

QUALITY-OF-LIFE IN LONG-TERM CARE

THE IMPACT OF NEIGHBOURHOOD TEAM DEVELOPMENT ON RESIDENT
QUALITY-OF-LIFE IN LONG-TERM CARE

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements
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ABSTRACT

By the year 2024, one in four adults in Canada will be over the age of 65. In Ontario alone, 100,000 residents live in long-term care (LTC). Residents sometimes experience poor quality-of-life (QOL). Culture change has been proposed as an approach to improve residents' QOL in LTC. One large LTC organization, Schlegel Villages, has developed and implemented an organizational culture change called Neighbourhood Team Development (NTD). This approach focuses on building cross-functional teams to enhance resident-centredness and promote QOL through optimizing residents' autonomy and dignity. Implementation of NTD started in 2013 in six LTC homes. The aim of this secondary analysis was to evaluate if NTD has an impact on residents' QOL in LTC. Using a quantitative repeated-measures design, residents from six LTC homes completed QOL assessments. Quantitative data were collected through the Resident Assessment Instrument-Minimum Data Set 2.0 (RAI-MDS) and the interRAI QOL Survey Short Form. QOL data were analyzed using a paired t-test to assess change scores between time point 1 (data collected between August 2011 and December 2012) and time point 2 (data collected between January 2014 and November 2015) for 232 residents. Study results demonstrate that NTD increased residents' QOL ($p = .003$). Organizational culture change such as NTD can lead to innovative approaches to improve the QOL of residents in LTC. This study contributes to literature examining culture change in LTC, and helps inform LTC care models, and interventions to increase residents' QOL in LTC.

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LIST OF ABBREVIATIONS

Activities of Daily Living (ADL)
Continuing Care Assistant (CCA)
Canadian Institute for Health Information (CIHI)
Canadian Institutes of Health Research (CIHR)
Clinical Action Protocols (CAPs)
Cognitive Performance Scale (CPS)
Depression Rating Scale (DRS)
Geriatric Depression Scale (GDS)
Health-Related Quality-of-Life (HRQOL)
Index of Social Engagement (ISE)
International Resident Assessment Instruments (interRAI)
Long-Term Care (LTC)
Markov Chain Monte Carlo (MCMC)
Minimum Data Set (MDS)
Neighbourhood Team Development (NTD)
Online Survey and Certification Automated Record (OSCAR)
Ontario Long Term Care Association (OLTCA)
Patient Empowering Scale (PES)
Person-Centred Nursing (PCN)
Quality-of-Care (QOC)
Quality-of-Life (QOL)
Randomized Controlled Trial (RCT)
Research Ethics Board (REB)
Resident Assessment Instrument-Minimum Data Set (RAI-MDS)
Short Form Health Survey (SF-36)
Variance Inflation Factor (VIF)

CHAPTER 1: INTRODUCTION

The population in Canada is aging rapidly (Statistics Canada, 2015a). By the year 2024, adults over 65 years of age will account for over 20% of the Canadian population (Statistics Canada, 2015a). According to the 2013 Long-Term Care (LTC) facilities survey, over 149,000 seniors lived in 1519 long-term care facilities across Canada (Statistics Canada, 2015c). Increased life expectancies of Canadian seniors have advanced the agenda to ensure quality-of-life (QOL) of residents in LTC (Sullivan & Asselin, 2013). Unfortunately, an extensive literature review revealed that a large proportion of residents in LTC experience poor QOL (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006; Dupuis, Whyte, & Carson, 2012; Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011; Kane, 2001; Kane, 2003; Sullivan & Asselin, 2013). Poor resident QOL in LTC is attributed to: (a) inadequate facility environment, (b) inflexible routines, (c) staffing shortages, (d) lack of effective models of care, (e) limited staff education, and (f) low standards for care (Kane, 2003).

Culture change and new care models have been proposed as approaches to improve residents' QOL in LTC (Zimmerman, Shier, & Saliba, 2014). Culture change promotes an environment focused on caring and improving resident QOL through staff and resident empowerment, and reflection of the attitudes and beliefs within the organization (Rahman & Schnell, 2008). White-Chu et al. (2009) states, "Culture change in long-term care facilities involves a shift in philosophy and practice from an overemphasis on safety, uniformity, and medical issues toward resident-directed, consumer-driven health promotion and quality of life" (p. 370). Traditionally LTC environments have followed a biomedical model of care (Dupuis et al., 2012). A biomedical care model focuses on the medical treatment of the resident, where residents and families are rarely consulted in the plan of care. Culture change differs from care

models in LTC. For example, the focal point of a care model is on how the delivery of care is organized. This places a focus on the staffing mix, resulting in task-orientated care models, including primary nursing or team nursing (Jennings, 2008). In contrast, Carson, Brown, d'Avernas, and Dunn (2015) describe culture change as a movement away from institutionalized care towards "living first," a social model focused on resident-centred care.

There is limited research demonstrating the impact culture change and new care models have had on resident QOL. A new organizational approach to culture change developed and implemented by Schlegel Villages, is called Neighbourhood Team Development (NTD). NTD combines the principles of culture change and innovative LTC models, and holds promise to increase QOL by focusing on cross-functional teams, consistent staffing assignments, and resident-centred care (Boscart et al., 2012). NTD has the potential to change the perception of LTC, and impact residents' QOL through culture change.

1.1 Outline of Thesis

This study employed a secondary data analysis to evaluate the impact of NTD on residents' QOL in LTC. An introduction to residents' QOL in LTC is presented in Chapter 1. Chapter 2 synthesizes and critically appraises relevant literature in five key areas pertinent to this study: (a) LTC, (b) QOL, (c) International Resident Assessment Instruments (interRAI), (d) interRAI QOL Survey, and (e) culture change. The methodology for this study is described in Chapter 3, including the design, setting, intervention, and data collection procedures. This is followed by a description of the data analysis procedures and strategies applied to handle missing data. In Chapter 4, characteristics of the participants are described, and the results for each research question are presented. Lastly, Chapter 5 provides a discussion of the results in the

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context of the existing literature, study strengths and limitations, and future implications for practice, education, policy, and research, followed by the conclusion.

CHAPTER 2: LITERATURE REVIEW

The following literature review will provide a summary of the current knowledge and key findings in five areas relevant to this thesis: (a) LTC, (b) QOL, (c) International Resident Assessment Instruments (interRAI), (d) interRAI QOL Survey, and (e) culture change. First, a general overview on LTC and the population is provided. Second, QOL is presented in the context of LTC, the domains of QOL, associated demographic factors, and QOL measurement tools. Third, interRAI instruments are discussed, with a focus on the interRAI QOL Survey. Lastly, literature on culture change is reviewed, including an analysis of research presenting the potential impact of culture change on QOL.

2.1 Long-Term Care and the Aging Population

The population of older adults in Canada is growing due to factors such as aging baby boomers, a longer life expectancy, and a lower birthrate (Statistics Canada, 2015e). In 2010, 14% of the population were considered to be seniors (aged 65 years and older); however, up to 25% of the population are expected to be seniors in 2036 (Statistics Canada, 2016). According to census data from 2011, 7.1% of older adults lived in a special care facility, including nursing homes, long-term care hospitals, and residences for senior citizens (Statistics Canada, 2015b). In Ontario alone, 100,000 seniors reside in LTC each year (Ontario Long Term Care Association [OLTCA], 2015). The trends as described above put an increasing demand on health care workers to provide quality care to a growing population of seniors.

Although most seniors prefer to age at home, there is an increased likelihood of living in a special care facility as one ages. Older adults between the age of 65-69 years account for 1% of LTC occupancy; whereas over 29% of residents in LTC are over 85 years of age (Statistics Canada, 2015b). Over 40% of older adults in their nineties live in a LTC home or a residence for

senior citizens. Women over 85 years of age account for 33.4% of the total number of people who reside in LTC, whereas men in the same age group account for 21.5% of the people living in LTC (Statistics Canada, 2015b).

2.1.1 Residents Living with Dementia in Long-Term Care

The incidence of dementia is expected to increase rapidly in the future due to population aging (Smale & Dupuis, 2004; World Health Organization [WHO], 2012). The WHO (2012) estimated that by 2050, over 115 million people worldwide will have dementia. In 2012, the WHO named dementia a public health priority, encouraging countries to respond.

The OLTCA (2015) reported that over 60% of residents in LTC have some form of dementia. The Canadian Institute for Health Information [CIHI] (2010) describes that approximately 37% of residents in Canadian LTC are documented as having severe or very severe cognitive impairment as scored on the Cognitive Performance Scale (CPS). Residents 85 years and older make up almost 60% of the seniors in LTC living with dementia. For those living with dementia, their functional status declines with the progression of the disease, resulting in additional care needs and potentially challenging or responsive behaviours (CIHI, 2010; WHO, 2012). The OLTCA (2015) estimated that responsive behaviour occurs in over 45% of LTC residents. Unfortunately, LTC staff are not always prepared to care for the complex needs of residents with dementia (Dupuis et al., 2014). In conclusion, the complex issues of LTC residents can lead to challenges in providing quality care and addressing QOL needs for residents.

2.2 Quality-of-Life (QOL)

The concept of QOL in LTC is increasing in popularity as our population ages (Sullivan & Asselin, 2013). However, gaps in research regarding QOL in LTC remain, including defining and measuring QOL, and recognizing potential interventions to increase QOL for residents of

LTC. The term QOL is widely used in LTC; however, experts struggle to agree on a standard definition (Sullivan & Asselin, 2013). QOL is complex and based on the subjective report of what an individual deems imperative to live a happy and important life full of meaning (Owen, 2006). The WHO (2015) states that an individual's QOL is the:

“...perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (para 2).

QOL is often confused with health-related quality-of-life (HRQOL). “Health-related quality of life (HRQOL) is a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning” (Office of Disease Prevention and Health Promotion, 2015, para 1). HRQOL looks at the effect of disease and treatment on QOL, differing from the concept of QOL, which looks beyond health-related factors to include areas such as income, social, and environment (Centers for Disease Control and Prevention, 2000). HRQOL “... goes beyond direct measures of population health, life expectancy, and causes of death, and focuses on the impact health status has on quality of life” (Office of Disease Prevention and Health Promotion, 2015, para 1).

2.2.1 Quality-of-Life in Long-Term Care

Why does QOL matter in LTC? In LTC, a cure is generally not possible. This results in changing the goal of care from healing to managing chronic illness and QOL (Sullivan & Asselin, 2013). QOL and quality-of-care (QOC) should not be confused. QOC involves the promotion of health and wellness through care delivery and reduction of adverse events; whereas, QOL looks at making life enjoyable (Xu, Kane, & Shamliyan, 2013). Traditionally, QOC was the outcome of choice for LTC (Xu et al., 2013). However, current research and

resident experiences demonstrate that QOL should be a focused outcome in LTC, as it is no longer only the process by which care is delivered that is important. QOL experiences of the resident should also be considered (Sloane et al., 2005). In order to evaluate how the Canadian health care system is meeting the needs of individuals and the population, subjective reports of QOL need to be a focused outcome measure in health care (CIHI, 2012b). The QOC received may impact resident QOL (Xu et al., 2013). In conclusion, it is important to find a balance in delivering both QOC and promoting QOL in LTC.

Kane (2003) noted that poor resident QOL in LTC is attributed to the following:

(a) a biomedical physical environment providing little privacy, (b) lack of opportunity for autonomy in daily life because of inflexible routines, (c) low staff levels, (d) lack of effective models of care, (e) limited education for staff to care for residents, and (f) low standards of care (Kane, 2003). Owen (2006) noted that QOL is directly associated with the current culture in LTC, in which residents are devalued, and not involved in directing their care. Despite its importance, minimal research is available on resident QOL in LTC (Kehyayan et al., 2015).

Unfortunately, residents living in LTC have historically reported poor QOL (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006; Dupuis, Whyte, & Carson, 2012; Hill, Kolanowski, Milone-Nuzzo, & Yevchak 2011; Kane, 2001; Kane, 2003; Sullivan & Asselin, 2013). This puts an increasing demand on policy makers and researchers to define QOL, identify correlates of QOL, and develop interventions that could optimize QOL for residents living in LTC.

2.2.2 Quality-of-Life Domains

Through measurement of QOL domains, researchers can determine what practices increase QOL in LTC (Kane, 2001). Optimized QOL should not be reduced to a lack of negative

outcomes. Simply measuring a lack of negative outcomes such as the absence of falls or bedsores does not constitute high QOL (Kane, 2001).

Published in 1962, an early theory that discusses QOL still referenced in literature today is Maslow's Hierarchy of Needs (Ventegodt, Merrick, & Andersen, 2003). Basic human needs are the foundation of this hierarchy, with a focus on the importance of personal growth for happiness which Maslow described as "self-actualization." Maslow's hierarchy suggested that fulfilling one's own physiological needs resulted in feelings of contentment and psychosocial and social wellbeing.

Maslow believed that QOL starts with meeting one basic need and moving sequentially through a hierarchy to meet all other human needs (Ventegodt et al., 2003). Maslow's hierarchy is comprised of eight needs: (a) physiological, (b) safety, (c) belongingness and love, (d) esteem, (e) need to know and understand, (f) aesthetic, (g) self-actualization, and (h) transcendence (Ventegodt et al., 2003). The base of the hierarchy starts with *physiological* needs which are the human requirement for nutrition and rest. The second need, *safety* is comprised of having safe shelter. *Belongingness and love* involve the requirement for love and acceptance. The need for *esteem* is achieved through obtaining feelings of respect and acknowledgment (Ventegodt et al., 2003).

Beyond the basic human needs is the desire for education and understanding, as seen in the *need to know and understand* (Ventegodt et al., 2003). This includes the knowledge of oneself and the world outside. The subsequent level, *aesthetic*, addresses the creative mind and the desire to utilize one's individual talents. Maslow defined the two final needs in the hierarchy as the need to achieve *self-actualization* and *transcendence*. In *self-actualization*, one would feel peace with what the meaning of life meant personally. Subsequently, when one is in a stage of

transcendence, one feels a valuable contributor to the world and integrated into society (Ventegodt et al., 2003).

Maslow argued that the majority of society will not meet the final two levels of this hierarchy (Ventegodt et al., 2003). In fact, he believed that the majority of society would not make it past level three or four. Indeed, people are constantly looking for personal growth, and self-actualization; however, priorities may change in the hierarchy based on the current situation of an individual (Ventegodt et al., 2003). For example, an older person who becomes chronically ill may experience a change in the physiological need to survive, and be required to move into a LTC home. This move may result in the older person distancing from the goal of self-actualization to meet a physiological need at the base of the hierarchy.

It is important to note that when created, the LTC environment was not the focus of Maslow's Hierarchy of Needs. Although Maslow's hierarchy is well known and utilized, it faces criticism regarding the hierarchal structure. Poston (2009) explained that not all persons will place the same worth on each need in the hierarchy, the sequence of achieving each need is individualized, and a person may regress at anytime through the hierarchy. Personal factors such as age, culture, and childhood experiences may impact where worth is placed in Maslow's hierarchy. McLeod (2014) criticizes the hierarchal structure noting that social economic status may also affect how a person transitions through the stages. Maslow proposed that a person must meet all physiological needs before moving up the hierarchy to meet needs such as love and belongingness; however, McLeod argues that those living at poverty level may meet needs higher on the hierarchy before fully satisfying all of their physiological needs. Therefore, the hierarchal structure of Maslow's framework cannot be assumed as the standardized sequence of motivation for achieving needs for all individuals.

A different viewpoint focusing solely on domains of QOL in LTC was proposed by Dr. Rosalie Kane (2001). Kane et al. (2003) recognized 11 domains related to QOL in LTC through a comprehensive literature, stakeholder, and expert review. The 11 domains identified included: (a) physical comfort, (b) functional competence, (c) autonomy, (d) dignity, (e) privacy, (f) individuality, (g) meaningful activity, (h) relationships, (i) enjoyment, (j) security, and (k) spirituality. These domains are described in the following sections.

The first two domains are foundational for QOL: security and physical comfort (Kane et al., 2003). *Security* is a basic need one requires to feel safe and offers predictability in the environment, with an absence of perceived peril (Kane, 2001). The domain of *physical comfort* ensures that physical symptoms such as pain or discomfort are relieved. Examples of physical comfort may include room temperature or an absence of shortness of breath (Kane, 2001).

The second subset of domains looks at the social aspect of QOL in LTC in four areas: (a) enjoyment, (b) meaningful activity, (c) relationships, and (d) functional competence (Kane et al., 2003). Residents need to feel a sense of *enjoyment* in their daily lives to optimize their QOL. This domain can be actualized in Activities of Daily Living (ADLs) such as enjoying meals or specific foods that the resident takes pleasure in. Enjoyment can also be linked to resident participation in *meaningful activity*. Meaningful activities are individualized activities that bring significance to life. Dependent upon the level of independence and ability of the resident, activities may vary. Residents' QOL domains also include the sense of positive *relationships*, where a resident feels they can both provide and accept friendship and love to a diverse population of people including their own family, peers, and staff. Kane (2001) states, "...relationships make life worth living..." (p. 297). *Functional competence* or independence, both cognitively and physically is an important component of QOL in LTC. This domain should

not be confused with the degree of independence with ADL activities; rather, it is related to the level of independence in a LTC environment, both within the physical layout, as well as within the rules and regulations of the facility (Kane et al., 2003).

The third subset of QOL domains in LTC consists of four aspects which help the resident to maintain a sense of individuality and positive feelings of self-worth: (a) dignity, (b) privacy, (c) individuality, and (d) autonomy (Kane et al., 2003). *Dignity* requires that each resident is treated with respect as an individual. *Privacy* is not to be confused with each resident having a single dwelling room, rather, it is promoting the idea that a resident is able to have solitude when required or can spend alone time with family and friends to allow for private conversation. The expression of self through one's identity leads to the domain of *individuality*. Individuality is often lost in LTC, leading to a decrease in resident choice, or the tenth domain, *autonomy*. The resident should be provided the opportunity to direct their care through personal choice. The final domain as presented by Kane et al. is *spiritual well-being*. This domain includes freedom to participate in religious activities as chosen by the resident.

According to Kane et al. (2003), these 11 domains all contribute to residents' QOL in LTC. However, it is important to note that each resident views QOL differently, and may value one domain over another (Kane, 2001). These domains help support the "consumer-driven" approach to LTC, therefore increasing the need to focus on residents' QOL in LTC (Kane, 2001).

While experts do not agree on one single set of QOL domains or a theory defining QOL in LTC, as described above, significant overlap occurs between the different descriptions (Kehyayan, 2011; Sloane et al., 2005; Xu et al., 2013). In the next section, factors that are associated with resident QOL in LTC will be reviewed.

2.2.3 What Factors are Associated with Residents' Quality-of-Life in Long-Term Care?

By understanding factors associated with QOL amongst LTC residents, we can identify groups at risk for poor QOL and target interventions to improve QOL for these residents (Sullivan & Asselin, 2013). Two systematic reviews have examined factors associated with QOL of LTC residents which will be discussed below (Bradshaw, Playford, & Riazi, 2012; Sullivan & Asselin, 2013).

Sullivan and Asselin (2013) completed a review of the literature to determine what correlates, tools, and interventions were being studied in relation to QOL in LTC. Inclusion criteria included primary sources and English peer-reviewed studies published between 1990-2011 that measured residents' QOL or HRQOL in LTC. A total of 26 articles were reviewed. Four categories of correlates to resident QOL in LTC were identified: (a) physical condition and function, (b) environment, (c) social support, and (d) mood/spirituality. Each category included several factors. For example, the category of physical condition and function included the number of chronic conditions, the level of independence, and continence status of a resident. Environmental factors included the privacy of the resident, ability to choose, and the reliability of staff members. Socioeconomic status, interactions with family or friends, and conflict within relationships were identified factors related to social support; whereas, mood/spirituality focused on factors such as depression, loneliness, isolation, being treated with respect by staff, and individuality. In conclusion, the review completed by Sullivan and Asselin determined that correlates of QOL could be explained through four common categories: (a) physical condition and function, (b) environment, (c) social support, and (d) mood/spirituality.

A second systematic review focusing on qualitative studies described factors correlated with resident QOL in LTC, and produced similar results (Bradshaw, Playford, & Riazi, 2012).

This review included English language studies that reviewed the subjective QOL of residents in LTC (n=31). Four themes promoting resident QOL emerged: (a) acceptance and adaptation to the living situation, (b) connectedness with others, (c) a homelike environment, and (d) caring practices (Bradshaw et al., 2012). Based on both reviews, common correlates of QOL for LTC residents included: (a) maintaining independence, (b) autonomy, (c) social engagement, and (d) a homelike environment with staff that are respectful, and recognize the individuality of each resident (Bradshaw et al., 2012; Sullivan & Asselin, 2013).

In addition to the systematic reviews discussed above, single study literature was reviewed. One example includes a large cross-sectional study looking at resident and facility factors associated with resident QOL in LTC (Degenholtz et al., 2006). Data from the Minimum Data Set [MDS] (a federally mandated set of items collected on each resident in LTC, utilized for assessment and care planning) and the Online Survey and Certification Automated Record (OSCAR) provided characteristics of the facility and residents (Degenholtz et al., 2006). The QOL tool by Kane et al. (2003) was used to determine residents' QOL for 2829 participants across 101 LTC facilities in the United States. Findings indicated that poor physical function, eyesight, incontinence, being bedridden, depression, and relationship conflict all have a negative association with QOL. However, positive social engagement scores were associated with higher QOL (Degenholtz et al., 2006). These results suggest that some correlates of QOL in LTC can be influenced by the practices and programs within the LTC facility that promote social engagement.

2.2.4 The Relationship between Resident Demographics and Quality-of-Life

Mixed findings were found in the literature regarding the relationship between demographics and residents' QOL in LTC (Kehyayan et al., 2016; Kranz, 2011; Tu, Wang, &

Yeh, 2006). In the following section, literature on demographic variables is reviewed in terms of negative or positive association with resident QOL.

A cross-sectional study across 48 LTC homes collected interRAI data from 928 residents to identify predictors of QOL in LTC (Kehyayan et al., 2016). The 50-item interRAI Self-Report Nursing Home Quality-of-Life Survey was used to collect the data. This tool is comprised of ten domains that measure QOL in LTC. Resident demographic variables were analyzed to examine association with overall QOL including: (a) religiosity, (b) education level, (c) age, (d) gender, and (e) marital status (Kehyayan et al., 2016). Findings indicated that religiosity had a significant positive association with QOL; whereas education was significantly negatively associated with QOL. Age, gender, and marital status were not associated with QOL in this study (Kehyayan et al., 2016).

Tu, Wang, and Yeh (2006) completed a cross-sectional study in southern Taiwan examining the relationship between resident demographic factors and QOL. Across eight nursing homes, 102 residents participated by completing a 33-item Quality-of-Life Index Nursing Home Version questionnaire (Ferrans & Powers, 1985). This questionnaire rates QOL within 33 items such as, “how satisfied are you with the amount of control you have over your life?” on a likert-type scale. Scoring for this questionnaire ranges from one “very dissatisfied/very unimportant” to six “very satisfied/very important.” Inclusion criteria for this study included: (a) 65 years of age or older, (b) lived in LTC for at least six months, and (c) an absence of moderate to severe cognitive deficits as determined by the Short Portable Mental Status Questionnaire. Higher QOL was found in Christian or Catholic residents ($p = 0.02$) as compared to residents with Buddhist or Taoist beliefs, and in married residents ($p = 0.08$) as compared to non-married residents (Tu et

al., 2006). Researchers found that gender was not associated with QOL ($p = 0.67$), which is consistent with findings in the Canadian Kehyayan et al. (2016) study.

Research demonstrating that QOL is associated with demographic variables is not consistently reported. For example, Kranz (2011) found different results than the Tu et al. (2006) study when assessing marital status. Kranz examined the relationship between marital status and QOL for 80 residents ranging from 72-99 years of age who lived in assisted living centers in Minnesota. Assisted living facilities provide an alternative to LTC, with a more flexible “home-like” environment (Kranz, 2011). Inclusion criteria for participation in this study were: (a) 65 years or older, (b) able to consent, and (c) lived in assisted living for a minimum of six months. Participants completed three tools with well-established psychometric properties:

(a) World Health Organization Quality-of-Life Survey (Skevington, Lotfy, & O’Connell, 2004), (b) Geriatric Depression Scale (GDS-short form) (Faulkner, 2001), and (c) the Patient Empowerment Scale (Friedman, Heisel, & Delavan, 2005). No correlation was found between QOL and marital status. These findings contradict the Tu et al. (2006) study findings discussed above; however, are consistent with the Kehyayan et al. (2016) results.

In conclusion, the literature demonstrates diverse findings on the relationship between QOL and demographic variables of age, gender, and marital status. This evidence points to the need for further research on the association between demographic variables and resident QOL in LTC, and the importance to decipher which variables are associated with QOL to identify at-risk groups for low QOL.

2.2.5 Quality-of-Life Measurement Tools

Measuring QOL in LTC is a challenging process for a variety of reasons. First, QOL is a subjective and individualized experience, making it difficult to find consensus on defining QOL

for all residents (Sullivan & Asselin, 2013). Second, Kane (2003) explains that the gold standard for measuring QOL is for the resident to self-report when possible. However, The OLTCA (2015) indicated that over 60% of residents in LTC in Ontario have a form of dementia. Cognitive impairment makes it challenging to assess QOL for residents in LTC (Kane et al., 2003).

Many tools have been used to assess QOL in LTC. The review by Sullivan and Asselin (2013) examined 23 studies using QOL tools including: (a) 16 quantitative studies, (b) five qualitative studies, and (c) two mixed-method studies. This review demonstrated wide variation in the QOL measurement tools used by researchers to measure QOL in LTC. Of the 16 quantitative studies, six used generic tools. Instruments measuring QOL in residents with dementia were found in three of the articles; whereas, resident variables such as depression and activities of daily living (ADL) were measured in addition to QOL in 12 of the studies. In addition to measuring QOL, two of the studies used Minimum Data Set (MDS) data in their research. Overall, tools varied in terms of QOL domains represented within the tool. Physical function, mental health, and systems of social support were commonly reflected in the domains of QOL surveys (Sullivan & Asselin, 2013).

There are some limitations to be considered in the review by Sullivan and Asselin (2013). First, it was identified that minimal overlap of QOL tools across the studies occurred, resulting in a decreased opportunity for comparison of studies. Some studies noted that QOL items were removed from tools for ease of use during the study, thus potentially affecting findings. Another limitation of the review is that most studies were conducted internationally, which may affect the generalizability of findings to North America. Of the 23 studies reviewed, only three were completed in Canada. Furthermore, the study samples consisted primarily of women, which may

lead to male QOL experiences in LTC being underrepresented. Finally, Sullivan and Asselin identified the need for further QOL research related to: (a) consistent QOL measurement tools for residents of all ages in LTC, (b) best practices for measuring QOL in residents with dementia, (c) larger studies on diverse populations for generalizability, (d) longitudinal studies, and (e) nursing perspectives on QOL, and the role of the nurse in supporting and sustaining QOL in LTC.

A more recent systematic review assessed psychometric properties of QOL measures for LTC (Aspden, Siobhan, Bradshaw, Playford, & Riazi, 2014). This review included studies published in English, and studies evaluating one or more properties of a QOL tool for residents in LTC. Exclusion criteria included populations that were mixed, including persons living outside of LTC unless researchers demonstrated that tools were assessed separately, and tools that measured constructs other than QOL. These criteria resulted in 15 studies reviewed, including 13 different instruments: (a) eight disease-specific, and (b) five generic tools. More than half of the QOL tools appraised by Aspden et al. (2014) were developed for residents with dementia. Tools measured a variety of QOL domains, with inconsistent use of domains across tools. The CONsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist by Mokkink et al. (2010) was used by two independent reviewers to evaluate the properties of each tool (Aspden et al., 2014).

Based on the results of the review, Aspden et al. (2014) recommended two tools to measure QOL in LTC: (a) QUALIDEM for residents with dementia (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2007), and (b) Kane's (2003) Quality-of-Life Index for residents who are cognitively intact. The QUALIDEM is a 37-item observational instrument to measure QOL for residents with dementia residing in LTC (Ettema et al., 2007). The Kane et al. (2003) Quality-of-

Life Index is a self-reporting scale for cognitively intact residents of LTC, which consists of 47 items and is based on 11 domains of QOL as developed by Kane et al. (2003). The criteria used by Aspden et al. (2014) to assess the strength of the measurement properties of the tools are available in Appendix A. The authors of this study reported a satisfactory test-retest reliability, inter-observer reliability, content validity, and construct validity for QUALIDEM. The Kane et al. (2003) Quality-of-Life Index was found to have satisfactory construct validity; however, less than half of the domains achieved internal consistency.

Some limitations of the review by Aspden et al. (2014) should be considered when interpreting findings. First, the review included only 13 QOL tools of the hundreds of QOL tools that have been developed (Coons, Rao, Keininger, & Hays, 2000). Second, Aspden et al. reviewed the methodological quality of the studies utilizing available published literature with the COSMIN tool, which can be subjective. None of the studies reviewed had a longitudinal research design, or tested the response of an intervention on QOL. However, the authors noted that QOL tools are not commonly used by LTC facilities to measure outcomes, and intervention studies focused on improving QOL within LTC are infrequent. In conclusion, Aspden et al. identified the need for further QOL studies to enhance knowledge of resident QOL in LTC.

The Aspden et al. (2014) and Sullivan and Asselin (2013) reviews demonstrated a lack of consensus on recommended tools to measure residents' QOL in LTC, and great diversity in QOL domains within tools. This demonstrates need for further research on QOL tools in LTC to find feasible, reliable, and valid tools. Neither of these systematic reviews included the interRAI Self-Report Nursing Home QOL Survey. However, interRAI tools are widely used in LTC settings internationally, allowing for comparison across various homes (Carpenter & Hirdes, 2013).

2.3 International Resident Assessment Instruments (interRAI)

The interRAI group is composed of researchers who create evidence-informed decision-making tools to assess vulnerable persons in diverse health care settings including LTC, community, and hospital settings (interRAI, 2017d). When developing and validating tools, interRAI researchers engage with key stakeholders such as clinicians, policy makers, and patients (interRAI, 2017a). All tools are well-established through rigorous testing for reliability and validity through standardized procedures determined by the interRAI Instrument and Systems Development Committee. Continuous quality improvement takes place to ensure all tools are up-to-date to meet the needs of the changing health care system, and address new emerging evidence (interRAI, 2017a).

There are numerous benefits to the use of interRAI assessment tools. First, the common language used across interRAI tools promotes efficiency and continuity of care for patients moving through various sectors of the health care system (Hirdes et al., 1999). Second, these assessments are standardized, therefore decreasing repetition of assessments by various health care providers and increasing identification of potential problems. Lastly, standardized tools allow for comparisons between and across populations in different care settings at an international level (Carpenter & Hirdes, 2013).

2.3.1 Resident Assessment Instrument-Minimum Data Set (RAI-MDS) in Long-Term Care

One tool originally created by interRAI that is commonly used in LTC today is the Resident Assessment Instrument-Minimum Data Set (RAI-MDS). The RAI-MDS for LTC uses a collection of standardized scales to comprehensively assess the clinical status of residents (interRAI, 2017b). Some examples of scales within the RAI-MDS for LTC include:

(a) Activities of Daily Living (ADL) Hierarchy, (b) Cognitive Performance Scale (CPS),

(c) Depression Rating Scale (DRS), and (d) the Index of Social Engagement (ISE) (CIHI, 2013).

Upon admission to LTC, a full RAI-MDS assessment is completed for every resident, which is repeated quarterly, and when a significant change in clinical status occurs (CIHI, 2012a). Upon completion of the data assessment, algorithms trigger Clinical Action Protocols (CAPs) to help health care providers create individualized care plans (Hirdes et al., 1999). CAPs help health care providers identify resident risks that may require preventative action, aid in decision-making, and identify the need for referral (interRAI, 2017a).

Through a phased-in process, the RAI-MDS was fully implemented across all LTC facilities in Ontario by 2010 (CIHI, 2012a). In Ontario, the RAI-MDS 2.0 is used, allowing for care planning and identification of resident risk factors (CIHI, 2017). At a systems level, the RAI-MDS 2.0 data contributes to planning system-wide quality improvement initiatives.

2.4 interRAI Self-Report Nursing Home Quality-of-Life Survey

In addition to the RAI-MDS 2.0 for LTC, the interRAI group has also developed a tool to measure QOL in LTC (interRAI, 2017c). This tool, known as the interRAI Self-Report Nursing Home Quality-of-Life Survey will hereinafter be referred to as the “interRAI QOL Survey” for this thesis. The purpose of the 50-item interRAI QOL Survey is to “give persons enrolled in formal care models the opportunity to share their perceptions on a variety of quality-of-life domains” (interRAI, 2017c, para 1). The scale consists of ten QOL domains including: (a) privacy, (b) food and meals, (c) safety and security, (d) comfort, (e) autonomy, (f) respect, (g) responsive staff, (h) staff-resident bonding, (i) activity option, and (j) personal relationships (Morris, 2010). These QOL domains in the interRAI QOL Survey are based on Maslow’s Hierarchy of Needs (Kehyayan et al., 2015). The eight response codes for this tool include:

(0) never, (1) rarely, (2) sometimes, (3) most of the time, (4) always, (6) don't know, (7) refused, and (8) no response or cannot be coded from a response (Morris, 2010). The interRAI QOL Survey does not include a response code five (5).

The style of response options in the interRAI QOL Survey follows that of a Likert-style scale. A Likert scale establishes the level of agreement from participants on a specific topic using a verbal or numerical rating scale (Dawes, 2008). Frequently used options on Likert scales vary from *strongly disagree* to *strongly agree*, with a neutral option in the middle.

The five responses in the interRAI QOL Survey (never to always) are equal in positive and negative response options for each item. Specifically, there are two positive and two negative response options on either side of "sometimes." This balances the available response options for the participant, which results in less influence to select one type of response. For example, if there is an unequal balance as evidenced by a 7-point Likert scale with only one positive response, a respondent may be more likely to choose a negative response (Dawes, 2008). Likert scales should not be confused with Likert-style items. Likert items should be treated as ordinal data. A Likert scale has four or more Likert items that combined measure one concept (Clason & Dormady, 1994). All 50 items combined in the interRAI QOL Survey for analysis form a Likert scale that measures QOL. Likert scales may be analyzed as an interval scale (Boone & Boone, 2012).

In addition to the 10 domains of QOL, the interRAI QOL Survey also includes two additional statements, one to measure global disposition, and the other statement an overall QOL proxy measure. "I tend to be happier than most other people" measures global disposition by adjusting for differences in responder's personality (Stones et al., 1996). The proxy question includes "I would recommend this site or organization to others" (Kehyayan et al., 2015). Only

two negatively phrased items were included out of the 50 items in the survey (Kehyayan et al., 2015; Morris, 2010).

Kehyayan et al. (2015) explain that the interRAI QOL Survey should only be used with individuals who score three or less on the CPS to ensure the individual is able to accurately complete the self-reporting survey. A CPS score of zero indicates that a person's cognition is intact; whereas a score of three indicates a moderate cognitive impairment, and a score of six indicates that the person has a very severe cognitive impairment (Morris et al., 1994).

The interRAI QOL Survey can be scored in three different ways: (a) overall QOL score, (b) domain specific scores, and (c) item specific scores (M. Jantzi, personal communication, January 21, 2016). The total score provides an overall understanding of the self-reported QOL of a resident; whereas, a domain or item-specific score provides valuable insight into the unique needs of a resident, and may inform quality improvement plans (M. Jantzi, personal communication, January 21, 2016). Each item has a score ranging from 0-4, with a domain score ranging from 0-24 based on the number of items within each domain. Appendix B identifies each domain within the interRAI QOL Survey, the number of items within each domain, and the total possible score.

2.4.1 Psychometric Testing on the interRAI QOL Survey

Kehyayan et al. (2015) tested the reliability and validity of the interRAI QOL Survey in 48 LTC homes across Canada. Residents who were English speaking, had a CPS score between 0-3, and had a previously documented RAI-MDS 2.0 assessment were included.

Reliability of the interRAI QOL Survey was determined through test-retest and internal consistency reliability testing (Kehyayan et al., 2015). The same assessor surveyed 22 residents twice within a 26-day time period from the initial assessment. The psychometric testing for the

Kehyayan et al. (2015) study used the Landis and Koch (1977) interpretation of kappa coefficients: (a) moderate: 0.41-0.6, and (b) substantial agreement: 0.61-0.80. Weighted kappa coefficients measured reliability scores varying between -0.1 to 0.8 between the initial and retest item scores for the interRAI QOL Survey. It is important to note that only one item scored poor or at -0.1, "I feel safe around those who provide me with support and care" (Kehyayan, 2011). The interRAI QOL Survey achieved moderate to substantial agreement in 58% of the kappa coefficients. A stronger association or higher weighted kappa coefficient was seen in residents who were surveyed twice within 14 days as compared to those who had a second interview completed outside of the 14-day timeframe. In conclusion, Kehyayan et al. (2015) determined that test-retest reliability of the interRAI QOL Survey was moderate.

Internal consistency of the interRAI QOL Survey was evaluated through Cronbach's alpha (Kehyayan et al., 2015). Described as a number between 0-1, the Cronbach's alpha value represents the level of internal consistency (Tavakol & Dennick, 2011). When test items are correlated, Cronbach's alpha is larger, indicating stronger internal consistency. However, a larger Cronbach's alpha does not always equal a stronger internal consistency. A Cronbach's alpha of .90 or higher may indicate redundancy (Streiner, 2003). The Kehyayan et al. (2015) study found good internal consistency per domain, with values ranging from .62 to .82, and an overall score of .93.

The validity of the interRAI QOL Survey was determined through content validity and convergent validity testing (Kehyayan et al., 2015). Content validity was evaluated by mapping the domains of the interRAI QOL survey against other QOL assessment tools that are widely used and are deemed to be reliable and valid. The tools used for content validity included Kane's Quality of Life Index (Kane, 2003) and the Ontario Hospital Association's (2001) LTC Resident

and Family Member Evaluation Surveys (as cited in Kehyayan et al., 2015). Kane's Quality of Life Index demonstrated internal consistency in a study which interviewed 1988 residents across 40 nursing homes in the United States (Kane et al., 2003). The Cronbach's alphas for this instrument ranged per domain from functional competence (.77) to meaningful activity (.53). The Ontario Hospital Association's (2001) LTC Resident and Family Member Evaluation Survey was chosen because the tool is used across Ontario, tool development was completed by experts in the field, and its face validity had been vetted (as cited in Kehyayan et al., 2015).

Study analysis indicated strong content validity after demonstrating a comparable map of domains covered between the interRAI QOL Survey, Kane's Quality of Life Index, and the Ontario Hospital Association's LTC Resident and Family Evaluation Survey (Kehyayan et al., 2015). Important to note was that the emphasis on spirituality and environmental domains differed between all three tools for measurement of resident QOL. For example, Kane's QOL measure has a stronger emphasis on spirituality compared to the interRAI QOL Survey.

For this study, Kehyayan et al. (2015) based convergent validity on the

“...underlying hypothesis that residents who reported high scores in their global disposition would also report high QOL in each of the domains and in overall QOL, but expecting that correlations with domain specific scores would be lower than the correlation with the overall QOL score” (p. 153).

A comparison of the global disposition question score and the domain specific mean QOL score was completed to determine convergent validity (Kehyayan et al., 2015). The association was also evaluated between the mean overall QOL score and the global disposition score. High overall QOL scores were associated with increased scores for the global disposition question, demonstrating good convergent validity for the interRAI QOL Survey.

In conclusion, the psychometric testing completed in the Kehyayan et al. (2015) study demonstrates the reliability and content and convergent validity of the interRAI QOL Survey.

Further research is recommended to include residents with CPS scores greater than 3 to determine the reliability and validity of this tool among this population.

2.4.2 Measuring Quality-of-Life in Long-Term Care with the interRAI QOL Survey

To date, only three articles have been published regarding the use of the interRAI QOL Survey (Godin et al., 2015; Kehyayan et al., 2015; Kehyayan et al., 2016). Of the three articles, two describe resident QOL scores in LTC, one of which also focuses on resident and facility predictors of QOL (Kehyayan et al., 2015; Kehyayan et al., 2016). The third article compares QOL measurements amongst residents, family, and staff (Godin et al., 2015).

Kehyayan et al. (2015) performed a cross-sectional study using the interRAI QOL Survey in 48 LTC homes in Canada, with a total sample of 928 residents. LTC facilities from the following provinces were included in the study: (a) Alberta, (b) British Columbia, (c) Manitoba, (d) Nova Scotia, (e) Ontario, and (f) Saskatchewan. Residents were included if they: (a) were fluent in English, (b) had at least one full RAI-MDS 2.0 assessment completed, and (c) scored between 0 and 3 on the CPS scale. Female participants made up 65.5% of the sample, with an average age of 80.2 years (SD=11.1) amongst the participating residents.

Each resident completed the interRAI QOL Survey at two time points, with follow-up assessments ranging between 2 and 26 days (Kehyayan et al., 2015). The same assessor completed the interRAI QOL Survey at each time point. Each QOL item was analyzed separately, domain scores were calculated, and the total QOL score was completed for each participating resident per data collection point. To demonstrate positive and negative scores, similar response categories were combined in the analysis of the data. For example, positive response categories “almost” and “most of the time” were combined during analysis, as were negative responses “rarely” and “never.”

Findings indicated that 91% of the residents reported that they felt positive about “feelings of safety” and “feeling safe among staff” (Kehyayan et al., 2015). The “opportunity for romance” item scored the lowest, with only 20.7% of residents feeling this aspect of QOL was met. All 10 domain scores of the QOL tool were reported in terms of the mean and standardized mean scores. The highest domain level scores were reported in “safety/security” (possible scoring range 0-20) and “privacy” (possible scoring range 0-16), both scoring a standardized score of 3.2; whereas the lowest QOL domain was seen in the “personal relationships” (possible scoring range of 0-20) domain with a standardized score of 2.0. The overall QOL mean score was not reported.

Several limitations of the Kehyayan et al. (2015) study need to be noted. As a convenience sample was used, the results may not accurately represent the population of residents in LTC. In addition, the inclusion criteria included a CPS score between 0 and 3, indicating intact cognition to moderate cognitive impairment. This may impact the generalizability of the study, as many residents in LTC have a cognitive impairment above this level. In addition, qualifications of the surveyors were unknown, although the researchers mention that all were trained prior to surveying residents. Nevertheless, this study includes a large sample of LTC residents representing six provinces (Kehyayan et al., 2015). In addition, the data collection protocol was rigorous and the collection of high-quality QOL data presented the first results of the use of the interRAI QOL Survey.

The second study by Kehyayan et al. (2016) used the same sample from the 2015 study to explore the predictors of QOL for residents of LTC including facility and resident characteristics. In this study, numerous structural characteristics of LTC were analyzed including the following: (a) type of ownership, and (b) geographic setting. LTC homes in rural settings, and privately

owned or municipal facilities were associated with higher QOL scores for residents of LTC as compared to urban or charitable homes (Kehyayan et al., 2016).

The same study (Kehyayan et al., 2016) also presented a number of other resident variables that were assessed for their association with QOL: (a) cognitive impairment, (b) ADL level of assistance, (c) bowel incontinence, (d) bladder incontinence, (e) depression, (f) aggressive behaviours, and (g) hearing impairment. Resident variables were assessed using resident data from the RAI-MDS 2.0 subscales: (a) CPS, (b) ADL Hierarchy Scale, (c) Depression Rating Scale, and (e) Aggression Rating Scale. Lower QOL scores were associated with mild cognitive impairment (CPS score of 2), extensive ADL assistance (higher ADL scores), hearing impairment, depression, aggressive behaviours, and bowel and bladder incontinence (Kehyayan et al., 2016).

Limitations of the Kehyayan et al. (2016) study are similar to those in the first study (Kehyayan et al., 2015), as the same design and sample were used. An additional limitation noted by Kehyayan et al. (2016) was that the RAI-MDS 2.0 and interRAI QOL Survey data collection did not occur simultaneously. Therefore, the gap of time between a RAI-MDS 2.0 assessment and an interRAI QOL Survey on the same resident may have impacted the association between predictors and QOL (Kehyayan et al., 2016).

The third study that used the interRAI QOL Survey in LTC compared measurement equivalence of QOL perspectives amongst residents, family, and staff (Godin et al., 2015). Participants were recruited from 23 LTC homes in Nova Scotia. The convenience sample consisted of 319 residents, 397 family members, and 862 staff members. The LTC facilities involved were separated into three categories of homes: (a) a traditional physical design, (b) a new augmented facility with a neighbourhood design, and (c) a new full-scope facility with a

neighbourhood design. The three categories of homes differed in the role of the continuing care assistant (CCA). While the augmented and full-scope facilities both demonstrated a physical neighbourhood design, the role of the CCA was broader within the full-scope facility. For example, the role of CCA at the full-scope facility included providing care needs, housekeeping, and dietary service; whereas, the CCA within the augmented facility provided care and minimal additional tasks such as housekeeping. Within the traditional physical design category, the CCA focused on providing care needs only.

Most participants were female including: (a) 73% of the residents, (b) 91% of staff, and (c) 78% of family members (Godin et al., 2015). Regardless of cognitive status, residents who lived in the home for a minimum of month were contacted for potential recruitment. The interRAI QOL Survey was administered to consenting residents, family members, and staff. The family member and staff interRAI QOL surveys were modified from first-person responses to address the participant. For example, resident responses of “I feel safe” were modified to address the family to “My family member is safe.”

An exploratory factor analysis was completed on the staff group only (Godin et al., 2015). As a result of the factor analysis, 20 items were excluded from the scale, resulting in 29 items. During analysis, a four-factor structure emerged: (a) care and support, (b) autonomy, (c) food, and (d) activities. A variance of 54% was attributed to these four factors in the final exploratory factor analysis.

The authors completed a confirmatory factor analysis on data from all three participant groups (Godin et al., 2015). The following statistics were set as the criteria to indicate good fitting models: (a) a comparative fit index $>.90$, (b) a root mean squared error of approximation $<.08$ and (c) a standardized root mean square residual $<.10$ (Godin et al., 2015). In the staff

perspective group, significant estimated parameters were found ($p < .05$); however, the goodness-of-fit statistics did not indicate a good model fit. This led to researchers removing three items from the model: (a) “when residents have company, they can visit in private,” (b) “residents’ personal information is kept private,” and (c) “residents’ can eat when they want.” Again in the family perspective group, estimated parameters were significant ($p < .05$); however, the goodness-of-fit statistics suggested a less than optimal model fit. Researchers thus removed two items from the model: (a) “my family member’s information is kept private,” and (b) “when my family member has company, he/she can visit in private.” The resident perspective group also demonstrated significant estimated parameters ($p < .05$); however, the goodness-of-fit statistics were not indicative of a good model fit. Two items were removed from the final group: (a) “When I have company, I can visit in private,” and (b) “I can be alone when I wish.”

The final analysis (testing the model across the three perspectives concurrently) found partial measure equivalence across items, as 15 items were found to be equivalent amongst the three participant groups according to the criteria (Godin et al., 2015). Equivalence amongst items demonstrates that the relationship between the scale item and QOL does not vary across the three perspectives. While partial equivalence does not represent agreement amongst the three perspectives groups, it is still valuable for researchers to understand various stakeholder perspectives of resident QOL in LTC for quality improvement planning.

The findings of the Godin et al. (2015) study allow for potential comparison of QOL predictors amongst the three groups; however, findings also indicate that the three different participant groups vary on their perspective of resident QOL. Staff and family perspectives had the highest equivalency amongst items with 76% equivalency; whereas family and resident equivalency was only 62% between items, and resident and staff even lower at 55%. These

results indicate that the best approach to measure residents' QOL is through self-reporting when able, rather than through staff or family reports which may reflect personal opinions of staff or family instead of resident views.

Limitations of the Godin et al. (2015) study included a significant portion of missing data and variance in the cognitive status of resident participants. Both these limitations may have impacted the final results. Staff missing data per item ranged from 4.2 to 17.9 %; whereas missing family data ranged from 1.5 to 50.1 % per item. The largest item for missing family data was "residents/staff asked before using my family member's things" (50.1%), with over 35% of the missing data for this item listed as not knowing the answer and 10% of respondents felt the item was not relevant. Missing resident data ranged from 1.3 to 21.3%. Godin et al.

acknowledged that while the emerging factors may not be able to characterize the individuality of QOL for all residents, the four factors demonstrate an opportunity to assess QOL for residents in LTC.

In conclusion, these three studies (Godin et al., 2015; Kehyayan et al., 2015; Kehyayan et al., 2016) are the first of their kind to utilize the interRAI QOL Survey in LTC for research. These studies demonstrate the capability of the interRAI QOL Survey to measure resident QOL in LTC, including encouraging psychometric properties of the survey. Further validation of this survey through additional research studies is recommended.

2.4.3 interRAI Self-Report Nursing Home Quality-of-Life Survey Short Form

Researchers designed a 31-item short form version of the interRAI QOL Survey in 2011 (interRAI, 2011). This short form version will be hereinafter referred to as the "interRAI QOL Survey Short Form." The interRAI QOL Survey Short Form is described in Table 7 (Appendix C) including: (a) the 10 domains of the interRAI QOL Survey Short Form, (b) the number of

items within each domain, and (c) the total possible score. While the interRAI QOL Survey Short Form maintained many items from the interRAI QOL Survey, an emphasis was placed on minimizing overlap amongst items.

Based on the psychometric properties of the interRAI QOL Survey (Kehyayan et al., 2015), items were reduced to develop the interRAI QOL Survey Short Form. Kehyayan et al. (2015) demonstrated the reliability, convergent validity, and content validity of the interRAI QOL Survey. The investigators found that the interRAI QOL Survey had an overall Cronbach's alpha score of .93 (Kehyayan et al., 2015); indicating probable item overlap, as a score of .90 or greater indicates potential item redundancy on a scale (Streiner, 2003). Upon completion, 31 items were remaining, resulting in the interRAI QOL Survey Short Form. Psychometric testing has not been published for the interRAI QOL Survey Short Form; therefore, further testing is recommended. Nevertheless, the interRAI QOL Survey Short Form is valuable to measure QOL in residents of LTC who are cognitively intact (CPS score of 0) to moderately cognitively impaired (CPS score of 3).

2.5 The Impact of Culture Change on Resident Quality-of-Life

Research suggests that culture change has the potential to improve resident QOL and is also associated with positive clinical outcomes such as a lowered incidence of restraint use in LTC (Pioneer Network, 2011). Culture change is a general term used in residential care to describe the promotion of a LTC environment focused on caring and improving resident QOL through staff and resident empowerment, and careful reflection of organizational attitudes and beliefs (Rahman & Schnell, 2008). The result is not a one-time event or intervention; rather, culture change is an on-going journey to improve quality in LTC (Carson et al., 2015). Culture change is "...based on person-directed values and practices where the voices of elders and those

working with them are solicited, respected and honored” (Pioneer Network, 2017, para 2).

Culture change in LTC is not a simple process and involves the whole LTC organization.

“Culture change may require changes in fundamental organizational and individual beliefs and philosophies, in practices, in physical environments, in relationships at all levels and in workforce models. These kinds of changes lead to better outcomes for elders, their families, and direct care workers” (Pioneer Network, 2017, para 5).

Koren (2010) defined six domains of culture change: (a) resident direction, (b) homelike atmosphere, (c) close relationships, (d) staff empowerment, (e) collaborative decision making, and (f) quality improvement processes. White-Chu et al. (2009) explained that in order for culture change to be implemented, culture should be shifted towards a focus on providing customer-focused care to residents. The fundamentals of culture change as identified by White-Chu et al. (2009) include: (a) promoting self-directed teams, (b) removing the hierarchal structure of LTC, and (c) emphasizing individualized care that focuses on resident choice.

A key component of culture change is person-centred care. McCormack et al. (2010) define person-centredness as:

“an approach to practice established through the formation and fostering of therapeutic relationships between all care providers, older people and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” (p. 13-14)

The terms of culture change and person-centred care are not synonymous. One can carry out person-centred care without culture change (Pioneer Network, 2016). Examples of person-centred care practices in LTC include offering choice to residents, such as flexible dining, bathing, and activity options, with care decisions directed by the resident (McCormack et al., 2012).

Examples of culture change in LTC include: (a) Eden Alternative, (c) Wellspring Innovative Solutions, (d) Golden Gate National Senior Care, (e) Greenhouse, and (f) the Holistic

Approach to Transformational Change (White-Chu et al., 2009). While the literature contains examples of culture change being implemented, there is limited research available on agreed upon culture change approaches, evaluation, and strategies for measuring the impact of culture change in LTC.

One organizational culture change approach that holds promise to help increase residents' QOL is the newly developed Neighbourhood Team Development (NTD) at Schlegel Villages (Boscart et al., 2012). Schlegel Villages acknowledges that traditional biomedical models in LTC create an institutionalized feeling (Carson et al., 2015). In response to this, Schlegel Villages embarked on a culture change journey in 2009 focusing on: (a) resident choice, (b) collaborative teams, (c) flexible living, (d) resident empowerment, and (e) meaningful activities. This resulted in a culture that puts "living first" (Carson et al., 2015). NTD focuses on an organizational culture change, including building cross-functional teams to enhance resident-centred care, and emphasizes QOL through maintaining the dignity and independence of residents. Through the promotion of best practice, NTD aims to improve QOL through culture change (Boscart et al., 2012). The evaluation of NTD as a culture change initiative is underway; however, no scholarly research is available.

2.5.1 Culture Change Research

By understanding the effect of culture change in LTC, we can identify how to best provide care for residents (Sullivan & Asselin, 2013). However, there is a gap in research literature demonstrating how culture change and person-centred care can influence residents' QOL, as well as limited understanding of what interventions could influence resident QOL. This section will review the current literature available on culture change research in LTC.

Shier, Khodyakov, Cohen, Zimmerman, and Saliba (2013) reviewed research (published between 2005-2012) to better understand the impact of culture change in LTC. Inclusion criteria for the review included: (a) studies completed in the US, Canada, and the UK, (b) studies using a comparison group, (c) studies that included at least one of six culture change domains defined by Koren (2010), (d) studies that reviewed resident and family outcomes, (e) studies that included service or care quality, staff, and organizational outcomes, and (f) studies with adequate data to look at intervention effectiveness. Thirty-six studies met these inclusion criteria: (a) 14 pre-post studies without concurrent control, (b) 10 pre-post studies with concurrent control, (c) seven randomized control trials (RCT), (d) two cohort studies, (e) one non-randomized control trial, (f) one cross-sectional study, and (g) one case study (Shier et al., 2014).

The Shier et al. (2014) review evaluated literature utilizing an analytic framework to determine the effect of culture change on quality in LTC. Each of the studies included in the review used different interventions to target Koren's (2010) six domains of culture change (Shier et al., 2014). Of the studies included in the review, 12 measured only one culture change domain, whereas more than one domain was assessed in 24 studies. The domain of "resident direction" was the most commonly assessed culture change domain across all studies, with a total of 24 studies evaluating this domain. It should be noted that this review ranged from assessing organizational culture change such as the implementation of the Green House Program (Kane et al., 2007) to small intervention studies targeting only single domains of culture change.

Among the studies included in the Shier et al. (2014) review, interventions varied from single to multicomponent, ranging in focus from staff empowerment and education, to creating a "homelike" atmosphere in LTC through the introduction of gardens. Several outcomes of culture change were measured including: (a) resident, (b) family, (c) quality of care and services,

(d) staff, and (e) organizational. More than one culture change outcome was assessed in 26 studies, with the most common outcome related to resident outcomes. Validated tools were used to measure outcomes in 26 of the studies. For example, the Geriatric Depression Scale (GDS) was commonly cited as the measurement tool for assessing depressive symptoms.

A positive impact due to culture change was demonstrated in 22 of the 36 studies (Shier et al., 2014). Examples of positively impacted outcomes included: (a) resident mood, (b) resident satisfaction, and (c) resident pain/comfort. Among the 14 studies that were unable to demonstrate statistically significant improvement, one noted clinical improvement of depressive symptoms (Shier et al., 2014). Negative outcomes that were statistically significant were reported in four of the studies. One study noted an increased rate of incontinence in residents in a Green House LTC in comparison to residents in a traditional LTC design (Kane et al., 2007).

Only one study included in this review (Shier et al., 2014) was completed in Canada (Hicks-Moore, 2005). In this Canadian study, the home environment was the only domain of culture change targeted (Shier et al., 2014). Researchers implemented music during dinner time in a LTC in south eastern Canada. Over four weeks, 30 residents were assessed for changes in agitation during dinner time. The Cohen-Mansfield Agitation Inventory was used to observe residents during dinner while relaxing music was played. The same residents were later observed during a different dinner without music for comparison. The incidence of resident agitated behaviours decreased from an average of 9.85 behaviours per day in total for residents without music played during dinner to 3.43 behaviours when music was played, indicating that music may have an influence on decreasing aggressive behaviours in LTC (Hicks-Moore, 2005).

Several difficulties in assessing outcomes related to culture change in these types of studies exist, and may contribute to difficulty demonstrating statistically significant findings

(Shier et al., 2014). Examples of barriers include lack of randomization, the complexity of culture change interventions, the length of time culture change interventions are required in order to see results, small sample sizes, numerous outcome measures, and a lack of agreement amongst researchers on what constitutes culture change and how to implement it. Limitations to this review included a wide variety of designs, populations, and interventions to impact culture change domains.

With 36 studies available on culture change in this review, and only one Canadian intervention study meeting the inclusion criteria, it is evident that further research is required to determine the impact of culture change in LTC (Shier et al., 2014). Researchers and clinicians require further understanding of how to successfully implement culture change and the length of time required to see positive changes. Limited research is available on the impact of culture change on QOL, especially in Canada.

A small number of studies have examined the impact of an organizational culture change, including The Eden Alternative (Bergman-Evans, 2004) and The Green House program in LTC (Kane et al., 2007). Bergman-Evans (2004) completed a quasi-experimental study in the United States to measure changes in QOL in residents who lived in an Eden Alternative LTC versus a traditional LTC. The Eden Alternative aims to remove the institutional feel from LTC, focusing on a “human habitat model.” In this model, pets, plants, and children are introduced into LTC. A focus is placed on companionship, and opportunities for residents to not only receive care, but also contribute. Inflexible routines are replaced with a spontaneous environment, and the decision-making process is placed at the level of the frontline staff. The Eden Alternative is an ongoing organizational culture change (Bergman-Evans, 2004).

Inclusion criteria for this study included: (a) English speaking residents, (b) residents who lived in LTC for six months or greater, and (c) intact cognition (Bergman-Evans, 2004). The Eden Alternative sample included 21 residents; whereas, the control group had 13 residents at the end of the intervention. Both groups were interviewed at baseline, and one year after the intervention started. In addition to chart reviews for medication and diagnostic data, two tools were used to measure changes in the residents following the introduction of the intervention: (a) The UCLA Loneliness Scale version 3 (Russell, 1996), and (b) GDS scale.

Bergman-Evans (2004) focused on three key areas she felt impacted resident QOL in LTC: (a) loneliness, (b) boredom, and (c) helplessness. The Eden Alternative group demonstrated significant decreases in the number of residents who felt helpless at baseline (38.1%) to post-intervention (23.8%), and boredom decreased from 33.3% at baseline to 23.8% post-intervention (Bergman-Evans, 2004). No change was noted in the loneliness of residents between the experimental and the control group. The results were statistically significant, as identified by decreased levels of boredom ($p = .01$) and helplessness ($p = .03$) when measured after the introduction of culture change (Bergman-Evans, 2004). In conclusion, the study by Bergman-Evans (2004) identified that feelings of loneliness, boredom, and helplessness are key concerns in residents of LTC, and the Eden Alternative has potential to impact resident QOL through addressing these three concerns.

Kane et al. (2007) performed a longitudinal study in the United States to examine the Green House program on resident QOL. Two LTC homes were studied for comparison (Cedars & Trinity LTC) with one LTC that had implemented the Green House program. The Green House program creates a homelike environment for people requiring nursing home care, promoting flexible routines, and resident preference (Green House Project, 2016). Care providers

work together with residents and family. Staff are trained to work in more than one capacity, with roles including: (a) cooking, (b) housekeeping, (c) laundry, (d) carrying out the care plan, and (e) providing personal care (Kane et al., 2007).

Data were collected from residents, family and staff interviews, and the MDS. Trained data collectors completed follow-up interviews every six months for a total of 18 months (Kane et al, 2007). In this study (Kane et al., 2007), residents completed in-person interviews using a Likert-style scale comprised of 11 QOL domains: (a) physical comfort, (b) functional competence, (c) privacy, (d) dignity, (e) meaningful activity, (f) relationship, (g) autonomy, (h) food enjoyment, (i) spiritual well-being, (j) security, and (k) individuality. In total, Green House residents scored higher on QOL in seven out of the 11 domains as compared to the traditional LTC home residents at Cedars: (a) privacy, (b) dignity, (c) meaningful activity, (d) relationship, (e) autonomy, (f) food enjoyment, and (g) individuality. However, residents living in the Green House only scored better on four out of 11 domains in comparison to the residents living at the traditional LTC home Trinity: (a) privacy, (b) dignity, (c) autonomy, and (d) food enjoyment.

Limitations of this study (Kane et al., 2007) included a small sample size, a sample that could not be randomized and consisted of Green House resident volunteers, and differences in sample demographics such as age and race. Further research is recommended on the impact of the Green House program on resident QOL, and the feasibility of the program.

In Canada, several organizations claim to implement culture change in LTC; however, minimal examples are available in the literature. A current culture change approach in LTC is NTD as developed by Schlegel Villages, which aims to increase the QOL of LTC residents (Boscart et al., 2012). This organizational change creates opportunities to develop teams to lead

person-centered care initiatives in LTC to positively impact residents and their families, teams, and the organization. NTD provides an approach to impact residents' QOL in LTC at both the level of the resident and organization.

A large study is currently in progress across Ontario to evaluate NTD on residents, family, team members, and organizational outcomes (Boscart et al., 2012). One of the foci of this larger study addresses residents' QOL in LTC. The purpose of this secondary analysis is to determine if NTD has an impact on residents' QOL in LTC. To date, there is no scholarly literature on the impact of NTD culture change in LTC.

2.6 Research Questions

The primary research question for this study was: Is there a significant difference in residents' QOL score following the implementation of Neighbourhood Team Development? A secondary research question addressed the correlates of residents' QOL in LTC: Do resident variables of age, marital status, and gender predict residents' QOL in LTC?

CHAPTER 3: METHODOLOGY

This secondary analysis employs a quantitative repeated-measures design to determine the impact of NTD on residents' QOL in LTC. In this chapter, the methodology for this study is presented including: (a) design, (b) setting, (c) intervention, and (d) data collection. This is followed by a thorough description of the approaches used for data analysis, with a focus on paired t-tests, multiple regression, and approaches to treating missing data.

3.1 Design

This study is a secondary analysis of data collected for a larger three-year (March 2013-August 2016) feasibility study evaluating NTD in LTC and its impact on resident-centredness (Boscart et al., 2012). The larger study is a mixed methods intervention study, using a repeated-measures design to collect quantitative and qualitative data. A repeated-measures design collects multiple measurements on the same subject(s) at different points in time (Sullivan, 2008). This design may detect the impact of interventions through changes in measurable outcomes over time.

The intervention consists of the implementation of NTD (Boscart et al., 2012). The large study commenced in March 2012, at which time baseline data were collected from a large sample, including 1149 residents and families, and 1500 staff from six LTC homes across Ontario. Interviews and focus groups provided qualitative data for the study, as well as observations and recording of interactions. As culture change is an organizational shift, all neighbourhoods within Schlegel Villages implemented NTD, therefore, a comparison group is unavailable for this pilot study. Quantitative data were collected through the use of RAI-MDS 2.0 admission and quarterly data, surveys, and quality indicators (Boscart et al., 2012).

This secondary analysis employs a quantitative repeated-measures design to determine the impact of NTD on residents' QOL in LTC. Resident variables were collected through the RAI-MDS 2.0 including: (a) demographic data, (b) cognitive status, and (c) length of stay. QOL data is collected through the use of the interRAI QOL Survey Short Form (Boscart et al., 2012). This secondary analysis is focused on the data set of January 2014- November 2015 and baseline data from August 2011-December 2012. Although this study is a secondary analysis, methods are consistent with the original Conestoga College Research Ethics Board (REB) application (#118). REB approval for this secondary analysis was accepted through an amendment to the original application. Note that resident QOL is only one part of the larger study to determine the effectiveness of NTD.

3.2 Setting

Schlegel Villages provides a home to 3000 older adults across Ontario, in 16 different locations (Schlegel Villages, 2016a). Schlegel Villages offers both independent and retirement living, assisted care, memory care, and LTC. This continuum of care provides a unique advantage to residents and families, allowing residents to stay within their community as their care needs change.

Schlegel Villages has a unique culture, mission, and company aspirations. The mission at Schlegel Villages (2014c) is “to provide holistic health care in a home environment, located within an internal neighbourhood design that promotes a caring community, with an emphasis on optimal health and life purpose for each resident” (para 1). The architecture of the neighbourhoods and the village is designed to promote a sense of community, and encourage socialization and meaningful connections amongst residents and teams (Schlegel Villages, 2014a). Schlegel Villages refers to their LTC facilities as “villages” rather than using words such

as facility or nursing home. Each village has multiple units or wings, named “neighbourhoods,” all with access to “main street living,” true to its mission. Each village is structured around the main street, featuring amenities such as a barber, pub, town square, and library (Schlegel Villages, 2014b).

3.3 Description of Intervention: Neighbourhood Team Development (NTD)

Building on the values and beliefs of a social model, Schlegel Villages began the implementation of NTD in 2013. NTD is based on, with permission, the Eden Alternative’s “Neighbourhood Guide,” a guide licensed by Vivage Quality Health Partners (Boscart et al., 2012). The Eden Alternative is dedicated to changing culture in LTC and to increase QOL through the empowerment of residents, staff, volunteers, and family members (Eden Alternative, 2014). The Eden Alternative (2014) philosophy promotes the building of elder-centred communities through transforming organizational practices that provide person-directed care, resulting in a “life worth living” for residents.

The physical layout of a neighbourhood focuses on a resident-centred design with private or semi-private rooms and common areas including: (a) country kitchen, (b) dining room, and (c) family room (Boscart et al., 2012). This allows opportunities for both resident privacy and community gathering to facilitate socialization. Flexible meal times are available through the onsite country kitchen, and an open team work area replaces the traditional closed nursing station design to encourage shared decision-making. This physical care environment allows for increased collaboration amongst residents, families, and team members, and promotes resident-centredness through encouraging resident autonomy and choice (Boscart et al., 2012).

NTD focuses on empowering team members by promoting a culture that builds cross-functional teams centered on delivering care and services to LTC residents in a neighbourhood

(Boscart et al., 2012). A focus is placed on maintaining the dignity and independence of residents while promoting best practices and work within a team (Boscart et al., 2012). Each neighbourhood within a village has a consistent staff team. Traditionally, health care teams include registered staff and personal support workers. Since the start of NTD, the neighborhood team consists of all health care disciplines, including facility and dietary staff, and a Neighbourhood Coordinator (NC). All members of the team are seen as equal, thus removing the hierarchy in LTC. The NC acts as a coach for the team, mentoring team members and promoting QOL through self-directed neighbourhood teams in a care environment focused on delivering resident-centred caring, and respecting residents' autonomy (Boscart et al., 2012). NTD places decision-making at the level of the neighbourhood team, rather than at the level of management (Boscart et al., 2012). A focus is placed on resident-centred care and offering choice. Carson et al. (2015) define key concepts of resident centred care as: (a) choice, (b) dignity, (c) respect, (d) self-determination, and (e) purposeful living. The NTD environment is focused on being a residents' home; rather than a team members' workplace (Carson et al., 2015).

The implementation of NTD is continuous (Boscart et al., 2012). NTD started with an organization-wide commitment to designate assigned teams in each neighbourhood and the appointment of NCs. The leadership team and all NCs received an in-depth three-day workshop. Subsequently, the NCs and directors provided NTD to their teams through monthly meetings. Team members from each neighbourhood attend a monthly gathering, led by the NC, to promote team development (Boscart et al., 2012). Topics and content of NTD development follow the NTD guide book (Carson et al., 2015) and include the organizational mission, team building skills, quality improvement, conflict resolution, recognizing valuable contributions, and models

of leadership. The NCs and directors continue their learning once a year with a three-day workshop and then support their teams to continually grow.

For the large pilot study, a team of researchers carefully measured and observed any resident, family, team and organizational impact of NTD for the duration of three years (Boscart et al., 2012). It is expected that NTD will continue after the three-year intervention study to continue the growth and development of the team and the LTC organization.

3.4 Data Collection

Data collection for this secondary analysis was part of the larger NTD study. The following section will describe the process of data collection for the secondary analysis including: (a) recruitment, (b) data collection procedure, (c) data collection instruments, and (d) data entry and storage.

3.4.1 Recruitment

Participants for the large three-year NTD intervention study were recruited by research assistants who obtained informed consent by following procedures as outlined in Conestoga College REB #118 approval. All residents, their families, and staff within these six villages were invited to participate. In total, 1149 residents and their families, and 1500 staff from six randomly selected LTC homes across Ontario were approached for the study.

This secondary analysis was based on data from the larger NTD study, with a focus on the sample of residents. As a result of two different research questions with different data collection needs, we end up with two different samples for this thesis. The primary research question for this thesis evaluates if NTD has an impact on resident QOL and included the following inclusion criteria: (a) living within one of the participating Schlegel villages,

(b) presenting with a CPS score equal to three or less, (c) ability to provide informed consent, and (d) completed the interRAI QOL Survey Short Form during time point 1 (between August 2011 and December 2012) and completed the same survey at time point 2 (between January 2014 and November 2015) (Boscart et al., 2012). Exclusion criteria for this sample included: (a) being acutely ill with a poor trajectory, (b) a CPS score of 4 or more, (c) an inability to complete the interRAI QOL Survey Short Form at both time point 1 and 2, and (d) palliative.

The inclusion criteria for the secondary research question varied slightly. While the first three inclusion criteria remained the same, the fourth item changed. Residents were required to complete the interRAI QOL Survey Short Form at only one point in time during the data collection period to demonstrate if resident variables predicted QOL. Exclusion criteria for the secondary research question included: (a) being acutely ill with a poor trajectory, (b) a CPS score of 4 or more, (c) an inability to complete the interRAI QOL Survey Short Form between August 2011-November 2015, and (d) palliative.

3.4.2 Data Collection Procedure

Resident QOL data is collected over the course of one year, with the interRAI QOL Survey Short Form. Team members received detailed training to facilitate QOL data collection including: (a) confidentiality considerations, (b) ethical considerations, (c) interRAI QOL Survey Short Form training, (d) interview preparation, and (e) interview principles (Jantzi, Curtin-Telegdi, & Eckel, 2017). Team members met with each resident once a year to complete the QOL scale in person. NTD started in March 2013, so as a result of the above inclusion criteria and data collection schedule, the selected sample included residents with a minimum exposure to NTD of nine months; whereas the maximum exposure of residents to NTD was up to 32 months at time point 2.

3.4.3 Data Collection Instruments

The interRAI QOL Survey Short Form was used to collect data for all residents who met the inclusion criteria to determine the overall QOL score at time point 1 and time point 2. The psychometric properties for the interRAI QOL Survey and development process for the interRAI QOL Survey Short Form are reviewed in the literature review of this thesis. To describe participant characteristics and allow for comparison with other studies, basic demographic variables were collected using the RAI-MDS 2.0 admission and quarterly assessment. Demographic variables collected included: (a) gender, (b) age, (c) marital status, (d) length of stay, and (e) CPS score. For this study, three demographic variables were analyzed to determine if they collectively predicted resident QOL: (a) age, (b) gender, and (c) marital status.

3.4.4 Data Storage and Entry

All team members were orientated on confidentiality considerations such as data security and maintaining records. All quantitative data are entered into Point of Care, a software program designed to collect and manage all resident data. All data were password protected, on a secure electronic database. Data extraction for this study occurred by an epidemiologist who anonymized all data prior to data analysis. All data will be destroyed and removed from the database after seven years.

3.5 Data Analysis

This secondary analysis used a quantitative data analysis approach, utilizing a paired t-test to address the primary research question: Is there a significant difference in residents' QOL score following the implementation of Neighbourhood Team Development? A multiple regression approach was used to answer the secondary research question: Do resident variables

of age, marital status, and gender predict residents' QOL in LTC? The interRAI QOL Survey Short Form response options (6) "don't know," (7) "refused," and (8) "no response or cannot be coded from a response" were treated as missing data to avoid skewing the total QOL score, and a multiple imputation approach to missing data was employed. The following section will outline: (a) common approaches used to address missing data, (b) the approach used to address missing data in this study, and (c) the methods of data analysis used to answer the research questions.

3.5.1 Addressing Missing Data

A common problem in research is missing data (Eekhout et al., 2014; Fayers & Machin, 2016; Penny & Atkinson, 2012; Rezvan, Lee & Simpson, 2013). Unfortunately, the problem of missing data in research is often unavoidable. Trends of missing data in specific domains may inform future research (Fayers & Machin, 2016). For example, if a domain consistently includes missing data on one specific item in older females, researchers may hypothesize that poor ratings of QOL in this item occur in this population. Missing data in QOL studies may lead to bias, poor representation of data, and inaccurate depiction of the final outcome. Self-reporting scales are susceptible to missing data, which can compromise the validity of results (Penny & Atkinson, 2012).

There are two categories of missing data in scales and measurements: unit non-response (total scale) and item non-response (Fayers & Machin, 2016). Unit non-response occurs when the full QOL assessment is missing. Item non-response occurs when a QOL assessment was completed, but contains missing data on various items or subscales of the assessment (Fayers & Machin, 2016).

There are numerous causes of missing data. Three categories for missing data include: (a) Missing completely at random (MCAR), (b) Missing not at random (MNAR), and

(c) Missing at random (MAR) (Fielding, Fayers, & Ramsay, 2009). MCAR data is missing randomly, and has nothing to do with the question being asked or participant characteristics. Data may be MCAR due to chance, and missing data is not influenced by the question being asked, or other characteristics of the participant (Sinharay, Stern, & Russell, 2001). For example, a respondent may miss answering an item on a survey by accident (Penny & Atkinson, 2012). MNAR data is associated with the missing value or data in the scale that would have been measured, and is the most difficult to deal with (Sinharay, Stern, & Russell, 2001). An example of MNAR data is when all participants who binge drink alcohol, tend to not report the number of drinks they consume per day on a survey. MAR data is not related to the missing variables in the dataset; however, it may be related to other characteristics of the participant (Sinharay, Stern, & Russell, 2001). For example, if highly educated individuals tend to not report alcohol habits, the data missing is considered MAR, as missing data is related to the education of the individual, not the amount of alcohol consumed.

Missing data patterns should be reviewed when considering the appropriate method to deal with the missing data (Penny & Atkinson, 2012). Three patterns of missing data include: (a) univariate, (b) monotone, and (c) arbitrary. When only one item is affected by missing data, a univariate pattern is assumed. In a case where missing data appears to have an order, a monotone pattern is assumed. A monotone pattern is seen when missing data follows a sequential pattern. For example, missing data starts at item number four on a survey, including all items missing thereafter. The third common missing data pattern for itemized surveys is an arbitrary pattern, where there is no identifiable pattern (Penny & Atkinson, 2012).

Methods to control for missing data may be applied at the level of the item score or the total score (Eekhout et al., 2014). For example, if analyzing at the level of a domain or subscale,

a subscale may be removed where a participant had missing data, or, if analyzing at the item level, the item may be removed. A number of approaches have been developed to deal with missing data, each with its own advantages and disadvantages. Some approaches to treating missing data may lead to a decrease in sample size and statistical power (Fayers & Machin, 2016). Expert opinions vary on the appropriate type of analysis that should be used. Introducing measures to reduce missing data during data collection is always the best option. Missing data should be treated based on the type of data missing, the type of study, and the amount of missing data (Fayers & Machin, 2016). In the following section, three approaches to missing data will be discussed: (a) complete case analysis, (b) recoding, and (c) multiple imputation.

3.5.2 Complete Case Analysis

In complete case analysis (or listwise deletion), all participants with missing data are removed from the sample for analysis (Fayers & Machin, 2016). While this method is simple, sample size will be reduced. The results from a complete case analysis may also be misleading. For example, a complete survey may be more likely to be seen in a resident who is healthy compared to a resident who is ill and struggling to complete the questions. In MCAR data, the complete case analysis method works for treating missing data (Fielding, Fayers & Ramsay, 2009). However, unless the missing data is confirmed MCAR, completed case analysis should not be used (Penny & Atkinson, 2012). In samples with over 5% data missing, complete case analysis is not recommended (Fayers & Machin, 2016).

3.5.3 Recoding Missing Data

A less common option to treat missing data involves the recoding of missing data. In two of the three studies with available literature on the interRAI QOL Survey, missing data were recoded as “sometimes” or 2 (Kehyayan et al., 2015; Kehyayan et al., 2016). By recoding data

with “sometimes,” this mid-point response introduces an option to decrease bias and maintain sample size in the QOL data. The “sometimes” option is exactly mid-way between the 0 and 4 score, and eliminates more extreme values such as 0 (Never) or 4 (Always). In the unpublished pilot study conducted by Morris (2009) this method of recoding missing data to “sometimes” was used (as cited in Kehyayan et al., 2015). Kehyayan (2011) compared three approaches to missing data in the analysis of the interRAI QOL Survey data: (a) complete case analysis, (b) recoding, and (c) mean imputation. Kehyayan (2011) concluded that recoding missing data to “sometimes” increased the interRAI QOL Survey overall mean score; however it led to a decreased domain level mean score, and decreased variation in the standard deviation.

3.5.4 Imputation of Missing Data

Imputing data involves using available data to inform missing values to create a complete dataset (Fayers & Machin, 2016). A review of available data is completed to find the best estimated value to replace missing data. The advantages of imputation of missing data include: (a) a complete data set can be used for analysis, (b) imputation and interpretation can be straightforward, and (c) maintenance of the sample size. The disadvantages of imputation of missing data are: (a) underestimated standard deviation, and (b) the false confidence that more data is available than actually occurred.

Many variations of imputation exist including: (a) mean imputation, and (b) multiple imputation (Fayers & Machin, 2016). In mean imputation, the average score of the available data replaces missing values (Eekhout et al., 2014). Advantages of mean imputation include the ease of replacing missing data and conducting the analysis. Disadvantages of this approach include underestimated standard deviation, a confidence interval appearing narrower than it truly is, falsely increased statistical power, and increased potential for type I errors (Penny & Atkinson,

2011). In studies with over 10% missing data, mean imputation is not recommended as it may lead to biased estimates (Eekhout et al., 2014).

In multiple imputation numerous complete datasets are produced, therefore maintaining sample size. As we are unable to be certain what the actual missing value is, multiple imputation implements variability into the multiple data sets, improving validity over other imputation approaches (Sterne, 2009). Due to this, disadvantages found in other missing data approaches such as underestimated standard deviations, confidence intervals, and correlations are reduced with multiple imputation (Fayers & Machin, 2016).

The multiple imputation process is composed of three phases: (a) imputation, (b) analysis, and (c) pooling (Eekhout et al., 2014). In the first phase, multiple complete datasets are created from the imputation of multiple plausible values for each missing value. In the second phase, each dataset is analyzed independently for results. The third phase, pooling, combines the results into one summary. Advantages of multiple imputation include a more accurate representation of standardized deviations and confidence intervals (Fayers & Machin, 2016).

Sterne et al. (2009) conducted a systematic review of articles using a multiple imputation approach for analysis in four widely known journals: (a) New England Journal of Medicine, (b) Lancet, (c) BMJ, and (d) JAMA. From 2002-2007, Sterne et al. found only 57 articles citing this approach. However, a more recent systematic review of the Lancet and New England Journal of Medicine concluded that 103 articles published between 2008 and 2013 utilized multiple imputation to treat missing data (Rezvan, Lee, & Simpson, 2013). This demonstrates an almost doubled frequency of this method being used in studies. Even more significant is that this large increase is the result of reviewing only two of the four original journals.

Godin et al. (2015) tested for equivalence in QOL reporting across family, staff, and residents in LTC. Missing data at the resident level in this study ranged from 1.3% - 21.3%. Due to the large volume of missing data and the advantages of the missing data approach, Godin et al. (2016) chose to address missing data using multiple imputation; whereas Kehyayan (2011) used three approaches to demonstrate differences in addressing missing data: (a) listwise deletion, (b) recoding, and (c) sample-mean imputation.

3.5.5 Current Study Missing Data Approach

To demonstrate the differences amongst missing data approaches, three methods were reported in this current study: (a) complete case analysis, (b) recoding, and (c) multiple imputation. As the data for this study is assumed to have an arbitrary missing data pattern with multiple continuous variables, multiple imputation and the Markov Chain Monte Carlo (MCMC) method was most appropriate for use. The MCMC method is a popular multiple imputation approach. MCMC results in a complete data set by producing multiple values to replace missing data (Allison, 2009). Allison (2009) explains the MCMC approach as,

“...generating predicted values based on the linear regressions, random draws are made from the (simulated) error distribution for each regression equation. These random ‘errors’ are added to the predicted values for each individual to produce the imputed values” (p.82).

The MCMC approach preserves variability in the data, maintaining standard deviations (Fayers & Machin, 2016). This is accomplished through applying transition probabilities, which allows for the possibility that two participants with similar missing data values can have different QOL profiles. For this study, a total of 10 plausible data sets were created utilizing the MCMC approach. Current research reports that a minimum of five data sets is recommended to decrease bias (Fayers & Machin, 2016).

3.5.6 Primary Research Question

In this repeated-measures design, a paired t-test was used to determine the impact of NTD on the QOL of residents in LTC, treating the interRAI QOL Survey Short Form as interval data for research analysis. A paired t-test demonstrates change through comparison of the population mean at two points in time. Data are organized in pairs, meaning the same participants are included at time point 1 and 2. In order to complete a paired t-test, two assumptions should be met prior to analyzing the data according to Walker and Almond (2010):

- 1) Data scores are available in pairs (matching measurement surveys are completed at two different time points by the same participant) and,
- 2) Normally distributed data utilizing continuous variables are present.

Combined, the 31 items on the interRAI QOL Survey provide a composite score to demonstrate QOL. By treating the Likert interRAI QOL Survey Short Form data as continuous and pairing data from time point 1 and 2, a paired t-test will demonstrate change in the overall QOL scores between the two points in time. Descriptive scores for each domain within the QOL short form tool between time point 1 and time point 2 were also reported.

3.5.7 Secondary Research Question

Multiple regression was used to address the secondary research question on resident variables predicting QOL. Multiple regression is used to determine the relationship between several independent variables and one dependent variable (Allison, 1999). Independent variables (age, marital status, gender) were combined in multiple regression analysis to determine whether collectively they are significant predictors of the dependent variable (resident QOL). The value of multiple regression is that it can determine the influence multiple variables have on a

dependent variable. Independent variables can be continuous or dichotomous in multiple regression (Walker & Almond, 2010).

The assumptions that must be met in order to conduct multiple regression according to Walker and Almond (2010) are:

- 1) The researcher has a normally distributed continuous dependent variable.
- 2) All independent data must be dichotomous or continuous data.
- 3) A linear relationship must occur between the independent and dependent variable.
- 4) Independent variables must not have a strong correlation with each other or analysis may be skewed. Multicollinearity can be screened with the Variance Inflation Factor (VIF).
- 5) The assumption of homoscedasticity was met (approximate equal standard deviations occur between the predictor and dependent variable).

A multiple regression test was used to analyze the collective prediction of QOL for the resident variables as defined. The independent variables include: (a) age, (b) gender, and (c) marital status. Marital status and gender were included in the regression as dichotomous data, whereas age was continuous data. The dependent variable included the QOL score. For the multiple regression analysis, the QOL scale was treated as a composite score, looking at the overall concept of QOL in LTC.

CHAPTER 4: Results

Overall, the results of this secondary analysis found that residents' QOL increased after the implementation of NTD. However, age, gender, and marital status were not found to collectively predict residents' QOL. In this chapter, the results will be discussed in detail, including the following features for each research question: (a) sample description, and (b) results. First, information on the data missing and data completion statistics are presented.

4.1 Missing data

Missing data per item on the QOL scale ranged from 1.5% to 17.7%. In total, 731 responses were missing out of 14 384 possible responses, indicating that approximately 5% of the total data were missing. The range of missing data on one scale ranged from 0-22 items. Appendix D describes the missing data per item, demonstrating that the item "Staff act on my suggestions" and "I tend to be happier than most other people" had the highest rates of missing data with 17.7% and 13.8% respectively, compared to the items "Staff take the time to have a friendly conversation with me" (1.5%) and "I get the services I need" and "I feel my possessions are safe" both (at 1.9%) with the lowest rates of missing data.

4.2 Data Completion Statistics

The sample for the primary research question of this secondary analysis consisted of 1149 residents across six villages who met the inclusion criteria. At baseline, 966 QOL assessments were completed on residents in six villages. At time point 2, there were 1017 QOL assessments completed on residents. This resulted in a sample of 232 participants who presented with paired data retrieved at both time point 1 (August 2011- December 2012) and time point 2 (January 2014-November 2015) data collection times. For the secondary research question, the

sample consisted of 1500 residents. As data were not required to be paired to answer the secondary research question, all residents with a completed interRAI QOL Survey Short Form between August 2011- November 2015 were included, resulting in a larger sample size.

4.3 Sample

Overall, 20% of residents in the villages met the inclusion criteria for the primary research question: (a) living within one of the participating Schlegel villages, (b) presenting with a CPS score equal to 3 or less, (c) able to provide informed consent, and (d) completed the interRAI QOL Survey Short Form during the time period at time point 1 (between August 2011 and December 2012) and time point 2 (between January 2014 and November 2015) (Boscart et al., 2012). Over 30% of residents had a CPS over 3 at either time point 1 or 2, excluding them from participating in the interRAI QOL Survey Short Form. The main reasons for an incomplete survey at either time point 1 or 2, based on a review of RAI-MDS 2.0 data, included: (a) being acutely ill with a poor trajectory, (b) a CPS score of four or more, and (c) palliative. On average, there were 817 days between time point 1 and time point 2 QOL assessments.

The primary research question for this study was: Is there a significant difference in residents' QOL score following the implementation of Neighbourhood Team Development?

4.4 Sample Description for the Primary Research Question

Residents (n=232) were largely female (68%), between the ages of 85-94 (42%) and unmarried (75%) (See Table 1). Over 56% of the participants demonstrated mild cognitive impairment (CPS score of 2), to moderate cognitive impairment (CPS score of 3). Most residents had a length of stay over one year (73%).

Table 1 Descriptive Analysis of Demographics for the Primary Research Question (n=232)

Variables	% (n)
<u>Age(years)</u>	
<65	18.5% (43)
65-74	8.2% (19)
75-84	24.6% (57)
85-94	41.8% (97)
95 and over	6.9% (16)
<u>Gender</u>	
Male	30.2% (70)
Female	67.7% (157)
Other	2.7% (5)
<u>Marital Status</u>	
Married	25.0% (58)
Other	75.0% (174)
<u>Length of Stay</u>	
<90 days	5.6% (13)
90 to 364 days	21.1% (49)
1 year or more	73.3% (170)
<u>CPS Score</u>	
0-Intact	26.7% (62)
1-Boderline intact	16.8% (39)
2-Mild Impairment	26.3% (61)
3-Moderate	30.2% (70)

Note. Demographic variables were obtained from the RAI-MDS 2.0 assessment available closest to the interRAI QOL Survey Short Form

4.5 Domain Scores for the interRAI QOL Survey Short Form

The distribution of QOL scores by domain is described in Table 9 (Appendix E). The results demonstrate a small increase in the mean QOL domain scores from time point 1 to time point 2, with the exception of Safety/Security (decreased in score from 9.68 to 9.48) and Comfort (decreased in score from 15.25 to 15.05).

4.6 Comparison of Quality-of-Life Scores Utilizing Different Missing Data Approaches

In the Kehyayan (2011) report, three approaches were used to treat missing data from the interRAI QOL Survey: (a) complete case analysis, (b) recoding as “sometimes,” and (c) mean imputation. As a result of the literature, three approaches to treat the missing data for this study were used to demonstrate differences: (a) complete case analysis, (b) recoding as “sometimes,” and (c) multiple imputation. The mean QOL scores are demonstrated in Table 2 when missing data were treated as complete case analysis, recoded as “sometimes” or 2, and using a multiple imputation approach. The complete case analysis approach decreased the sample size from 232 to 57, a reduction in sample size to less than 25%, therefore decreasing statistical power. Both recoding the missing data and the multiple imputation approach resulted in a decreased mean at time point 1 and time point 2 versus the complete case analysis method.

Table 2 Distribution of Quality-of-Life Scores Utilizing Different Missing Data Approaches

	Complete Case Analysis (n=57)			Recoded as 2 (n=232)			Multiple Imputation (n=232)		
	Mean	SD	N	Mean	SD	N	Mean	SD	N
Time point 1	90.3	15.5	57	84.1	16.5	232	85.2	16.8	232
Time point 2	91.1	17.5	57	87.3	17.2	232	88.7	17.4	232

4.7 Results: Quality-of-Life Scores Before and After Neighbourhood Team Development

All assumptions were met prior to analysis, with the QOL scores being normally distributed. The overall QOL scores for 232 residents at time point 1 and time point 2 after the implementation of NTD were compared using a paired t-test. Missing data was addressed using a multiple imputation MCMC approach. A total of 10 data sets were created with multiple plausible imputations for missing data, with a relative efficiency over 99.5%.

There was a statistically significant difference between time point 2 QOL scores (M=88.7 SD=17.4) and time point 1 (M=85.2, SD=16.8) $t(231) = -2.96, p = 0.0034$, with scores

improving between time point 1 and time point 2. The results suggest that NTD has a statistically significant impact on the QOL of residents in LTC.

The secondary research question for this study was: Do resident variables of age, marital status, and gender predict residents' QOL in LTC?

4.8 Sample Description for the Secondary Research Question

In total, 1500 residents had both a completed RAI-MDS 2.0 assessment and an interRAI QOL Survey Short Form during the study time frame of August 2011-November 2015. Each interRAI QOL Survey Short Form was paired with a RAI-MDS 2.0 assessment from the same resident. The mean timeframe between completion of the RAI-MDS 2.0 and the interRAI QOL Survey Short Form was 30.16 days.

Residents were largely female (68%), between the ages of 85-94 (48%) and unmarried (75%) (See Table 3). Over 70% of the participants demonstrated a mild to moderate cognitive impairment (CPS score of 2 to 3), and most residents had a length of stay over one year (68%).

Table 3 Descriptive Analysis of Demographics for the Secondary Research Question (n=1500)

Variables	% (n)
<u>Age</u>	
<65	7.4% (111)
65-74	6.6% (99)
75-84	25.0% (375)
85-94	48.1% (721)
95 and over	12.9 (194)
<u>Gender</u>	
Male	32.3% (484)
Female	67.7% (1016)
<u>Marital Status</u>	
Married	24.9% (373)
Other	75.1% (1127)
<u>Length of Stay</u>	
<90 days	6.4% (96)
90 to 364 days	25.8% (387)
1 year or more	67.8% (1017)
<u>CPS Score</u>	
0-Intact	14.3% (215)
1-Borderline intact	14.3% (215)
2-Mild Impairment	29.2% (438)
3-Moderate Impairment	42.1% (632)

Note. The total sample of residents for the secondary research question did not require both time point 1 and time point 2 interRAI QOL Survey Short Form data, resulting in a larger sample size (n=1500).

4.9 Results of Quality-of Life Predictors: Age, Gender, and Marital Status

To determine if the variables of age, gender, and marital status collectively predicted residents' QOL, a multiple regression analysis was completed. All assumptions were tested and met to run a multiple regression analysis. The Variance Inflation Factor (VIF) was reviewed on all independent variables to test for multicollinearity: (a) age (1.03), (b) gender (1.12), and (c) marital status (1.11). High multicollinearity is demonstrated with a VIF of 10 or greater,

therefore all variables tested negative (Kleinbaum et al., 2014). The interRAI QOL Survey Short Form missing data were imputed using the MCMC multiple imputation method. The multiple regression results demonstrated that none of the variables of age ($p = 0.2403$), gender ($p = 0.3750$) or marital status ($p = 0.2698$) were significant predictors of residents' overall QOL score (See Table 4).

Table 4 Results of Quality-of-Life Predictors: Age, Gender, and Marital Status (n=1500)

Model	B	Std Error	95% CI		T	P
			Lower	Upper		
Intercept	90.6	3.95	82.86	98.33	22.94	<0.001
Age	-0.05	0.047	-0.146	0.037	-1.17	0.2403
Gender	-1.03	1.16	-3.311	1.248	-0.89	0.3750
Marital Status	-1.37	1.25	-3.826	1.070	-1.10	0.2698

Note. The total sample of residents for the secondary research question did not require both time point 1 and time point 2 interRAI QOL Survey Short Form data, resulting in a larger sample size (n=1500).

CHAPTER 5: DISCUSSION

This study makes a number of new contributions to the literature on culture change and residents' QOL in LTC. First, study findings suggest that culture change in the form of NTD results in improved QOL for LTC residents with a CPS score of 0-3. Second, the study provides new information about the use of the interRAI QOL Survey Short Form in LTC. Third, this study confirms previous literature on selected correlates of QOL among LTC residents. These three key findings will be discussed in this chapter, followed by the strengths and limitations of the study, the implications for practice, education, policy, and research, and lastly, the study conclusion.

5.1 The Impact of Neighbourhood Team Development on Resident Quality-of-Life

Based on interRAI QOL Survey Short Form data from 232 residents across six Ontario LTC homes, study results suggest that NTD improves residents' QOL in LTC. A p value $<.05$ indicates that the likelihood of the results being due to chance is less than 5%, thus reaching a level of statistical significance (Heavey, 2015). A statistically significant difference ($p = .003$) and a positive change score of 3.5 suggests that NTD has a statistically significant impact on QOL in LTC, specifically in residents with a CPS score of 0-3. This is the first study to examine the impact of the culture change intervention NTD on residents' QOL. The core components of NTD include: (a) maintaining the dignity and independence of residents, (b) consistent staffing, (c) cross-functional teams, (d) resident-centred care, (e) empowering team members, and (f) the physical neighbourhood design.

Limited research is available to demonstrate the impact that culture change has on residents' QOL in LTC. In a comprehensive review, Shier et al. (2014) noted that culture change interventions vary greatly in the literature and that few studies measured QOL in relation to

culture change. Only a small number of studies have examined the impact of organizational culture change on QOL in LTC, including the Eden Alternative (Bergman-Evans, 2004) and Green House program (Kane et al., 2007).

Bergman-Evans (2004) measured QOL changes in residents who lived in a human habitat model as seen in the Eden Alternative LTC, versus a traditional LTC. The researcher focused on three key areas she felt impacted resident QOL in LTC: (a) loneliness, (b) boredom, and (c) helplessness. There was a statistically significant decrease in the number of residents who felt boredom ($p = .01$) and helplessness ($p = .03$) one year after the implementation of the Eden Alternative.

While this secondary analysis and the Bergman-Evans (2014) study varied in methodology and intervention, they had similarities. First, the culture change approaches implemented were based on similar principles: (a) an aim to remove the institutional feel from LTC, (b) increase the focus on resident companionship, (c) address inflexible routines, and (d) place decision making at the level of the team member. Second, there is similarity in the assessment of QOL as the concepts of loneliness, boredom, and helplessness overlap with the interRAI QOL Survey Short Form domains. Last, both studies found an improvement in some areas of QOL in residents who lived in a home that supported and implemented culture change.

Kane et al. (2007) also assessed the impact of an organizational culture change on residents' QOL. The organizational culture change implemented in the Kane et al. study was the Green House program, focusing on a homelike environment, flexible routines, and accommodating residents' preferences. The evaluation of the Green House program found similar results to the secondary analysis of NTD in comparison to two LTC facilities with

traditional designs. In the Kane et al. study, residents living in a Green House LTC home had higher QOL scores in seven of the 11 domains compared to the first LTC comparison facility: (a) privacy, (b) dignity, (c) meaningful activity, (d) relationship, (e) autonomy, (f) food enjoyment, and (g) individuality. However, Green House residents only scored better on four of 11 domains as compared to the second comparison LTC facility: (a) privacy, (b) dignity, (c) autonomy, and (d) food enjoyment.

While this secondary analysis focusing on NTD and the Kane et al. (2007) Green House studies differ in the organizational culture change and methodology, some comparison can be made. First, both studies measured residents' QOL using self-report Likert-style scales. Second, staff in both culture change interventions were cross-trained to promote resident choice and provide flexible routines. Third, the environment in both programs was designed to be "homelike." Lastly, both studies found an improvement in residents' QOL when living in a home that supported culture change, versus a more traditional organization.

The findings from this secondary analysis confirm that residents' QOL is impacted by NTD, as there is a statistically significant difference in residents' QOL scores after implementation. However, from a clinical perspective, a statistically significant result does not always provide sufficient evidence to change clinical practice. To that extent, clinical or applied researchers explore clinical significance to determine if there is a large enough difference to change clinical practice. While a statistically significance difference is determined by a test, clinical significance requires a subjective judgment made by subject matter experts and clinical researchers to determine if the results are significant enough to be considered clinically relevant (Heavey, 2015). Further evaluation of NTD by clinical researchers, subject matter experts, team members, residents and families in regards to residents' QOL, including residents

with dementia and other focused resident outcomes from the larger NTD study is recommended to determine the clinical significance of this intervention.

While a small statistically significant difference was noted, NTD was not fully implemented for some participants at the time of the second data collection period. This is due to the nature of culture change, which is an ongoing process (Carson et al., 2015). In addition, the NTD implementation was scheduled over 30 months, starting in March 2013. Therefore it is expected that longer-term follow-up may result in an increased effect of NTD. This study is unique as it is the first to evaluate the effect of NTD on residents' QOL in LTC in Canada. Study results, suggesting a positive impact of NTD on the QOL of residents in LTC with a CPS score of 0-3, add to the literature examining the impact of culture change in LTC.

5.2 Measuring Quality-of-Life in Long-Term Care: The interRAI QOL Survey Short Form

The complexity of measuring residents' QOL in LTC is highlighted throughout this thesis. No published research is available using the interRAI QOL Survey Short Form version to measure QOL for residents in LTC. This is the first study to examine the impact of a culture change in LTC, specifically NTD, on QOL as measured by the interRAI QOL Survey Short Form. Study results suggest the tool is able to measure QOL in residents with a CPS score of 0-3, and is sensitive to change. Researchers do not agree on a gold standard approach to measuring QOL in LTC (Aspden et al., 2014; Degenholtz et al., 2006). Measuring QOL remains difficult, as it is subjective (Owen, 2006). This study adds further understanding to the measurement of QOL in LTC including: (a) literature on the use of the interRAI QOL Survey Short Form, (b) potential scoring opportunities for the tool, and (c) how to treat missing data.

In conducting this study, three approaches on how to report the interRAI QOL Survey scores were found in the literature: (a) overall QOL score (Kehyayan, 2011), (b) domain score

(Kehyayan, 2011; Kehyayan et al., 2015; Kehyayan et al., 2016), and (c) item scores (Kehyayan, 2011; Kehyayan et al., 2015). In this study, the overall QOL score was used to assess QOL changes in LTC residents following the implementation of NTD, thereby adding to the limited research available on different scoring options of the interRAI QOL Survey.

Missing data can be a challenge to address while conducting research. Previous studies report on a variety of approaches to treat missing data in the interRAI QOL survey. Two previous studies (Kehyayan et al., 2015; Kehyayan et al., 2016) used recoding to treat missing data. While recoding is a simple approach to employ, research demonstrates that recoding missing data may lead to an increased overall mean score, a decreased mean domain score, and a decreased variation in the standard deviation in the interRAI QOL Survey (Kehyayan, 2011).

Multiple imputation is increasing in popularity as an approach to treat missing data (Rezvan, Lee, & Simpson, 2013; Sterne et al., 2009). The study by Godin et al. (2015) is the only known study to use a multiple imputation approach to treat missing data with the interRAI QOL Survey. Therefore, this secondary analysis is only the second study to treat missing data in an interRAI QOL Survey using a rigorous multiple imputation approach.

The method of multiple imputation reduces the potential for underestimated standard deviations, confidence intervals, and correlations, all common disadvantages of using other missing data approaches (Fayers & Machin, 2016). By using multiple imputation, the validity of results are improved as variability is introduced into the datasets, and sample size is maintained (Sterne, 2009). In this secondary analysis, a sample size of 232 was maintained with the use of multiple imputation compared to a sample size of only 57 using complete case analysis on the same dataset.

This study adds to the literature related to the use of the interRAI QOL Survey Short Form in LTC, scoring options, and potential best practices in addressing missing data, including adding to the growing literature on the use of multiple imputation in research studies. Previous studies used the interRAI QOL Survey with 50 items versus the 31 items in the interRAI QOL Survey Short Form. As this was the first known study to use the interRAI QOL Survey Short Form in LTC, overall QOL score comparisons are unavailable. This secondary analysis establishes that the interRAI QOL Survey Short Form is a feasible option to measure QOL in LTC residents with a CPS of 0-3, and is less of a burden than the 50-item interRAI QOL Survey for respondents to complete. This secondary analysis, in addition to the study conducted by Kehyayan et al. (2015), demonstrates that QOL assessment through self-reporting tools in residents with mild to moderate cognitive impairment is possible, thus impacting gold standard evaluation measures of QOL in LTC. However, it should be noted that published literature on the reliability and validity of the interRAI QOL Survey Short Form is unavailable; therefore, further testing is recommended. By using the interRAI QOL Survey Short Form in LTC, there are opportunities for international benchmarking, and opportunities for facilities to identify key areas of QOL they are not meeting, thus allowing facilities to implement organizational changes to improve residents' QOL.

5.3 Correlates of Quality-of-Life in Long-Term Care Residents

This study confirms the results of previous studies on selected correlates of residents' QOL in LTC. This section describes resident demographic information from the NTD study and compares the findings and correlates to published literature.

5.3.1 Resident Demographics in Long-Term Care

Resident characteristics in this secondary analysis of 232 residents in six Ontario LTC facilities are very similar to the sample of residents in the Kehyayan et al. (2015) study using the interRAI QOL Survey in 48 LTC homes across Canada. Resident characteristics of this secondary analysis sample used in the primary research question presented as: (a) 75% of the residents were unmarried, (b) 67.7% of the sample was female, (c) 41.8% were aged 85-94 years, and (d) 56.5% had a mild (score of 2) to moderate (score of 3) cognitive impairment as measured by the CPS. These resident characteristics are very similar to those found by the Kehyayan et al. (2015) study: (a) 79% unmarried, (b) 65.5% female, (c) 43.3% over the age of 85 years, and (d) 46.3% had a score of 2-3 on the CPS. These similarities provide some support for considering the NTD sample as representative of a larger Canadian population of residents in LTC with a CPS score of 0-3.

5.3.2 Quality-of-Life Correlates in Long-Term Care

Earlier identification and intervention for groups of LTC residents at risk for poor QOL is possible with a better understanding of which factors impact QOL in LTC (Sullivan & Asselin, 2013). The results of this study indicate that age ($p = 0.2403$), gender ($p = 0.3750$) and marital status ($p = 0.2698$) did not predict QOL. Results were not statistically significant. These findings are consistent with previous research. Kehyayan et al. (2016) did not find a significant association between age, gender, or marital status and residents' QOL in LTC. Similarly, Tu et al. (2006) reported that gender was not associated with QOL for residents in LTC.

In contrast to this secondary analysis, Tu et al. (2006) determined that marital status (being married) was a significant predictor of QOL. However, notable differences should be considered in the Tu et al. sample versus this secondary analysis. First, the Tu et al. sample

consisted of 53.9% male participants, in comparison to the 32.3% of male participants as seen in this secondary analysis. Second, the Tu et al. sample was gathered solely from nursing homes in Taiwan. Third, 85.2% of the Tu et al. sample were considered married in the analysis of predictors; whereas, only 25% of this secondary analysis participants were married. To note, the Tu et al. study definition of married included married and widowed, differing from this secondary analysis, which excluded being widowed in the definition. If the Tu et al. study had used the same definition of married as this secondary analysis, 27.5% of participants would have been much more comparable to the 25% married participants as seen in this secondary analysis. The variance in the demographic sample, in addition to differences in the definition of “married” between the studies, may further explain why a difference in results was seen.

The variable of age was treated as continuous data in this secondary analysis. The results indicate that each year a resident ages, their corresponding QOL score decreases by 0.05; however, this study did not find this rate of change significant ($p = 0.2403$). While age itself may not predict QOL, it may be that factors associated with the aging process that predict QOL. For example, Kehyayan et al. (2016) found the following resident factors to be negatively associated with QOL: (a) mild cognitive impairment, (b) higher ADL score, (c) bowel and bladder incontinence, (d) depression, and (e) hearing impairment. The process of aging is a complex, unique, and a personal experience (Dionigi, 2015). While age alone does not predict QOL amongst residents living in LTC, factors that increase with aging such as morbidity and functional decline may predict QOL. As functional status declines with age, ADL scores may increase, leading to an association between age and ADL scores, and QOL. As cognitive impairment scores may increase with age, an association between cognitive impairment and age

may be seen. These confounding factors of aging may be better predictors of QOL, rather than age.

5.4 Secondary Analysis Strengths and Limitations

This secondary analysis had a number of strengths and limitations. Study strengths include the large sample size and data collection across six different LTC homes. The RAI-MDS 2.0 scale used is standardized, reliable, valid, and used internationally allowing for comparison amongst facilities. This study, as well as the previous literature on the interRAI QOL Survey (Kehyayan et al., 2015, Kehyayan et al., 2016), confirm that QOL can be assessed in residents with a mild to moderate cognitive impairment, and through a self-reporting survey. While missing data ranged from 1.5% to 17.7% per item, a rigorous approach of multiple imputation was implemented to address the missing data. Overall, these factors contribute to the strength of this study, add new knowledge and information to research on QOL measurement in LTC, including the interRAI QOL Survey Short Form, and approaches to treating missing data in self-reporting tools.

Study limitations include the use of only one type of LTC home, Schlegel Villages, and in only one geographical location, Ontario. This limits the generalizability of findings nationally, internationally, and with different types of facilities. As the intervention is ongoing, data collection at time point 2 was collected over 24 months, therefore residents had varying lengths of exposure to NTD, which may have affected the outcome. Furthermore, a large portion of residents did not meet the inclusion criteria to participate in the study, and a large loss of participants occurred in the sample due to death, discharge, and/or change in cognition or status over the study period. Lastly, a strict criterion for inclusion required a CPS score of three or less to ensure capacity to complete the survey. This inclusion item limited the ability to generalize the

results to all residents in LTC, as a significant proportion of LTC residents have some degree of cognitive impairment (Kehyayan et al., 2015).

While the implementation of NTD demonstrated a statistically significant improvement in residents' QOL, we cannot be certain that the change was due to NTD alone, as compounding factors may have influenced the QOL scores. The timeframe between interRAI QOL Surveys and RAI-MDS 2.0 assessments varied, which may lead to a change in the strength of association between resident characteristics and QOL scores, as resident characteristics may have varied between assessment times (Degenholtz et al., 2006; Kehyayan et., 2016).

No scholarly manuscripts are currently available to validate the psychometric properties of the interRAI QOL Survey Short Form. Subscale reliability and validity for the interRAI QOL Survey Short Form are unavailable, therefore making it challenging to demonstrate with certainty statistical change at the domain level. There is little research using the interRAI QOL Survey. This is the first known study using the interRAI QOL Survey Short Form in a research study; therefore, no comparison sample is available. Further research on the psychometric properties and use of the interRAI QOL Survey Short Form in LTC is needed.

5.5 Implications for Practice, Education, Policy, and Research

There are a number of implications arising from the study findings, including: (a) practice, (b) education, (c) policy, and (d) research. These implications are discussed in the context of the secondary analysis findings following the implementation of NTD in LTC.

5.5.1 Implications for Practice

NTD provides a model to support organizational culture change in LTC. The demand on health care workers to provide quality care in everyday practice is substantial. Kane (2003) describes the reasons why residents' QOL is poor in LTC: (a) a biomedical physical

environment, (b) lack of autonomy due to inflexible routines, (c) low staff levels, (d) ineffective models of care, (e) limited staff education, and (f) low standards for care. NTD was designed to increase residents' QOL through an organizational approach to culture change. In the following section, NTD is described in context of the six factors contributing to poor resident QOL in LTC as identified by Kane (2003).

First, NTD creates a physical environment that mimics a village. This changes the focus of LTC to a homelike environment, rather than the biomedical physical design. Second, NTD supports the autonomy of residents through flexible routines, prioritized by resident preference, which builds on the second issue in LTC affecting QOL as described by Kane (2003). Third, NTD promotes a team model with cross-functional teams, providing opportunities for cross-training. Utilization of cross-functional teams has the potential to support low staffing levels in LTC. Fourth, NTD introduces a new approach to organizational culture change, providing an approach that is effective in addressing residents' needs, and has potential to increase resident, family, and staff satisfaction. Fifth, NTD provides frequent opportunities for team development through regularly scheduled educational and team building opportunities. Finally, resident-centred care is the focus of everyday practice in NTD, resulting in high standards of care as a priority for all team members. NTD as described above addresses the Kane (2003) factors contributing to poor QOL in LTC. By supporting an NTD approach within LTC, opportunities to increase QOL in LTC as identified in previous literature can be addressed, and an impact on residents' QOL in LTC can occur.

As discussed above, one of the core components of NTD is resident-centredness. Similarly, culture change focuses on consumer-driven, resident-centred care (White-Chu et al., 2009). However, implementing resident-centred care and culture change into practice can be

difficult. In order to ensure true person-centred care is put into practice, the Person-Centred Nursing (PCN) Framework can help integrate theory-to-practice (McCormack & McCance, 2006).

The PCN Framework focuses on four constructs: (a) prerequisites, (b) the care environment, (c) person-centred processes, and (d) outcomes. Nursing characteristics are the focus of the *prerequisites* construct. The characteristics of nurses in the PCN Framework include: (a) being professionally competent, (b) interpersonal skills, (c) commitment to the job, (d) clarity of beliefs and values, and (e) knowing ‘self’ (McCormack & McCance, 2006).

The delivery of care is the focal point of the *care environment* in the PCN framework (McCormack & McCance, 2006). Within this construct, special attention is paid to ensure the team has the appropriate skill mix, effective staff relationships, shared power and decision making, innovation and risk taking, a supportive organization structure, and the physical environment. In the NTD intervention, team members are cross-trained and require an appropriate skill mix to succeed, including interpersonal communication and skills to maintain effective relationships with their team members. Power and decision making is placed at the team level, which requires a supportive organization, with a risk-taking and innovative culture. The physical environment of NTD supports person-centred care through a design that supports neighbourhoods centred around Main Street. As seen through these examples, NTD delivers the principles of the *care environment* construct, thus supporting person-centred nursing in LTC.

Person-centred processes are achieved through the delivery of holistic care, shared decision making, sympathetic presence, engagement, all while ensuring the beliefs and values of the resident are at the centre of care (McCormack & McCance, 2006). In the NTD intervention, a focus is placed on resident-centred care, directed by the preferences and needs of the consumer

through shared decision making and engagement of residents, thus supporting the person-centred processes of the PCN framework.

When successful person-centred nursing is implemented, *outcomes*, the centre of the PCN framework are achieved including: (a) satisfaction with care, (b) involvement in care, (c) feeling of well-being, and (d) creating a therapeutic environment (McCormack & McCance, 2006). The PCN framework can help facilitate the implementation of NTD, and put the person-centred care theory into practice, while also offering up a framework to help evaluate NTD effectiveness, specific to concepts of person-centred care. To initiate effective culture change in practice, members of the health care team require additional education to support culture change, policy is required to advocate for residents' rights in LTC, and evidence-based research is needed to provide direction on how to sustain and evaluate culture change in LTC. These key areas will be described in the context of culture change and NTD below.

5.5.2 Implications for Education

This secondary analysis establishes that culture change initiatives such as NTD have an impact on residents' QOL in LTC. Increasing residents' QOL in LTC occurs through caring practices by team members (Bradshaw et al., 2012). By providing education related to caring for seniors we will increase the knowledge, confidence, and proficiency of health care workers to provide care to older adults (Sinha, 2012). First, increased education on geriatrics is imperative to developing the attitudes and values in health care providers to implement and sustain culture change. Second, education should be focused on key attributes of health care providers to help deliver person-centred care. Third, a focus should be on developing leadership skills not only at the management level, but within all LTC staff. These focused areas of education are discussed in the section below, in the context of resident QOL, NTD, and culture change in LTC.

Kaasalainen et al. (2006) conducted a cross-sectional survey to understand if new graduate RNs in Canada were prepared to care for geriatric patients. The results of this study concluded that an overwhelming 77% of participants felt that RN new graduates were unprepared to care for the geriatric patient. The *Living Longer, Living Well* report released by the Ontario Ministry of Health and Long-Term Care also notes key recommendations including a requirement for all interprofessional team members to receive training in geriatrics (Sinha, 2012):

“A strategy that provides the right education and training opportunities will ensure that Ontario gains an informed workforce that will have the necessary knowledge, skills, and confidence to identify issues of need amongst older adults while delivering them the right care, in the right place, at the right time” (p. 23).

The literature demonstrates a need for additional geriatric training for staff in LTC to deliver better care for Canadian seniors. Training should not only be implemented at the undergraduate nursing level, but in all training programs for LTC employees, including personal support worker curriculum. By increasing geriatric knowledge among health care providers, we influence the care quality provided to seniors and may increase residents' QOL in LTC.

This current study confirms that age, gender, and marital status do not predict residents' QOL. However, an emphasis should be placed on domains and factors associated with QOL in LTC to prepare future health care providers to recognize at-risk groups for poor QOL. This knowledge also helps health care providers identify interventions that may improve residents' QOL in LTC. For example, Degenholtz et al. (2006) identified that social engagement was associated with higher QOL. By introducing this knowledge in educational programs, health care providers may identify opportunities for increased social engagement in LTC, thus impacting residents' QOL. By educating the future workforce to acknowledge that resident QOL

experiences should be balanced with the priority to deliver good QOC in LTC, we move in a positive direction towards advancing residents' QOL in LTC.

Beyond training in geriatrics, health care providers require education and training in fundamental areas that support and sustain culture change initiatives. One key component of NTD, resident-centred care, impacts residents' QOL in LTC. The McCormack and McCance (2006) PCN framework can be utilized as a guide for implementing person-centred care into the curriculum for all health care providers. While the PCN framework is focused on nursing, in order to promote true culture change and impact residents' QOL in LTC, education should be focused on all members of the health care team. The PCN framework as a guide could serve as a framework for education in other training programs for health care providers who work in LTC, including those for personal support workers.

In the PCN framework, *prerequisites*, the qualities and characteristics required of a nurse to deliver effective person-centred care, should be the foundation of education for health care providers. Effective culture change is achieved through empowerment of all members of the care team, and an understanding of values and beliefs of persons within that team (Rahman & Schnell, 2008). By using the PCN framework as a guide, education should focus on teaching interpersonal skills, holistic care, and how to build effective relationships. Through NTD, team members work together in cross-functional teams. Decision-making is placed at the level of the neighborhood team in collaboration with the resident, rather than management, thus removing the hierarchy in LTC. Critical thinking should be reinforced with a focus on shared decision-making. McCance and McCormack (2006) identify the need to provide training to develop professional competency through decision-making and prioritization skills in addition to the practical skills required for the role, supporting the knowledge required for a team member to

succeed in a cross-functional NTD team. The appropriate skills mix can be reinforced through education, thus continuing to build effective cross-functional teams. Through the development of the qualities and characteristics of health care providers to provide person-centred care, we can ultimately impact the QOL of residents in LTC.

NTD requires strong communication skills for effective culture change with all members of the care team including patients, family members, team members, and management. This requirement for NTD supports McCormack and McCance's (2006) statement on "...developed interpersonal skills reflects the ability to communicate at a variety of levels" (p. 475). In NTD, the resident is the focus of care, including maintaining independence, promoting dignity, and providing resident choice. By focusing education on developing a sense of identity in the profession, a commitment to nursing as a career is developed, centering care around the patient (McCormack & McCance, 2006). In order to implement and sustain effective culture change, staff must reflect on their own ideals, values, and beliefs. All education should be centred on the person-centred context, with the nurse's beliefs and values driving all care practices (McCance, McCormack & Dewing, 2011). Intentionally placed opportunities for reflection in education will help develop an understanding of personal beliefs and values, helping students to "know self," thus helping them to best deliver care (McCormack & McCance, 2006).

Last, a focus should be placed on advancing leadership skills in LTC. Grabowski et al. (2013) noted that competent leadership, including leadership stability, is essential to implement successful culture change. Workplace culture and leadership are key organizational components to delivering effective person-centred nursing care (McCormack & McCance, 2006). Therefore, a strong emphasis in education should also be placed on developing attributes of strong leaders, and healthy workplace culture. Leadership skills not only need to be developed at the manager

level, but also within the front-line staff to facilitate collaborative decision making (Koren, 2010). In NTD, developing leadership abilities in all LTC staff helps place decision-making at the level of the neighbourhood team, thus removing the hierarchy in LTC.

Education empowers health care workers to provide quality care, and staff empowerment is key to advancing the agenda of culture change in LTC. This secondary analysis establishes that culture change initiatives in LTC, such as NTD, impact residents' QOL. By focusing education for health care providers on geriatric care, understanding residents' QOL in LTC, and key components of culture change, we develop the knowledge, skills, and inherent abilities in the workforce of tomorrow to implement and sustain culture change in LTC, thus impacting residents' QOL.

5.5.3 Implications for Policy

The OLTC (2017) advocated for the care of seniors to be prioritized by the Federal Government, to ensure a sustainable system to care for the growing complex needs of seniors in LTC. In addition, the OLTC (2017) identified that 30 000 LTC beds require transformation prior to their 2025 license expiring. Furthermore, as LTC is considered an "extended" service, there is inequity in LTC services both across Canada and within provinces (Canadian Healthcare Association, 2009). Every resident deserves the right to experience the highest QOL in LTC. Organizational culture change approaches such as NTD need to be a public priority to: (a) address the complex needs of seniors, (b) increase residents' QOL, and (c) bring equality to LTC homes across Canada.

NTD and culture change address the satisfaction and QOL of residents in LTC. However, LTC homes in Ontario do not make resident satisfaction a priority. LTC homes commenced annual submissions of Quality Improvement Plans (QIP) in 2015 to Health Quality Ontario.

Priority indicators were selected to help facilitate change and improvement in LTC homes. Seven priority quality indicators were selected in 2015 including: (a) falls, (b) antipsychotic prescribing, (c) pressure ulcers, (d) incontinence, (e) restraints, (f) emergency department visits, and (g) resident experiences. LTC homes were asked to identify one or more of the indicators as a focus for their annual QIP plan. However, only 60% of LTC homes chose to focus on resident experiences as a priority quality indicator for the 2015/2016 year. The results of the QIP annual submissions and the NTD study highlights the need for a strategy to address the issue of poor QOL in residents of LTC, and policy needs to make residents' QOL and satisfaction a priority in LTC.

The Canadian Healthcare Association (2009) released the policy brief, *New Directions for Facility-Based Long Term Care*. The recommendations of this policy are still relevant and of concern today in LTC, and directly reflect the pillars of NTD. The Canadian Healthcare Association (2009) presented seven key recommendations for LTC: (a) ensure adequate and sustainable funding for facility-based long term care tied to pan-Canadian principles, (b) focus on quality and accountability to Canadians, (c) invest in health human resources, (d) reflect a shared approach to risk, (e) guarantee reciprocity between the provinces and territories, (f) develop cultures of caring, and (g) respect volunteers and families. Many of these recommendations are addressed within NTD to improve QOL in LTC. Four of these key areas will be addressed in the following section in the context of NTD: (a) focus on quality and accountability to Canadians, (b) invest in health human resources, (c) develop cultures of caring, and (d) respect volunteers and families.

The call to focus on quality and accountability to Canadians recommends looking at outcomes of QOL as just as important as quality-of-care (QOC) (Canadian Healthcare

Association, 2009). The 2008 recommendations concluded that resident, family, staff satisfaction and QOL data should be collected yearly as a requirement, and a focus should be on investing in leadership and staff training, all while supporting more research in LTC. A key pillar of NTD is empowering team members to become leaders, and investing in staff training to promote cross-functional teams. NTD meets this recommendation as it focuses on QOL as a LTC outcome, and focuses not only on the resident, but staff and family satisfaction with yearly QOL surveys. NTD promotes research in LTC with several stakeholders including: (a) residents, (b) family members, and (c) staff.

QOL and QOC are maintained in LTC through an investment in health human resources, and educated health care workers (Canadian Healthcare Association, 2009). The policy brief recommends optimizing full scope of practice in staff, implementing minimum staffing level standards across Canada, and a recruitment strategy to obtain committed staff. NTD introduces cross-functional teams, and decision making is removed from management and placed at the team level, optimizing the role of team members. Cross-functional teams help manage staffing levels, as team members are cross-trained.

A third recommendation from the Canadian Healthcare Association (2009) that supports QOL is “develop cultures of aging.” The Canadian Healthcare Association states, “bureaucratic traditions must give way to cultural transformation” (p.11). This requires a focus on making facilities an attractive location to work and live, focusing less on the tasks and regulations of LTC. NTD focuses on a philosophy of a “life worth living” through elder and person-centred communities (Eden Alternative, 2014). The NTD pillars directly mimic the recommendations of the policy brief through a continuous approach, implemented over 30 months, and ongoing

organizational changes. After all, “Creating a ‘home’ is a journey, not a destination” (Canadian Healthcare Association, 2009, p.25).

The final recommendation from the Canadian Healthcare Association (2009) is to “respect volunteers and families.” This can be done through welcoming family members to involve themselves in residents’ day-to-day lives as part of the multidisciplinary team. NTD invites family members to be part of the neighborhood team, and encourages all members of the team to participate in research to better understand the impact of NTD .

The Canadian Healthcare Association (2009) also called for standardized assessment tools across sectors for decision making, service requirements, funding, and measuring resident outcomes. Improved continuity is possible when a standardized language is implemented across the continuum of care. The interRAI QOL Survey Short Form and RAI-MDS 2.0 have the opportunity to provide this continuity (Hirdes et al., 1999). The Health Quality Ontario (2016) online QIP interface provides two standardized tools to measure consumer satisfaction:

(a) Nursing-Home Consumer Assessment of Healthcare Providers and Systems, and (b) interRAI QOL Survey. However, the Health Quality Ontario report identifies that a significant proportion of LTC homes chose to use their own facility built tools, rather than use the standardized tools provided. In fact, of the LTC facilities that chose to focus on the quality indicator of *resident experiences*, between 16.5%- 23% of the homes chose one of the standardized tools for measurement. This further supports the notion that a strategy for use of standardized tools for both QOL assessment and quality indicators is needed in LTC. This secondary analysis provides further evidence and support that the standardized interRAI QOL Survey Short Form is an efficient method to gather data and assess resident QOL

NTD and the movement towards culture change in LTC support the 2015 Patients First: Action Plan for Health Care (Ministry of Health and Long-Term Care, 2015). The plan to “put patients first” focuses on a four pillar plan: (a) improving *access* to care, (b) *connect* services closer to home, (c) *inform* patients and public in health decision making, and (d) *protect* and sustain our universal health care system. As a result, patients’ health care experiences are the focus of improvement. The resident-centred focus of NTD contributes to a patient-centred health care system that the Patients First: Action Plan for Health Care is centred on.

Study results from this secondary analysis add to the call for patient-centered health care in Ontario, support the need for a focus on resident satisfaction in LTC, and are consistent with the recommendations of the Canadian Healthcare Association’s (2009) *New Directions for Facility-Based Long Term Care*. Furthermore, NTD prioritizes seniors care, provides a culture change approach to bring more equality amongst LTC services, meets the complex needs of older adults in LTC, and could serve as a model for the identified need for transformation of 30 000 LTC beds by 2025 (OLTCA, 2017). In conclusion, NTD as an organizational culture change provides the opportunity for all residents in LTC to experience high QOL.

5.5.4 Implications for Research

Study findings point to the need for further research in three key areas: (a) further data on using the interRAI QOL Survey in LTC, (b) new understanding of the impact of NTD, and (c) correlates of QOL in LTC residents. Future research using the interRAI QOL Survey Short Form is recommended, including additional samples for comparison. Testing the psychometric properties of the interRAI QOL Survey Short Form is suggested to add to the knowledge on the reliability and validity of this tool. Clear guidelines on potential scoring options and best practices of using this tool, including how to address missing data, will help inform future

research. Further research is also needed on national and international comparisons of QOL in LTC.

Additional research is needed to explore the impact of NTD in LTC. Longer term follow-up is recommended once data is collected after the full implementation of NTD. More rigorous research approaches such as RCTs may help determine the impact of NTD on residents' QOL in LTC. Qualitative research may add to an understanding of implementation facilitators and barriers of NTD, and also perceptions of the benefits of the NTD in LTC. Currently, qualitative research on the outcomes of NTD is in process in the larger NTD study (Boscart et al., 2012).

Population aging is leading to a rapid increase of older adults with dementia (Smale & Dupuis, 2004; WHO, 2012). With over 60% residents in LTC estimated as having some form of dementia (OLTCA, 2015), further research is required to measure QOL in residents with dementia in relation to the impact of NTD.

Lastly, supplementary research is needed to understand what QOL correlates are impacted by culture change in LTC. Research demonstrates that spirituality is a significant predictor of resident QOL (Kehyayan et al., 2016; Tu et al., 2006). Additional research to explore how and why spirituality can impact residents' QOL may contribute to new spirituality focused interventions in LTC, thus potentially increasing residents' QOL. Additional opportunities for research may also include looking at the impact of NTD on RAI-MDS scale scores. Potential RAI-MDS scales that could be reviewed include: (a) Activities of Daily Living (ADL) Hierarchy, (b) Pain Scale, (c) Depression Rating Scale (DRS), (d) the Index of Social Engagement (ISE), and (e) CPS. The CPS score should be examined further in relation to QOL to determine if cognitive impairment impacts residents' QOL. These correlates may be more amenable to change than the demographic variables assessed in the current study.

NTD supports the Canadian Institutes of Health Research [CIHR] (2016) strategy for Patient-Oriented Research (SPOR). As cited by CIHR (2016), this type of research “...is about ensuring that the right patient receives the right intervention at the right time” (para 1). SPOR involves research that is multidisciplinary and outcome driven, as seen in NTD. SPOR includes partners in federal, provincial, and territorial sections including: (a) patients and caregivers, (b) researchers, (c) health practitioners, (d) policy makers, (e) provincial/territorial health authorities, (f) academic institutions, (g) charities, and (h) the private sector. Through including patients as partners in research, outcomes, systems and practices are improved, as priorities are identified by patients themselves. Increased quality is achieved through evidence-informed health care (CIHR, 2016). The SPOR initiative helps advance the agenda for further research to determine strategies to increase residents’ QOL in LTC, as can be seen in the organizational culture change NTD.

Advances in research define new areas of development required in practice, education, policy, and research. The agenda to increase residents’ QOL in LTC is on the rise due to the increased life expectancies of seniors living in Canada (Sullivan & Asselin, 2013). This study further acknowledges implications for practice, education, policy, and research to advance residents’ QOL in LTC, and ensure all residents of LTC are entitled to the highest possible QOL.

CHAPTER 6: CONCLUSION

Poor QOL is a widely reported outcome among LTC residents. With population aging, the number of adults over the age of 65 is expected to increase rapidly. Among these older adults, many will require LTC due to complex care needs. QOL is a multidimensional concern cited by residents in LTC. QOL is individualized; therefore it is difficult to identify which factors impact residents’ QOL in LTC.

LTC facilities should be encouraged to look at QOL as a key outcome measure for LTC. Culture change in LTC has the potential to increase the QOL of residents in LTC through encouraging resident-centred care that focus on homelike environments. By increasing residents' QOL in LTC, we put forward a culture of “living first” for the residents of LTC (Carson et al., 2015).

The results of this secondary analysis inform future culture change strategies in LTC including implementation practices and organizational changes, environment, and staffing models. This study adds to knowledge on the use of the interRAI QOL Survey Short Form as a tool to measure QOL in LTC, and helps provide culture change findings that are applicable to cognitively intact to moderately cognitively impaired residents in LTC homes across Canada.

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Appendix A

Table 5 Measurement Property Criteria

Property Reliability	Rating Criteria
Internal consistency	<ul style="list-style-type: none"> + Cronbach's α of scale between 0.70 and 0.95 ? Cronbach's α not determined - Cronbach's $\alpha(s) < 0.70$ or > 0.95
Reliability	<ul style="list-style-type: none"> + ICC or weighted Kappa ≥ 0.70 ? ICC or weighted Kappa not determined - ICC or weighted Kappa < 0.70
Validity	
Content validity	<ul style="list-style-type: none"> + Clear description of measurement aim, target population, concepts being measured and item selection AND target population and investigators OR experts involved in item selection process ? A clear description of above aspects lacking OR only target population involved in item selection - No involvement of target population in item selection
Hypothesis testing	<ul style="list-style-type: none"> + At least 75% of results in accordance with hypotheses ? No hypotheses formulated in advance - Less than 75% of results in accordance with hypotheses
Responsiveness	<ul style="list-style-type: none"> + Smallest detectable change $<$ minimal important change OR Minimal important change outside the limits of agreement OR responsiveness ratio > 1.96 OR area under curve ≥ 0.70 ? Doubtful design or method - Smallest detectable change \geq minimal important change OR minimal important change equal or inside limits of agreement OR responsiveness ratio ≤ 1.96 OR area under curve < 0.70

Note: Adapted from Aspden, T., Bradshaw, S., Playford, E. D., & Riazi, A. (2014). Quality-of-life measures for use within care homes: a systematic review of their measurement properties. *Age and Ageing*, 43(5), 596-603. doi: 10.1093/ageing/afu089.

Appendix B

Table 6 interRAI Self-Report Nursing Home Quality-of-Life Survey Domain Scores

Domain	Number of Items	Possible domain score
Privacy	4	0-16
Food/Meal	5	0-20
Safety/Security	5	0-20
Comfort	5	0-20
Autonomy	6	0-24
Respect	5	0-20
Responsive Staff	4	0-16
Staff-resident bonding	5	0-20
Activity Option	5	0-20
Personal Relationships	5	0-20

Note: adapted from Kehyayan et al. (2015). Residents' Self-Reported Quality of Life in Long-Term Care Facilities in Canada. *Canadian Journal on Aging* (34)2, 149-164.

Appendix C

Table 7 interRAI Quality-of-Life Survey Short Form Domain Scores

Domain	Number of Items	Possible domain score
Privacy	1	0-4
Food/Meal	3	0-12
Safety/Security	3	0-12
Comfort	5	0-20
Autonomy	4	0-16
Respect	4	0-16
Responsive Staff	3	0-12
Staff-resident bonding	3	0-12
Activity Option	3	0-12
Personal Relationships	2	0-8

Note: adapted from interRAI (2011). *interRAI self-report nursing home quality of life survey short form v.1.*

Appendix D

Table 8 Distribution of Missing Data at Time Point 1 and Time Point 2 (n=232)

Domain	# valid responses	# missing responses	% Missing
<u>Privacy</u>			
1a. My privacy is respected when people care for me	450	14	3.0%
<u>Food/Meal</u>			
2a. I have enough variety in my meals	451	13	2.8%
2b. I get my favorite foods here	451	13	2.8%
2c. I can eat when I want	428	36	7.8%
<u>Safety/security</u>			
3a. I feel my possessions are safe	455	9	1.9%
3b. I feel safe when I am alone	454	10	2.2%
3c. If I need help right away, I can get it	451	13	2.8%
<u>Comfort</u>			
4a. I get the services I need	455	9	1.9%
4b. I would recommend this site or organization to others.	444	20	4.3%
4c. This place feels like home to me	453	11	2.4%
4d. I can easily go outdoors if I want	438	26	5.6%
4e. I tend to be happier than most other people	400	64	13.8%
<u>Autonomy</u>			
5a. I decide when to go to bed and get up	454	10	2.2%
5b. I can go where I want on the “spur of the moment”	450	14	3.0%
5c. I can control who comes into my room	441	23	5.0%
5d. I can have a bath or shower as often as I want	430	34	7.3%
<u>Respect</u>			
6a. Staff pay attention to me	450	14	3.0%
6b. I can express my opinion without fear of consequences	434	30	6.5%
6c. I am treated with dignity by the people involved in my support and care	449	15	3.2%
6d. Staff respect what I like and dislike	434	30	6.5%
<u>Responsive Staff</u>			
7a. The care and support I get help me live my life the way I want	437	27	5.8%
7b. Staff act on my suggestions	382	82	17.7%
7c. Staff respond quickly when I ask for assistance	439	25	5.4%

Domain	# Valid Responses	# Missing Responses	% Missing
<u>Staff-Resident Bonding</u>			
8a. Some of the staff know the story of my life	409	55	11.9%
8b. Staff take the time to have a friendly conversation with me	457	7	1.5%
8c. I consider a staff member my friend	446	18	3.9%
<u>Activity</u>			
9a. I have enjoyable things to do here on weekends	443	21	4.5%
9b. I participated in meaningful activities in the past	449	15	3.2%
9c. If I want, I can participate in religious activities that	430	34	7.3%
<u>Personal Relationships</u>			
10a. Another resident here is my close friend	444	20	4.3%
10b. People ask for my help or advice	445	19	4.1%

Note. This missing data does not represent statistics from full QOL assessments missing at either point in time, as these participants did not meet inclusion criteria.

Appendix E

Table 9 Descriptive Overall Mean Quality-of-Life Scores by Domain (n=232)

<u>Domain</u>	<u>Time Point 1</u>			<u>Time Point 2</u>	
	<u>Possible Range</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>Mean</u>	<u>Standard Deviation</u>
Privacy	0-4	3.27	0.87	3.44	0.83
Food/Meal	0-12	7.42	2.78	8.15	2.80
Safety/Security	0-12	9.68	2.20	9.48	2.32
Comfort	0-20	15.25	3.41	15.05	3.85
Autonomy	0-16	10.32	3.77	11.08	3.52
Respect	0-16	12.75	2.77	13.20	2.75
Responsive Staff	0-12	8.57	2.41	8.98	2.40
Staff-resident	0-12	7.04	2.87	7.66	2.81
Activity Option	0-12	7.23	2.89	7.51	2.77
Personal Relationships	0-8	3.63	2.22	4.14	2.40

Note. Time Point 1 data were collected from August 2011-December 2012. Time point 2 data were collected from January 2014-November 2015.