy and O'Shea (2009) explain that overall perceptions of quality of life were influenced by opportunities for "privacy, social activities, and interaction" (p.1035). Environmental influence on quality of life is identified within quality of life domains as a component that can either support or constrain opportunities for personal and interpersonal expressions of care.

The impact of facility level variables, such as size and ownership has had a largely inconclusive impact on quality of life, but the proportion of private rooms is

positively associated with comfort and satisfaction (Calkins & Cassella, 2007; Dobbs & Montgomery, 2005; Kane et al., 2004). Recent research conducted by the Care and Construction project with cognitively intact residents found that when facility characteristics were considered a higher proportion of private rooms in the nursing home was associated with higher quality of life (Earl et al., 2013).

A smaller proportion of private rooms is associated with higher levels of aggression and responsive behaviours, which suggests that behavioural disturbances from residents with cognitive impairment may be minimized by enhancing privacy and reducing invasion of personal space (Brodaty, 2002). Private rooms offer residents a space where individual possessions can be kept and can reinforce feelings of security and individuality (Innes, Kelly, & Dincarslan, 2011). Decorating a private space can create an opportunity to involve both the resident and family in creating a space with familiar objects and decorations, where they can continually decorate and personalize the space together (Davis et al., 2009). Private rooms are associated with increased perception of choice and control, and increased satisfaction during family visits (Calkins & Cassella, 2007).

Homes with a higher proportion of private rooms tend to have additional spaces both on and off the neighbourhood for social interaction (Cutler, Kane, Degenholtz, Miller, & Grant, 2006). A building design that supports variation includes private and public spaces both inside and outside the facility, which contributes to greater choice and control within the home, and is associated with improved well-being (Parker et al., 2004). Access to space outside the individual resident room supports opportunities for social interaction but also the achievement of individual activities that mirror life previous to

the home. A physical design which includes private and communal space, can support the continuation of previously enjoyed activities; including items such as card tables for games or chairs with accessible light sources for reading (Shields & Norton, 2006).

Residents with cognitive impairment benefit from a balance between public and private space. This concept is known as "gradation of space" and gives residents with dementia an opportunity to exercise choice between individual and communal activities (Barnes, 2002). After examination of preliminary results within the Green House project, researchers noted that for residents with dementia, socializing with visiting family often took place within the common areas rather than in private rooms (Lum et al., 2008). Residents with greater dependency were more likely to move about the unit and occupy communal space, whereas residents with more cognitive capacity choose to remain in their room (Barnes, 2006; Kovach, 1997). It was suggested that residents with more cognitive challenges were often in communal space because it afforded more opportunity for social engagement, and staff surveillance, as opposed to residents who were more independent and would retreat to their rooms as desired (Barnes, 2006). The distance between resident room and congregate space and use of that space are negatively correlated, where the "the probability of a resident using a particular space decreased as the distance between the space and the resident's bedroom increased" (Pinet, 2008, p. 7). Given the increase in new small home designs there is value in understanding the use of space and activity participation across the various home environments (Barnes, 2006).

Importance of size. While proportion of private rooms is consistently associated with quality of life, the impact of size and capacity of homes is largely understudied, with no standard size known to result in increased resident quality of life. The Design for

Caring Environments (DICE) study in the UK examined the impact of building size on resident quality of life and found that large homes (those with more than 40 beds) had the higher scores for items related to safety and small (less than 31) "scored the best in terms of comfort, normalness, choice and control" (Torrington, 2007, p. 517). Barnes (2002) noted within the literature that resident satisfaction is impacted when the number of residents exceeds 50, but there is no definitive range that is identified as a standard or optimum size. On the other hand, Temkin-Greer, Zheng, Cai, Zhao and Mukamel (2010) found no impact of facility size on resident quality of life and quality of care. The impact of overall size of the building is inconclusive in relation to quality of life and further research should analyze overall building size as an independent variable in relation to quality of life (Dobbs & Montgomery, 2005).

In addition to variation in building size, there is limited information concerning what constitutes "small" unit sizes, where unit size refers to the number of residents living in one neighbourhood or group. Calkins (2011) described small units as those ranging from 9 to 24 residents with more friendship formation, motor functioning and mobility in contrast to those larger units which result in greater cognitive, physical deterioration and responsive behaviours. Group living arrangements in Sweden vary with suggested resident density of eight to nine, with separation between therapeutic and recreational common space (Annerstedt, 1993). Whereas additional Swedish research describe group living arrangements as designed for six to eight residents (Andrén & Elmståhl, 2002; Kihlgren et al., 1993). Japanese group homes are built to house five to nine residents (Onishi et al., 2006). Green House (GH) homes are single unit designs, which house ten to twelve residents (The Green House Project, 2013). It is unclear what

contribution neighbourhood size makes “in comparison with the other environmental factors that are commonly associated with small units, such as homelikeness, safety and familiarity” (Fleming & Purandare, 2010, p. 1086).

Units within nursing homes that have a smaller number of residents are suggested to be beneficial for persons with cognitive impairment. Reduced density limits excessive noise and overstimulation, both of which can lead to challenging behaviours and negative affect (Day, 2000). Further, the size and number of residents in the neighbourhood impact quality of life where small neighbourhood size is positively associated with increased opportunities for social interaction and friendship formation among residents (Day, Carreon, & Stump, 2000; Netten, 1989).

When considering the physical size of the neighbourhood, it is important to acknowledge that smaller neighbourhoods size is closely related to the number of staff. In preliminary analysis of the Green House® homes, family members appreciated the small number of staff in the home because they felt it enhanced familiarity with the care workers and provided a greater opportunity for staff to form meaningful relationships with the residents (Lum et al., 2008). This suggests that the smaller neighbourhood design in conjunction with augmented staffing ratios contribute to positive family perceptions of resident quality of life. Although staffing ratios are important to examine for long-term care practice, they are beyond the scope of this project, but neighbourhood design and staff ratio is an important area for future research.

The Nova Scotia Context

Released in 2006, the Continuing Care Strategy proposed a range of policy directions for home and residential care over a ten-year time span. One outcome of the

strategy was the creation of new nursing homes, which resulted in three distinct types of construction models of nursing homes in Nova Scotia (Table 1).

Table 1.

Models of Care in Nova Scotia

	New – Full-scope	New – Augmented	Traditional
Physical Design	Small, self-contained households	Small, self-contained households	Traditional floors/units
Staff Approach	CCAs responsible for all tasks, including dietary and environmental	CCAs provide care needs, one support staff provides both dietary and environmental	CCAs provide care needs, one support staff provides dietary and one support staff provides environmental

Homes classified as new-full scope have fewer beds than traditional, and units are described as “households” or “neighbourhoods” (Department of Health and Wellness, 2007). The staffing approach focuses on eliminating separation of tasks by specialty and instead focusing on a full scope approach, which sees cleaning, personal care and household chores being completed by continuing care assistants. New-augmented homes were replacement homes, meaning they are new buildings with neighbourhood designs, similar to the new-full scope homes. New-augmented homes have a mix of staffing assignments, with continuing care assistants providing personal care, and additional support staff assisting with both dietary and environmental needs. Traditional homes are existing buildings with larger floor/unit design. The approach to staffing in traditional homes includes continuing care assistants providing personal care, and dedicated dietary and environmental staff. New-full scope and new-augmented homes have similar

physical design and construction; the primary difference between the two models is the staffing approach (see Table 1).

Gaps in Research and Practice

The literature review revealed a paucity of information regarding the impact of facility size, unit density, and their relative impact on residents with cognitive impairment. Limitations to physical functioning and behaviours resulting from cognitive impairment can be mediated by physical design elements, and given that residents are being admitted with more severe impairments it is necessary to explore the degree to which size and design impact quality of life.

The literature review revealed that there is potential to further explore resident quality of life from a family member perspective. The bulk of the available research examines the potential for environment to impact family and resident use of space, but there are few studies that explicitly examine quality of life from a family perspective, and not simply as a proxy. In particular, the information regarding family perceptions of varied physical design and facility characteristics is largely unknown within the context of residents with cognitive impairments. The review demonstrated few studies examining homelike design elements and resident quality of life in a Canadian context.

The creation of new homes in Nova Scotia offers a unique opportunity to examine differences between homes across the province, but as of yet, there has been no indication of the impact of different models of care on cognitively impaired resident quality of life. It has been eight years since the CCS was implemented, and in January 2014, the Department of Health and Wellness announced they would begin the process of reviewing the advances made since the implementation to ensure that services reflect

current needs (Department of Health and Wellness, 2014a). At the same time that the review was announced, the province of Nova Scotia expressed their intention to create a provincial dementia strategy (Department of Health and Wellness, 2014b). Therefore this research, focused on the impact of differing home environments on cognitively impaired residents in long-term care, can provide timely input as the province evaluates their existing services and plans for the needs of future.

Chapter 4: Methodology

The Nova Scotia Centre on Aging collected the data for this secondary analysis through the *Care and Construction Project: Assessing Differences in Nursing Home Models of Care on Resident Quality of Life,* an interdisciplinary research project with the aim of better understanding what aspects of long-term care homes contribute to resident quality of life in Nova Scotia. Data collection occurred from 2012 to 2013 within 23 participating nursing homes (also known as study sites) and included a variety of methodologies including surveys, focus groups, interviews, case studies, and activity monitoring. Administrators in the study sites completed a facility profile to provide information about their facility's staffing and physical characteristics.

The methods section will be organized in two parts, with each demonstrating how each research question was answered by the various data sources.

Family Member Survey: Facility Characteristics and Resident Quality of Life

Question 1: From the family perspective, to what extent do facility characteristics impact resident quality of life for those with cognitive impairment?

The first research question seeks to better understand, from a family perspective, to what extent facility characteristics impact cognitively impaired resident's quality of life. To answer this question, both family member and facility profile surveys were examined to obtain information regarding facility characteristics and resident quality of life.

In June 2012, family members of residents living in 23 participating nursing homes across Nova Scotia completed a survey regarding their perception of their

resident's quality of life. The term "family" was defined as a person who identified as kin, a close friend, or person with was involved in the resident's life and had knowledge of their experience in the nursing home. Family members were initially selected based on their status as the primary contact for the resident with the nursing home and were sent a recruitment letter describing the project and the options to complete the survey. Surveys were available in the nursing home and could be completed on paper and returned to the project office. In addition, family members were provided with a secure website information and could complete the survey online. The online information was not made publically available to ensure that only family members from participating study sites were completing the survey. Following the initial letter to families and recruitment within the home, additional efforts began in July/August 2012 to boost recruitment, which included mailing surveys directly to family members. Once all data collection was complete, 397 family member surveys were completed, for an overall response rate of 17%.

Measuring cognitive ability. In order to analyze only the information from family members of residents with cognitive impairment, a cognitive ability measure was created from items within the family member survey to isolate those family members of residents with cognitive challenges. A generalized dementia diagnosis is identified as memory impairment in combination with speech and language challenges and the ability to plan, make judgments and carry out complex tasks (Alzheimer's Association, 2012). Three items within the survey examined family perception of resident cognition and included: (1) ability to remember things, (2) ability to think and solve day-to-day problems, and (3) the ability to communicate. The items were rated on a Likert scale

from one indicating no challenges, to four indicating great challenges. Based on a score from one to four, an average cognitive ability score was calculated.

A reliability analysis was conducted to examine the three cognitive ability items with a resulting alpha of .782, indicating a relatively robust internal consistency. However, when corrected item-total correlation was examined, the communication item had corrected item-total correlation of only .473. After taking out the communication item, the two-item scale had an alpha of 0.873 with item corrected correlations of .811 (Table 5). A Cronbach's alpha score of 0.873 indicates a high level of internal consistency. The significant difference in item correlation provided sufficient justification to remove the communication item from the scale as the lower correlation and alpha mean that it may not be adequately measuring the same construct as the remaining variables (Meyers, Gamst, & Guarino, 2006). The overall improvement in alpha and item-total correlation provided sufficient justification to retain only the two-items as the overall measure of cognitive ability.

Table 2.

Cognitive Ability Reliability Analysis

Items	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation
Usual ability to remember things	3.33	1.926	.806
Usual ability to think and solve day-to-day problems	2.56	1.048	.786
Ability to communicate	5.85	5.320	.473

Figure 2 demonstrates the range of cognitive ability scores across the full data set (n=397). Ability to remember things and solve day-to-day problems composed the cognitive ability scale, which had an overall mean of 2.37 (SD=.885).

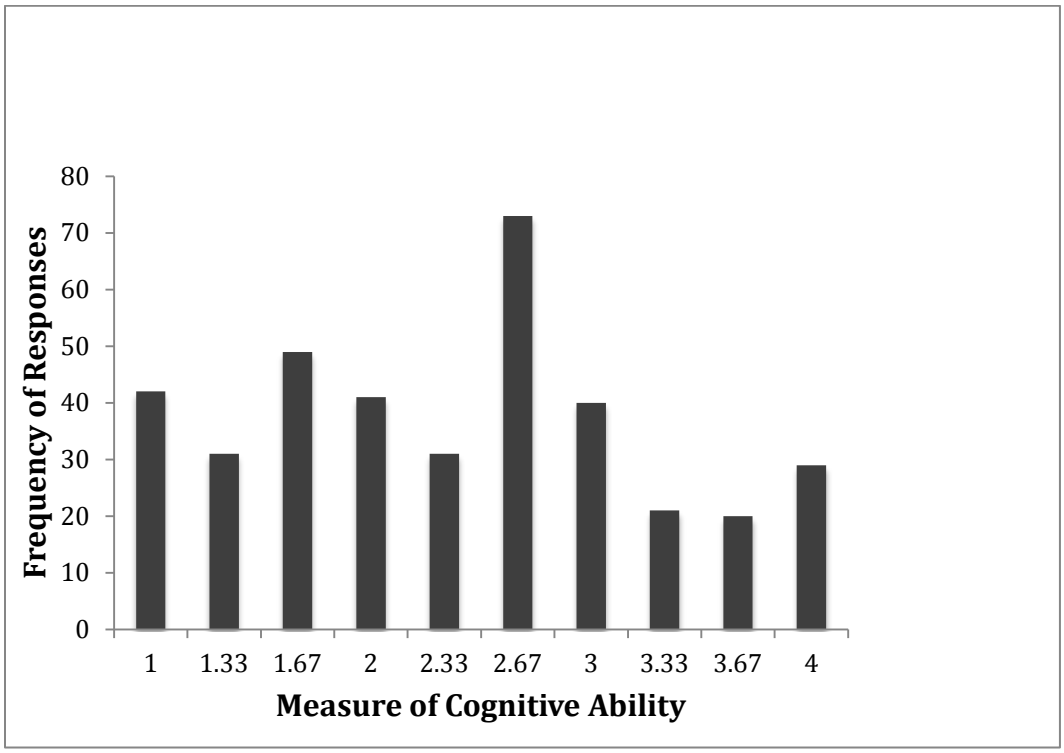

Figure 2. Distribution of Cognitive Ability Scores

Based on cognitive ability responses, family member surveys were retained for further analysis if they scored 2.5 or higher. A cognitive ability score of 2.5 or higher indicated that family perceived their resident to have more cognitive challenges. When asked to rate the resident's usual ability to remember things, family members considered the resident very forgetful or unable to remember anything. With respect to ability to think and solve day-to-day problems, family members of residents with cognitive impairment indicated that the resident had either some difficulty, a great deal of difficulty, or was unable to think or solve problems. The cut off of 2.5 was chosen because it best reflected those residents who were perceived to have greater cognitive

impairment, and an increase in cut off value would have further reduced the sample size and limited potential analysis.

Once the cognitive ability score cutoff was implemented, 125 residents were taken out of further analysis as they scored less than 2.5 on the measure of perceived cognitive ability, nine surveys were taken out due to missing data within the cognitive ability items, resulting in a final sample size of 263 family member respondents.

Family Survey Sample

Of the 263 family members of residents with cognitive challenges, the percentage of family members and residents who were female was 77%. An overwhelming majority (69%) indicated that they were the adult children of the resident and 16% were a spouse. Nearly half of family members were between the ages of 55-64. This is consistent with the ages for resident with nearly all residents 65 and over, and 53% of residents age 85 and over.

Table 3.

Family Member and Resident Demographics

		n	% of total
Gender	Male	57	23
	Female	194	77
Relationship	Spouse	42	16
	Child	182	69
	Other	39	15
Family Member Age	25-54	48	19
	55-64	113	45
	65+	92	36
Employment Status	Retired	152	61
	Paid Employment	97	39

Continued on next page

Education	No High School	25	10
	High School	57	22
	Post Secondary	122	46
	Post Secondary+	45	17
Resident Gender	Male	59	22
	Female	202	77
Resident Age	18-64	8	3
	65-84	114	44
	85+	139	53

The majority of family members indicated that they themselves were married (79.5%), and currently retired (56.2%). Although over half of family members indicated they were retired, 39% indicated that they are still engaged in paid employment.

Relationship with resident. In addition to demographic information, the survey asked respondents to comment on their current relationship with the resident in the nursing home, and 80% indicated that their relationship was very close and 69% spoke on the phone more than once a week (Table 4). Prior to the move to the nursing home, nearly 60% of family members considered themselves to have been the primary caregiver to the resident, and 22% having assisted the primary caregiver (Table 4). When asked if the amount of time spent visiting had changed after moving to the home, 62% indicated that the amount of time spent visiting had remained the same, and 28% said it had decreased. Over 60% of family member respondents indicated that they visited the resident more than once a week.

Table 4.

Relationship to Resident

		n	% of total
How often do you visit?	< Once a week	32	12
	1 per week	67	26
	> Once a week	162	62
How long is the average visit?	< 1 hr	51	20
	1-2 hrs	134	52
	2-5 hrs	73	28
	>5 hrs	2	1
How often do you talk on the telephone?	< Once a week	20	18
	1 per week	14	13
	> Once a week	77	69
Has the amount of time you spent visiting changed between now and when they moved in?	No, it has remained the same	160	62
	Yes, it increased	29	11
	Yes, it decreased	71	27
Care role before the nursing home			
	Primary Caregiver	155	59
	Assisted with Care	58	22
	Other	48	18

Facility Profile

Facility profiles provided information regarding the design and capacity across the 23 participating homes. Facility profiles were created by the research team and asked administrators to provide information regarding total square footage, number of residents, presence of a dementia care unit, and the estimated proportion of residents with cognitive impairment (Appendix A). The new-full scope homes were opened most recently, and all indicated that they had private bedrooms. New-full scope homes had the smallest bed

capacity and consequently smallest total square footage. Average square footage per resident was calculated by dividing total facility square footage by number of beds, and it was found that new-augmented homes had the largest total square footage per resident. All but one of the new-augmented homes were replacement facilities, and had the smallest average number of residents per neighbourhood/cottage. Traditional homes had the largest total number of residents at both the facility and neighbourhood level. There were nearly double the number of residents per neighbourhood in the traditional style compared to the new-full scope and new-augmented homes.

Table 5.

Summary of Facility Profiles (n=23)

		New-Full Scope (n=11)	New-Augmented (n=5)	Traditional (n=7)
Total square footage	Mean	43869.45	87291.6	134901
	Range	32168-67000	31458-150000	47967-284180
Number of beds per facility	Mean	50	91	202
	Range	36-71	32-156	72-474
Average square feet per resident	Mean	877	959	667
Number of residents per neighbourhood/cottage/unit	Mean	13	11	27
	Range	12-16	9-13	24-33
Estimated proportion with moderate to severe impairment	Mean	67.2	61	68
	Range	44-83*	40-75	45-78

*Missing data from one home

Of the 11 new-full scope homes, nine did not have a dedicated dementia unit. None of the new-augmented homes had a dementia unit, and five of the seven traditional homes did. The estimated proportion of residents with moderate to severe dementia was consistent across all three home types.

InterRAI Nursing Home Quality of Life Survey

The instrument used to assess quality of life within the survey data is the interRAI Family Survey on Nursing Home Quality of Life (Appendix B). The quality of life survey is composed of multiple indicators that examine perceived resident quality of life. The ten domains include: privacy, food/meal, safety/security, comfort, autonomy, respect, responsive staff, staff-resident bonding, activity option, and personal relationships. Each domain contained between four and six individual questions for a total of 50 items. The responses for each item were organized in a Likert scale, with responses scored from 0 to 4, and measured as Never (0), Rarely (1), Sometimes (2), Most of the Time (3), Always (4). The domains are important because it is with those items that the dependent variable of quality of life was created.

The dependent variable of resident quality of life was created using higher order factor analysis of items in the ten domains of the interRAI quality of life survey. The factor analysis completed by the Care and Construction project identified care and support, autonomy, activities, and food as those constructs that encompass resident quality of life. These four areas represent the dependent variable of perceived resident quality of life. A complete list of the individual items that comprise resident quality of life can be found in Appendix C. [1]

Analysis Procedure

In order to prepare the data for analysis, variables of interest from the family and facility surveys were first identified, and then depending on the type of variable

[1] Additional information regarding dependent variable can be found in the forthcoming paper by Godin, J., Keefe, J., Kelloway, E.K., & Hirdes, J. (2014). Nursing home resident quality of life: Testing for measurement equivalence across resident, family, and staff perspectives. Unpublished manuscript submitted to the *Journal of Gerontology*.

(dichotomous, continuous, scale), the variables were arranged to allow for inclusion in a regression analysis.

Independent Variables

Family Survey Variables. Demographic information from the survey was collected for both the family member and resident to assess the relationship between personal factors and the quality of life. These demographic data were age, sex, relationship status, education, relationship to resident, and employment status. An effort was made to retain the original groups within the chosen variables, but given the large number of groups in particular questions it was necessary to collapse the groups into smaller, meaningful categories. There were originally 9 groups for family member age, which were then recoded into three groups for further analysis: (a) 25-54, (b) 55-64, and (c) 65+. Resident age originally had 8 categories and was recorded into three: (a) 18-64, (b) 65-84, and (c) 85+. Family member education mirrored Statistics Canada's indicators for educational attainment, the question originally had 6 categories and was then recoded to be: (a) no high school diploma, (b) high school graduate, (c), post secondary, and (d) post secondary plus. Post secondary includes those who have completed some college and university, and post secondary plus those who have gone beyond an undergraduate degree.

Family member relationship status was originally 5 categories, and was subsequently recoded into three: (a) married, (b) widowed, (c) not married. Family member employment status was 4 categories and recoded to: (a) retired and (b) paid employment. Family members were asked to provide their relation to the resident, initially the question had 9 categories, but was recoded into three groups: (a) spouse, (b)

child [including in-law], and (c) other. Care and support role prior to resident living in the nursing home was established with 5 categories, which were collapsed into three: (a) primary caregiver, (b) assisted primary caregiver, and (c) other. Length of stay in the nursing home was composed of 6 categories, which was then recoded into one dichotomous question: (0) less than 24 months, and (1) 24 months or longer.

Facility Profile Variables. In the facility profile, the items of interest included: total square footage of the facility, total number of residents, number of residents in the neighbourhood, and proportion of residents with moderate to severe cognitive impairment. All of the following were continuous variables, and no recoding was applied. Model of care represented the three home types including new-full scope, new-augmented, and traditional. New-full scope and new-augmented were entered into the regression analysis, leaving traditional as the reference category.

Family Survey Scales. Groups of items that assess both resident's physical ability and homelikeness were combined into scales. Homelikeness was measured by taking the mean of 7 items that focused on physical design and atmosphere (Table 7). Homelikeness response categories were organized in a Likert scale from (1) strongly disagree, to (5) strongly agree. Cronbach's alpha for the homelikeness scale was .874, with an overall mean of 4.05.

Table 6.

Homelikeness Items

Item	Min	Max	Mean	SD
My family member's nursing home is clean	2	5	4.5	.67
The area in which my family member lives looks homelike	1	5	3.9	1.0
People from the community are involved in my family member's nursing home	1	5	3.8	.96
My family member's nursing home feels cold and sterile (reverse coded)	1	5	4.5	.96
I feel welcome at my family member's nursing home	1	5	4.5	.75
There is a feeling of warmth and coziness about my family member's nursing home	1	5	3.8	1.0
I feel an attachment to my family member's nursing home	1	5	3.6	1.0

Space and Relationships. In addition to the homelikeness scale, a single item question asked to determine if the space in which the resident lives (unit, neighbourhood) supported him/her to maintain relationships with other residents. The question was scored using the same response categories as homelikeness, and had a mean of 3.28.

Physical ability was assessed as the mean of three items that focused on performance of personal care tasks, ability to move around the nursing home, and ability to get in and out of bed or a chair. Response categories for the physical ability questions were scored from (1) ability to perform tasks independently, to (5) unable to move around the home. A complete list of response categories for physical ability questions can be found in Appendix B. Physical ability had an alpha of .847, and a mean of 3.02.

Table 7.

Physical Ability Items

Item	Min	Max	Mean	SD
Ability to perform personal care tasks	1	4	3.28	.933
Ability to move around the nursing home	1	5	2.97	1.399
Ability to get in and out of bed or a chair	1	5	2.80	1.491

The analysis procedures for the quantitative results required the completion of four steps (1) imputation of missing data, (2) correlation matrix, (3) multilevel regression, (4) facility level regression. Once the independent variables of interest were identified within the family and facility survey data sets, the next step was to assess the missing data.

Multiple Imputation

The method for handling missing data was multiple imputation. Multiple imputation is an analysis procedure, which allowed for the use of the entire available data set, without the deletion of existing data (Patrician, 2002; Young & Johnson, 2013). Multiple imputation is predictive, where it replaces missing data with plausible values and requires the imputation of separate data sets before creating a final pooled data set (Shafer & Olsen, 1998).

Imputation was determined to be the most appropriate manner for handling the missing data because it allowed for the full data set to maintain variability, and the creation of multiple data sets maintained the integrity of original data while incorporating existing uncertainty (Wayman, 2003). Other techniques for handling missing data can result in the loss of cases or variables to extensive missing values, or mean substitution

which can either diminish or increase item-item correlation (Shafer & Olsen, 1998). Typically, the number of imputation sets depends on the extent of the missing data, in order to observe healthy convergence across the data; twenty imputations were required for this data set, meaning that once twenty individual data sets were imputed, one final pooled data set resulted. Imputation was completed using the freeware "R". The procedure used the "MICE" package. Data files were converted from SPSS to Excel, where missing data was re-coded to a blank cell.

Once the data were loaded into "R", patterns of missing data were analyzed based on the questions with the largest number of missing responses. Missing data occurred most often when family members could not speak to task related to the nursing home life, such as capacity to decide when to take a bath or shower, or when the resident was unable to complete the task without help (see Table 8). It is reasonable to conclude that family members might not have knowledge or be aware of policies regarding certain tasks overseen by direct care staff, which is a limitation of assessing resident information from a family member perspective.

Table 8.

Patterns of Missing Data (n=263)

Item	Missing Type	*n*	%
Take a bath or shower whenever he/she wants	Don't Know	52	19.8
	Unable to Complete	48	18.3
Can go where he/she wants on the "spur of the moment"	Don't Know	13	4.9
	Unable to Complete	71	27
Can express his/her opinion without fear of consequences	Don't Know	16	6.1
	Unable to Complete	44	16.7
Can easily go outdoors if he/she wants	Don't Know	6	2.3
	Unable to Complete	52	19.8
Decides how to spend his/her time	Don't Know	9	3.4
	Unable to Complete	46	17.5

Predictor matrix. Once each variable has been entered into the imputation a predictor matrix is created. The predictor matrix includes each variable in both the rows and columns; with each row telling which variable is being used to impute which variable. Resident level variables are changed to "2" and facility level variables are changed to "1", demonstrating the multilevel nature of the data set. The minimum correlation was set to 0.2**.**

Profile correlation. Once the predictor matrix was amended to reflect the multilevel nature of the data, a correlation matrix was created to examine the relationships between the independent variables. The correlation matrix revealed high correlation values between facility level variables, which is confirmed by van Buuren and

Broothuis-Oudshoorn (2011), who noted in their manual for the imputation program that imputing missing data can lead to unique challenges, such as the collinearity when there is a large alpha and small number of participants.

The facility level variables that were mostly highly correlated (greater than 0.9), with each other included: the number of residents per neighbourhood, total number of residents in the facility, ownership of facility, and presence of a dementia care unit. The correlations between these variables were considered extremely strong and required the variables be removed from the multilevel model. The variables were retained for future analysis, but given the strength of the correlation they could not be entered into the model as they were too highly predictive of each other and would present a skewed representation of the effect size.

Correlation Matrix

The correlation matrix was created to examine the relationships between the independent variables that will be included in the multilevel model from (1) family member gender, family member age, education level, employment status, (2) resident's physical ability, (3) homelikeness scale, space and relationships, (4) model of care, and (5) total square footage, and proportion of residents with moderate to severe cognitive impairment.

Multilevel Regression

Once the data were imputed, a complete data set was available to begin analysis. To reiterate the first research question, the goal is to examine from the family perspective, if physical environment and design characteristics impact perceived resident quality of life. The research questions focused on the relationship between facility and

individual variables and "the simultaneous study of resident and facility level variables calls for an approach that accounts for the nested structure of the data" (Bravo, De Wals, Dubois, & Charpentier, 1999). Multilevel analysis was theoretically appropriate because the data were clustered within facilities and "the clustering violates the assumption of independence of observations" required for separate regression techniques (Dobbs & Montgomery, 2005, p.465). The impact of the nested data was determined by examining the interclass correlation (ICC), which demonstrated how much variance is due to residence in a specific facility (Peugh, 2010). By calculating the average variance across all twenty imputed data sets, the ICC was found to be 0.18. This suggests that 18% of the variance in family perception of resident quality of life is between facilities, which provides justification for the use of multilevel modeling. Within statistical literature, an ICC of .10 to 0.30 is considered moderate to large (Scherbaum & Ferreter, 2009), providing the justification to use a multilevel analysis approach to examine both family and facility survey responses on resident quality of life.

A multilevel model (also known as a hierarchical regression), was constructed by entering independent variables in a step-wise fashion similar to the correlation matrix, beginning first with demographic variables, and ending with second level, facility variables. In order to maintain a model that most accurately represents the relationship between explanatory and response variables, a p-value criteria of 0.3 was established, meaning that if at the point of entry into the model an item or scale has a p-value larger than 0.3 that variable will not be included within further analysis. Given the small sample size and large number of proposed explanatory variables, insignificant p-values are

possible; by removing those variables with large p-values the model can more accurately detect potential relationships.

Facility Characteristics Regression

Given that the research question seeks to identify a relationship between facility characteristics and quality of life, an additional regression analysis was completed including facility characteristics that were unable to be entered into the multilevel model due to their collinearity. The items in the facility regression were: presence of a dementia unit, total square footage, proportion of residents with moderate to severe cognitive impairment, number of residents in the unit, and total number of residents in the building. This regression analysis is distinct from the multilevel model as it only includes second level independent variables regressed onto perceived resident quality of life.

Case Study

Question #2: In what way does the physical environment impact family and resident use of space?

The second research question will focus on qualitative data collected from the case study component of the Care and Construction project. The case study approach focused on three facilities, each representing a home from a distinct model of care. Within each facility, there were two care constellations composed of a resident, family member, and staff member. Case study data was comprised of separate in-depth interviews with a care constellation that included a resident, family and staff member at three periods of time from each facility type. One care constellation in each home had a resident who was cognitively intact and able to complete an interview, and one care constellation that included a resident who was unable to speak for themselves.

The analysis for this project focused only on the family members of residents who could not speak for themselves (n=3). The three interviews with family members were conducted approximately three months apart in 2012 (March/April, July/August, November/December), resulting in a total of nine interview transcripts. In addition to the interviews, participant observation methods were used to explore the environment and resident typical daily activity within each nursing home, including interactions with family members. Observation took place over four hours, with individual observation times lasting between fifteen to thirty minutes. Participant observation was conducted with those residents whose family members completed interviews.

The second research question explores how family members and residents interact in the environment. Rather than seeking correlations between facility and quality of life, the question examined to what extent the home design impacts residents' use of space and family members' perception of quality of life for residents with cognitive impairment.

Family Member Interview Data Collection. The administrator of the home, had a clerk approach the resident and family member to determine if they were interested in receiving information about the study, identified potential participants for the case study in each of the three study sites. One researcher from the project team was responsible for completing all of the care constellation interviews within their designated home for the duration of data collection.

Family member interviews took place at the nursing home where the resident resided and private space was provided by each of the nursing homes to ensure the interviewee was comfortable speaking candidly. Permission was obtained from the

participants to audio-record the interviews during the informed consent process. For the residents who were incapable of providing informed consent or assent, their family member was asked to consent on their behalf. Verbal consent and assent was confirmed prior to each interview at each time point with a brief review of the consent materials. Interview times varied across the cases, but averaged approximately 1-$1^{1/2}$ hours in length. Family member participants were provided with one $25 gift card at each interview point to recognize the time and travel expenses associated with participation. The gift card was given to the family member at the beginning of each interview and they were informed that the card was theirs to keep if they chose to discontinue their participation.

Participant Observation Data Collection

Participant observation methods were employed at each of the three data collection points. Participant-observers spent approximately four hours (in blocks of 1/2 hour to 2 hours, guided by the activities of the resident) with the resident in a one-day period, with observation sessions generally occurring on the day following the interview. The participant observer shadowed the resident in all public areas of the nursing home, and in the resident's own room, if permitted, as the resident went through their daily activities. Residents were instructed that they could ask for privacy during the observation period at any time.

Although the research questions focus on the family member's perception of resident quality of life, the inclusion of participant observation data was helpful to give a contextual description of the homes. Participant observation accounts provided a description of the individual neighbourhood and unit, beyond facility characteristics

found in the facility profiles or in the family member interviews. My role as a participant observer allowed me to document my impressions of the home in a systematic manner that related to constructs identified as important for resident quality of life. In addition, the participant observation data was crucial to answering the second question, which focused on the interaction and activities of family and residents in the physical environment. The observations provided insight into activities that the dyads engaged in and provided context when family members described their perception and activities in the home.

Participant observation field notes were recorded immediately following observation times (Appendix D). Notes were only recorded during an observation time when the participant observer was out of sight from the resident. There were two separate participant observers throughout the course of data collection, both employed by the Care and Construction Project. The first research assistant completed the participant observation for time one and time two. After time 2, I completed the third round of data collection, as a part of my role as a research assistant with Care and Construction.

Family Member Interview and Participant Observation Guides

Interview guides were created by senior researchers on the project team with following a purposive search for quality of life literature (see Fancey, Keefe, Stadnyk, Gardiner, & Aubrecht, 2012). The family member interview guide can be found in Appendix E. The interview questions were designed to provide insight into resident quality of life, from the three participant perspectives. Interview questions pertained to the topics of environment, meaningful activities, meaningful relationships, homelikeness of the nursing home, and resident autonomy and affect. Separate interview guides were

created for the case study based on the different perspective, each contained similar questions pertaining to resident quality of life. The individual guides included participant specific probes to better understand the resident from their unique perspective and provide information that only they would know. For example, the family guide asked for information about life previous to the facility and specific family supports which staff were likely not aware of. Given the longitudinal nature of data collection, the interview guides were revisited following the first data collection and questions were amended to capture the element of change. Interview guides were not changed from time two to time three.

The elements captured in the participant observation guides were the key themes reflective of the overall study: homelikeness and physical environment; meaningful relationships; meaningful activities; resident autonomy; resident affect; and staffing model/ interactions. The participant observer described her observations, inferences as well as any personal reflections in the observation guide. A specific section for personal impressions and inferences was provided on the guide and allowed the observer to note their questions, concerns, or perspective following each observation period. The participant observation guide did not change over the time periods.

Case Study Analysis

All interviews were transcribed verbatim. Participant observation logs were compiled in a Word document. Both interview transcripts and observation logs were stored in Atlas TI software. Team members met after each time period to review the transcripts and develop a list of codes. Using the established coding framework, the research assistants coded the data in Atlas Ti software. All transcripts were sent to the

researchers to check for accuracy. Following each interview, completed transcripts were provided to all participants for review. No participants indicated any issues or necessary changes. The principal investigators in the case study working group cross checked the codes for each time period and then consulted a second researcher in the case study working group for additional comments and analysis. The memo function of Atlas TI was used to identify any issues or discrepancies during the coding process.

Initial coding of the interviews and observations were analyzed for components of the conceptual model such as autonomy, affect, meaningful activities, meaningful relationships, physical environment, and homelikeness. The identification of the six primary components of quality of life acted as the preliminary open coding, the secondary analysis was axial coding and included creating connections between the existing codes.

For this research, the secondary analysis of the case study data used inductive thematic analysis. The preliminary coding included two broad themes identified as homelikeness and physical design (Appendix F). The transcripts were examined with the preliminary coding from the project analysis intact, but only those passages that were coded as representing "homelikeness" and "physical environment" were examined. Once those transcripts including homelikeness and physical environment were isolated, the quotes were analyzed further and organized into three broad themes: personal space and identity, social engagement, and individual resident needs. Participant observation records were coded using the same coding structure as the family interviews, the descriptions of the physical environment and events within the observation time were first organized based on case and then in relation to their congruence or discordance with

interview themes. In addition to the thematic analysis, participant observation field notes were used to create a visual depiction of the neighbourhood/unit at each study site. The graphics were used to illustrate the family member and participant descriptions of the physical environment, and while they are did not include all components of the environment (closets, storage, other resident rooms); they contribute to our understanding of the variations in layout in each home.

Case Study Participants

Similar to the family member survey, the case study defined family as an individual who had a close relationship with the resident and was able to speak to the day-to-day experience of the resident's life in the nursing home. All residents had lived in the home 12-24 months; both residents in the full scope and augmented homes had previously lived in other nursing homes, whereas the resident in the traditional had moved from the community. Pseudonyms have been used to protect participant identities. The family member participants remained consistent, except for a small change in the new-full scope home following time one data collection. Originally, the participants included both the resident's son and his wife. Following the first interview the son was unable to continue to participate, so his wife completed the subsequent interviews. A graphic representation of the case study constellations can be found below, with the pseudonyms for the residents and family members (Figure 3).

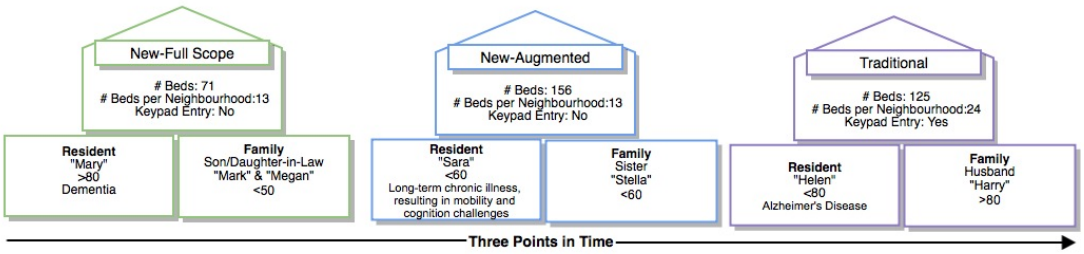

Figure 3. *Case Study Participants*

Full-Scope: Mary, Mark and Megan. The resident in the full-scope home had a diagnosis of dementia of unknown type. The resident, known as Mary, was in a wheelchair and non-ambulatory, requiring full assistance from staff or family to move around the neighbourhood for the duration of data collection. Verbal communication fluctuated, but primarily consisted of singular responses (yes/no), with the majority of her communication being non-verbal facial cues. Family member interviews were completed with the resident's son, and daughter-in-law during time one, with subsequent interviews completed by only the daughter-in-law.

During the participant observation, Mary was most often observed in common areas within her neighbourhood, including in the dining room and living room. She remained in her room to sleep or nap, but otherwise staff moved her wheelchair to the living space in the center of the neighbourhood.

New-Augmented: Sara and Stella. Sara, the resident in the new-augmented home, had a chronic, degenerative disorder that impacted mobility, cognitive functioning and communication. Sara was in a wheelchair and required complete assistance from family and staff to ambulate in the neighbourhood. The resident had minimal verbal communication challenges; she was able to answer simple questions and sat in on all family member interviews. During the participant observation, Sara remained in her room

for the majority of the observation periods, and would be found outside only for meals and physical therapy sessions. The resident's sister, Stella, completed all the family member interviews.

Traditional: Helen and Harry. The resident in the traditional home, Helen, was diagnosed with Alzheimer's disease. During time one, Helen was walking independently on the locked unit, but during the interview at time two, Harry indicated that a progressive decline in balance resulted in multiple falls and Helen was placed in a wheelchair by time two data collection. Although she was in the wheelchair, she was fully ambulatory and moved without assistance. The resident's husband, Harry, completed all of the family member interviews. Helen was the only resident to ambulate independently, and spent the majority of her waking hours walking or wheeling throughout the main hall of the unit. Both the participant observer and her husband remarked that she was rarely stationary.

Ethical Considerations

There were unique ethical issues to be considered when I began my secondary data analysis and we are examining participants who cannot speak for themselves. All identifiable information had been removed from all of the data sets (both survey and case study), but my participation in the data collection mean that I was aware of who the case study participants were after my time spent with them during the participant observations. Given the small number of residents and family members within the case study, additional care was given within the results and analysis to limit specific information regarding a single individual being released. The measures to limit the opportunity for identification of participants included limiting the amount of specific demographic

information disclosed for individual participants (i.e. specific diseases), and consultation with thesis supervision committee regarding the scope of descriptions provided in the results. Taking these considerations into account, the research was approved by both my thesis committee and the University Research Ethics Board (UREB) at Mount Saint Vincent University (#2013-097) as an expedited review for secondary data analysis.

Chapter 5: Results

Survey Results

The results section is organized in sequence, first with the correlation matrix, multilevel model, and exploration of facility characteristics. The quantitative results are in reference to the first research question: from the family perspective, to what extent do facility characteristics impact resident quality of life for those with cognitive impairment?

Correlation matrix. The correlation matrix examines the bivariate relationships between the independent variables (Table 9). Within the demographic variables, a positive correlation exists between family member age 65 and over, and retirement (r=.510) and a negative correlation between the family member's gender and being retired (r =-.170). Among the second level facility variables, significant positive correlation exists between the homelikeness scale and single item space and relationships (r= .565) and model of care (r=.202, r=.278). Further, there is a negative correlation between homelikeness and total square footage of the facility (r=-.383).

Table 9.

Correlation Matrix

		1	2	3	4	5	6	7	8	9	10	11	12	13
1	Family Gender													
2	FamAge55-64	.137*												
3	FamAge65+	-.197**	-.679**											
4	High School	-0.017	0.104	-0.044										
5	Post Secondary	0.076	0.075	-0.102	-.534**									
6	Paid Employment	0.078	0.067	-0.096	0.014	0.005								
7	Retired	-.170**	-.128*	.510**	0.055	-0.051	-.255**							
8	Physical Ability Challenges	0.03	-.138*	.162*	-0.119	-0.014	-0.069	0.051						
9	Homelikeness	-0.035	-0.023	0.036	-0.017	0.023	0.002	0.071	0.013					
10	Space and Relationships	-0.037	0.003	-0.011	-0.032	-0.006	-0.022	0.036	-.183**	.565**				
11	New-Full Scope	-0.05	-0.032	0.054	0.079	0.003	0.03	0.05	-0.011	.202**	0.116			
12	New-Augmented	-0.098	0.079	-.197**	0.022	-0.016	0.047	-.143*	-.138*	.278**	.215**	-.501**		
13	Square footage of the facility	.162*	-0.003	-0.047	-0.043	-0.002	-0.039	-0.085	0.067	-.382**	-.277**	-.570**	-.127*	
14	% of moderate to severe cog.imp	0.11	0.102	-0.06	0.015	0.101	0.01	0.058	0.022	-0.036	0.046	-0.051	-.204**	0.089

*Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Variance in Quality of Life Across Model

In order to examine the difference in mean quality of life across all three models an ANOVA was conducted with the full imputed data set. Overall quality of life was assessed across all three models, with an average of 2.75 (Figure 4).

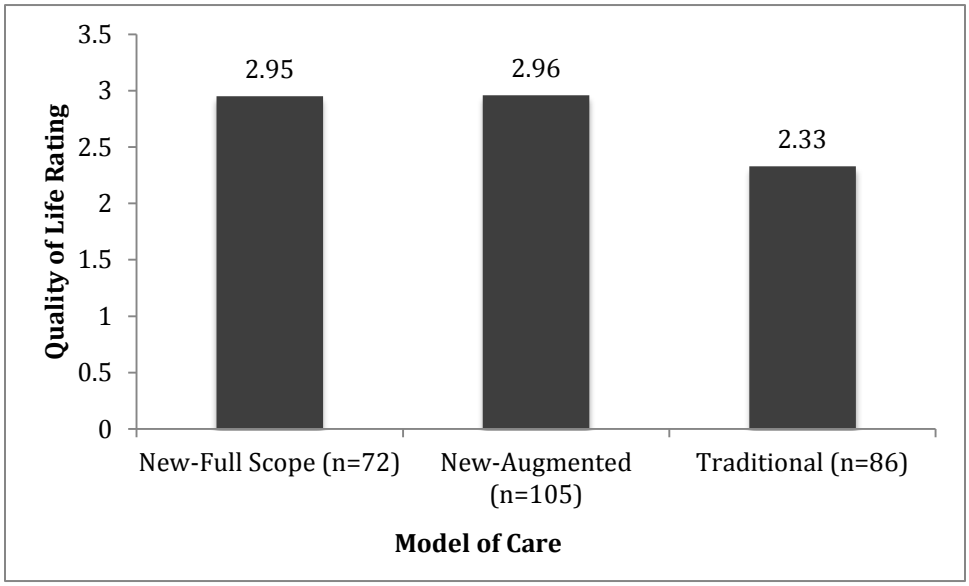

Figure 4. *Average Resident Quality of Life Across Model (n=263)*

A limitation of completing an ANOVA with multiple imputed multilevel data is that the statistical software will not pool the between group and within group differences, which necessitates the manual calculation of the complete F statistic. Manually pooled F statistic is 18.91, $p<0.001$, and indicates that there is a significant difference in quality of life between the newly built homes and the traditional. Simply put, there is no significant difference in family perception of quality of life for those residents with cognitive impairment, between new-full scope and new-augmented, but these new home styles are significantly different than the traditional.

Hierarchical Regression Results

The results provided have been pooled from 20 imputed data sets. Demographic items were added in the first block and none of the individual items, or the block itself was significant *(p*=0.78). The demographic variables were trimmed, meaning that the items with the higher p-values were taken out of further analysis and only those few items that remained were included in further analysis, but once the most non-significant items were taken out, the demographic variables still exceeded the re-determined cut off of *p*=0.3 (Table 11).

Table 10.

All Demographic Variables

Variable	Estimate	SE	t-Ratio	DF	p-Value
(Intercept)	2.99	0.21	14.34	196.90	0.00
Family Gender	-0.12	0.14	-0.84	161.49	0.40
FamAge55-64	-0.09	0.16	-0.60	185.86	0.55
FamAge65+	0.08	0.25	0.31	47.48	0.76
High School	-0.04	0.16	-0.27	112.34	0.79
Post Secondary	-0.13	0.14	-0.95	119.85	0.34
Paid Employment	-0.04	0.27	-0.17	194.60	0.87
Retired	0.00	0.18	0.02	47.96	0.98
				(7, 1608.53)	0.78

Table 11.

Final Multilevel Model (n=263)

Variable	Estimate	SE	t-Ratio	DF	p-Value
Block 1					
Intercept	2.92	0.19	15.49	218.31	0.00
Family Gender	-0.12	0.14	-0.89	150.37	0.37
FamAge55_64	-0.10	0.14	-0.67	225.38	0.50
FamAge65Plus	0.09	0.18	0.53	101.39	0.60
				(3, 1121.49)	0.35
Block 2					
Intercept	2.82	0.11	24.67	106.75	0.00
Physical Ability	-0.05	0.06	-0.87	69.67	0.39
				(1, 95.22)	0.39
Block 3					
Intercept	2.78	0.09	30.29	59.87	0.00
Homelikeness	**0.45**	**0.13**	**3.57**	**38.51**	**<0.001*****
Space and Relationships	0.19	0.13	1.51	21.90	0.15
				(2, 90.41)	**<0.001*****
Block 4					
Intercept	1.95	0.50	3.89	23.94	0.00
Homelikeness	**0.43**	**0.12**	**3.44**	**46.92**	**<0.0001*****
Space and Relationships	0.19	0.13	1.48	21.88	0.15
New-full scope	0.16	0.20	0.83	106.37	0.41
New-augmented	0.16	0.19	0.82	151.13	0.41
				(2, 538.27)	0.65
Block 5					
Intercept	2.05	0.51	4.05	21.02	0.00
Homelikeness	**0.43**	**0.13**	**3.37**	**38.73**	**<0.001*****
Space and Relationships	0.18	0.13	1.43	21.46	0.17
Square Footage	**0.00**	**0.00**	**-1.98**	**72.87**	**<0.05***
Proportion of residents with moderate-severe cognitive impairment	0.00	0.01	0.65	171.92	0.52
				(2, 471.35)	0.09

Note: All continuous variables have been centered
*p<0.05 **p<0.01 *** p<0.001

The results of the multilevel model demonstrate that the first block, which included individual resident and family member variables, was not significantly related to overall quality of life (Table 10).

The second block included the physical ability scale, which did not approach significance and was removed from further analysis. The third block included two variables, the homelikeness scale and a single item related to space and relationship building. The homelikeness scale was significant ($p<0.001$). The space and relationship building item was not significant, and was removed from further analysis. As a whole, the third block, which included the point at which homelikeness was entered into the model, was significant ($p<0.001$).

The fourth block was the point at which model of care was entered into the multilevel model, with traditional model of care was used as the reference category. Model of care was not significant. The final block includes facility variables and at the item level square footage was negatively correlated with quality of life ($p<.05$). Although the square footage item reached significance, facility characteristics as a block did not reach significance.

Overall, the multilevel model results demonstrated that the homelikeness scale and single item measure of square footage was related to resident quality of life. At the block level, only homelikeness was significant, and facility characteristics did not emerge as significant.

Exploring facility characteristics further. A separate regression analysis was conducted with only facility characteristics regressed on resident quality of life. All but two facility level variables were too highly correlated to enter into the multilevel analysis,

but given the interest in physical environment it was important to explore only facility level characteristics (Table 12). When only facility characteristics were considered, the number of residents in the neighbourhood/unit was negatively correlated with overall resident quality of life.

Table 12.

Facility Characteristics and Resident Quality of Life

Variable	Estimate	SE	t-Ratio	DF	p-Value
Intercept	2.75	0.10	26.97	104.63	0.00
Dementia Unit	0.07	0.21	0.31	104.88	0.76
Square Footage	0.00	0.00	-1.03	178.19	0.31
% of residents with moderate to severe cognitive impairment	0.01	0.01	1.26	185.87	0.21
Number of Residents in unit	**-0.04**	**0.02**	**-2.58**	**190.82**	**<0.01****
Number of residents in building	0.00	0.00	0.68	219.56	0.49
				(5, 2345.48)	**<0.001*****

p*<0.05 ***p*<0.01 * *p*<0.001

As a whole, the block of facility characteristics was significantly related to family perception of quality of life for residents with cognitive impairment. The correlations between the variables could account for the significance of the block. The negative correlation of both the number of residents in the unit, and the total of square footage in the building (as seen in the full multilevel model) makes sense given that those homes in both the new-full scope and new-augmented have smaller square footage and in turn a smaller number of residents per unit. Square footage and number of residents in the unit are also related in the correlation matrix, making it reasonable to assume that they are

measuring a similar construct. The significance of the number of residents in the neighbourhood is consistent with the previous finding of a significant negative relationship between square footage and quality of life within the full multilevel model.

Case Study Results

The case study results are in reference to the second research question, which aimed to understand how the physical environment impacted family and resident use of space.

The interviews and participant observation revealed three intersecting themes across family members interviews: personal space and identity, social engagement, and individual resident needs.

Personal Space and Identity

The two most frequently occurring codes within the physical environment themes were “actions that make the environment inviting” and “resident’s room becomes home”. All three cognitively impaired residents had their own private bedrooms and family members indicated that having their own room was a positive component of the nursing home environment. The private bedroom was valued because it offered privacy and opportunities to decorate the resident’s room with personal items.

Sara, the resident in the new-augmented home, spent the majority of her time in her room. The participant observer noted that the resident’s room was filled with personal mementos and decorative objects, and seasonal ornaments. When asked about the elaborate furnishings in the room, the resident’s sister, Stella, remarked that shopping and organizing her room was something that she and the resident did together when they went on outings outside the nursing home. The process of decorating the resident room was described by the family to be creating a connection to the resident’s life prior to living in

the nursing home. The resident's sister used the decoration of the resident room as a continuation of the resident's previously enjoyed activities. The interviewer asked Stella and Sara if the room was arranged in a way they liked, and if the decorations in the room changed very often. Stella, the sister of the resident in the new-augmented home said "you know I just try to make it as…homey as ever… and with nice things". Stella often shopped for decorations and additions to the room, and considered adding items to the room as a continuation of the residents' previous activities, saying that " if she [Sara] was in her own place she would be adding them herself, if she wasn't in long term care, and in a chair, because she did collect a lot". During each visit the resident's room had a large number of personal items that her sister changed out periodically, on the second visit, the family and participant observer noted the removal of closet doors in the resident room. The family wanted more space to display the resident's movie collection, and environmental staff in the home assisted in taking off the closet doors to add more space for the resident's growing movie collection.

Harry, the husband of Helen, in the traditional home mentioned that having a private bedroom meant that she was able to bring personal items and some furniture pieces, which was helpful with visitors, creating an opportunity to reminisce. When asked what about the building was important to make it homelike, Harry described the benefits of having a private room.

> Well the fact that you bring your own furniture in and you can do anything you want in the room…as far as favourite pictures and things like that and you can use those as topics of conversation during visits…and say remember this one, and remember this one. No, I, it would be no different than home…it would be no different than home. *[Harry-husband in traditional home]*

Megan and Mark, the son and daughter-in-law of the resident in the new-full scope home described the resident's room as valued for the privacy it provided and echoed benefit of bringing personal items, but the family was less connected to the individual resident room and instead identified the entire neighbourhood as her home. The interviewer asked them if the Mary's room felt like home and Megan responded that "I think so cause we put the pictures up right away and her knick knacks and her TV". Mark agreed with Megan, but went on to connect homelikeness with the entire neighbourhood.

> Well the bigger picture, to me, well I call it her pod or whatever you want to call it, the entire wing that she is in is her home, so the eating area is her…it's her kitchen. It's her kitchen and the living room; it's just that its shared with some other people…that's home. Her room is where she sleeps but other than that she's out of her room. *[Mark-son in new-full scope]*

The organization of the new-full scope building consisted of central kitchen, dining, and living area. The neighbourhood is located on the first floor of the building, with glass doors that opened onto an enclosed patio (Figure 5). Mark described the central organization of the communal areas as being desirable because they are reminiscent of a private dwelling, saying that it "makes sense, the open kitchen, it's all part of what maybe even you and I are used to at home, you become social". Figure 5 is a visual representation of the neighbourhood compiled from participant observation field notes. It is important to note that while the new-full scope and new-augmented have similar design principles, such as an enclosed courtyard, open communal spaces, the diagrams do show that their designs and layout are unique and distinct.

Figure 5. New-Full Scope Layout

The participant observer noted that the organization of the living and dining space were both more reminiscent of non-institutional dwellings because of the lack of structural separation between dining and living areas. The new-full scope and new-augmented homes were similar in construction, both neighbourhoods were located on the first floor, and led out onto small, enclosed courtyards, and had minimal separation between dining and living space (see Figure 5 and Figure 6).

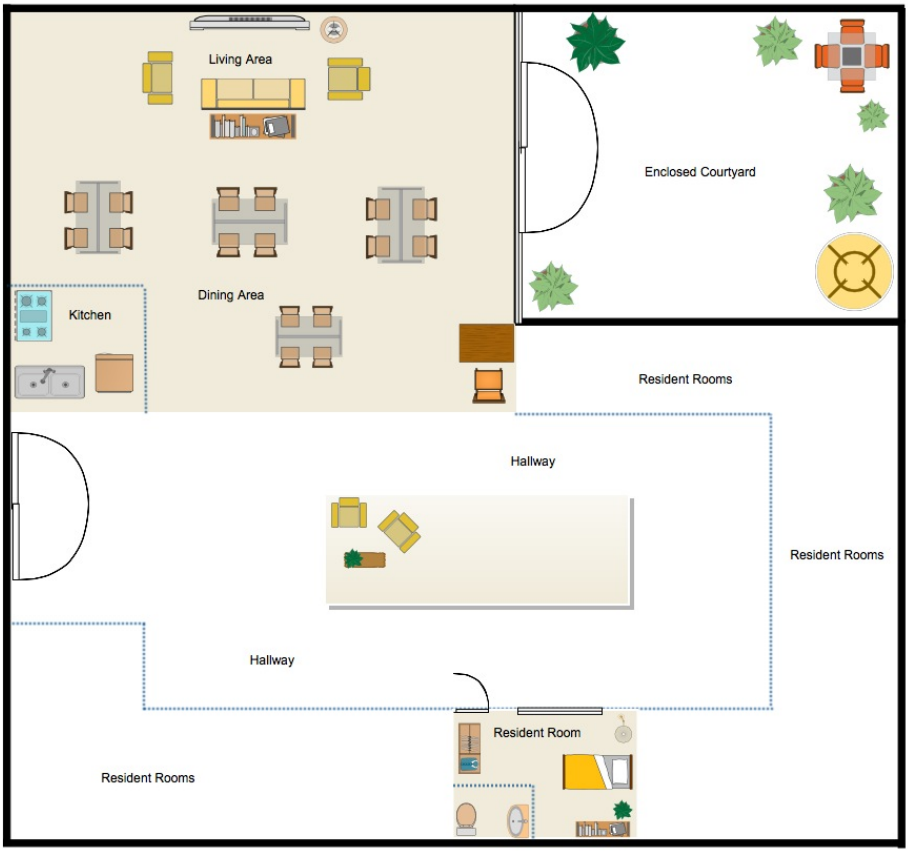

Figure 6. New-Augmented Layout

Megan, the daughter-in-law in the new-full scope home noted that previous to moving to the nursing home, Mary would often help the daughter in the garden, and that gardening was one of their shared activities. Megan reminisced that in warmer weather they would go into the courtyard together, and pick flowers and "just trying to make real life". Similar to the resident in the new-augmented, the design and activities within the surroundings created connection to familiar activities that reinforced resident identity prior to living in the home.

Atmosphere. When asked to describe the home and the resident's room, family members in the full scope and augmented homes used similar terminology, describing the homes as "comfortable", "cozy", and "welcoming". The connection between having private and personal space, was connected to an objective, physical component of the home, whereas atmosphere and comfort is related to more subjective feelings that are evoked in that space. Often, the family members were unable to definitively articulate the aspects of the home that embodied these descriptions. The original coding described the appearance of the home, and the most frequent example of appearance included light. Megan, the daughter-in-law in the new-full scope home said that the home was "a great place, it's new and it's great, and it's bright and it's airy. It's all the good stuff". Harry, the husband in the traditional home also mentioned the light and atmosphere of the home.

> Oh yeah and everybody, people that come in, strangers will say oh, that have been in other institutions oh my god the size of the rooms, they are nice, they are bright you know. But it makes it so bright! Makes [sic] it so beautiful and bright! It can be minus 18 out, but inside you're warm and it's sunny and the ambience here is beautiful. Beautiful. *[Harry-husband in traditional home]*

Cleanliness and the smell in the home were described by both Mark, who echoed his wife's comments saying that "it's bright, airy, it feels homey, it's not stuffy, it doesn't stink". Stella, the sister in the new-augmented home described the home as "comfortable", saying "there are [sic] none of those kind [sic] of smells that would turn you off on walking in".

Both Mark and Megan, in the new-full scope home, had previously described the entire neighbourhood as the residents home and had a positive perception of the design and organization of the home, but when asked if there were any challenges or barriers to "homelikeness", they both noted challenges in personalizing a single room. Megan said

that “well you only have one room so it’s kind of hard with the bed in the middle it’s kind of hard to make it too homey, but there are pictures and there are knick knacks so it’s just as homey as it is going to be”. Interestingly, both Megan and Mark described at length the ways in which Mary’s room, and the entire neighbourhood were homey, but was then followed by Mark saying that “I spent all my life in hotels and I don’t mind this room. No really, I am looking at it; it’s like another hotel room”. This demonstrates the dichotomy between the feelings of comfort and homelikeness, and the descriptions of the features in the home. For example, the entrance of the new-full scope building was designed to look like a small village courtyard with storefronts lining the main hall. Mark and Megan had positive comments about the appearance, but then compared it to a theme park, Megan said “the entrance is kind of interesting, the first time you walk in you are like ‘am I at Disney world’ or like ‘where am I?’ with the little store concept”. The comments highlight the disconnect between previous comments which describe the organization of the communal areas in the neighbourhood as reminiscent of a private home, yet the resident’s room and the entrance of the building are akin to a resort or hotel.

Social Engagement

All three residents had communication and mobility limitations, which impacted their ability to participate in social activities within the home. As previously described, Megan, the daughter-in-law of the resident in the new-full scope model, described the central living and kitchen environment as the space where the most social activity occurred, saying that “it’s the most social place in the room, always people [sic] coming and going. There is always somebody coming and going or “saying I’m hungry”. The participant observer noted that in the living room there was a desk, which was where staff

sat at a desk to complete their paper work, “so there was always someone there, walking by”. Mary, the resident in new-full scope spent the majority of her time in communal areas, and the participant observation revealed multiple instances where the resident could be found sitting in her wheelchair in the living room, listening to music, while watching the staff clean the kitchen and move about the neighbourhood.

> [The residents] are mostly in the kitchen area/sitting area somewhere there most of the day unless they have to nap and sleep or something in their room, but other than that they’re not in their rooms staring at the wall, they’re generally all out together if need be [sic] and socializing or being with somebody. *[Megan-daughter-in-law in new-full scope home]*

It is important to note that the new-full scope home did not have a nurse’s station, but rather a desk with cabinet where staff would sit to complete paperwork. This is in contrast to the traditional home which had a conventional nursing station in the middle of the main hall (Figure 7).

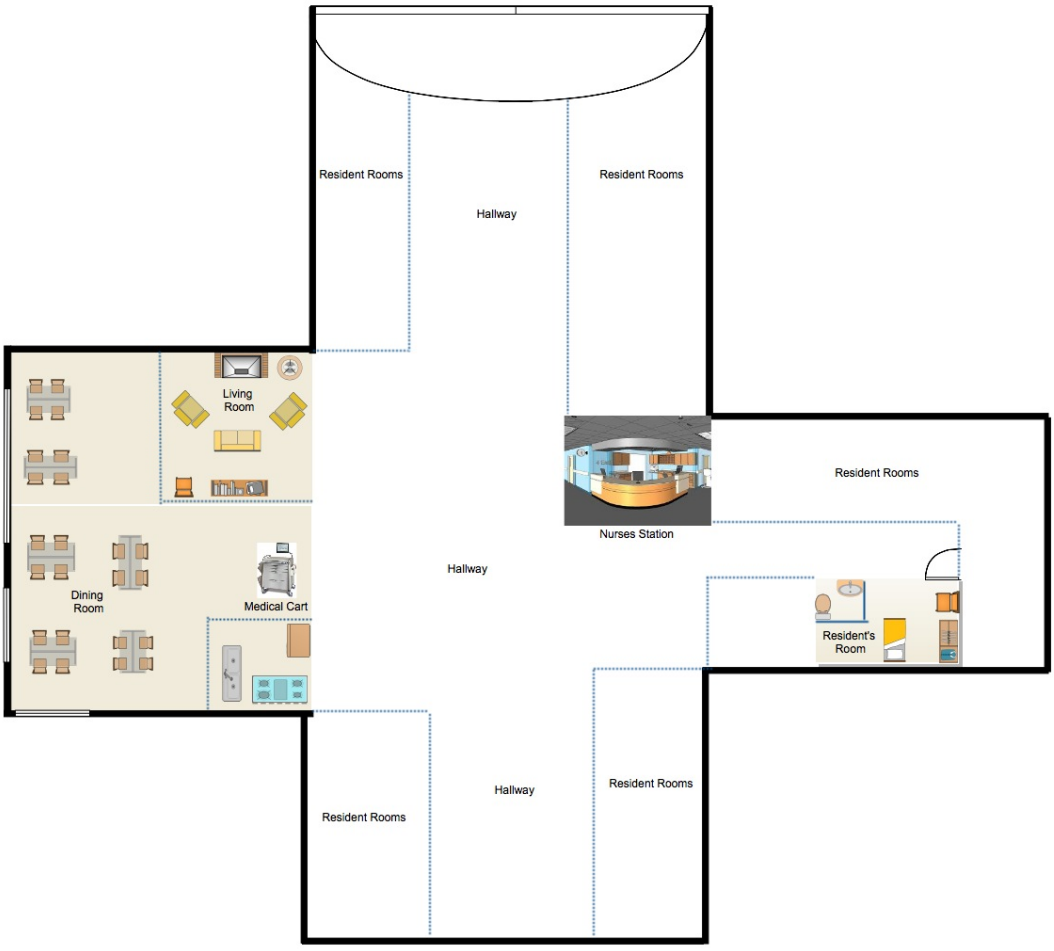

Figure 7. Traditional Layout

Sara, the resident in the new-augmented home, spent the majority of time in her private bedroom watching movies. She did not often desire to leave her room to participate in organized activities, but the participant observation noted that during multiple observation periods the resident would ask to remain in her room watching television with her door open to the hallway.

> I asked if she would like me to close the door or turn up the volume on the TV "no" she said, and that was that, she really did not seem to mind. A little later on, we heard staff members chatting and laughing in the halls and I looked at [Resident] and she was giggling as well. It seems as though she keeps her door open as an entertainment factor because about 10 minutes later we could hear someone playing the fiddle down the hall, you could hear it all the way into her room. *[Participant observation field notes]*

The circular arrangement of the living area within the new-augmented home meant that residents and staff were frequently walking by the resident's room, and was in close proximity to the dining and living room. Although the resident preferred to spend her time in her room, her location allowed her to listen and observe activity in the neighbourhood.

Given that both residents in the new-full scope and new-augmented had serious mobility challenges which left them unable to move unassisted, their primary social connections apart from family visits were observing activity rather than directly participating. The resident in new-full scope would observe staff and other residents as they moved about the unit from the dining or living room area and staff would walk by and say hello to the resident and she would smile and watch activities if she was not directly participating. The location of the resident appears to be important when thinking about their proximity and positionality in relation to staff and other residents. Whether it is sitting in a communal area or in a centrally located bedroom with the door open, both offer unique ways to engage socially.

Intergenerational relationships. Megan, in the new-full scope home, had a small child and the home has a play area where he can play while they visit. The addition of toys and space to play creates a comfort for the family knowing that they can have their

children enjoy. The family enjoys having space both in the neighbourhood and throughout the building to visit. Additional activity areas outside the neighbourhood allows resident and family to get away from the cottage to visit or stay in the neighbourhood as they choose.

Prior to moving to the current home, Mary had lived in another nursing home and the family could compare the experiences. They appreciated having a choice in where they visited; they could stay in the neighbourhood or go to other areas in the home, particularly a children's play area outside the neighbourhood. Megan described their experience in a previous nursing home, saying, "We used to leave in tears because it was disgusting, here it's fine and it's easy and you leave feeling good…in an atmosphere that you wouldn't mind being in yourself." Megan described the experience of visiting with the home with her son, where "he can play, we do play doh or we do whatever…you know he can go to grammas and put the tv on cartoons."

The combined dining and living space in the new-augmented home was the smallest of the three homes, with residents having to cross through the dining area to get to a living space with couches and a television. The communal space was the site of family visiting during the holiday seasons for the family in the new-full scope home

> We were here, when we were decorating her Christmas tree, we were sitting on the couch and some ladies [residents] were folding laundry and they were doing their little thing and they, you know he was just having a ball, and so they look at each other and said, "Oh isn't it nice to hear a child." And it's true; it's nice to hear a child, that's real life. *[Megan-daughter-in-law in new-full scope]*

Stella, the sister of the resident in the new-augmented home described the size of the neighbourhood with its capacity to enable relationship building with the staff saying that "it's a little bit smaller in scale, which then gives the staff more opportunity to you

know really become knowledgeable about their residents." The potential for interaction with staff in particular was mentioned in both the new-full scope and new-augmented homes.

In the new-augmented home the resident's room looked onto a courtyard, and her sister remarked that she appreciated having something beautiful to look at. Having a beautiful space may seem unimportant or superficial, but for someone who spends a lot of time in a space it could be very important, appealing surroundings whether it be in the room our outside, is valued when the resident spends large amounts of time in the same space. The augmented home had an enclosed greenhouse on the second floor of the building. The use of the green house was described in initial interviews as a positive selling point for the facility, but further reflection revealed the while the family appreciated the beauty of the space, they seldom used it and instead favoured the computer room in the neighbourhood. Access to a computer room created an opportunity for social activity between Stella and Sara, where they could look on-line and share emails from family in other provinces. While the green space may be beautiful to look at, the family does not use the space on a regular basis.

Similar to the family in the new-full scope, areas within the home that create an opportunity for socializing and shared activities are valued. Outdoor features including a courtyard off of the kitchen and living area have the potential to be used for intergenerational socializing. Again, the space is useful in relation to the opportunities for social activity that it provides. The greenhouse and the outdoor areas are accessible to the resident and include wheelchair accessible features to enable her continued use.

> They have nice courtyards for going outside, the big one here, on this level, they have a swing that umm the wheelchair locks into, so we can use that, we do that. Now that my granddaughter is a little older this summer we will be using it more. There is lots of space to walk around her. They have done an amazing job with the flower planting. Which is always nice. It's very pleasing to the eye to look at, even from outside. *[Stella, sister in new-augmented home]*

Given that both families in the new-full scope and the new-augmented have smaller children that visit the home, a variety of spaces that are appealing to the entire family contribute to a positive visiting experience.

Individual Resident Needs

A benefit of the case study data is that we are able to examine unique residents over an extended period of time, rather than aggregated data from a large number of residents. The thematic analysis revealed a third theme, which focuses on the environment facilitating individual resident needs. Each of the three residents had unique health challenges, which impacted their ability to engage in various activities, but the environment had an important role in facilitating desired activities. Sara had mobility limitations, which impacted her ability to move independently around the home, but her real enjoyment came from spending time in her bedroom. The ability to personalize the room fostered an ownership of the space, and facilitated individually desired activity. The room supported both her personal care needs and her social needs.

Helen, the resident in the traditional home, was the most physically active resident, and had the most dramatic health changes over the course of observation and interviews. The traditional home featured a unit that consisted of one long main corridor with a smaller hallway located perpendicularly (Figure 7). At the juncture between the two halls was the nurse's station and entrance to the dining room and living room. The doors that

were locked by passcode had a mural of an ocean scene painted on both double doors. Helen was not featured prominently in the other content areas because the components of the home that are important to her husband's perception of her quality of life focused on the ability of the environment to facilitate her pacing. The sub-theme focuses on change over time and explores change in health status and use of environmental features.

Time. Although the case study interviews and participant observations occurred at three time points, over a ten-month period, there was no drastic change in family member perceptions of the physical environment and their use of design features within the home. The greatest change was seen in the health of the resident, which impacted their participation in activities in the home. During the first time period, Helen was walking unassisted and the participant observer noted that the resident would walk to the end of the hallway, stop, sit on the bench, remove her shoes, put her shoes back on, and then continue walking. As the time progressed, she was unable to walk unassisted and was placed in a wheelchair. She continued to pedal her feet in the wheelchair and use the corridor railings to propel herself up and down the hall. The resident's husband, Harry, was adamant that the home was ideal for her needs, as walking freely was integral to her quality of life. When asked what other aspects of the nursing home were important he said, "it's all the same for her…. the autobahn, that's her autobahn." The participant observer noted that the mural on the doors and decorations hung from the ceiling were not indicative of something found in a private dwelling, but as the family member noted the resident did not take any notice of the decorations or furnishings on the unit. The furnishings and design elements related to social engagement and homelikeness were not as important to this resident, as she would rarely remain still long enough to eat or sit in

the living room area, and "All she wants to do is be, is be mobile, and this is just a wonderful facility to be able to do that...she is accomplishing something when she is walking". The design elements that were vital to her quality of life supported her individual needs, which consisted primarily of walking in the halls.

As the resident's health condition deteriorated and she moved from walking to the wheelchair, the resident relied more heavily on using the railings to pull herself along the hallway. Harry was asked how Helen was managing with her health changes and he said that "She is pedalling away with her feet…yes with her feet, definitely and the bars; she pulls herself along with the bars, dramatic change since our last visit." The participant observations described Helen's movements in the home as her health declined, and noted that because of the nurses station in the middle of the long hall there was a large gap between the railings, where laundry carts and medical carts could often be found. Harry told the interviewer that the design of a private home in the community would be inappropriate for Helen because of her desire to pace.

> She's got to be mobile. My gosh, she'd, she'd go crazy. She'd go, you know, the frustration would be unbelievable…'cause she can't sit like, for instance in a chesterfield chair and watch TV…she can't do that. She's got to be in the wheelchair and out in the aisle, going you know? Sometimes she ends up [laughing] in the corner and gets stuck and things like that, but she works her way out of it! *[Harry-husband of resident in traditional home]*

Helen would pedal around items blocking her path in the hall, and although Harry noted that she sometimes had challenges maneuvering in the unit, the participant observer did not note any instances where she was not able to move around the unit unassisted. That being said, the resident had a visible improvement in mood and affect when her husband

arrived each day, and appeared to appreciate when her husband or the participant observer gave her a break and pushed her in her chair.

Summary of Case Study Findings

Family member interviews and participant observation revealed that physical design elements are related to the reinforcement of resident identity. The resident's room and other communal space in the neighbourhood are areas that foster social engagement. Features of the home that can be enjoyed by all ages are important so that family feel comfortable bringing their children and grandchildren to the home to visit, fostering intergenerational relationships. The family and participant observer perceived positive association between individual needs and the environment when the space facilitated the achievement of individual resident's desired activity, whether walking the halls or watching movies in their room.

Chapter 6: Discussion

Across Nova Scotia the number of older adults with cognitive impairment is increasing, which creates a need to better understand how current long-term care services are serving the population. The creation of new and renovated nursing homes recommended by the Nova Scotia Continuing Care Strategy has led to diversity in the physical design of long-term care homes across the province. Although there is existing literature regarding dementia friendly design elements, it is not yet known if variation in the physical design of homes in Nova Scotia has an impact on cognitively impaired resident quality of life. As Nova Scotia creates a dementia strategy, understanding the relationship between physical environment and quality of life for residents with dementia is vital to creating or sustaining homes that reflect the unique needs of residents with cognitive impairment. Data collected from family member surveys, nursing home profiles, and case studies were analyzed in an attempt to fill a gap in our understanding regarding the unique perspective of family members of residents with cognitive impairment.

The sample of family members in this study is similar in characteristics to studies including family members of residents in long-term care in terms of their sex, education, relationship with the resident, and visiting patterns. The family members within both the survey and case study had a history of close involvement in the resident's lives, and providing care prior to a loved one with dementia in the home is an indication that care will continue after their relative moves to a nursing home (Yamamoto-Mitani, Aneshensel & Levy-Storms, 2002).

Facility Characteristics and Resident Quality of Life

The first research question examined the extent to which facility characteristics impacted family perception of cognitively impaired resident quality of life. A multilevel model, correlation matrix, and linear regression, demonstrate that in fact, facility characteristics are related to family member perception of resident quality of life. The multilevel model results suggest that homelikeness and square footage of the facility are related to overall resident quality of life.

Homelikeness is the largest single contributor towards family member perceptions of resident quality of life when all other variables are considered. If we examine how homelikeness was measured, the individual items reflect both tangible positive elements of a home, such as cleanliness, but more than anything, they are attempting to quantify the elusive feeling of home. The feeling of attachment to a space, warmth, and feeling welcomed are subjective phenomena and are different for everyone. Although there is no universal “home”, those feelings that of comfort and warmth can be more readily identified in smaller spaces, rather than large homes with a larger number of residents in the neighbourhood. Neighbourhood style design arrangements may be perceived to be more homelike because they offer a variety of communal and private spaces, similar to private dwellings, which can create a welcoming space to encourage intimate conversations and shared activity (Davis et al., 2009; Gaugler, Andersen, & Leach, 2004). A positive perception of homelikeness is important from a family perspective because a space that feels warm and evokes feelings of comfort creates an atmosphere that is more welcoming to family and visitors, which is important for residents with

cognitive challenges, who often experience a loss of social connection and loneliness (Cahill & Diaz-Ponc, 2011).

The correlation matrix revealed a correlation between model of care, homelikeness, and square footage. Homes that were newly built (full-scope and augmented) have fewer residents than traditional, and therefore smaller total square footage. Smaller homes were perceived by family to be more homelike, which makes sense when thinking about how neighbourhood style units may compare to private dwellings. The focus on communal living and dining areas and a private bedroom are more familiar to family members rather than larger spaces, which may be reminiscent of hospital or medical architecture. Participant observation noted that the traditional homes had visible medical carts and nursing stations, which is in contrast to new models of care where medical paraphernalia was hidden from view.

Although the new builds have smaller total square footage, they have more square footage per resident. In addition, the newly constructed homes have a larger proportion of private rooms. In two single item questions, the survey asked family members to rate the importance of physical design features and 94% of family members indicated that a private bedroom was important, and 97% that ability to personalize their room and space was important. These findings are consistent with available research, which suggests that private rooms are positively related to resident quality of life because they offer an opportunity for family to be engaged in personalizing the space, choice in activity, and improved family satisfaction during visits (Calkins & Cassella, 2007; Davis et al., 2009). Furthermore, Cutler et al. (2006) suggest that those homes with a greater proportion of

private rooms tend to have communal areas around the home that can facilitate social interaction, and contribute to feelings of homelikeness.

Size

The negative correlation between family perception of square footage and quality of life for persons with cognitive impairment suggests that as the total size of the facility increases, resident quality of life decreases. The finding that reduced size is related to cognitively impaired resident quality of life is consistent with current research which suggests that smaller total facility size is more closely related to comfort and quality of life, but their findings are not directed towards cognitively impaired residents (Torrington, 2007; Barnes, 2002).

Family perception of cognitively impaired resident quality of life increases as the number of residents in the neighbourhood decreases. Less residents in the neighbourhood can mean more space in communal areas for family to interact with residents, reduced crowding in living spaces, and a smaller number of residents in the neighbourhood could mean that there is more opportunity for family to become more familiar with other residents and staff. The finding that smaller neighbourhood size is related to quality of life is related to family perception of homelikeness. Neighbourhoods that offer spaces where family can watch television with the resident, visit in the garden, and decorate for holidays, contribute to an environment that feels warm and welcoming for family members and residents.

Current research would suggest that a smaller number of residents in the neighbourhood are important because they reduce overstimulation, and increase the opportunity for social interaction, factors that might contribute to resident quality of life

(Day, Carreon, & Stump, 2000; Netten, 1989). Chappell and Reid (2000) suggest that reductions in the number of residents in the unit benefit residents with cognitive impairment because it can positively contribute to residents navigating capacity, and greater chance of social interaction with other residents. Overall, the quantitative analysis demonstrates that there is an effect of environment on family perception of cognitively impaired resident quality of life.

Family, Resident, and Environment Interaction

The second research question explored the ways in which the physical environment impacted family member and resident use of space. The focus was on the relational, and activity based interactions within the varying physical designs and assessing the person-environment fit. The case study findings highlighted the family member's focus on both the objective and subjective perceptions of the home within the themes of personal space, identity, and atmosphere and comfort. The survey results indicated that a private bedroom was important to nearly all family member respondents (Calkins & Cassella, 2007; Davis, 2009). The resident's bedroom was a place where family members could bring beloved items of furniture and create an opportunity to remember life prior to living in the nursing home. Creating a familiar space can support family and residents with cognitive challenges because it can stimulate social activity (Kihlgren et al., 1992; Davis et al., 2009). Megan, the daughter-in-law of the resident in the new-full scope home used the phrase "that's real life" and "making real life" multiple times in her interviews when describing activities that she participated in with her mother-in-law in the home. Megan had a history with Mary, with shared activities and memories that were no longer accessible due to cognitive impairment. An accessible

courtyard and private bedroom augmented Mary's reduced physical capacity, which allowed for the continuation of previously enjoyed activities. Smaller neighbourhood arrangements offer a larger proportion of private bedrooms, but more importantly, they have communal spaces that can be used by both residents and family to engage in social activities.

Family members and the participant observer had a positive perception of the neighbourhood design, with the communal living arrangement supported in the literature, suggesting that neighbourhood design reinforces the focus on homelike activities and experiential memories (Chaudhury, 2003; Innes, Kelly, & Dincarslan, 2011). Having a space that is comfortable for both family members and residents to visit and share in an activity is important because family members have improved satisfaction with their visiting and may feel more comfortable bringing children to the home to visit (Angelilli, 2006; Cioffi, Fleming, Wilkes, Sinfield, & Le Miere, 2007). Simple and inexpensive additions to the physical environment, such as a play area for children, or a basket of toys for kids to access when entering the home, can create a space that is welcoming to the entire family. As the results demonstrate, nearly 40% of the family members were still engaged in paid employment, and many have children or grandchildren of their own, and having a space where they can comfortably bring children can lead to less stress when organizing visits to the nursing home. If a child feels comfortable in the space there is less stress worrying about child care and more focus can be on an enjoyable visit between the family and resident. Opportunities for intergenerational contact are important for residents because they are an active, rather than passive form of engagement (Lee, Camp, & Malone, 2007). Although a resident may not be able to engage in a conversation

with a child, having children in the nursing home can be an important step to reducing the barrier between life outside and inside the home. Nursing homes can be a foreign environment for family members, but particularly for children who may not have a sustained contact with a resident in a nursing home. Nursing homes that offer space for the entire family, including children, can reduce the fear and stigma of nursing homes for a new generation of family members.

Home or Hotel

As with any communal living arrangement, there is no one size fits all design, but elements that were perceived to positively contribute to family perceptions of homelikeness both in the survey and case study included the space feeling comfortable and inviting. The challenge with these terms is their subjectivity. The philosophy behind environmental redesign promotes a "physical space that is not meant to be homelike, but to be a true home in all respects" (Jenkins, Sult, Lessell, Hammer & Ortigara, 2011, p.5). An important aspect of the findings to further explore regards the subjective feelings and positive comparisons between the nursing home to a hotel. Features in the physical environment are observable, and therefore easily are considered by family when choosing a home. Research examining nursing home choice found that "consumers were more likely to choose nursing homes of high hotel service quality but not clinical care quality", with hotel service quality including cleanliness, size and space in resident room (Persis-Katz et al., 2013). New home designs may have pleasing features (enhanced entrance ways, unique design features), but those aspects of the home included in the homelikeness scale, such as warmth, cleanliness, welcoming, could be found in a variety of home styles.

Mark, the son of the resident in the new-full scope home had a positive perception of the design of the home, yet compared the home to a hotel or an amusement park. Nursing homes are a foreign environment for most individuals and it is challenging to draw meaningful comparisons between private homes and group living environments with support staff, organized activities, and communal meals. Family members may find that comparing the nursing home to a hotel is the most meaningful comparison they can make with limited experience in long-term care. This highlights an important opportunity for care coordinators at the time of admission to educate and inform family members and residents about what to expect from a nursing home. Furthermore, once placed in a nursing home, administrators, directors of care, and support staff have a responsibility to engage with family members to assess their needs and expectations.

Person-Environment Fit

The theoretical framework provides insight into examining the balance between the resident cognitive challenges and the capacity of the physical environment to compensate for the perceived losses. Within the case studies, residents were often unable to engage in activities due to cognitive challenges, but the structure of the neighbourhood or unit contributed to their continued participation in desired activities. Environment can support resident choice, whether it is staying in their room watching television, or walking in an unobtrusive environment. A key component of the fit between person and environment was the resident's ability to exercise choice and autonomy in their own environment. Whether it was staying in their own room and passively observing activity, or actively moving around the home, the true fit between person and environment was

observed when the resident was able to conduct the activities that were important to them in the given space.

Family had positive perceptions of the environment when the resident was able to continue valued activities in the home. Although family members had positive perceptions of the physical design and features in the home, negative comments regarding medical carts in the halls, handrail gaps, lighting, and design features that were not utilized by residents, were described only by the participant observers. The family focused on those components of the building that were supporting the resident, whereas the participant observer was more likely to describe those areas that presented a challenge. For example, a perceived limitation by the participant observer of the traditional home was the reduced access to communal spaces because of long hallways, which are reminiscent of hospital architecture (Cutler, Kane, Degenholtz, Miller, & Grant, 2006). And yet, the family member interviews revealed that the design of the unit was ideal for the resident, as she needed to be constantly moving, and the long hallways afforded her that opportunity, and family perceived that a smaller space would not accommodate her needs.

Although not from the family perspective, the participant observations provided necessary context to both the physical environment, understanding which areas of the home they are referencing in the interviews, and how the environment shapes their interactions. The challenge of assessing quality of life from the family perspective is the inherent limit in their ability to speak to all aspects of the resident life, simply because they are not in the home at all times, and may not have visited different homes with which to compare their current experience. The integration of participant observation

with family interviews provided an opportunity to both acknowledge differences between observer and family perceptions, and examine researcher assumptions regarding homelikeness and desirable features.

Implications for Policy, Practice, and Future Research

The findings revealed that smaller homes, and homelike design elements contribute to family perceptions of cognitively impaired resident quality of life. The number of residents entering long-term care with dementia related illnesses is only expected to grow, and the findings demonstrate that facility characteristics and design elements are related to family perception of resident quality of life. Although the there is a positive relationship between smaller facilities and quality of life, given the current fiscal limitations, building or renovating homes to reflect the neighbourhood design is not always a possibility. Although there are areas in the home that may be aesthetically pleasing, it is those areas that promote activity and social engagement that are positively contribute to family member and resident interactions. Creating space within any home to accommodate private family visits, including an area for small children, can positively contribute to positive family perceptions of the physical environment. The case study data reveals that the aspects of private rooms that are important is bringing personal items of furniture and being allowed to update the décor with the resident, all of which can be incorporated in semi-private living arrangements.

The research focused on family perception of cognitively impaired resident quality of life. The examination of quality of life from the family perspective is important for nursing homes because family are an integral role of the care team. Policies within the home that encourage family members to engage in activities in the home, such as

encouragement and support to bring in personal items, decorating for holidays, and create private areas for family activities, can strengthen the connection to the home and facilitate engagement opportunities which benefit the resident.

Family members may benefit from increased information when assisting a loved one in finding a nursing home, and upon entering a home to identify if the design of the home is suited to the resident's needs. Family's unique knowledge of resident's needs and previously enjoyed activities can assist homes in tailoring their spaces to support resident quality of life. Nursing homes are not familiar environments for most family members, and this research highlights the need for an increased focus on orienting family members to the nursing home environment. Administrators and directors of care should be in close contact with family members to discuss what the home has to offer both the family and residents. Aligning the family member and resident needs with what the nursing home has available can make

At a larger policy level, when planning committees are created to oversee the creation, renovation, or replacement of nursing homes, family members should be included in the planning process so that their needs and the needs of residents who cannot speak for themselves are represented.

Moving forward, this research highlights the need to expand our understanding of family perception of resident outcomes in long-term care, and could be expanded to include additional measures of cognition, such as charting data to assess resident cognition and compare to current findings within the study sites in Nova Scotia.

Limitations

A clear challenge with this data was examining resident quality of life from the perspective of someone other than the resident. Family members may not be able to speak to phenomena within the home because they are not present at all times. Although the perspective of family was chosen because it is unique and largely unexamined, it is important to note that assessing quality of life from an "outside" perspective can mean that there are areas of importance to residents that have been left undiscovered.

Furthermore, the examination of cognitive impairment from the perspective of family meant that cognition was measured without clinical indicators of diagnosis or disease. A limitation of using secondary data is the inability to ascertain diagnostic information to corroborate the perceived level of impairment. It is possible that by reducing the sample size further to include those residents who family perceive to have greater cognitive impairment would have provided further insight into residents with more severe cognitive impairment.

The literature suggested that there was a relationship between the severity of impairment and perception of the importance of physical design and based on the sample size and regression techniques, it was not possible to draw comparisons between degrees of impairment and additional independent variables.

In terms of research methodology, the limitations of the research lie primarily in the small sample size. Although the imputation procedures were successful in reducing the impact of missing data, the number of cases within the total data set limited the ability to detect an effect with the large number of proposed independent variables. The

multilevel procedures necessary for the nested nature of the data meant that a larger number of cases would have been more successful at detecting potential effects.

In the case study constellations, there were a small number of cases representing cognitive impairment, and residents were not included or excluded based on diagnostic criteria, but rather their inability to provide information in an interview. Therefore, similar to the survey limitations, the case study was limited because it did not specify the degree or type of cognitive impairment. Future research should be conducted with residents of comparable cognitive limitations to determine if the diagnosis and type of impairment impacts family member perceptions of resident quality of life.

Furthermore, the case studies have limited generalizability because of the small sample size, but also because each resident in the case studies had a private room. Social engagement with the family member was found to be important in the case studies, but none of the residents shared a room, even the resident in the traditional home, which typically has a larger proportion of shared, semi-private rooms.

Conclusion

This study reinforces the importance of physical environment and design features on family member perceptions of quality of life for residents with cognitive impairment in nursing homes. The findings are consistent with current literature concerning the benefit of smaller, neighbourhood style homes, and the importance of interactional space for family and residents. The findings reveal that those elements that positively contribute to perceptions of quality of life include homelike design elements, total square footage, and neighborhood size. Those spaces in the home that reinforce resident personal identity

and contribute to social engagement are perceived as positively contributing to cognitively impaired resident quality of life.

References

Alzheimer's Association. (2012). Alzheimer's Association Report, 2012 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 8,* 131-168.

Alzheimer's Australia. (2004). Dementia care and the built environment, Position Paper 3. Retrieved from http://www.fightdementia.org.au/common/files/ NAT/20040600_Nat_NP_3DemCareBuiltEnv.pdf

Alzheimer's Society of Canada. (2010). Rising Tide: The Impact of Dementia on Canadian Society. Retrieved from http://www.alzheimer.ca/~/media/Files/national/ Advocacy/ ASC_Rising%20Tide-Executive%20Summary_Eng.ashx

Andrén, S., Elmståhl, S. (2002). Former family carers subjective experiences of burden. *Dementia, 1,* 241-254. doi:10.1177/147130120200100209

Angelelli, J. (2006). Promising models for transforming long-term care. *The Gerontologist, 46,* 428-430. doi:10.1093/geront/46.4.428

Annerstedt, L. (1993). Development and consequences of group living in Sweden. A new mode of care for the demented elderly. *Social Science & Medicine, 37,* 1529-38. doi:10.1016/0277-9536(93)90187-9

Barnes, S., & the DESIGN IN CARING ENVIRONMENTS STUDY GROUP. (2002). The design of caring environments and the quality of life of older people. *Ageing and Society, 22,* 775-789. doi:10.1017/S0144686X02008899

Bauer M. (2006). Collaboration and control: Nurses' constructions of the role of family in nursing home care. *Journal of Advanced Nursing, 54*(1), 45-52. doi:10.1111/j.1365-2648.2006.03789.x

Beer, C., Flicker, L., Horner, B., Bretland, N., Scherer, S., Lautenschlager, N. T., Schaper, F., & Almeida, O. P. (2010). Factors associated with self and informant ratings of the quality of life of people with dementia living in care facilities: A cross sectional study. *Plos One, 5*(12), 1-6. doi:10.1371/journal.pone.0015621

Borkan, J. M. (2004). Mixed methods studies: A foundation for primary care research. *Annals of Family Medicine, 2,* 4-6. doi:10.1370/afm.111

Bowers, B. J. (1988). Family perceptions of care in a nursing home. *The Gerontologist, 28,* 361-368. doi:10.1093/geront/28.3.361

Bravo, G., De Wals, P., Dubois, M.F., & Charpentier, M. (1999). Correlates of care quality in long-term care facilities: A multilevel analysis. *The Journals of*

Gerontology.Series B, Psychological Sciences and Social Sciences, 54(3), 180-8. doi:10.1093/geronb/54B.3.P180

Brod, M., Stewart, A.L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *The Gerontologist, 39*(1), 25-35. doi:10.1093/geront/39.1.25

Brodaty, H., Draper, B., & Low, L-F. (2002). What environmental and staffing characteristics predict behavioural and psychological symptoms of dementia in nursing home residents? *Psychogeriatrics, 2,* 47-53. doi:10.1111/j.1479-8301.2002.tb00033.x

Brune, K. (2011). Culture change in long-term care services: Eden-Greenhouse-Aging in the community. *Educational Gerontology, 37,* 506-525. doi:10.1080/03601277.2011.570206

Burgener, S. C., Twigg, P., & Popovich, A. (2005). Measuring psychological well-being in cognitively impaired persons. *Dementia, 4,* 463-485. doi:10.1177/1471301205058303

Cahill, S., & Diaz-Ponce, A. M. (2011). 'I hate having nobody here. I'd like to know where they all are': Can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment? *Aging & Mental Health, 15,* 562-572. doi:10.1080/13607863.2010.551342

Calkins, M. P. (2005). Environments for late-stage dementia. *Alzheimer's Care Quarterly, 6*(1), 71-75.

Calkins, M. P. (2002). The nursing home of the future: Are you ready? *Nursing Homes: Long Term Care Management, 51*(6). 42-47.

Calkins, M. (2003). Powell Lawton's contributions to long-term care settings. *Journal of Housing for the Elderly, 17*(1/2), 67-84. doi:10.1300/J081v17n01_06

Calkins, M., & Cassella, C. (2007). Exploring the cost and value of private versus shared bedrooms in nursing homes. *The Gerontologist, 47,* 169-183. doi:10.1093/geront/47.2.169

Calkins, M. P. (2011). Evidence-based design for dementia: Findings from the past five years. *Long-Term Living: For the Continuing Care Professional, 60*(1), 42-45.

Canadian Healthcare Association. (2009). *New Directions for Facility-Based Long Term Care*. Ottawa: Author. Retrieved from http://www.cha.ca/wp-content/uploads/2012/11/CHA_LTC_9-22-09_eng.pdf

Canadian Institute for Health Information. (2009). When a nursing home is home: How do Canadian nursing homes measure up on quality? *Continuing car reporting system (CCRS): Analyses in brief and analytical reports.* Retrieved from https://secure.cihi.ca/free_products/CCRS_QualityinLongTermCare_EN.pdf

Canadian Medical Association. (2013). The Need for Health Infrastructure in Canada. *Recommendations submitted to Hon. Denis Lebel, PC, MP. Minister of Transport, Infrastructure and Communities.* Ottawa. Retrieved from http://www.cma.ca/multimedia/CMA/Content_Images/Inside_cma/Submissions/2013/Health-Infrastructure_en.pdf

Chalfont, G. E., & Rodiek, S. (2005). Building edge: An ecological approach to research and design of environments for people with dementia. *Alzheimer's Care Quarterly, 6,* 341-348.

Chapin, M. K. (2010). The language of change: finding words to define culture change in long-term care. *Journal of Aging, Humanities, and the Arts, 4,* 185-199. doi:10.1080/19325614.2010.508332

Chappell, N. L., & Reid, R. C. (2000). Dimensions of care for dementia sufferers in long-term care institutions: Are they related to outcomes? *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 55*(4), 234-44. doi:10.1093/geronb/55.4.S234

Chaudhury, H. (2003). Quality of life and place-therapy. *Journal of Housing for the Elderly, 17*(1-2), 85-103. doi:10.1300/J081v17n01_07

Cioffi, J. M., Fleming, A., Wilkes, L., Sinfield, M., & Le Miere, J. (2007). The effect of environmental change on residents with dementia. *Dementia, 6,* 215-231. doi:10.1177/1471301207080364

Cohen, J. (1988). Statistical power analysis for the behavioural sciences (2nd Ed.) Hillsdale, NJ: Lawrence Erbaum Associates.

Cohen-Mansfield, J., & Werner, P. (1998). The effects of an enhanced environment on nursing home residents who pace. *The Gerontologist, 38,* 199-208. doi:10.1093/geront/38.2.199

Conde-Sala JL, Garre-Olmo J, Turró-Garriga O, López-Pousa S, & Vilalta-Franch J,. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: The patient's perception compared with that of caregivers. *International Journal of Geriatric Psychiatry, 24,* 585-94. doi:10.1002/gps.2161

Cooney, A., Murphy, K., & O'Shea, E. (2009). Resident perspectives of the determinants of quality of life in residential care in Ireland. *Journal of Advanced Nursing, 65,* 1029-1038. http://dx.doi.org/10.1111/j.1365-2648.2008.04960.x

Cooney, T. M., & McClintock, J. (2006). Family members' perspectives on environmental changes in a long-term care facility: Lessons from a case study. *Ageing International, 31*(1), 71-92. doi:10.1007/s12126-006-1005-7

Crespo, M., Hornillos, C., & de Quirós, M. B. (2013). Factors associated with quality of life in dementia patients in long-term care. *International Psychogeriatrics / IPA, 25,* 577-85. doi :10.1017/S1041610212002219

Crespo, M., de Quirós, M. B., Mar Gomez, M., & Hornillos, C. (2011). Quality of life of nursing home residents with dementia: A comparison of perspectives of residents, family, and staff. *The Gerontologist, 52,* 56-65. doi:10.1093/geront/gnr080

Crews, D. E. (2005). Artificial environments and an aging population: Designing for age-related functional losses. *Journal of Physiological Anthropology and Applied Human Science, 24(1),* 103-109. doi:10.2114/jpa.24.103

Cutchin, M. P. (2005). Spaces for inquiry into the role of place for older people's care. *International Journal of Older People Nursing* in association with *Journal of Clinical Nursing, 14(8b),* 121-129.

Cutler, L. J., Kane, R. A., Degenholtz, H. B., Miller, M. J., & Grant, L. (2006). Assessing and comparing physical environments for nursing home residents: Using new tools for greater research specificity. *The Gerontologist, 46,* 42-51. doi:10.1093/geront/46.1.42

Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *The Gerontologist, 40,* 397-416. doi:10.1093/geront/40.4.397

Davis, S., Byers, S., Nay, R., & Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia, 8,* 185-203. doi:10.1177/1471301209103250

Degenholtz, H. B., Kane, R. A., Kane, R. L., Bershadsky, B., & Kling, K. C. (2006). Predicting nursing facility residents' quality of life using external indicators. *Health Services Research, 41,* 335-356. doi: 10.1111/j.1475-6773.2005.00494

Department of Health and Wellness (2006). Continuing Care Strategy. Retrieved from http://www.gov.ns.ca/health/ccs_strategy/Continuing_Care_Strategy.pdf

Department of Health and Wellness. (2007). Long Term Care Facility Program Requirements. RFP No. 60131638. Appendix C. Retrieved from http://novascotia.ca/dhw/ccs/policies/Long-Term-Care-Facility-Program-Requirements.pdf

Department of Health and Wellness. (2014a). Continuing Care Strategy review begins. Retrieved from http://novascotia.ca/news/release/?id=20140131007

Department of Health and Wellness. (2014b). Nova Scotia's dementia strategy. Retrieved from https://novascotia.ca/dhw/ccs/dementia-strategy/

Devlin, A. S., & Arneill, A. B. (2003). Health care environments and patient outcomes: A review of the literature. *Environment and Behaviour, 35,* 665-694. doi:10.1177/0013916503255102

Dijkstra, K., Pieterse, M., & Pruyn, A. (2006). Physical environmental stimuli that turn healthcare facilities into healing environments through psychologically mediated effects: systematic review. *Journal of Advanced Nursing, 56,* 166-181. doi:10.1111/j.1365-2648.2006.03990.x

Dobbs, D., & Montgomery, R. (2005). Family satisfaction with residential care provision: A multilevel analysis. *Journal of Applied Gerontology, 24,* 453-474. doi:10.1177/0733464805279374

Driscoll, D. L., Appiah-Yeboah, A. Salib, P., & Rupert, D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology (University of Georgia).* Paper 18. http://digitalcommons.unl.edu/icwdmeea/18

Dröes, R-M., Boelens-Van Der Knoop, E., Bos, J., Meihuizen, L., Ettema, T., Gerritsen, D., Hoogeveen, F., De Lange, J., & SchöLzel-Dorenbos, C. (2006). Quality of life in dementia in perspective. *Dementia, 5,* 533-558. doi:10.1177/1471301206069929

Dupuis, S. L., & Norris, J. E. (2001). The roles of adult daughters in long-term care facilities Alternative role manifestations. *Journal of Aging Studies, 15,* 27-54. doi:10.1016/S0890-4065(00)00015-3

Earl, M., Warner, G., Andrew, M., Godin, J., Keen, S., & Morrison, A. (2013, October). *"It's as much like home as you can have": Assessing the impact of changes to nursing home design and model of care on resident quality of life.* Paper presented at the meeting of the Canadian Association of Gerontology, Halifax, Nova Scotia.

Edelman, P., Fulton, B. R., Kuhn, D., & Chang. C. H. (2005). A comparison of three methods of measuring dementia-specific quality of life: Perspectives of residents, staff, and observers. *The Gerontologist, 45,* 27-36. doi:10.1093/geront/45.suppl_1.27

Edvardsson, J. D., Sandman, P-O., & Rasmussen, B. H. (2005). Sensing an atmosphere of ease: a tentative theory of supportive care settings. *Scandinavian Journal of Caring Science, 19,* 344-353. doi:10.1111/j.1471-6712.2005.00356.x

Falk, H., Wijk, H., & Persson, L-O. (2009). The effects of refurbishment on residents' quality of life and wellbeing in two Swedish residential care facilities. *Health & Place, 15,* 717-724. doi:10.1016/j.healthplace.2008.11.004

Fancey, P., Keefe, J., Stadnyk, R., Gardiner, E., & Aubrecht, K. (2012). Understanding and assessing the impact of nursing home approach to care and physical design on residents and their families: A synthesis of the literature. *Seniors Housing & Care Journal, 20,* 99-114.

Fleming, R., & Purandare, N. (2010). Long-term care for people with dementia: environmental design guidelines. *International Psychogeriatrics, 22,* 1084-1096. doi :10.1017/S1041610210000438

Garre-Olmo J, López-Pousa S, Turon-Estrada A, Juvinyà D, Ballester D, & Vilalta-Franch J. (2012). Environmental determinants of quality of life in nursing home residents with severe dementia. *Journal of the American Geriatrics Society, 60,* 1230-6. doi:10.1111/j.1532-5415.2012.04040.x

Gaugler, J. E. (2005). Family involvement in residential long-term care: A synthesis and critical review. *Aging & Mental Health, 9*(2), 105-118. doi:10.1080/13607860412331310245

Gaugler, J. (2006). Family involvement and resident psychosocial status in long-term care. *Clinical Gerontologist, 29*(4), 79-98. doi:10.1300/J018v29n04_06

Gaugler, J., Anderson, K., & Leach, C. (2003). Predictors of family involvement in residential long-term care. *Journal of Gerontological Social Work, 42*(1), 3-26. doi:org/10.1300/J083v42n01_02

Gaugler, J., & Holmes, H. (2003). Families' experiences of long-term care placement: Adaptation and intervention. *Clinical Psychologist, 7*(1), 32-43. doi:10.1080/13284200410001707463

González-Salvador, T., Lyketsos, C. G., Baker, A., Hovanec, L., Roques, C., Brandt, J., & Steele, C. (2000). Quality of life in dementia patients in long-term care. *International Journal of Geriatric Psychiatry, 15*(2), 181-9. doi:10.1002/(SICI)1099-1166(200002)15:2<181::AID-GPS96>3.0.CO;2-I

Grant, L. A. (1996). Assessing environments in Alzheimer special care units: Nursing unit rating scale. *Research on Aging, 18(3),* 275-291. doi:10.1177/0164027596183001

Harmer, B. J. & Orrell, M. (2008). What is meaningful activity for people with dementia living in care homes? A comparison of the views of older people with dementia, staff and family carers. *Aging & Mental Health, 12,* 548-558. doi:10.1080/13607860802343019

Harvey, R. J., Skelton-Robinson, M., & Rossor, M. N. (2003). The prevalence and causes of dementia in people under the age of 65 years. *Journal of Neurology, Neurosurgery & Psychiatry, 74*, 1206-1209.

Hirdes, J. P., Ljunggren, G., Morris, J. N., Frijters, D. HM., Soveri, H. F., Gray, L., Bjorkgren, M., & Gilgen, R. (2008). Reliability of the interRAI suite of assessment instruments: a 12-country study of an integrated health information system. BMC Health Services Research, 8(277), 1-11. doi:10.1186/1472-6963-8-277

Innes, A., Kelly, F., & Dincarslan, O. (2011). Care home design for people with dementia: What do people with dementia and their family carers value? *Aging & Mental Health, 15,* 548-556. doi:10.1080/13607863.2011.556601

Jenkins, R., Sult, T., Lessell, N., Hammer, D. & Ortigara, A. (2011). Financial implications of The Green House Model. *Seniors Housing & Care Journal, 19*, 3-22.

Kane, R. A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *The Gerontologist, 43*, 28-36. doi:10.1093/geront/43.suppl_2.28

Kane, R. L., Bershadsky, B., Kane, R. A., Degenholtz, H. H., Liu, J. J., Giles, K., & Kling, K. C. (2004). Using resident reports of quality of life to distinguish among nursing homes. *The Gerontologist, 44,* 624-32. doi:10.1093/geront/44.5.624

Kane, R. A., Lum, T. Y., Cutler, L. J., Degenholtz, H. B., & Yu, T. (2007). Resident outcomes in small-house nursing homes: A longitudinal evaluation of the initial green house program. *Journal of the American Geriatrics Society, 55,* 832-839. doi:10.1111/j.1532-5415.2007.01169.x

Kehyayan, V. (2011). Relationships between Quality of Life and Selected Resident and Facility Characteristics in Long Term Care Facilities in Canada. (Unpublished doctoral dissertation). University of Waterloo, Waterloo, Ontario, Canada.

Kihlgren, M., Brane, G., Karlsson, I., Kuremyr, D., Leissner, P., & Norberg, A. (1992). Long-term influences on demented patients in different caring milieus, a collective living unit and a nursing home: A descriptive study. *Dementia, 3*, 342-349.

Kovach, C., Weisman, G., Chaudhury, H., & Calkins, M. (1997). Impacts of a therapeutic environment for dementia care. *American Journal of Alzheimer's Disease and Other Dementias, 12*, 99-110. doi:10.1177/153331759701200302

Kutner, N. G., Mistretta, E. F., Barnhart, H. X., & Fielding Belodoff, B. B (1999). Family members' perceptions of quality of life change in dementia SCU residents. *Journal of Applied Gerontology, 18*, 423-439. doi:10.1177/073346489901800402

Lawton, M. P. (1974). Social ecology and the health of older people. *American Journal of Public Health, 64,* 257-60. doi:10.2105/AJPH.64.3.257

Lawton, M.P., Winter, L., Kleban, M.H., & Ruckdeschel, K. (1999). Affect and quality of life: Objective and subjective. *Journal of Aging and Health, 11*(2), 169-98. doi:10.1177/089826439901100203

Lawton, M. P., & Van Haitsma, K. (1996). Observed affect in nursing home residents with Alzheimer's disease. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 51B*(1), 3-14. doi:10.1093/geronb/51B.1.P3

Lawton, M. P. (1997). Measures of quality of life and subjective well-being. *Generations, 21,* 45-47.

Lawton, M. P. (2001). The physical environment of the person with Alzheimer's disease. *Aging and Mental Health, 5*(2), 56-64. doi:10.1080/13607860120044828

Lee, M. M., Camp, C. J., Malone, M. L. (2007). Effects of intergenerational Montessori-based activities programming on engagement of nursing home residents with dementia. *Clinical Interventions in Aging, 3,* 477-483.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64*(3), 510-519.

Low, L. F., Draper, B., & Brodaty, H. (2004). The relationship between self-destructive behaviour and nursing home environment. *Aging & Mental Health, 8*(1), 29-33. doi:10.1080/13607860310001613301

Lum, T. Y., Kane, R. A., Cutler, L. J., & Yu, T. C. (2008). Effects of green house nursing homes on residents' families. *Health Care Financing Review, 30*(2), 35-51.

Malmberg, B., & Zarit, S. H. (1993). Group homes for people with dementia: A Swedish example. *The Gerontologist, 33,* 682-686. doi:10.1093/geront/33.5.682

Majerovitz, S. D., Mollott, R. J., & Rudder, C. (2009). We're on the same side: Improving communication between nursing home and family. *Health Communication, 24*(1), 12-20. doi:10.1080/10410230802606950

Marquardt, G., & Schieg, P. (2009). Dementia-friendly architecture: Environments that facilitate wayfinding in nursing homes. *American Journal of Alzheimer's Disease and Other Dementias, 24(4),* 333-340. doi:10.1177/1533317509334959

Marquardt, G., Johnston, D., Black, B., Morrison, A., Rosenblatt, A., Lyketsos, C., & Samus, Q. (2011). Association of the spatial layout of the home and ADL abilities

among older adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 26*(1), 51-57. doi:10.1177/1533317510387584

Mayo Clinic (2011). *Early-onset Alzheimer's: When symptoms begin before age 65.* Retrieved from http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048356

McAllister, C. L., & Silverman, M.A. (1999). Community formation and community roles among persons with Alzheimer's disease: A comparative study of experiences in a residential Alzheimer's facility and a traditional nursing home. *Qualitative Health Research Qualitative Health Research, 9*(1), 65-85. doi:10.1177/104973299129121703

Montgomery, R. J. (1999). The family role in the context of long-term care. *Journal of Aging and Health, 11,* 383-416. doi:10.1177/089826439901100307

Morgan, D. G., & Stewart, N. J. (1998). High versus low density special care units: impact on the behaviour of elderly residents with dementia. *Canadian Journal on Aging/ La Revue canadienne du viellissement, 17,* 143-165. doi :10.1017/S0714980800009235

Moyle, W., Mcallister, M., Venturato, L., & Adams, T. (2007). Quality of life and dementia. *Dementia, 6,* 175-191. doi:10.1177/1471301207080362

Naleppa, M. J. (1997). Families and the institutionalized elderly, *Journal of Gerontological Social Work, 27 (1-2),* 87-111. doi:10.1300/J083v27n01_07

Netten, A. (1989). The effect of design of residential homes in creating dependency among confused elderly residents: A study of elderly demented residents and their ability to find their way around homes for the elderly. *International Journal of Geriatric Psychiatry, 4,* 143-153. doi:10.1002/gps.930040305

Nova Scotia Legislature. (2013). Nova Scotia house of assembly on public accounts. Retrieved from http://nslegislature.ca/index.php/committees/committee_hansard/C7/pa2013jan09.

Novella, J. L., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F., & Blanchard, F. (2001). Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. *Quality of Life Research, 10,* 443-452. doi:10.1023/A:1012522013817

Onishi, J., Suzuki, Y., Umegaki, H., Endo, H., Kawamura, T., Imaizumi, M., & Iguchi, A. (2006). Behavioural, psychological and physical symptoms in group homes for older adults with dementia. *International Psychogeriatrics, 18(1),* 75-86. doi:10.1017/S1041610205002917

Parker, C., Barnes, S., McKee, K., Morgan, K., Torrington, J., & Tregenza, P. (2004). Quality of life and building design in residential and nursing homes for older people. *Ageing and Society, 24,* 941-962. doi:10.1017/S0144686X04002387

Passini, R., Pigot, H., Rainville, C, & Tetreault, M-H. (2000). Wayfinding in a nursing home for advanced dementia of the Alzheimer's type. *Environment and Behaviour, 32,* 684-710. doi:10.1177/00139160021972748

Patrician, P. A. (2002). Focus on Research Methods: Multiple Imputation for Missing Data. *Research in Nursing & Health, 25,* 76-84. doi:10.1002/nur.10015

Pesis-Katz, I., Phelps, C. E., Temkin-Greener, H., Spector, W. D., Veazie, P., & Mukamel, D. B. (2013). Making difficult decisions: The role of quality of care in choosing a nursing home. *American Journal of Public Health,* e1-e7.

Peugh, J. L. (2010). A practical guide to multilevel modeling. *Journal of School Psychology, 48,* 85-12. doi:10.1016/j.jsp.2009.09.002

Pinet, C. (2008). Distance and the use of social space by nursing home residents. *Journal of Interior Design, 25(1),* 1-15. doi:10.1111/j.1939-1668.1999.tb00331.x

Prince Edward Island Department of Health and Wellness. (2012). *Prince Edward Island's manor replacement program profiled nationally.* Retrieved from http://www.gov.pe.ca/health/index.php3?number=news&dept=&newsnumber=8275&lang=E.

Rabins, P. V., Kasper, J. D., Kleinman, L., Black, B. S., & Partick, D. L. (1999). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Journal of Mental Health and Aging, 5(1),* 33-48.

Rabig, J., & Rabig, D. (2008). From 'nursing home' to 'home': The small house movement. *Long-Term Living: For the Continuing Care Professional, 57(3),*12-16.

Rabig, J., Thomas, W., Kane, R., Cutler, L., & McAlilly, S. Radical redesign of nursing homes: applying the Green House concept in Tupelo, Mississippi. *The Gerontologist, 46,* 533-539. doi:10.1093/geront/46.4.533

Rahman, A. N., & Schnelle, J. F. (2008). The nursing home culture-change movement: Recent past, present, and future directions for research. *The Gerontologist, 48,* 142-148. doi:10.1093/geront/48.2.142

Ready, R. E., Ott, B. R., & Grace, J. (2004). Patient versus informant perspectives of quality of life in mild cognitive impairment and Alzheimer's disease. *International Journal of Geriatric Psychiatry, 19,* 256-265. doi:10.1002/gps.1075

Reid, R., Chappell, N., & Gish, J. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia, 6,* 89-104. doi:10.1177/1471301207075640

Reimer, M. A., Slaughter, S., Donaldson, C., Currie, G., & Eliasziw, M. (2004). Special care facility compared with traditional environments for dementia care: A longitudinal study of quality of life. *Journal of the American Geriatrics Society, 52,* 1085-1092. doi:10.1111/j.1532-5415.2004.52304.x

Robichaud, L., Durand, P. J., Bédard, R., & Ouellet, J. P. (2006). Quality of life indicators in long-term care: Opinions of elderly residents and their families. *Canadian Journal of Occupational Therapy.Revue Canadienne d'Ergothérapie, 73*(4), 245-51. doi :10.2182/cjot.06.003

Robinson, C. A., Reid, R. C., & Cooke, H. A. (2010). A home away from home: The meaning of home according to families of residents with dementia. *Dementia, 9,* 490-508. doi:10.1177/1471301210381679

Schafer, J. L. & Olsen, M K. (1998). Multiple imputation for multivariate missing-data problems: A data analyst's perspective. *Multivariate Behavioural Research, 33,* 545-571. doi:10.1207/s15327906mbr3304_5

Scherbaum, C. A. & Ferreter, J. M. (2009). Estimating statistical power and required sample sizes for organizational research using multilevel modeling. *Organizational Research Methods, 12,* 347-367. doi: 10.1177/1094428107308906

Schwarz, B., Chaudhury, H., & Tofle, R. (2005). Effect of design interventions on a dementia care setting. *American Journal of Alzheimer's Disease and Other Dementias, 19*(3), 172-176. doi:10.1177/153331750401900304

Shields, S., & Norton, L. (2006). In Pursuit of the Sunbeam: A Practical Guide to Transformation from Institution to Household. Action Pact Press. Retrieved from http://www.commonwealthfund.org/Resources/2007/Jul/In-Pursuit-of-the-Sunbeam--A-Practical-Guide-to-Transformation-from-Institution-to-Household.aspx

Slaughter, S., Calkins, M., Eliasziw, M., & Reimer, M. (2006). Measuring physical and social environments in nursing homes for people with middle-to late-stage dementia. *Journal of the American Geriatrics Society, 54,* 1436-1441. doi:10.1111/j.1532-5415.2006.00851.x

Statistics Canada (2011). *2011 Census: Age and Sex.* Government of Canada. Retrieved from http://www.statcan.gc.ca/daily-quotidien/110928/dq110928a-eng.htm

Stewart, A., & King, A. (1994). *Conceptualizing and measuring quality of life in older populations.* In R. Abeles et al. (Eds.), Aging and the Quality of Life. New York: Springer Publishing Company.

Temkin-Greener, H., Zheng, N. T., Cai, S., Zhao, H., & Mukamel, D. B. (2010). Nursing home environment and organizational performance: association with deficiency citations. *Medical Care, 48(4),* 357-364. doi:10.1097/MLR.0b013e3181ca3d70

Teresi, J. A., Holmes, D., & Ory, M. G. (2000). The therapeutic design of environments for people with dementia: Further reflections and recent findings from the National Institute on Aging Collaborative Studies of dementia special care units. *The Gerontologist, 40,* 417-421. doi:10.1093/geront/40.4.417

The Green House Project. (2013). *The Green House Core Values.* Retrieved from http://thegreenhouseproject.org/green-house-model

Torrington, J. (2006). What has architecture got to do with dementia? Explorations of the relationship between quality of life and building design in two EQUAL projects. *Quality in Ageing-Policy, Practice and Research, 7(1),* 34-48. doi:10.1108/14717794200600006

Torrington, J. (2007). Evaluating quality of life in residential care buildings. *Building Research & Information, 35,* 514-528. doi:10.1080/09613210701318102

Train, G., Nurock, S., Kitchen, G., Manela, M., & Livingston, G. (2005). A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long-term care settings. *International Psychogeriatrics, 17,* 237-251. doi:10.1017/S1041610205001729

U.S. Congress, Office of Technology Assessment, Special Care Units for People With Alzheimer's and Other Dementias: Consumer Education, Research, Regulatory, and Reimbursement Issues, OTA-H-543 (Washington, DC: U.S. Government Printing Office, August 1992).

van Buuren, S. & Broothuis-Oudshoorn, K. (2011). mice: Multivariate imputation by chained equations in R. *Journal of Statistical Software, 45,* 1-68.

Verbeek, H., van Rossum, E., Zwakhalen, S. M. G., Kempen, G. I. J. M., & Hamers, J. P. H. (2009). Small, homelike care environments for older people with dementia: a literature review. *International Psychogeriatrics, 21,* 252-264. doi:10.1017/S104161020800820X

Vogel A, Bhattacharya S, Waldorff, F. B,, & Waldemar, G. (2012). Proxy-rated quality of life in Alzheimer's disease: A three-year longitudinal study. *International Psychogeriatrics / IPA, 24*(1), 82-9. doi:10.1017/S1041610211001128

Voutilainen, P., Backman, K., Isola, A., & Laukkala, H. (2006). Family members' perceptions of the quality of long-term care. *Clinical Nursing Research, 15*(2), 135-149. doi:10.1177/1054773805285697

Wang, J., Chang, L. H., Eberly, L. E., Virnig, B. A., & Kane, R.L. (2010). Cognition moderates the relationship between facility characteristics, personal impairments, and nursing home residents' activities of daily living. *Journal of the American Geriatrics Society, 58*(12), 2275-83. doi:10.1111/j.1532-5415.2010.03173.x

Wayman, J. C. (2003). Multiple imputation for missing data: What is it and how can I use it? Paper presented at the 2003 Annual Meeting of the American Educational Research Association, Chicago, IL.

White, H. K., Corazzini, K., Twersky, J., Buhr, G., McConnell, E., Weiner, M. & Colon-Emeric, C. S. (2012). Prioritizing culture change in nursing homes: Perspectives of residents, staff, and family members. *Journal of the American Geriatrics Society, 60,* 525-531. doi:10.1111/j.1532-5415.2011.03840.x

World Health Organization (1997). Measuring Quality of Life- The World Health Organization Quality of Life Instruments. Division of Mental Health and Prevention of Substance Abuse. Retrieved from http://www.who.int/mental_health/media/68.pdf

Young, R., & Johnson, D. (2013). Methods for handling missing secondary respondent data. *Journal of Marriage and Family, 75,* 221-234. doi:10.1111/j.1741-3737.2012.01021.x

Zeisel, J., Silverstein, N. M., Hyde, J., Levkoff, S., Lawton, M. P., & Holmes, W. (2003). Environmental correlates to behavioural health outcomes in Alzheimer's special care units. *The Gerontologist, 43,* 697-711. doi:10.1093/geront/43.5.697

Zimmerman, S., Anderson, W. L., Brode, S., Jonas, D., Lux, L., Beeber, A. S., Watson, L. C., Viswanthan, M., Lohr, K. N., & Sloane, P. D. (2013). Systematic review: Effective characteristics of nursing homes and other residential long-term care settings for people with dementia. *Journal of the American Geriatrics Society, 61,* 1399-1409. doi:10.1111/jgs.12372

APPENDIX

Appendix A: Facility Profile

Profile of Nursing Homes:
Physical and Social Environment of Study Sites

A Component of the Care and Construction Project

Introduction:

Each component of the Care and Construction study is designed to add to our understanding of models of care and how they impact resident quality of life. The purpose of this profile is to provide descriptive information on the physical and social environment of the facility. The information you provide will contribute to a better understanding of the nursing home environment and will be used to help us interpret the results from the surveys, focus groups, interviews and case studies. As you are completing the profile, if you have any questions or require clarification, please contact the project office by telephone (902-457-6218) or by E-mail (careandconstruction@msvu.ca).

To be completed by a senior administrator

Date: _____

If this document is found, please return to:

Care and Construction Project Office
Nova Scotia Centre on Aging
166 Bedford Highway
Halifax, NS, B3M 2J6
T: (902) 457-6218; 1-877-302-4440 (toll-free)
E: careandconstruction@msvu.ca

GENERAL INFORMATION

SECTION 1: The Environment

1.1. Name of facility:

_____

1.2. Year facility originally opened:

_____

1.3. Is this a replacement facility? Yes __ No __

1.3.a. If Yes, Year of Replacement: _____

1.4. Which of the following best describes the ownership and management of the facility?

a. __ Municipal
b. __ Private Nonprofit
c. __ Private for Profit
d. __ Other (please specify) _____

1.5. Does this facility have a board of directors? Yes __ No __

SECTION 2: Communication and Orientation

2.1. Is there a handbook for residents (e.g., rules, rights, policies, etc.)? Yes __ No __

2.2. Is there a handbook for family members (e.g., rules, rights, policies, etc.)? Yes __ No __

2.3. Is there a handbook for staff (e.g., policies, operating procedures, and philosophy of care)? Yes __ No __

2.4. Does the facility have an orientation for new residents? Yes __ No __

2.5. Does the facility have an orientation for family members of new residents? Yes __ No __

2.6. Does the facility have an orientation program for volunteers? Yes __ No __

2.7. Is there an orientation program for new staff? Yes __ No __

2.8. Are staff meetings held at the following levels?			2.9. If yes, how often			
	Yes	No	Once a Week	Once or Twice a Month	Less Than Once a	Only When Needed

					Month	
a. Facility-wide						
b. Neighbourhood/Unit						
c. Floor						
d. Other						

2.10. Can you identify items that are commonly on the agenda for staff meetings?

_____

_____

_____

_____

SECTION 3: Staffing Profile

3.1. How many direct care staff members are there?

_____ per unit/neighborhood **OR** _____ per floor

3.2. Direct Care Staff		
Personnel – Do not include contract staff or professionals paid by an outside institution		
	FTE of personnel currently employed	
	Regular FTE	Casual FTE
a. Registered nurses		
b. Licensed practical nurses		
c. Continuing care assistants/Personal care workers		
d. Occupational therapists		
e. Physiotherapists		
f. Recreation therapists		
g. Other therapists (specify)_____		
h. Therapist aids		
i. Dieticians		
j. Social workers		
k. Activity/Recreation staff		
l. Other direct care staff not included above (specify)		

3.3. General Services		
Personnel – Do not include contract staff or professionals paid by an outside institution		
	FTE of personnel currently employed	
	Regular FTE	Casual FTE

a. Administration (include Directors, Unit/Ward clerks)		
b. Dietary (food service)		
c. Dietary (cooks)		
d. Housekeeping, laundry		
e. Plant operation, maintenance, and security		
f. Other (specify)		

3.4. Approximately, how many volunteers help out in the facility? _____

3.5. In what areas do they help out?

a. Recreation activities Yes __ No __
b. Religious/cultural activities Yes __ No __
c. Arts/crafts Yes __ No __
d. Library Yes __ No __
e. Dietary Yes __ No __
f. Meals Yes __ No __
g. Other (please specify_____):
Yes __ No __

SECTION 4: Physical Features & Capacity

4.1. Total square footage of the facility (building):
_____

4.2. Total square footage of space for use by residents inside the facility (e.g. bedrooms, dining room, bathrooms, quiet areas, common areas, exercise room, chapel):
_____

4.3. Total number of beds (excluding respite beds):
_____

4.4. Total number of respite beds:
_____

4.5. Briefly describe the layout of your facility (e.g., floors, wings, units, neighborhoods).

_____

_____

_____

_____

4.6. Total number of residents:

_____

4.6.a. Total number of residents aged 65 years of age or older:

_____

4.6.b. Total number of residents under the age of 65:

_____

4.6.c. Estimate the proportion of residents who have moderate to severe cognitive impairment: _____

4.7. How many residents are there per floor? _____

4.8. How many residents are there per neighbourhood/unit?_____

4.9. How many residents have private rooms? _____

4.10. How many residents have shared rooms? _____

4.10.a. How many rooms house two residents? _____

4.10.b. How many rooms house more than two residents? _____

4.11. How many residents have private bathrooms? _____

4.11.a. Do private bathrooms have bathtubs and/or showers? Yes __ No __

4.12. How many residents have shared bathrooms? _____

4.12.a. Generally, how many residents share each bathroom? _____

4.13. Is there a space/area where staff can have privacy from residents during their breaks?

Yes __ No __

The Social/Care Environment
SECTION 5: Personal Possessions and Behavior

5.1. This section includes questions about the rules and expectations for residents. Check the boxes that best describes the policies and procedures in this facility. The following categories are used:

1. *Encouraged* – this kind of behavior or activity is encouraged here.
2. *Supported*– this kind of behavior is supported; no special attempt is made to change it.
3. *Discouraged* – an attempt is made to discourage or to try to stop this behavior.
4.

	Encouraged	Supported	Discouraged
a) Personalizing one's own room	1	2	3
b) Moving furniture around the room.	1	2	3
c) Doing some laundry in the bathroom (e.g., washing socks or underwear).	1	2	3
d) Preparing a snack on the floor/unit.	1	2	3
e) Choosing when to eat a meal.	1	2	3
f) Closing the door to one's room.	1	2	3
g) Choosing when to go to bed.	1	2	3
h) Choosing when to rise.	1	2	3

SECTION 6: Resident & Family Participation

6.1. Are residents able to participate in the work being done at the nursing home (e.g., laundry, meal preparation, cleaning)? Yes __ No __

6.1.a. If so, on average what proportion of residents participate? _____

6.2. Is there a resident's council (i.e., residents who are elected or volunteer to represent residents at regularly scheduled meetings?) Yes __ No __

6.2.a. How engaged is the council in activities, decisions and bringing forth issues?

_____ Rarely/Never
_____ Sometimes
_____ Regularly

6.2.b. What are the areas that the council is concerned with?

_____

_____

_____

6.3. Is there a family council (i.e., family who are elected or volunteer to represent family members at regularly scheduled meetings? Yes __ No __

6.3.a. How engaged is the council in activities, decisions and bringing forth issues?

_____ Rarely/Never
_____ Sometimes
_____ Regularly

6.3.b. What are the areas that the council is concerned with?

_____

_____

_____

6.4. Are there facility-organized "house/unit meetings" for residents (a general meeting open to all residents)? Yes __ No __

6.5. Are there committees at your facility on which residents or family members are members?

Yes __ No __

If so, list the most common committees

Committee Name

a. _____

b. _____

c. _____

d. _____

e. _____

6.6. Does your facility produce a newsletter? Yes __ No __

6.7. Does your facility have bulletin board designated for residents or families? Yes __ No __

SECTION 7: Decision Making

7.1. To what extent are residents involved in policy making in the following areas?

	Staff/ administration basically decide by themselves	Staff/ administration decide but residents have input	Residents decide but staff have input	Residents basically decide by themselves
a) Planning entertainment such as parties or movies	___	___	___	___
b) Planning educational activities such as courses and lectures.	___	___	___	___
c) Planning welcoming or orientation activities.	___	___	___	___
d) Deciding what kinds of new activities or programs will occur.	___	___	___	___
e) Making rules about attendance at activities.	___	___	___	___
f) Planning daily or weekly menus.	___	___	___	___
g) Setting mealtimes.	___	___	___	___
h) Setting visitors' hours.	___	___	___	___
i) Deciding on the decor of public areas (e.g., pictures, plants, etc.)	___	___	___	___
j) Dealing with safety hazards.	___	___	___	___
k) Dealing with residents' complaints	___	___	___	___
l) Changing in staff (hiring or firing).	___	___	___	___
m) Moving a resident from				

	Staff/ administration basically decide by themselves	Staff/ administration decide but residents have input	Residents decide but staff have input	Residents basically decide by themselves
one bed or room to another.				

7.2. Do staff from different disciplines/professions meet collectively to discuss cases?

Yes __ No __

7.2.a. If yes, who is involved and briefly describe the practice used?

_____

_____

_____

_____

7.3. Are there special programs or approaches in practice in the facility? (e.g., Eden Alternative, Montessori, Specialized Dementia Care Unit, etc.) Yes __ No __

7.4. If yes, describe one of the special programs or approaches in practice in the facility.

a. Special Program/Approach Name	b. How many years has this program/approach been in place?
1. _____	_____

c. Can you describe the strengths of this special program or approach?

_____

_____

_____

_____

d. Can you describe the challenges of this special program or approach?

_____

_____

_____

_____

7.5. Describe any additional special programs or approaches in practice in the facility (e.g., Eden Approach, Dementia Care Units, etc.)

a. Special Program/Approach Name	b. How many years has this program/approach been in place?
2._____	_____

c. Can you describe the strengths of this special program or approach?

_____

_____

_____

_____

d. Can you describe the challenges of this special program or approach?

_____

_____

_____

_____

SECTION 8: Facility Services

8.1. Please indicate which of the following services are provided by this facility and estimate their usage.

			On average, proportion of residents who use this service
a. Physical therapy	Yes __	No __	_____%
b. Occupational therapy	Yes __	No __	_____%
c. Recreation therapy	Yes __	No __	_____%
d. Psychotherapy or personal counseling.	Yes __	No __	_____%
e. Religious advice or counseling	Yes __	No __	_____%
f. Barber or beauty service.	Yes __	No __	_____%
g. Providing transportation (e.g., minibus or pickup car)	Yes __	No __	_____%
h. Other_____	Yes __	No __	_____%

8.2. Is there flexibility in the time at which residents can choose to be awakened in the morning?
Yes __ No __

8.3. Is there flexibility in the time at which residents can choose to take baths or showers?
Yes __ No __

8.4. Is there flexibility in the time at which residents can choose to go to bed (lights out) at night?
Yes __ No __

8.5. Are there flexible visiting hours? Yes __ No __

SECTION 9: Facility Activities

9.1. For each activity, indicate the frequency of each activity and estimate the extent of participation.

	Very rarely or never	Only a few times a year	Once or twice a month	Once a week or more	On average, proportion of residents who participate in this activity
a. Exercise or other physical fitness activity.	___	___	___	___	_____%
b. Outside entertainment (e.g., pianist or singer).	___	___	___	___	_____%
c. Discussion groups.	___	___	___	___	_____%
d. Self-help or mutual support group.	___	___	___	___	_____%
e. Films or movies.	___	___	___	___	_____%
f. Club, social group, or drama or singing groups.	___	___	___	___	_____%
g. Classes or lectures.	___	___	___	___	_____%
h. Bingo, cards or other games.	___	___	___	___	_____%
i. Parties.	___	___	___	___	_____%
j. Religious services.	___	___	___	___	_____%
k. Social hours (e.g., coffee or cocktail hours).	___	___	___	___	_____%
l. Arts and crafts.	___	___	___	___	_____%

Completed by: _____

Date: _____

Position at facility:_____

Number of years at facility:_____

Completed with input from others? Yes __ No __

If yes, who contributed input (name and title)?
_____

Thank You for Taking the Time to Complete this Nursing Home Profile

Appendix B: Family Member Survey

Family Survey on Nursing Home Quality of Life

A Component of the Care and Construction Study

www.careandconstruction.ca

INTRODUCTION:

This survey asks you to share ***your perspective, as a family member*** of a nursing home resident, on the resident's experience of living in the nursing home. When we say "family member", we mean someone who is a family member or close friend, and is closely involved in the day-to-day life of the resident. When we say "nursing home", we mean the facility in which they currently reside. Topics that are covered in this survey include the physical space and atmosphere, the way in which care is provided, relationships and activities within the nursing home, and other general questions related to your experience as a family member.

The survey should take you approximately 30 minutes to complete. The survey is voluntary. You do not have to answer any question you do not want to and you may stop at any time. All information obtained in the survey will be kept confidential. All results of the survey will be presented at the group level, and will not identify individuals. There are no right or wrong answers. The retention of your completed survey will be governed in accordance with the approved application to Mount Saint Vincent University Research Ethics Board. This research has been reviewed and approved by several university ethics review boards. If you have any questions about how the survey is being conducted and wish to speak to someone who is not directly involved in it, you may contact the Chair of the Mount Saint Vincent University Research Ethics Board at (902) 457-6350 or via e-mail at research@msvu.ca.

By completing this survey, you are indicating that you agree to participate in this study.

Deadline to complete and return the survey is **July 31, 2012.**

If this survey is found, please return to:
Care and Construction Project Office
Nova Scotia Centre on Aging
166 Bedford Highway
Halifax, NS, B3M 2J6
T: (902) 457-6218; 1-877-302-4440
E: careandconstruction@msvu.ca

Date: _____

SECTION 1: A PROFILE OF YOUR FAMILY MEMBER WHO LIVES IN THE NURSING HOME

First, we would like to know some general information about your family member who lives in the nursing home.

1.1. Name of nursing home where your family member currently lives:

_____
_____

1.2. Name of nursing home unit/household/cottage:

_____

1.3. In total, how long has your family member lived in *thi*s nursing home? (If the same operator but a different building, please respond based on the new building) [Select one]

- o Less than 1 month
- o 1 month to almost 3 months
- o 3 months to almost 6 months
- o 6 months to almost 12 months
- o 12 months to almost 24 months
- o 24 months or longer

1.4. Has your family member requested or is expecting a transfer to another nursing home?

○	○
No	Yes

1.5. What is your relationship to your family member who resides in a nursing home? [Select one]

- o My Spouse/Partner
- o My Father/Mother
- o My Mother-in-Law/Father-in-Law
- o My Grandparent
- o My Aunt or Uncle
- o My Sister or Brother
- o My Child
- o My Friend
- o Other *(Please specify):*_____
  _

1.6. To which age group does your family member belong? [Select one]

o 18 to 34	○ 65 to 74
o 35 to 44	○ 75 to 84
o 45 to 54	○ 85 to 94
o 55 to 64	○ 95 or older

1.7. What is your family member's gender?

_____

SECTION 2: RESIDENT QUALITY OF LIFE (inter*RAI* Family Survey on Nursing Home Quality of Life©)

This section of the survey deals with various aspects of your family member's quality of life and experience of living in the nursing home. There are no right or wrong answers, and the focus is on what life is like in the nursing home. For some items, you may need to use the Don't Know response (DK) or Not Applicable (NA) if your relative is severely cognitively or physically impaired or you don't feel you have adequate information about your family member's care to rate the item.

2.1. Privacy Items

First, let's consider privacy.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable

_____ a. My family member can be alone when he/she wishes.
_____ b. When my family member has company, he/she can visit in private.
_____ c. My family member's privacy is respected when people care for him/her.
_____ d. My family member's personal information is kept private.

2.2 Food/Meal Items

The items that follow are about food.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK)Don't Know NA) Not applicable

_____ a. My family member likes the food in this home.
_____ b. My family member enjoys mealtimes.
_____ c. My family member gets his/her favorite foods in this home.
_____ d. My family member can eat when he/she wants.
_____ e. My family member has enough variety in his/her meals.

2.3 Safety/Security Items

Now let us consider safety.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable

_____ a. My family member's possessions are safe.
_____ b. My family member is safe when he/she is alone.

_____ c. Staff/residents ask before using my family member's things.
_____ d. My family member is safe around those who provide him/her with support and care.
_____ e. If he/she needs help right away, he/she can get it.

2.4 Comfort Items

The items that follow focus on your family member's life in the nursing home.
For each statement please answer with one of the following choices:
0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable
_____ a. My family member gets the services he/she needs.
_____ b. I would recommend this site or organization to others.
_____ c. This place feels like home to my family member.
_____ d. My family member can easily go outdoors if he/she wants.
_____ e. My family member is bothered by the noise here.

2.5 Make Daily Decisions Items (Autonomy)

These items deal with how daily decisions are made.
For each statement please answer with one of the following choices:
0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable
_____ a. My family member decides when to go to bed and get up.
_____ b. My family member decides how to spend his/her time.
_____ c. My family member can go where he/she wants on the "spur of the moment."
_____ d. My family member can control who comes into his/her room.
_____ e. My family member can have a bath or shower as often as he/she wants.
_____ f. My family member decides how his/her money is spent.

Now let's consider how your family member feels about staff in the nursing home.
For each statement please answer with one of the following choices:
0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA)Not applicable
_____ a. Staff pay attention to my family member.
_____ b. My family member can express his/her opinion without fear of consequences.
_____ c. My family member is treated with dignity by the people involved in his/her support and care.
_____ d. My family member is careful about what he/she says around staff.
_____ e. Staff respect what my family member likes and dislikes.

These items deal with how responsive staff are to your family member's needs.
For each statement please answer with one of the following choices:
0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

DK) Don't Know NA) Not applicable

_____ a. Staff respond quickly when my family member asks for assistance.
_____ b. My family member's services are delivered when he/she wants them.
_____ c. The care and support my family member gets help him/her live their life the way he/she wants.
_____ d. Staff act on my family member's suggestions.

Next, let us consider the relationships between staff and your family member
For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable

_____ a. Some of the staff know the story of my family member's life.
_____ b. Staff take the time to have a friendly conversation with my family member.
_____ c. Staff talk to my family member about how to meet his/her needs.
_____ d. My family member considers a staff member his/her friend.
_____ e. Staff are open and honest with my family member.

Now, let us consider how your family member feels about activities.
For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable

_____ a. My family member has enjoyable things to do here on weekends.
_____ b. My family member does things that keep him/her mentally active.
_____ c. My family member can take part in activities off his/her unit.
_____ d. My family member participated in activities that are meaningful to him/her in the past week.
_____ e. If my family member wants, he/she can participate in religious activities that have meaning to him/her.

Personal Relationship Items (Presence of Friends)

Finally, let us consider your family member's relationships with others.
For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always
DK) Don't Know NA) Not applicable

_____ a. Another resident here is my family member's close friend.
_____ b. My family member has people who want to do things together with him/her.
_____ c. People ask my family member for help or advice.
_____ d. My family member plays an important role in people's lives.
_____ e. My family member has opportunities for affection or romance.

SECTION 3: YOUR FAMILY MEMBER'S HEALTH

The next section asks you to provide information about the physical and cognitive abilities of your family member who lives in the nursing home.

3.1. How would you describe your family member's usual ability to remember things? [Select one]

- o Able to remember most things
- o Somewhat forgetful
- o Very forgetful
- o Unable to remember anything

3.2. How would you describe your family member's usual ability to think and solve day-to-day problems? [Select one]

- o Able to think clearly and solve problems
- o Having a little difficulty
- o Having some difficulty
- o Having a great deal of difficulty
- o Unable to think or solve problems

3.3. How would you describe your family member's ability to communicate? [Select one]

- o Able to communicate verbally
- o Able to communicate non-verbally
- o Unable to communicate

3.4. How would you describe your family member's ability to perform personal care tasks (i.e., brushing teeth and/or hair, washing up, dressing, going to the toilet)? [Select one]

- o Able to perform personal care tasks independently, without reminder
- o Able to perform personal care tasks independently, with a reminder
- o Able to perform personal care tasks with assistance from staff
- o Staff perform personal care tasks for my family member

3.5. How would you describe your family member's ability to move around the nursing home? [Select one]

- o Able to move around independently, without assistive devices (e.g., cane, walker)
- o Able to move around independently, with an assistive device (e.g., cane, walker)
- o Able to move around independently, with a wheelchair or scooter
- o Able to move around with assistance, with a wheelchair or scooter
- o My family member is not able to move around the nursing home.

3.6. How would you describe your family member's ability to get in and out of bed or a chair? [Select one]

- o Able to get in and out of bed/chair independently, without assistive devices (e.g., cane, walker)
- o Able to get in and out of bed/chair independently, with an assistive device (e.g., cane, walker)

- o Able to get in and out of bed/chair with assistance from a staff or family member.
- o Able to get in and out of bed/chair with assistance from a lift.
- o My family member is not able to get in and out of bed/chair.

3.7. If your family member experiences difficulty in performing daily physical functions, would you say these difficulties are due to: [Select one]

- o Physical ability challenges (strength, movement limitations)
- o Cognitive ability challenges (remembering when and/or how to perform the function)
- o Both physical and cognitive ability challenges

SECTION 4: PHYSICAL SPACE AND FEEL OF THE NURSING HOME

Now we would like your opinion, as a family member who visits the nursing home, about the nursing home's physical design and layout and how you feel generally about the nursing home's atmosphere.

4.1 Physical Design and A Homelike Atmosphere

For each statement please answer with one of the following choices:

1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. My family member's nursing home is clean.	1	2	3	4	5
b. The area in which my family member lives looks homelike.	1	2	3	4	5
c. People from the community are involved in my family member's nursing home.	1	2	3	4	5
d. My family member's nursing home feels cold and sterile.	1	2	3	4	5
e. I feel welcome at my family member's nursing home.	1	2	3	4	5
f. There is a feeling of warmth and coziness about my family member's nursing home.	1	2	3	4	5
g. I feel an attachment to my family member's nursing	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
home.					

4.1. What are the strengths/key features of your family member's facility's space that help make the facility feel like a home?

Please print:

_____

_____

_____

_____-

_____

_____

4.2. What are the challenges/limitations of your family member's facilitiy's space that prevent the facility from feeling like a home?

Please print:

_____

_____

_____

_____-

_____

_____

4.3. **Please indicate how important the following features are, or would be to you, as a family member who visits the nursing home.**

For each statement please answer with one of the following choices:

1) Not important 2) Somewhat important 3) Important 4) Very Important

	Not Important	Somewhat Important	Important	Very Important
a. Private bedroom	1	2	3	4
b. Family member can	1	2	3	4

	Not Important	Somewhat Important	Important	Very Important
personalize their room/space				
c. Private bathroom	1	2	3	4
d. Resident living room (reading, socializing, watching TV)	1	2	3	4
e. Multi-purpose room (e.g., group activities for recreation, music, leisure),	1	2	3	4
f. Homelike dining area	1	2	3	4
g. Access to community space in the outdoors (seating area, walking paths)	1	2	3	4
h. Private meeting spaces (visits, family gatherings)	1	2	3	4

4.4. In what ways does the space in which your family member lives (unit, household) **enhance your visits with him/her?**

Please print:

_____

_____

_____

_____

_____

4.5. In what ways does the space in which your family member lives (unit, household) **present challenges for your visits with him/her?**

Please print:

_____

_____

_____

_____-

_____

_____

SECTION 5: RELATIONSHIPS

Next, we would like your opinion, as a family member of someone living in a nursing home, about your relationship with your family member, nursing home staff and your perspective about his/her relationships with others.

5.1. **Family & Staff Relationships**

For each statement please answer with one of the following choices:

1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. I am comfortable bringing my concerns to a staff member.	1	2	3	4	5
b. Staff members are friendly to me.	1	2	3	4	5
c. Staff members are respectful of me.	1	2	3	4	5
d. Staff members explain things in a way that is easy for me to understand.	1	2	3	4	5
e. Staff members try to discourage me from asking questions about my family member.	1	2	3	4	5

5.2. What features of the nursing home and the way care is provided there **support the relationship between you and your family member's care team?**

Please print:

_____

_____

_____

_____-

_____

_____

5.3. What features of the nursing home and the way care is provided there **present challenges for the relationship between you and your family member's care team?**

Please print:

_____

_____

_____

_____-

_____

_____

5.4 Resident & Staff Relationships

For each statement please answer with one of the following choices:
1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree
DK) Don't know NA) Not applicable

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	DK	NA
a. There is mutually respectful relationship between my family member and staff who provide care for him/her (or his/her care team).	1	2	3	4	5	DK	NA
b. My family member's care team has supported my family member in maintaining relationships with his/her family, friends, and the local community as they wish.	1	2	3	4	5	DK	NA

5.4. What features of the nursing home and the way care is provided there **support the relationship between your family member and his/her care team?**

Please print:

_____

_____

_____

_____-

_____

_____

5.5. What features of the nursing home and the way care is provided there **present challenges for the relationship between your family member and his/her care team?**

Please

print_____

_____

_____

_____-

_____

_____

Family & Resident Relationships

How would you describe your *current relationship* with your family member? [Select one]

- o Very close
- o Somewhat close
- o Indifferent
- o Somewhat distant
- o Very Distant

5.6. What features of the nursing home and the way care is provided there **support the relationship between you and your family member?**

Please print:

_____

_____

_____

_____-

_____

_____

5.7. What features of the nursing home and the way care is provided there **present challenges for the relationship between you and your family member?**

Please print:

_____

_____

_____

_____-

_____

_____

5.8. **Resident Relationships**

For each statement please answer with one of the following choices:

1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. The space in which my family member lives (unit, neighborhood) supports him/her maintain relationships with other residents	1	2	3	4	5
b. My family member's care team supports him/her in maintaining relationships with other residents.	1	2	3	4	5

SECTION 6: ACTIVITIES AND SOCIAL INTERACTIONS

The next section asks you to think about the opportunities for you and your family member to participate in meaningful activities at the nursing home. When we say "meaningful activities" we mean *any way you spend time with your family member that contributes to positive feelings for you* (e.g., having a meal/beverage together, going for a walk, watching TV, dancing, reading, looking at pictures, folding laundry, quietly visiting).

Meaningful Activities

6.1. What are some of the things that you and your family member enjoy doing together?

Please print:

_____

_____

_____

_____-

_____

_____

6.2. What are some of the things that you and your family member would like to do at the nursing home, but currently cannot?

Please print:

_____

_____

_____

_____-

_____

_____

6.3. What features of the nursing home and the way care is provided there **support your family member's ability to take part in activities?**

Please print:

_____

_____

_____

_____-

_____

_____

6.4. What features of the nursing home and the way care is provided there **present challenges for your family member's ability to take part in activities?**

Please print:

_____

_____

_____

_____-

_____

_____

6.5. **These questions ask you to consider how supported <u>you</u> feel when taking part in some specific activities in the nursing home.**		
NO	YES	*For each statement below, please check "no" or "yes".*
○	○	a. When you visit the nursing home do you have the opportunity to go outdoors with your family member, if they are able?
○	○	b. When you visit the nursing home do you have the opportunity to participate in recreational or social activities with your family member, if they are able?
○	○	c. When you visit the nursing home do you have the opportunity to prepare a beverage or request a beverage (coffee, tea, juice) for yourself and your family member?
○	○	d. When you visit the nursing home do you have the opportunity to share a meal with your family member, if they are able?

6.6. How often do you visit your family member in the nursing home? [Select one]

- o Less than once a week
- o Once per week
- o More than once per week

6.7. How often do you speak to your family member on the telephone? [Select one]

- o Less than once a week
- o Once per week
- o More than once per week
- o Not applicable (family member does not have phone)

6.8. How long would your average visit with your family member be at the nursing home? [Select one]

- o Less than one hour
- o 1-2 hours
- o 2-5 hours
- o More than 5 hours

6.9. Has the amount of time you spend visiting with your family member changed between now and the time he/she moved into the nursing home? [Select one]

- o No, it has remained the same [go to question 6.10]

- o Yes, it has increased [go to question 6.9a]
- o Yes, it has decreased [go to question 6.9a]

6.9.a. If yes, what has contributed to this change in the amount of time spent visiting your family member since he/she moved into the nursing home?

Please print:

_____

_____

_____

_____-

_____

_____

6.10. How many minutes do you have to travel between your home and the nursing home to visit your family member?

Please print: _____

SECTION 7: DECISION MAKING

This section asks you to think about the ways in which you and your family members are included, or not included in decisions about the care and services your family member receives.

7.1. Resident Involvement in Decision Making

For each statement please answer with one of the following choices:
1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree
DK) Don't know NA) Not applicable

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	DK	NA
a. My family member is involved in decisions about his/her care as often as he/she wants to be.	1	2	3	4	5	DK	NA
b. My family member is able to influence the activities and time he/she	1	2	3	4	5	DK	NA

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	DK	NA
spends with others.							

7.2. Family Involvement in Decision Making

For each statement please answer with one of the following choices:

1) Strongly Disagree 2) Disagree 3) Neutral 4) Agree 5) Strongly Agree

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a. I am able to be involved in the decisions about my family member's care as often as I want to be.	1	2	3	4	5
b. I am able to influence the activities and time I spend with my family member.	1	2	3	4	5

7.3. What features of the nursing home and the way care is provided there **supports you and your family member's ability to be involved in decision making**?

Please print:

_____

_____

_____

_____-

_____

_____

7.4. What features of the nursing home and the way care is provided there **challenges you and your family member's ability to be involved in decision making**?

Please print:

_____

_____

_____

_____-

_____

_____

SECTION 8: RESIDENT WELL BEING

The next section asks your opinion about your family member's mood, and general experience living in the nursing home.

8.1Your Family Member's Mood

Normally, how would you describe your family member's mood since they moved into the nursing home?

For each statement please answer with one of the following choices:
0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

	Never	Rarely	Sometimes	Most of the time	Always
a. He/she appears to be happy	0	1	2	3	4
b. He/she appears to be lonely.	0	1	2	3	4
c. He/she appears to be bored.	0	1	2	3	4
d. He/she appears to be content.	0	1	2	3	4
e. He/she appears to be sad.	0	1	2	3	4
f. He/she appears to be fearful.	0	1	2	3	4
g. He/she appears to be stimulated.	0	1	2	3	4
h. He/she appears to be angry.	0	1	2	3	4
i. He/she appears to be well rested.	0	1	2	3	4

8.1. Has his/her overall mood changed since he/she moved into the nursing home?

○ ○

No Yes

8.2. What features of the nursing home and the way care is provided there **have a positive impact on your family member's mood**?

Please print:

_____

_____

_____

_____-

_____

_____

8.3. What features of the nursing home and the way care is provided there **have a negative impact on your family member's mood**?

Please print:

_____

_____

_____

_____-

_____

_____

8.4. How would you describe your family member's overall quality of life? [Select one]

- o Very poor
- o Poor
- o Neutral
- o Good
- o Very good

8.5. Given your family member's current health status, how would you describe his/her overall experience of living in this nursing home. [Select one]

- o Very poor
- o Poor
- o Neutral
- o Good
- o Very good

SECTION 9: A PROFILE OF THE PERSON WHO COMPLETED THIS SURVEY
This section ask you to provide some general information about yourself, and your role as a support for your family member.

9.1. To which age group do you belong? [Select one]

- o 18 to 24
- o 25 to 34
- o 35 to 44
- o 45 to 54
- o 55 to 64
- ○ 65 to 74
- ○ 75 to 84
- ○ 85 to 94
- ○ 95 or older

9.2. What is your gender?

_____

9.3. What is your relationship status? [Select one]

- o Never married
- o Common-law
- o Married
- o Divorced/Separated
- o Widowed

9.4. What is the highest grade or level of school that you have completed? [Select one]

- o 8th grade or less
- o Some high school but did not graduate
- o High school graduate or GED
- o Some college/university
- o College/university graduate
- o More than 4-year university degree

9.5. Which of the following best describes your employment status? [Select one]

- o Retired
- o Paid Employment: Full-time
- o Paid Employment: Part-time
- o Not currently employed

9.6. Which of the following best describes your role in the care and support of your family member prior to their move to the nursing home? [Select one]

- o Primary caregiver (lived with family member)
- o Primary caregiver (did not live with family member)
- o Assisted primary caregiver
- o Did not provide care or support to my family member
- o Other (Please specify:_____)

Thank You for Completing This Survey

Appendix C: Dependent Variable: Resident Quality of Life

Care and Support
My family member's privacy is respected when people care for him/her
My family member is safe around those who provide him/her with support and care
If he/she needs help right away, he/she can get it
My family member gets the services he/she needs
Staff pay attention to my family member
My family member can express his/her opinions without fear of consequences
My family member is treated with dignity by the people involved in his/her support and care
Staff respect what my family member likes and dislikes
Staff respond quickly when my family member asks for assistance
My family member's services are delivered when he/she wants them
The care and support my family member gets help him/her live their life the way he/she wants
Food
My family member likes the food in this home
My family member enjoys mealtimes
My family member gets his/her favourite foods in this home
My family member has enough variety in his/her meals
Autonomy
My family member can be alone when he/she wishes
My family member can eat when he/she wants
My family member can easily go outdoors if he/she wants
My family member decides when to go to bed and get up
My family member decides how to spend his/her time
My family member can go where he/she wants on the "spur of the moment"
Residents control who comes into their room
Staff respect what my family member likes and dislikes
Activities
My family member has enjoyable things to do here on the weekend
My family member does things that keep him/her mentally active
My family member can take part in activities off their unit
Residents have participated in meaningful activities in the past week

Appendix D: Resident Participant Observation Guide (Case Study)

Section I:

Care & Construction: Assessing Difference in Nursing Home Models of Care on Resident QOL Case Study - Participant Observation Guide

Participant/Resident Observation Guide:

Within the case study methodology, to complement the data obtained by self-report through the semi-structured interviews, participant observation will be used to gain a detailed description of the experience of the resident within the model of care, with emphasis on key factors that contribute to resident quality of life: meaningful relationships, meaningful activities, autonomy, and homelikeness (Table 1).

Table 1: Elements Contributing to Resident Quality of Life

Element	Behavioral Examples
Meaningful Relationships	· "Verbal or nonverbal communication and interaction with others in the community" (Hinman, 2002) · Verbal or nonverbal communication and interactions with staff members
Meaningful Activities	· Engagement/participation "in conversations, recreational activities, visitations, and/or group dining" (Hinman, 2002) · Engagement in physical activity: duration and type (e.g., seated, vs. standing, vs. walking/wheeling, vs. exercise) · Functional autonomy, independence · Sleep
Resident Autonomy	· Expression/realization/achievement of own choice/preference (e.g., activities, schedule, physical/functional autonomy) · Expressions/illustrations relating to security/safety (physical and psychological)
Resident Affect	· "Expression of feelings or moods, such as smiling, laughing, or crying, that reflect one's ability to cope with life's stressors, anxieties, and satisfactions" (Hinman, 2002) · Expressions of aggression, agitation, loneliness, pain, dignity, comfort, security
Homelikeness	· Presence of personal affects (e.g., photos, furniture, pillows, blankets, media, children, pets, plants, etc.) · Characteristics of the physical structure of the facility (e.g., bedroom, living space, dining/kitchen space, bathroom space, storage, lighting, size, proximity to other relevant spaces)

References:
Hinman, M. R. & Heyl, D. M. (2002) Influence of the Eden Alternative on the functional status of nursing home residents. *Physical & Occupational Therapy in Geriatrics, 20*, 1-20.
Simons, H. (2009). Case study research in practice. London: Sage.

Section II:

Care & Construction: Assessing Difference in Nursing Home Models of Care on Resident QOL Case Study – Participant Observation Log Book:

Case ID:_____

Name of Facility:_____

Unit: _____

Date:_____

Observer: _____

Collection Period: 1 2 3 Observation Start Time:_____End Time:_____

Situation: _____

	Detailed Description	Notes
Location (Physical Space and Homelikeness; note also position of the Resident and the PO.):		Physical Environment (Design & Homelikeness):

	Detailed Description	Notes
Participants: S#=Staff; FM#=Family Member; V#=visitor (non-family); R# = Resident		Staffing Model/Interactions:
Events/Activities: Describe the events that occurred during the time period, with emphasis on the activities and interactions identified in Table 1.		Notes regarding Autonomy: Notes regarding Affect:

Section III:

Care & Construction: Assessing Difference in Nursing Home Models of Care on Resident QOL Case Study - Participant Observer Journal

Case ID:_____

Name of Facility:_____

Unit:_____

Date:_____

Observer: _____

Collection Period: 1 2 3 Observation Start Time:_____End Time:_____

Situation: _____

Appendix E: Family Member Interview Guide (Case Study)

Care & Construction: Assessing Differences in Nursing Home Models of Care on Resident QOL
Case Study - Family Member Interview Guide

Case ID:_____

Facility Name: _____

Unit: _____

Date:_____

Interviewer: _____

Instructions for Interviewer:

Objective of the interview: To examine resident quality of life through the residents' experience with different models of care. These interviews should examine the following: dynamics and interactions among the individuals, and dynamics and interactions with broader environment (social and physical), context around resident quality of life.

Before commencing the interview, the interviewer will obtain informed consent. The consent form explains the purpose and content of the study.

Study Overview:
In this study, we want to get a better understanding of what is important to you and your family member living in this facility. I'll be asking questions about you, [resident's name], things that you and [resident] do, your experiences of the staff and the facility as we talked about in the consent form.

Section I: General Information
First, I want to ask you some questions about you and [resident].

1. What is your age? _____

2. What is your gender? _____

3. What is your relationship status?
   - o Single
   - o Common-law
   - o Married
   - o Divorced/Separated
   - o Widowed

4. What is your employment status?
   - o Retired What did you do for a living?_____
   - o Paid Employment: Full-time In what field? _____
   - o Paid Employment: Part-time In what field? _____
   - o Not currently employed
   - o A full time student

5. What is the highest grade or level of school that you have completed?
   - o 8th grade or less
   - o Some high school but did not graduate
   - o High school graduate or GED
   - o Some college/university
   - o College/university graduate
   - o More than 4-year university degree

6. What is your relationship to [resident]?

   _____

7. In general, how would you say your health is?
   - o Excellent
   - o Very good
   - o Good
   - o Fair
   - o Poor

8. Do you have any long-term health conditions? ?

_____

Next, I'd like to ask you a few questions about [resident's name].

9. What is [resident's] age? _____

10. What is [resident's] gender? _____

11. What is [resident's] relationship status?
   - o Single
   - o Common-law
   - o Married
   - o Divorced/Separated
   - o Widowed

12. What was [resident's] primary occupation/job?

_____

13. What was the highest grade or level of school that [resident] completed?
   - o 8th grade or less

o Some high school but did not graduate
o High school graduate or GED
o Some college/university
o College/university graduate
o More than 4-year university degree

14. In general, how would you say [resident's] health is?
o Excellent
o Very good
o Good
o Fair
o Poor

15. In total, about how long has [resident] lived in *this* nursing home?
o Less than 1 month
o 1 month to almost 3 months
o 3 months to almost 6 months
o 6 months to almost 12 months
o 12 months to almost 24 months
o 24 months or longer

16. Where did [resident] live before coming here?
o Another long term care facility For how long? _____ years and _____ months
o Assisted living type facility For how long? _____ years and _____ months
o Home of you or another person For how long? _____ years and _____ months
o Own home

17 Has [resident] or you requested or is expecting a transfer to another nursing home?

○ ○
No Yes

If yes, for what reason?

<u>Section II:</u>

I want to ask you some questions about your history and relationship with [resident's name].

(Note to interviewer: The intent of this is to help the family member relax and also to create a conversational atmosphere for the interview.

1. Describe your role with [resident] prior to them coming to the facility.

(Note to Interviewer: Make sure these points are covered by using the following probes; lived with person or apart (how far away), amounts and kinds of help provided, was person the main caregiver or were there others)

2. Can you tell us a bit about the relationship that you have with [resident]? *(Note to Interviewer: Make sure these points are covered by using the following probes;* closeness, changes in relationship since coming to facility).

3. How did [resident] come to live here? *(Note to Interviewer:* probe for events leading to admission).

4. Describe your visit pattern in facility.
(Note to Interviewer: Make sure these points are covered by using the following probes; how often, how long per visit, changes in visiting pattern and why, what you typically do during a visit)

<u>Section III:</u>
Now I want to ask you questions about [resident's] ability to do the things they want and need to do.
(Note to Interviewer: These questions are intended to help understand the functional status of resident in context of care facility, and role of family member in context of care facility.)

1. What kinds of things does [resident] need help with here?
(Note to Interviewer: Make sure these points are covered by using the following probes; mobility, eating, dressing, getting to bathroom, getting to dining room, getting to recreational activities, participating in activities, remembering to do things, supervision requirements, booking appointments, getting to appointments.)

2. What things do staff members help with? What things do you help with?

<u>Section IV:</u>
We are interested in knowing about how much choice and control that you and [resident] have in what happens in the facility. Sometimes this is called AUTONOMY.

1. Does [resident] take part in decision making? Do they have opportunities to make choices?
(Note to Interviewer: Make sure these points are covered by using the following probes; choices about care, what things to do, when to get up.)

2. Do you take part in decisions made about care or activities?
(Note to Interviewer: Make sure these points are covered by using the following probes; care routines, activities resident participates in, health-related decisions such as when to seek a doctor's input.)

3. 3, Do you think that [resident] is safe here?

(Note to Interviewer: Make sure these points are covered by using the following probes; supervision, security, abuse-free.)

Section V:
We are interested in your comments about the facility and [resident's] room.

1. Does this facility feel homelike to [resident] and you?
   (Note to Interviewer: Make sure these points are covered by using the following probes; cold and sterile vs. warm and cosy, evidence that resident feels welcome and cared for, clean, homelike design. What practices within this facility help [resident] feel like they are at home? In what ways is this nursing home not like living at home for [resident]?)

2. Do you feel welcome here?
   (Note to Interviewer: Make sure these points are covered by using the following probes; What makes it feel homelike or welcoming here for you? What aspects are not as welcoming?)

3. Are visitors and community members welcome?
   (Note to Interviewer: Make sure these points are covered by using the following probes; do you see community members or other visitors when you come here?)

Section VI:
We are interested in hearing about your relationship with the staff.

1. How would you describe the relationship?
   (Note to Interviewer: Make sure these points are covered by using the following probes; respect, friendliness, concern. Can you get the information you need about [resident's name] or things that are going on here? Can you get your questions answered?)

We are also interested in the relationship that staff have with [resident].

2. How would you describe the relationship?
   (Note to Interviewer: Make sure these points are covered by using the following probes; respect, listen to concerns, kind.)

Section VII:
Next, I would like to ask you about the activities that [resident] takes part in.

1. What kinds of activities does [resident] enjoy in the facility? How are they supported by staff or by you to take part in these (if needed)? Are there activities that the resident would like to do but is unable to do?
   (Note to Interviewer: Make sure these points are covered by using the following probes; unable to do because not available in facility? Not enough volunteers or staff to help?)

We are also interested in the things that you do with [resident] in the facility.

2. For example, do you take part in:
   - meals
   - coffee or snack breaks
   - recreational activities
   - going outdoors
   - taking [resident] out
   - other activities that you want to do with [resident]?

3. Are there things about the facility or staff that help you do the things that you want to do with [resident's name]? Are there things about the facility or staff that prevent you from doing things that you want to do?

Section VIII:

Sometimes a person's overall mood shows how they are doing in a facility. We are interested in your opinion of [resident's] overall mood since moving here.

1. How would you describe [resident's] mood since they moved in here?
   (Note to Interviewer: Make sure these points are covered by using the following probes; happy? content? bored? lonely? fearful? sad? angry?)

2. Are there activities, events, places or people that cause a change in his/her mood?
   (*Note to Interviewer: Make sure these points are covered by using the following probes; aspects of facility, staff or volunteer interaction, family, etc. What events or activities contribute to positive changes in affect or mood? What events or activities contribute to negative changes in affect or mood?)*

Section IX:

Finally, I would like to ask you about [resident's] quality of life here at [nursing home].

1. How would you describe [resident's] quality of life here?

2. Is there anything that might improve their quality of life?
   (Note to Interviewer: Make sure these points are covered by using the following probes; aspects of facility or staffing, other things such as medical care, family involvement.)

(Note to Interviewer: Other constructs you may wish to explore include; privacy, food, safety, comfort, autonomy, respect, feelings about how treated by staff, bonding with staff, dong what they want to do, personal relationships, being able to go where they want, pain, distress, loneliness, physical activity, fatigue.)

Thank and Close

Appendix F: Physical Environment Codes

Open Code	Properties
Homelikeness-resident	Resident clearly feels or shows examples of the facility being their home/ or not their home
Homelikeness-food and eating	Discussion of the food in the facility, eating breakfast, how food is cooked/served etc.
Homelikeness-appearance	Brightness, lighting
Homelikeness/Autonomy – privacy issues	Person in their room they did not know about/ staff respecting privacy by knocking on the door
Physical environment a barrier****	How the environment inhibits the person from moving around easily or socializing etc. Ex. Wheelchairs in the hallways
Physical environment a facilitator	How the environment assists the individual. Ex. Handrails along the corridors.
Physical environment accessible****	Barriers that might be more unintentional (the hallway is wide but because people leave their wheelchairs in the hallway movement of people with visual impairments is inhibited).
Physical environment actions that make environment inviting	Seasonal decorating/ having a bbq outside for lunch/ decorating a room
Physical environment favourite spaces	Mention of favourite spaces within the facility
Physical environment inviting	How the environment is inviting/uninviting for those entering it. Ex. the environment has a nice smell and is not appalling upon entering.(or non-inviting)
Physical environment other parts of facility/unit seen as “home”	Ex. the resident spends a lot of time in the kitchen as they are most comfortable there.
Physical environment presence/ absence of medical items	Ex. shower chairs, medication carts, etc are prominent on the unit
Physical environment the resident’s room becomes “home”	Ex. the resident decorates the room to their liking, the resident spends a lot of time in their room, the residents room is their “space”