Widening the View: A Standardized Approach to Capturing Family Members' Perspectives on Quality of Life in Long-term Care

by

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A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Public Health Sciences

Waterloo, Ontario, Canada, 2023

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The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

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Author's Declaration

This thesis consists of material all of which I authored or co-authored: see Statement of Contributions included in the thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

This thesis consists in part of four manuscripts written for publication. All manuscripts were written by the doctoral candidate and supervised by Dr. John Hirdes. Under his supervision, the doctoral candidate obtained ethics approval, study design, recruitment, data collection, statistical analysis, and manuscript writing. Dr. John Hirdes supervised the manuscript's writing, editing and revisions. The following manuscripts will be submitted for publication:

Chapter 3: Manuscript #1- Complementing Perspectives on Quality of Life" How Family Perspectives on Quality of Life in Long-Term Care are Measured: A Scoping Review

Chapter 4: Manuscript #2- Different Perspectives on Quality of Life in Canadian Long-Term Care Facilities- A Multi-Study Analysis of Resident and Family Member Ratings

Chapter 5: Manuscript #3- Capturing the Unique Voice of Families- Developing a Quality of Life Survey for Families of Nursing Home Residents

Chapter 6: Manuscript #4- Assessing the Psychometric Properties of a New Instrument to Hear Family Perspectives on Quality of Life in Long-Term Care

Chapters 1, 2 and 7 were written by the doctoral candidate and supervised by Dr. John Hirdes and were not written for publication.

Abstract

Background and Rationale: Family members provide important functional and socio-emotional support to residents living in Long-Term Care (LTC). With high rates of cognitive impairment among residents, family member input is increasingly valued in new LTC standards provided by Health Standards Organization (HSO), given their unique perspectives, knowledge, and role in the resident's circle of care. A standardized instrument to collect this input is lacking in the current literature.

Methods: A scoping review was conducted to gather and evaluate the existing literature studying the instruments used to evaluate family perspectives on Quality of Life (QoL) in LTC. This and retrospective analyses of secondary data collected from 3 previous studies using the interRAI Family QoL LTCF instrument (FamQoL V1), informed the development of a new instrument, the interRAI Family QoL LTCF Version 2 (FamQoL V2). An expert panel participated in the Delphi method to gather expert input into the development of a Version 2 interRAI Family QoL-LTCF (FamQoL V2) Instrument, through the Seniors Quality Leap Initiative (SQLI). Primary data were then collected from 38 LTC homes in Canada and the US with a total of 716 unique family members responding. These data were used to examine the psychometric properties of the instrument, develop summary scales, and examine distributions of Family QoL perspectives in North American LTC homes.

Results: The previously published instruments varied considerably with item counts ranging from 21 to 104 and 4 to 15 summary domains. While several common item themes were identified (e.g., living environment, resident care, autonomy, security, global recommendations), others were less consistent among the instruments (e.g., administration, admission process, therapies). Family members had lower positive response rates on the items with higher missing or non-response rates (e.g., bath/shower when wish, affection and romance, social activities). They scored higher than residents on items related to staff responsiveness and trust and lower than residents on items related to social life and personal control. Several Delphi rounds were conducted to build consensus, resulting in a 25-item FamQoL V2 instrument with 12 shared QoL-LTCF and 13 unique FamQoL V2 items. The instrument had strong performance. Five summary scales were developed through factor analysis, with Cronbach's alpha ranging from 0.88 to 0.92.

Conclusion: This dissertation provides actionable evidence that supports the Quadruple Aim of Healthcare Improvement, meeting new national LTC standards, and assisting LTC homes in their quality improvement efforts. Through an extensive scoping review, analysis of a large and multi-study secondary dataset, expert Delphi input, multi-country primary data collection and psychometric testing, and family member feedback, a FamQoL V2 instrument was developed and accepted by a large consortium of LTC providers and researchers (SQLI). The instrument is operationally feasible, with a shorter number of items compared to other surveys and interoperability with other interRAI instruments. The scientific work underlying this instrument's development has been reviewed and approved by interRAI's Instrument and Systems Development (ISD) Committee and the FamQoL V2 is now included in interRAI's published manual for QoL measures. An evidence-informed, reliable instrument is now available for jurisdictions to standardize how this important perspective is collected and measured in LTC.

Acknowledgements

An excited teleconference call with Dr. John Hirdes in 2015 was the launching point in what would become a seven-year commitment in service of advancing quality of life in nursing homes. John, your patient mentorship, guidance, and instruction have been the opportunity of a lifetime and I feel so very grateful to have had it. Your appreciation of the demands in LTC, particularly during the COVID-phase of this program, made all the difference and helped me keep moving forward- if slowly.

A special thank you to John's team including Julie Koreck, who worked wonders managing John's schedule, and dealing with last minute changes with kind swiftness and Micaela Jantzi, thank you for providing such excellent support and making data management look easy! To the rest of the 'Hirdes Group'- past and present- I wasn't on campus often, but you always welcomed me nto the team and were so encouraging. Thank you for inspiring me with your achievements, laughs, and learning in Belgium and Brisbane, along with other adventures!

I offer sincere thanks to the esteemed members of my thesis proposal and defense committees; Dr. George Heckman; Dr. Carrie McAiney, Dr. Paul Katz, Dr. Troy Glover, and Dr. Mirou Jaana. I feel so lucky to have benefited from your sure and trusted guidance and shared passion for improving the lives of seniors. To the broader Seniors Quality Leap Initiative (SQLI), who supported and contributed to this body of work in substantial ways, thank you. You are the very best examples of the SQLI mission at work. You continued through some of the most challenging times LTC has experienced and are incredible role models.

Thank you to all those in nursing homes, whether you participated in this study or not, live there, work there or visit there, you are a vital part of this research being dreamed up and delivered. To our healthcare workers, support services, administration staff and all members of the LTC team, you inspire me each day with your commitment to quality. You do God's work, and we are all so lucky to be associated with you. In particular, a hearty thank you to those LTC team members, residents and family members who participated in this study.

To the Great People at Shannex who do incredible work every day, thank you. Elizabeth McNamara, who inspired with her own example and was a constant source of encouragement- thank you for your patience and compassion as I bit off a bit more than I chew sometimes. That extends to my entire team, past and present. Keith, Heidi, Anjana, Bhushan, Vicki, and Christy- you were either steady sources of encouraging words and support or were highly tolerant during my periods of overextension! Or both! Either way, thank you. Kim, Marian, Mary Frances, Kathy, Lisa, Nicole, and so many others helped me through this program, in so many ways. To Jason Shannon and the rest of the executive leadership team- thank you for believing in me, this research and providing such incredible support, mentorship, and opportunity. I will never forget it.

To my friends and family, a huge thank you for the support, patience, and more over the last seven years and beyond. My daughter Sidney and grandson Jude; I love you so much, am so very grateful for your support and proud of who you are. To my partner Derek, you always believe in me and have supported this in every way- I am so grateful. My mother, Betty Gillis, provided the best examples early on and to this day, inspiring me to keep learning and growing. Michael, Debra and my nieces and nephews, the Fosters- you helped keep me sane with family game nights, campfires, and clay nights. All- simply put, I feel your love stream flow.

Dedication

This dissertation is dedicated to my father, Gordie Norman, who passed during this research. To Nanny and Grandad Gillis, who lived at home until the end, basking in the glow that family provides. To our great-aunt, Dr. Jane Norman, there are no words to describe the impact you had on so many of us during your time here- your examples of service, compassion and learning are in my heart, always. To Naomi Black, who continues to advocate for seniors from her nursing home room, and the 'Flamingos' among her.

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List of Abbreviations

LTC - Long-Term Care

QOL - Quality of Life

QOC - Quality of Care

SQLI - Seniors Quality Leap Initiative

CPS - Cognitive Performance Scale

ISD - Instrument Standards Development

Chapter One

Value Beyond a Proxy: Considering the Family Member's Perspective in Describing Quality of Life in Long-Term Care

Introduction and research problem

There is a growing movement among North American Long-Term Care (LTC) policy and standards makers toward recognizing consumer perspectives and experiences in the healthcare system and long-term care specifically. Higher consumer expectations of transparency and inclusion regarding the delivery and quality of care in LTC have resulted in efforts to measure these experiences (Frentzel, et al., 2012; Williams, Straker, & Applebaum, 2016). Value-Based Purchasing initiatives in the US and the far-reaching, substantial impacts of the global COVID-19 pandemic in LTC, have led providers, policymakers, and researchers to ask new questions about how value is determined and who should be tasked with the responsibility of making these determinations.

With population aging globally, there is an on-going demand for LC services. As a result, many countries are searching for appropriate instruments they can use to gather feedback, make improvements, and continue to strive for a high-quality service and experience for LTC residents and their families. Measures of resident "satisfaction" or ratings on quality of care and more recently, quality of life, are increasingly relied upon as an information source to shape policies, quality improvement initiatives, and placement decisions (Ejaz, Straker, Fox, & Shobhana, 2003; Kane, et al., 2005; Porter, 2010; Frentzel, et al., 2012; Williams, Straker, & Applebaum, 2016; Morris, et al., 2018).

Most approaches to measuring the quality of care or quality of life in LTC are directed at the residents themselves, using self-reported surveys (Frentzel, et al., 2012; Kehyayan V, 2015) or clinically based outcome measures (Zimmerman, 2003; Frijters DH., 2013). Family members are often asked to act as a "proxy" for the resident's experiences, in cases where there is substantial cognitive impairment. It is estimated that at least 40% of LTC residents in Canada have severe cognitive impairment and approximately 89% have some form of cognitive impairment either from stages of dementia or other conditions such as stroke or trauma (CIHI, 2023). Therefore, family members can play a critical role in improving our understanding of the value being delivered in these homes. While family members are not reasonable *proxy* sources for a resident's subjective quality of life, they have perspectives and perceptions on quality of life in the LTC home that may be useful to administrators, policy makers and researchers (Kane, et al., 2005; Godin, Keefe, Kelloway, & Hirdes, 2015).

Beyond their value in providing a separate perspective of the resident experience, family members can provide useful input based on their unique role in the delivery of care, decision-making, and support to residents in LTC. Family member involvement generally falls into categories that include direct care, overseeing care/advocacy, socio-emotional support, and visiting (Gaulgler, 2005; Ryan & McKenna, 2014; Puurveen, Baumbusch, & Gandhi, 2018). More recent studies have added learning and contributing to the community, as family members have taken on leadership positions within the LTC facility through family and resident councils and other committees (Puurveen, Baumbusch, & Gandhi, 2018). Studies suggest that residents are also affected by the experiences of their family members (Li, Li, & Tang, 2016; Roberts & Ishler, 2017). The relationship that develops between a care provider and a resident's family influences the relationship between the resident and the care provider. This is particularly true in cases where there is heavy family involvement in care and communication. Family members often continue their caregiving role even after their loved one has been admitted to a LTC home. Their involvement and presence in the LTC home give them a unique consumer perspective that can inform efforts to improve the quality of care being delivered (Frentzel, et al., 2012; Kane, et al., 2005). Standards for delivering person-centered care programs in Canadian Long-Term Care homes increasingly recognize the importance of meaningful engagement with family members (HSO, 2023; Accreditation Canada, 2023).

The new HSO standards for Long-Term Care place substantial importance on family members, who they refer to as "essential care partners" or ECPs (HSO, 2023). HSO adopts Healthcare Excellence Canada's definition of ECPs, being "A person or persons chosen by a resident, or if incapable, their substitute decision maker, to participate in the resident's ongoing care. An essential care partner can be a family member, close friend, private care provider, or other caregiver. A resident has the right to include or not include an essential care partner in any aspect of the resident's care. Depending on the jurisdiction, an essential care partner may be referred to by other terms, such as designated support person or essential family caregiver" (Healthcare Excellence Canada, 2021b). This research study's definition of family member is aligned with HSO's work.

HSO further defines how ECPs should be engaged. Standard 1.1 (strategic plan is informed by needs and experiences of all stakeholders, including residents, substitute decision makers, essential care partners, etc.), and 2.3 (the home leaders and team promote the role and presence of essential care partners) which includes standards regarding communication and visiting the home. Standard 3.1.11 references the requirement of collecting and communicating the results from quality of life surveys. These standards are currently being evaluated alongside provincial licensing requirements and will be used as the foundation for Accreditation Canada standards (Arulnamby and Sinha, 2023).

Family members are an important member of the resident’s circle of care and can help LTC home administrators and healthcare workers improve quality of life for residents in their communities. Capturing the important voice of the family member presents methodological and conceptual challenges for LTC providers, policy makers, and researchers. This dissertation seeks to examine the need for a new standardized instrument to capture this voice, identify essential aspects and features of that instrument’s design and test a draft version of this instrument.

Current Methods for Assessing Quality of Life in LTC

QoL is a multidimensional concept that can take on many meanings across different settings. In LTC, QoL is an important aspect in assessing overall quality in the home. In addition to quality of care indicators, some survey instruments have been developed to complement QoC with the more subjective aspects of QoL. Some instruments accommodate specific disease states, such as the D-QoL gathering feedback from residents living with dementia or their proxies (Brod, 1999, Crespo, 2012). Other instruments measure Health-related QoL by incorporating aspects of the resident’s physical health and functional status (Ware, 1992). Other instruments, such as the interRAI Resident Self-Reported Quality of Life Survey for Long-Term Care Facilities, focus on broad domains of QoL and rely on other available and reliable measures of health status and quality of care (Kehyayan, 2015.

Standardized surveys continue to be the most common method used to obtain the perspectives of family members in LTC (Ejaz, Straker, Fox, & Shobhana, 2003; Kane, et al., 2005; Voutilainen, Backman, Isola, & Laukkala, 2006; Crespo Bernaldo de Quiros, Gomez, & Hornillos, 2011; Frentzel, et al., 2012; Godin, Keefe, Kelloway, & Hirdes, 2015; Oosterveld-Vlug, Onwuteaka-Philipsen, Pasman, van Gennip, & de Vet, 2015; Office of the Seniors Advocate, 2017; Morris, et al., 2018). Surveys are economical and have the potential to reach large populations, increasing generalizability of the results and potentially enabling longitudinal and cross-sectional analysis. Instruments measuring clinical quality indicators (QIs) providing outcome and process-based metrics of quality of care (QoC) are distinct from those measuring quality of life (QoL). Both types of measures should be employed to provide a comprehensive evaluation of overall quality in LTC. Indeed, initiatives such as the Institute for Healthcare Improvements Quadruple Aim require a multidimensional focus that includes QoC and QoL measures (IHI, 2023).

There are limitations with the existing instruments to capture family member experiences in LTC. There are very few validated tools that aim to collect data from the family member specifically. In most cases these surveys are used as a proxy for the resident. Non-response bias and missing values are common problems, as family members may not be positioned or willing to answer for the resident. Some research points to a lack of agreement between resident, family, and staff responses. Residents typically rate quality of care higher in specific domains (Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011). Studies have found acceptable agreement in more objectively observable areas such as, physical functioning, overall health, physical environment, and communication. Lower agreement rates appear in more subjective domains including, depressive symptoms and psychosocial well-being (Neumann, Araki, & Gutterman, 2000; Frentzel, et al., 2012; Godin, Keefe, Kelloway, & Hirdes, 2015). One possible explanation is that residents may not consistently communicate their emotional state, due to cognitive impairment, communication challenges or opportunity.

It has also been argued that proxies should never be used to assess quality of life for a resident due to their subjective and idiosyncratic nature. Certainly, self-reported quality of life is ideal, and conflicting results between resident and family ratings can make it challenging to translate the input into action. Family member ratings converge with resident ratings in some aspects of QoL in areas such as, care and support, food, autonomy, and activities (Godin, Keefe, Kelloway, & Hirdes, 2015; Office of the Seniors Advocate, 2017) but pursuing agreement implies that the resident offers the only true perspective. A standardized and valid instrument that reflects these dynamics, does not currently exist in the literature on family instruments.

The interRAI Resident Self-Reported Quality of Life Survey for Long-Term Care Facilities

The interRAI Resident Self-Reported Quality of Life Survey for Long-Term Care Facilities (interRAI QoL) is a 50-item instrument that is part of a larger suite of tools developed for use across Long-Term Care homes (Morris, et al., 2018; Kehyayan V, 2015; Kehyayan V, 2016). Items are organized by domains such as, Food, Caring Staff and Social Life. The instrument is designed to be self-reported and is used with residents who are assessed with a Cognitive Performance Scale (CPS) ranging from 0 (intact) to 3 (moderate impairment). Responses to items are on a scale rating how often a statement is true, ranging from 0 ‘never’ to 4 ‘always’ and have scoring options for non-responses (‘don’t know’, ‘prefer not to answer’ or ‘not applicable’).

Research context

LTC in North America has been a challenging healthcare setting for some time. In Canada, increasing acuity of admitted residents over the last decade has placed more strain on already scarce staff to meet demands (Curry, 2015; Chamberlain, 2019; Yuting, et al., 2023). A substantial portion of the work of this dissertation took place during an unprecedented time in this strained setting. The COVID-19 pandemic, beginning in early 2020, had its earliest and deadliest effects in LTC. It continues to have serious implications for residents, staff, and families. During the first two waves of COVID-19 between March 1, 2020 to February 29, 2021, Canadian LTC residents accounted for 3% of the country's COVID-19 infections and 43% of the COVID-19 related deaths (CIHI, 2021). Changes to visitor restrictions and the extension of those changes have hindered family involvement and input. Communication challenges and staffing shortages have raised the stakes for family members in terms of their contributions to resident life at a LTC facility (Chamberlain et al., 2023; Cooke, Wu, Bourbonnais, & Baumbusch, 2023).

At the time of data collection presented in Chapter 5, residents, families, and staff were finishing their second year dealing with COVID-19 related changes. While the investigators do not expect this context to change the content or validity of the instrument, it is an important lens through which to view the results and feedback provided by the family members at that time.

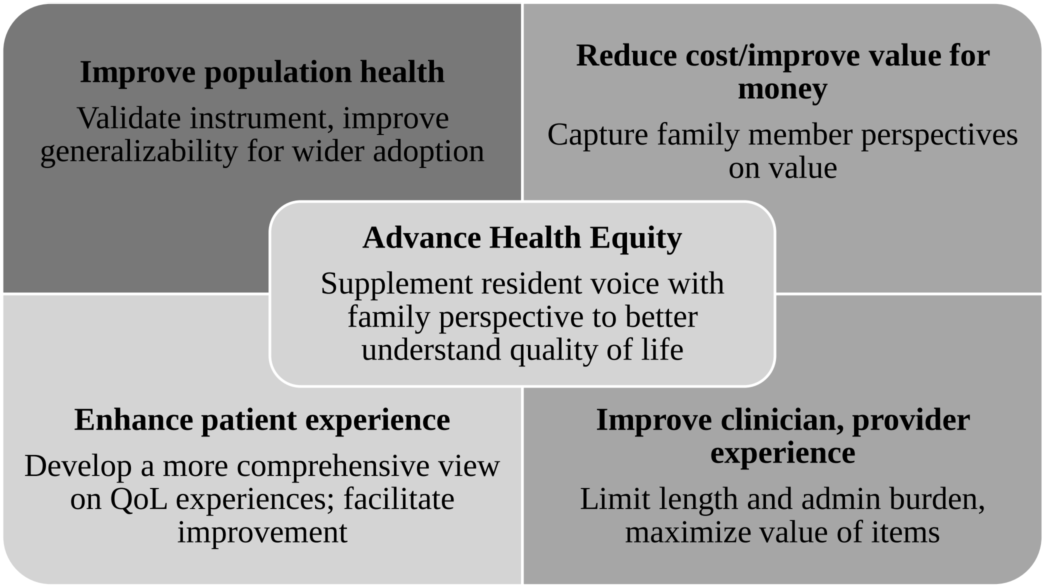
Theoretical/Conceptual Framework: the Quintuple Aim for Healthcare Improvement and Advancing Health Equity

This research is informed by Quintuple Aim framework for healthcare improvement and health equity (IHI, 2023). The framework, developed in 2008 by Berwick and others and initially referred to as the “triple aim” (Berwick, et al., 2008), sought to balance and optimize the aims of improving population health, the care or patient experience and increase value for money or reduce costs. An update in 2014 added a fourth aim, often identified as clinician experience or provider satisfaction, aims to improve the well-being of care teams (Bodenheimer, et al., 2014). This was partly in response to growing reports of burnout and dissatisfaction among healthcare workers.

In 2022, Nundy and team introduced a fifth aim; advancing health equity (Nundy, et al., 2022). The COVID-19 pandemic shone a much-needed light on health inequities across the system, which have exposed our most vulnerable and marginalized populations, including older adults, to higher levels of infection, hospitalization, and mortality. In Long-Term Care, older adults and particularly those with advanced-stage dementia or severe cognitive impairment, cannot advocate for themselves the way other healthcare system users can. Similarly, they may not be able to communicate needs, desires, or suggestions. This difficulty creates the potential for health inequities among LTC residents.

While this research is aligned broadly with each of the five aims of this conceptual framework, as a priority it seeks to advance health equity by capturing a supplemental, trusted, and familiar voice. The priorities of improving the family members’ perspectives on QoL align this work to improve “value for money” from family members by including domains that are most relevant to them. The inclusion of appropriate resident-focused items positions this instrument to also advance the resident experience through a more complete perspective on quality in the home.

Figure 1.1. Dissertation Alignment with Quintuple Aim Framework for Healthcare Improvement and Advancing Health Equity



In health systems for Long-Term Care, the family member is sometimes considered the consumer of the system's service: through financial exchange, formal roles like substitute decision maker, or as the resident's main point of contact. In the aim of improving value for money, we consider the family to be one reliable source from which to assess that value. Their input regarding experiences with the provider can point to improvements in value creation within the system. Similarly, family members can provide input into patient satisfaction by offering their perspectives, experiences, and observations in the home.

Evidence supports the reliance on dynamic care teams, including family members, to support residents living in LTC. How they experience their time in the home, their views on the quality of care or quality of life of residents and their trust in staff, can influence resident outcomes and work satisfaction of staff. Strengthening family perspectives supports the aim to improve clinician and provider experience. Similarly, the family member is a critical stakeholder in managing and improving the population level health of older adults, often taking on caregiving, functional or socio-emotional support.

Outline of dissertation

The Quintuple Aim framework provides the theoretical and conceptual underpinnings of this dissertation. In Chapter 2, a summary of the study rationale, objectives, research ethics considerations and methods that informed this dissertation is provided. Chapters 3 to 6 contain the substantive work of this dissertation and will be submitted to peer-reviewed journals for publication. To ensure this body of research advances health equity in LTC, Chapter 3 explores the topic of measuring family perspectives on quality of life in Long-Term Care through a scoping review, discussing current instruments, strengths, and gaps in the research. Chapter 4 provides an analysis of several studies gathering family input in LTC using previous versions of a family survey developed by interRAI. This review considers non-response, missing values, and agreement between residents and families.

Chapter 5 applies this analysis, along with additional research from the scoping review in Chapter 3, to the development of a new family survey instrument. An expert group including multiple stakeholders (e.g., clinicians, providers, family member representatives, researchers) drafted a new Family instrument. The team's aim was to limit the number of items in the instrument to minimize administrative burden involved in data collection and interviews. Selected items must provide useful and actionable insight and establish summary domains and benchmarks, making it easier to communicate results, set goals and improve the provider experience.

In Chapter 6, the new family survey instrument is tested in several LTC homes across North America and a summary of those results are presented. Chapter 6 aims to improve population health by examining the validity, reliability, and general performance of the new instrument. Increasing generalizability of the survey will support broader populations benefiting from this perspective. Summary scales were also developed and tested for validity, supporting clinicians and health providers to easily interpret results and develop improvements. Chapter 7 presents the key findings of the previous four chapters and discusses limitations, implications and potential future studies that would further the evidence on this topic.

Chapter Two

Study Rationale and Objectives

Family members play a vital role in the LTC setting. Through these functions, family members are often positioned to directly observe and influence the experience of their loved one, in addition to the operation of the facility. This ability of family members to influence and observe has never been more understood than it has through the lens of the COVID-19 pandemic.

Beyond providing important insights into the Quality of Care (QoC) being experienced in the nursing home and the resident's Quality of Life (QoL), family members can provide unique perspectives about experiences in LTC. Perspectives regarding transitions, communication with clinicians, bereavement support and symptom management have proven to be reliable insights in policy development, quality improvement and program design (Voutilainen, Backman, Isola, & Laukkala, 2006; Cohen, et al., 2012; Sussman & Dupuis, 2012).

Despite the clear value and insights family members can provide regarding the quality of life in a LTC home, instruments to capture this perspective specifically are largely missing in the peer-reviewed literature. The purpose of this study is to explore the existing methods to capture the unique perspectives from family members in a LTC setting, then develop and evaluate a standardized tool. To reach that aim, the specific objectives of the study are to:

1. Conduct a scoping review of the current literature regarding family engagement in LTC, including measurements, instruments, and results (Chapter 3- Manuscript #1),
2. Examine the rates of non-response, agreement and disagreement between resident and family responses based on secondary data collected in previous studies (Chapter 4- Manuscript #2),

3. Develop a draft version of a Quality of Life instrument for LTC family members, including summary scales (Chapter 5- Manuscript #3),
4. Conduct an evaluation of the results, reliability, and convergent validity of the above tested instrument (Chapter 6- Manuscript #4).

Chapter Three (Manuscript #1)

"Complementing Perspectives on Quality of Life" How Family Perspectives on Quality of Life in Long-Term Care are Measured: A Scoping Review

Introduction

Throughout the experience of selecting, moving in, living, and dying in Long-Term Care (LTC) facilities, family members play an integral role in the well-being and quality of life (QOL) experienced by their loved ones residing in those settings (Sussman & Dupuis, 2012; Roberts & Ishler, 2017). Family members advocate for their loved ones in LTC, make decisions to maintain or enhance the resident's QoL, and influence quality initiatives in the home (Barken & Lowndes, 2018; Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011). The COVID-19 pandemic has raised awareness of the influence family members, friends, and other frequent visitors (hereafter referred to as family members) have on resident care and support. Both the resident and family member's QoL are substantially impacted whenever a familial connection is interrupted (Baumbusch & Phinney, 2014; Cooke, Wu, Bourbonnais, & Baumbusch, 2023).

QOL is a subjective concept with varying emphasis placed on health and functional status, quality of care and other aspects of well-being (e.g., socialization, spirituality) (Kane R. A., 2003; Shippee T. P., 2015). Long-term Care based quality of care indicators are now widely available in the US and Canada through the use of comprehensive assessments such as the interRAI instruments, their outcome scales, and quality indicators (Nursing home compare, 2023; Your health system, 2023). These same instruments also provide comprehensive insight into objective aspects of well-being, including health and functional status (Morris, 1990). Self-reported QOL instruments can focus on the more subjective nature of QOL, assessing factors such as dignity and autonomy, as well as resident experience measures such as satisfaction with services, food, and activity programming (Kane R. A., 2003; Kehyayan V, 2015; Kehyayan V, 2016).

While a self-report from residents is a preferred measure of QOL, high rates of cognitive impairment in nursing homes have led to a growing demand for other perspectives on the matter (Kane, et al., 2005; Godin, Keefe, Kelloway, & Hirdes, 2015). Attempts to assess other perspectives on a resident's quality of life have mostly taken the form of proxy reports. The varying perspectives on QOL between family members and residents make proxy reporting troublesome, with family members attempting to put themselves in the resident's shoes and attempt to respond as they would (Kane, et al., 2005; Kothari & Kirschner, 2006; Frentzel, et al., 2012).

Previous scoping and systematic reviews have been conducted on the broader topic of family involvement in LTC (Puurveen, 2018, Hovenga, 2022), its' impact on resident, staff and family-outcomes (Ausserhofer, 2016), and interventions to increase engagement (Becque, 2019, Veiga-Seijo, 2022). There is an increasing amount of literature on the specific topic of measuring family perspectives in LTC, the instruments used, and scales developed. A recent systematic review explored instruments and scales used to measure family satisfaction with the services provided in nursing homes (Vassimon-Barroso, 2021) and another also examined family instruments in LTC but specific to food services (Pankhurst, 2021). The work of Vassimon-Barroso et al is similar in focus to this scoping review, with some key differences. This scoping review is focused on family perspectives on quality of life, rather than their level of satisfaction with the nursing home service. It is also targeting instruments that do not collect proxy reports from family members but rather, seek the family's own perspective.

This review aims to summarize the available evidence on measurement tools that assess the family member's unique perspective on QOL in LTC, not as a proxy for the resident, but based on their own experiences and the factors they consider to be important to the resident's QOL. This study will provide an easy to interpret summary of instruments that researchers can use to inform the future evolution of standardized tools. This closes an important gap in the existing literature and examines a topic of increasing importance as rates of cognitive impairment in nursing home residents remain high, leaving a substantial portion of residents unable to provide their own direct feedback.

Research Questions

The purpose of this study is to explore the evidence regarding the Quality of Life of family members who are a primary visitor/family contact for a resident living in LTC. To that end, two research questions were proposed: (1) what instruments or measurements have been used to evaluate family member experiences and perspectives regarding quality of life in LTC and (2) what are the strengths, limitations and gaps identified with those measurements.

Methods

This review employs the five-stage methodological framework for scoping studies specified by Arksey and O'Malley (Arksey H, 2005). The results of each step are detailed below. Tricco et al further summarized these guidelines and recent evidence and updates into a PRISMA-Scoping Review Checklist (Tricco, 2018).

Identifying Relevant Studies

Relevant articles from 2000 to 2022 were identified in MEDLINE, Pubmed and CINAHL. This focused the review on studies conducted during a time when family members were being increasingly acknowledged as a vital member of LTC home communities. A variety of search terms were used to capture the appropriate studies on this topic (Table 3.1). For each of the key terms, synonyms and related terms were searched. A librarian reviewed the search string for electronic databases.

In addition to the peer-reviewed evidence, a grey literature search was done in May 2019, April 2022 and again in April 2023 using similar key concepts and search terms as outlined in Table 3.1. In addition to a general Google search, various government and stakeholder group websites were reviewed for relevant material on this topic.

Table 3.1. Keywords and search terms

Population	Concept	Context
Family	Quality of life	Long-term care
Loved ones	Well-being	LTC
Most frequent visitor	Satisfaction	Nursing home
Essential care provider	Perspective	Residential care home
Families	Engagement	Home for the aged
Next of kin	Measurement	Residential care
Adult children	Indicator	Long-term residential care
Children of impaired parents	Instrument	Assisted living
Extended family	survey	Nursing facility
Informal caregiver		
Family members		

Selecting Studies

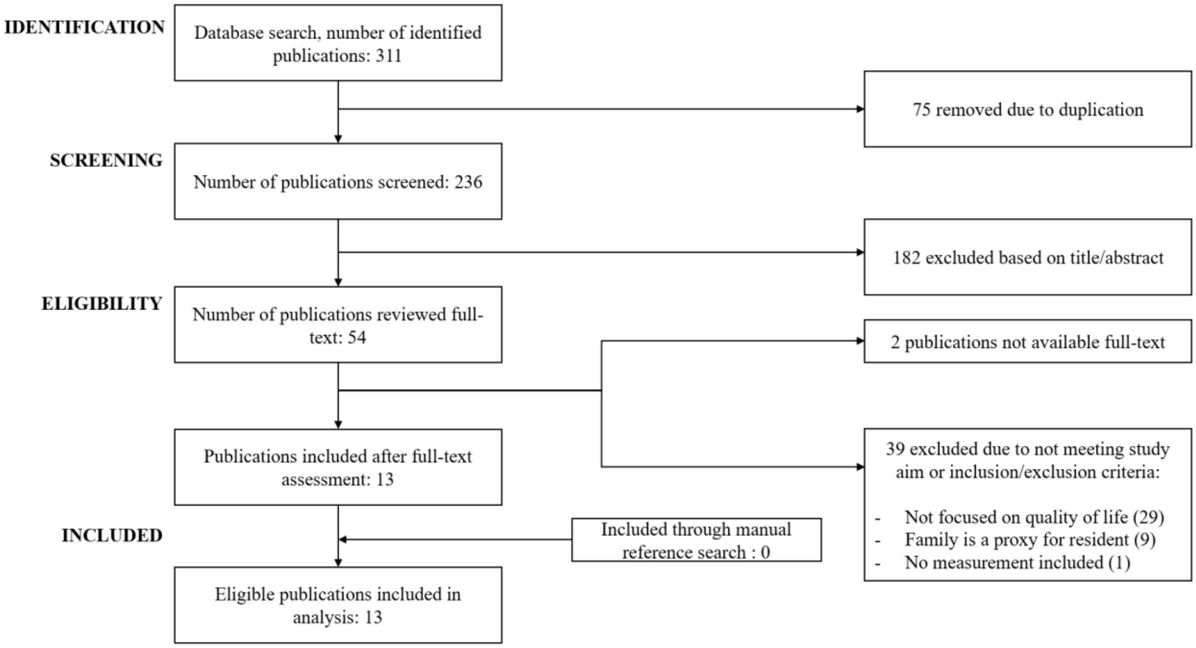
The following criteria were used to screen titles and abstracts for inclusion in this study: studies occurred in a LTC home, were focused on evaluating family member perspectives on quality of life and included a validated measurement instrument. International studies were included if the full article was available in English. All study types were considered. One reviewer screened titles and abstracts for inclusion. A second reviewer was identified for this study however, COVID-19 related delays and conflicts prevented the inclusion of their results at the time of writing.

The following exclusion criteria applied to study selection, during both the title/abstract and full text review:

- Studies that were focused primarily on evaluating resident interventions from the family member perspective, legal aspects of family relationships or on interventions aimed at increasing family member participation or engagement,
- Studies that primarily evaluated types and/or frequency of family involvement, perspectives on quality of care only or where the respondent is a proxy for the resident.

The search yielded 311 articles from the various databases searched and grey literature. After removing duplicates, 182 article titles and abstracts were reviewed for relevance, screening out 73% of the studies. The remaining 54 studies were accessed to review the full text, upon which another 39 were excluded based on eligibility and two due to the full text not being available in English. 13 articles were included in this scoping review. This process is summarized below in Figure 3.1.

Figure 3.1. PRISMA flow-chart illustrating the identification and selection process and results



Data Extraction and Analysis

For the selected studies, key information was extracted on a data extraction form by the author. Extracted data included the first author, year of publication, study objectives, type of data and research design, study setting, sample size, measurement of family perspectives on QoL, any psychometric properties provided for that measurement, domains included in the measurement, and main findings.

Results

This study identified 13 articles that met the selection criteria described. All studies included were conducted in North America, the majority in the United States. 10 of the articles were published in peer-reviewed academic journals, one was a Masters' level thesis manuscript, and two articles were government reports. While the publication years ranged from 2001 to 2022, nine of the 13 studies were published in the last 10 years. A list of the included studies is shown in Table 3.2, in order of publication year.

Table 3.2. Eligible studies, ordered by publication year

Author(s)	Publication Year	Sample Size	Instrument
Marisetti, Anuradha Rao	2001	2,631	Family Evaluation Survey for LTC (Marisetti, 2001)
Ejaz et al	2003	239	Ohio long-term care facilities family satisfaction scale (Ejaz, Straker, Fox, & Shobhana, 2003)
Castle, Nicholas	2004	387	Nursing facility family satisfaction questionnaire (NF-FSQ) (Castle, 2004)
Health Quality Council of Alberta	2008	11,311	CAHPS Nursing Home Survey: Resident and Family Member Instruments (Alberta, 2008)
Frentzel et al	2012	885	CAHPS Nursing Home Survey: Resident and Family Member Instruments (Frentzel, et al., 2012)
Godin et al	2015	397	interRAI Family Survey for Long Term Care (Godin, Keefe, Kelloway, & Hirdes, 2015)
Li et al	2016	9,645	CAHPS Nursing Home Survey: Resident and Family Member Instruments (Li, Li, & Tang, 2016)
British Columbia Office of the Seniors Advocate	2016	21,344	interRAI Family Survey for Long Term Care, with additions (Office of the Seniors Advocate, 2017)
Shippee et al	2017	27,596	Minnesota family satisfaction with resident NH care (Shippee, Henning-Smith, Gaugler, Held, & Kane, 2017)
Roberts et al	2017	14,979	Ohio long-term care facilities family satisfaction scale (Roberts & Ishler, 2017)
Shippee et al	2020	1,304	Ohio long-term care facilities family satisfaction scale and Minnesota family satisfaction with resident NH care (Shippee, Ng, Restorick Roberts, & Bowblis, 2018)
Mukamel et al	2021	4,074	Not provided (Mukamel, Saliba, Weimer, & Ladd, 2021)

Nwakasi et al	2022	33,504	Ohio long-term care facilities family satisfaction scale (Nwakasi, Mehri, & Parajuli, 2022)

Description of Studies and Resident Characteristics

Of the 13 included studies: four were primarily aimed at developing and validating a new measurement instrument; four were exploring associations between results from an existing measurement instrument and other quality outcomes or factors; three were describing and reporting the results from an existing instrument, and two were validating an existing measurement instrument through psychometric analysis. The included studies explored seven unique measurement instruments relating to the family member experience in LTC.

Research Question 1- what instruments or measurements have been used to evaluate family member experiences and perspectives regarding quality of life in LTC?

The seven unique measurement instruments included in this study are shown in Table 3.3, along with the year of development, number of items in the instrument, and the rating scale. The number of items ranged from 21 to 104, with most instruments having less than 50 satisfaction items included and minimal background items. Commonly used background items were relationship with the resident, rating of resident's health and visitation frequency. Table 3.4 demonstrates each instruments' definition of the "family" member.

Table 3.3. Family Quality of Life in LTC Year of Development, Background Items, QoL Items and Rating Scale

Measurement Instrument	Year Developed	Number of Background Items	Number of QoL Items	Rating Scale
Family Evaluation Survey for LTC	2001	2	36	“yes”, “somewhat”, “sometimes” or “no” “don’t know” “Excellent”, “Very Good”, “Good”, “Fair”, or “Poor”
Ohio long-term care facilities family satisfaction scale	2003	17	62	‘‘yes, definitely,’’ ‘‘yes, I think so,’’ ‘‘no, I don’t think so,’’ ‘‘no, definitely not,’’ and ‘‘don’t know’’, ‘‘not familiar with service.’’
Nursing facility family satisfaction questionnaire (NF-FSQ)	2004	Not provided	23	Visual analog rating scale from 1 to 10, “don’t know”
CAHPS Nursing Home Survey: Resident and Family Member Instruments	2005	Not provided	25	1 = never, 2 = sometimes, 3 = usually, 4 = always.
Minnesota family satisfaction with resident NH care	2008	4	35	Rating scale of 1 to 5, don’t know, not applicable
interRAI Family Survey for Long Term Care	2015		48	scale of 0 ‘never’ to 4 ‘always’, ‘don’t know’
interRAI Family Survey for Long Term Care, with supplementary BC items	2017	8	104	scale of 0 ‘never’ to 4 ‘always’, ‘don’t know’

Table 3.4. Family Respondent Definition by Family QoL in LTC Instrument

Measurement Instrument	**Respondent Criterion**
Family Evaluation Survey for LTC	A close relative of the resident or any person who visited the resident very often and was considered a significant visitor
Ohio long-term care facilities family satisfaction scale	The family member or friend or interested party who is most involved with the care of the resident
Minnesota family satisfaction with resident NH care	18 years or older, and a family member of a current or recent (prior six months) nursing home resident; meeting at least one of the following: (1) the person who visits the nursing facility most often, (2) the person who attends the care conferences for the resident, (3) the person who holds the resident's power of attorney for health care. or (4) the person who is notified of any change in the resident's health or functional status
Nursing facility family satisfaction questionnaire (NF-FSQ)	Family member of resident with length of stay > 30 days, non-hospice
CAHPS Nursing Home Survey: Resident and Family Member Instruments	The party responsible for a resident at the facility for length of stay >= 30 days
interRAI Family Survey for Long Term Care	Family member of current resident, as determined by staff
interRAI Family Survey for Long Term Care, with supplementary BC items	Most frequent visitor, as determined by staff

Each of the seven included instruments defined domains or scales that represent the multi-dimensional construct of family perceptions on quality of life. While the items and domains vary by instrument, some common patterns exist. Domains or items concerning resident care, the living environment and food were common across all instruments. Additional family-specific domains were also present (e.g., communication with staff, administrative services) but these were less consistent. Table 3.5 describes the domains used across the included instruments. All but one instrument included a global measurement domain, which were very consistently used.

Typical items were “Would you recommend this facility to a family member or friend” combined with an item asking about overall satisfaction with the facility.

Table 3.5. Number and Description of Domains by Family QoL in LTC Instrument

Measurement Instrument	Number of Domains	Domain Descriptions
Family Evaluation Survey for LTC	5	Living Environment, Communication with Staff, Quality and Services, Resident Care, Global Questions
Ohio long-term care facilities family satisfaction scale	12	Direct Care and Nurse Aides, Professional Nurses, Environment, Receptionist and Phone, Administration, Meals and Dining, Activities, Social Services, Therapy, Laundry, Admission, Choice, Overall Satisfaction
Minnesota family satisfaction with resident NH care	4	Care, Staff, Environment, Food
Nursing facility family satisfaction questionnaire (NF-FSQ)	8	Admission, Activities, Autonomy and Privacy, Physical Environment, Safety and Security, Caregivers, Meals/food, General Satisfaction
CAHPS Nursing Home Survey: Resident and Family Member Instruments	6	Staff and Administration, Resident Care, Food and Meals, Autonomy and Resident Rights, Physical Aspects of the Facility, Global Measurement
interRAI Family Survey for Long Term Care	5	Care and Support, Food, Activities, Autonomy, Overall Quality of Life
interRAI Family Survey for Long Term Care, with British Columbia supplement	15	Privacy, Food and Meals, Safety and Security, Comfort, Autonomy, Respect by Staff, Staff Responsiveness, Staff-Resident Bonding, Activities, Personal Relationships, Medications, Doctor/Physician Care, Physical Environment, Hand Cleaning, Overall Experience

Research Question 2- what are the strengths, limitations and gaps identified with those measurement instruments?

A summary of the available psychometric properties and missing data rates for the included instruments is shown in Table 5, followed by a more detailed review of each instrument. This is followed by a brief description of each of the seven included instruments.

Table 3.6. Available Psychometric Properties and Missing Values, by Family QoL in LTC Instrument

Measurement Instrument	**Content Validity (factor loadings) <0.3**	**Internal Consistency (Cronbach's alpha) < 0.7**	**Missing Data % Range (Items with > 20% missing data)**
Family Evaluation Survey for LTC	Not provided	Cronbach's alpha .63 to .95 Inter-item Correlation .32 to .84	1.5 to 46.7 "does the resident get help eating" (24.7%) "enough time taken to feed resident" (48.2%)
Ohio long-term care facilities family satisfaction scale	Factor loadings .39 to .80 Correlation with Global Rating .33 to .74	Cronbach's alpha 0.66 and above Intraclass Coefficient .49 to .88	Not provided
Minnesota family satisfaction with resident NH care	Not provided	Not provided	Not provided
Nursing facility family satisfaction questionnaire (NF-FSQ)	Factor loadings 0.62 to 0.81	Cronbach's alpha .77 to .86	1.0 to 3.4
CAHPS Nursing Home Survey: Resident and Family Member Instruments	Confirmatory Factor Analysis N/A Correlation with Global Rating .24 to 0.7	Cronbach's alpha .75 to .90 Interunit Reliability .48 to .89 Intraclass Coefficient .04 to .13	Not provided
interRAI Family Survey for Long Term Care Version 1	Not provided	Cronbach's alpha .82 to .93	1.5 to 50.1
interRAI Family Survey for Long Term Care, with British Columbia supplement	Not provided	Not provided	Not provided

Family Evaluation Survey for LTC

This instrument was developed by Anuradha Marisetti at the University of Toronto in 2001 as part of a Master's level dissertation (Marisetti, 2001). While literature that informed this instrument may be outdated, the domains and items are generally consistent with newer tools. The study reported low missing data rates, with the exception of two items that were later removed (Marisetti, 2001). While the researchers reported good internal consistency, construct validity was poor relative to more recently developed tools. The authors of this scoping review were unable to identify more recent studies citing this instrument.

Ohio long-term care facilities family satisfaction scale

The Ohio instrument was developed by Ejaz et al. in 2003 as part of a state-wide initiative and is the most commonly used instrument found in this review (Ejaz, Straker, Fox, & Shobhana, 2003). The initial stages of development included a review of the literature and existing tools, as well as expert consultation to prioritize items. This instrument has an accompanying resident instrument, with which it shares a set of core items. Relative to the other instruments reviewed, the Ohio survey is longer at 62 items across 15 domains, and slightly more complex in its scoring and use of skip pattern questions. Scoring options use a likert-type scale with options from "yes, definitely" to "no, definitely not". The instrument reported strong content validity and internal consistency in a sample of 239 respondents.

Minnesota family satisfaction with resident NH care

This instrument was developed in 2008 for the University of Minnesota, by R.L. Kane and Vital Research, a contracted research and evaluation firm (Shippee, Ng, Restorick Roberts, &

Bowblis, 2018). While the development steps and psychometric assessment results of the instrument are not published, articles citing this tool reference several updates that have occurred over the years. The current tool has 35 items across four broad domains: Care, Staff, Environment and Food and uses a 5-point likert scale.

Nursing facility family satisfaction questionnaire (NF-FSQ)

The NF-FSQ instrument was developed in 2004 by Nicholas Castle, with an aim to develop a tool that would demand minimal personnel time, costs and be appropriate for wide use (Castle, 2004). The NS-FSQ has 21 items across seven domains and two global items, the briefest instrument found in this scoping review. Family member input was included in the development of domains to identify the areas that were most important to them. A review of the literature, examination of existing surveys, and an expert panel helped identify the most ideal three items to include in each domain. A study using a sample of 387 responses showed low missing data rates, ranging from 1.0 to 3.4% at the item level. All factor loadings were above 0.3 and Cronbach's alpha for all domains were above the recommended level of 0.7 (McHorney, Ware, Lu, & Sherbourne, 1999).

CAHPS Nursing Home Survey: Resident and Family Member Instruments

This instrument was developed in 2005 by Frentzel et al. to complement the existing nursing home resident survey developed by CAHPS, an organization that designs, administers, and reports on various aspects of consumers' experiences in healthcare settings (Frentzel, et al., 2012). This instrument was also more commonly referenced in the literature and is one of the briefer tools, with 25 items. The instrument has two versions- a long-term resident stay and a short-term discharged stay- as well as an accompanying resident self-report version with select common items. A strength of the CAHPS is its consideration of proxy bias, as items were excluded if they were either hidden or obvious proxy items. Strong internal consistency results were demonstrated during the development of this tool, but content validity statistics were somewhat limited and missing values were not published.

interRAI Family Survey for Long Term Care Version 1

The interRAI Family Survey for LTC was developed from the validated and widely used Resident Self-Report on Quality of Life in LTC instrument (Kehyayan V, 2015; Morris, et al., 2018). It was used initially in a 2015 study by Godin et al. to evaluate measurement equivalence across resident, family, and staff responses to the same items (Godin, Keefe, Kelloway, & Hirdes, 2015). Residents, staff, and family members responded to the same items, which had been slightly reworded for each respondent group. The intention of this study was to develop a measure that would allow comparison predictors of quality of life for residents. The study confirmed the varying perspectives of these three groups but identified four factors (care and support, satisfaction with food, autonomy, and activities) where there was more agreement in their perceptions of quality of life. The psychometric properties of the family instrument were not measured in this study, although some factors were identified as having a poor fit in the hypothesized model, compared to resident and staff responses.

interRAI Family Survey for Long Term Care, with British Columbia supplement

In 2017, the British Columbia Office of the Seniors' Advocate conducted a province-wide survey of nursing home residents and family members (referred to as "Most Frequent Visitor"), using the version 1 of the interRAI Family Survey for LTC referenced previously, as a foundation (Office of the BC Seniors Advocate, 2017). A 14-month consultative process with residents, family members, clinicians, community stakeholder groups and researchers were used to identify supplementary non-interRAI items to include, resulting in the 104 items and eight domains in the final instrument. Psychometric properties of this expanded tool were not assessed in the study.

Discussion

The instruments reviewed considered the unique perspectives of family members and included items that inquire about their perspective, separate and distinct from the resident’s perspective. These ratings should not be used as proxy substitutes for resident ratings, but rather as unique and valuable perspectives to create a more fully rounded view on quality in the home. They each considered a range of domains that aim to describe the construct of family perspectives in the nursing home. Studies showed good psychometric properties including internal reliability and content validity for several instruments. Criterion validity, including concurrent and predictive, and content validity, were not reported in any of the instruments included in this study. In assessing the quality of instruments designed to capture family perspectives on QoL in LTC, the lack of a “gold standard” external measurement presents challenges, particularly as it relates to evaluating criterion validity. While there were some common domains in the seven instruments reviewed, the wide range of topics covered in the various Family surveys and lack of content validity results, indicate a lack of consensus on what the relevant topics are in Family QoL perspectives in LTC.

Respondent and staff burden in terms of administrative time, data entry or other costs, are important considerations in the development of these instruments. Instruments should be relatively simple and brief, focusing on the most important factors (Castle, 2004). The research evaluated in this scoping review demonstrate that while some instruments had a higher number of items (> 50) and may take longer to complete, family members respond reliably with several studies showing high participation rates and low missing values.

Limitations

A limitation of this scoping review is the lack of a second reviewer for screening and reviewing articles. Additional reviewers can improve the objectivity and reliability of the scoping review results and application of inclusion and exclusion criteria.Another is the potential for proxy-related bias in these instruments. Some articles were explicit in the criteria of family respondents and the perspective respondents are intended to take when answering the survey (i.e., scoring as they think the resident would score vs. scoring based on their own perspective of that item). While in most instruments, items were worded to provide a clear non-proxy response from family members, a review of individual items show a combination of proxy-based vs. consumer-based wording. As an additional and distinct source of feedback on quality of life in LTC, this inconsistency may yield results that are not truly reflective of the family member's perspective but instead, an attempt by the family member to assume how the resident feels about a particular item.

To protect the privacy and anonymity of responses, limited information is collected that could potentially identify the resident or family member. Information such as Cognitive Performance Scales, CHESS scores and other outcomes could tell us more about family member perspectives and experiences within cohorts of residents or during specific phases of their LTC stay, including palliative care. Regular resident assessments collected valuable information that may be relevant in the context of family QoL but presently, these records are not linked, also for privacy reasons. Future studies could explore results at unit or neighborhood levels to better understand changes in family QoL in the context of resident characteristics.

Family members were defined liberally in most of the instruments reviewed, allowing for the selection of the person who is in the best position to observe and respond about their perspectives. This was not consistent however, with some instruments defining the respondent based on visitation specifically (e.g., the interRAI Family Survey for Long Term Care, with BC additions) and others not referencing visitation at all (e.g., the CAHPS Nursing Home Survey: Family Member). Some tools have exclusions based on visitation frequency (e.g., exclude responses if less than four visits in a year) but most did not. These inconsistencies may influence the interpretation of results, the selection, and perspectives of respondents.

While the authors made efforts to capture a variety of urban, suburban, and inner-city participants and facilities in the development of these tools, state-specific approaches may reduce generalizability, particularly in more culturally diverse regions. Future research into the factors of importance to family members across a variety of cultures and backgrounds, would add to the evidence on this topic. Many states and provinces have implemented summary quality measures for the public to use in evaluating nursing homes, such as CMS's 5-star health quality measure and CIHI's Your Health System. To date, these measures have focused primarily on QoC and compliance measures and have yet to incorporate measures of QoL, from residents or family members. A standardized, validated instrument that can be used nationally for both stakeholder groups, may make this incorporation more feasible.

Conclusion

In Canada and the US, an effort has been made to establish validated tools and measurements to better inform consumers about nursing home quality. State-led efforts in the US have resulted in several validated tools but most studies have been limited to the state where the instrument was developed (Shippee, Ng, Restorick Roberts, & Bowblis, 2018). Factors such as the states' Medicaid reimbursement rates and other policies may influence aspects of family perceptions. While each individual instrument is useful in describing family member perspectives on quality of life in the nursing home, this may limit generalizability, the completion of meta-analysis and state comparisons.

In Canada, a similar effort is underway, primarily in collaboration with interRAI, an international network of researchers and practitioners, committed to providing reliable, high-quality data that can be used to improve health care. An initial version of their family survey for long-term care was developed as an offshoot from the resident self-report version, with resident-focused items reworded slightly to capture the family member's perspective (Godin, Keefe, Kelloway, & Hirdes, 2015). A later study added several items to this instrument that aimed to capture the unique experiences and perspectives of family members, including visitation experience, communication with staff and engagement in care but the expanded version was not tested for validity or reliability (Office of the Seniors Advocate, 2017).

The interRAI instrument is appealing for many reasons. The accompanying resident self-report on quality of life in the nursing home, is widely used and required in some provinces (Morris, et al., 2018). Potential to link these results with data from other interRAI tools, including their Long-Term Care Facilities (LTCF) comprehensive assessment (Morris, et al., 2019) and its associated outcome scales and quality indicators, could provide meaningful insight into the relationship between family perspectives, resident's self-reported quality of life and quality of care outcomes. The LTCF is also widely used across Canada and in the United States, or a previous version (Your health system, 2023).

Of the instruments reviewed in this study, several had been used state or province-wide and a few had been used nationally or internationally. The Ohio, Minnesota and CAHPS instruments have been used state-wide, with limited multi-state participation and evaluation. The CAHPS instrument is associated with the Centers for Medicare & Medicaid Services and although not used nationally, is used the most widely in the US, with limited use in Canada. The interRAI family instrument has been used in several Canadian provinces and its complement, the Resident Self-Report QoL instrument, has widespread use in Canada and internationally (Kehyayan V, 2015; Morris, et al., 2018).

The development, results, and use of validated instruments to assess family perspectives on quality of life in long-term care, has shown to be a worthwhile undertaking in understanding the nursing home experience and informing quality improvement initiatives (Williams, Straker, & Applebaum, 2016; Li, Li, & Tang, 2016; Roberts & Ishler, 2017). High rates of cognitive impairment in nursing homes, increasing relevance of engaging families in national quality standards and the impacts and reflections from COVID-19, have made family member perspectives on quality in LTC homes of high importance. This scoping review identified the validated tools in the literature and assessed their strengths and limitations. Strong validity testing on the widely used instruments, both the resident and family versions, would add to its' coverage of quality of life concepts for both groups and identify its predictive value. This would further enhance the usefulness of results. Factors such as a wide range of domains, proxy-response bias, lack of validity testing and inconsistent exclusionary criteria (e.g., visitation frequency, definition of "family") illustrate the need for a nationally developed, validated instrument.

The new Health Standards Organization LTC standards released in 2023 introduces the role of "Essential Care Partner" or ECP, which "can be a family member, close friend, private care provider, or other caregiver" (HSO, 2023). ECPs are featured prominently in the model of People-Centered Care and the associated standards nursing homes in Canada will need to comply with. Understanding what is important to ECPs as it relates to quality of life in the home and having a standardized, valid way to measure that, will help LTC homes successfully transition to these standards.

Taking various important perspectives into account provides a more complete picture of QoL in LTC homes. Family members are in positions to observe many aspects of QoL in these homes, so having a core set of items that are paralleled between resident and family instruments can help administrators and healthcare workers understand and improve on the aspects of QoL that are important to residents. Of the seven instruments reviewed, three shared a core set of items with a resident version of the instrument. The Ohio, Minnesota, CAHPS and interRAI instruments share some number of items with a complementary Resident QoL instrument. This approach allows decision-makers to compare results by stakeholder group- not for full agreement, but to complete the picture of quality in the home.

Chapter Four (Manuscript #2)

Different Perspectives on Quality of Life in Canadian Long-Term Care Facilities- A Multi-Study Analysis of Resident and Family Member Ratings

Background

Quality of life (QoL) is a holistic concept that can take on different meanings depending on the context and assessor (Neumann, Araki, & Gutterman, 2000; Kane, et al., 2005; Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011; Godin, Keefe, Kelloway, & Hirdes, 2015). In North American nursing homes, quality of life usually refers to a broad range of domains that are important to residents, along with their health and functional status (Kane, 2003; Morris, et al., 2018). The World Health Organization defines QoL as “an individual's 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” (WHO, 2023). While this definition is not specific to the LTC experience and reflects mainly health-related QoL aspects, the subjective nature of the judgement of QoL and importance of the person’s values, aligns with psychosocial and resident experience QoL this research references.

QoL may be influenced by disease states, socio-demographic factors about the respondent and structural aspects of the facility, making it difficult to assess in a standardized way (Cohen, Forbes, & Garraway, 1996; Shippee T. P.-S., 2015; Shippee, Henning-Smith, Gaugler, Held, & Kane, 2017; Hennings & Froggatt, 2019). Many tools aim to gather self-reports directly from residents but high levels of dementia and cognitive impairment in nursing homes can limit the ability of residents to provide this feedback (CIHI, 2023).

Family members play an important role in nursing homes, often providing socio-emotional support, assisting with care, and advocating for the resident’s experiences in the home (Legault

& Ducharme, 2009; Baumbusch & Phinney, 2014; Cohen, et al., 2014). There is some evidence that family members can also influence quality of care outcomes through their involvement and unique experiences (Gaulgler, 2005; Durkin, Shotwell, & Simmons, 2014; Ryan & McKenna, 2014; Li, Li, & Tang, 2016). Policy makers, administrators, and standards organizations for LTC increasingly recognize the role and value of family members in providing a full picture of quality of care and quality of life in nursing homes based on their unique role and perspectives (Kehyayan V, 2015; Accreditation Canada, 2023; HSO, 2023).

There has been progress toward standardized quality measurements in LTC and having a comprehensive understanding of quality in our LTC homes, both in care and quality of life, has gained importance particularly since the COVID-19 pandemic (Frijters D.H., 2013; Kehyayan V., 2015; Morris, et al., 2018; Chamberlain S.E, 2023). Standardized assessments such as the interRAI LTCF, have enabled the LTC sector to derive clinical quality indicators across jurisdictions that are risk-adjusted based on resident profiles (Zimmerman, 2003; Frijters DH., 2013; CIHI, 2023). When measuring quality of life indicators, the ideal approach is to use resident self-reports when possible, considering the resident's level of cognitive functioning (Neumann, Araki, & Gutterman, 2000; Oosterveld-Vlug, Onwuteaka-Philipsen, Pasman, van Gennip, & de Vet, 2015; Morris, et al., 2018). Family members can be a valuable additional source of feedback about quality of life in the home.

With previously collected data from three studies using the resident and version 1 family interRAI Quality of Life instrument, this study aims to compare how residents and family members respond to the same quality of life items. By understanding the level of concordance between their perceptions about quality of life, we can gain a fuller understanding of what domains family members are in the best position to provide feedback on, what discordance in results may mean in terms of quality in the home and how we can improve the collection of these valuable data going forward.

Methods

The first aim in this study was to assess and compare rates of non-response and missing items among resident and family member responses to an initial version of interRAI's quality of life instrument. The second aim was to examine how residents and family members rated various domains of quality of life in long-term care facilities and the degree to which those ratings agree across the different respondent groups.

Design and Settings

This was a retrospective analysis of secondary data gathered through three independent studies in Canadian Long-Term care settings. Each study used the interRAI Resident Self-report QoL instrument (Morris, et al., 2019) and Version 1 of the interRAI Family QoL instrument. Some studies augmented those instruments slightly or added items- the analysis of this study is based on a set of 48 interRAI items that were consistent across all studies.

Study #1- Nova Scotia

This study by Godin et al. gathered resident, family, and staff responses to the interRAI Resident Self-report and Version 1 Family QoL instruments for LTC (Godin, Keefe, Kelloway, & Hirdes, 2015). These instruments contained the same items, with slight rewording for the family version. Twenty-three publicly funded Nova Scotia nursing homes participated, resulting in 364 family member responses and 315 resident responses. Residents had to have been at the home for at least one month to participate and family members were invited to participate based on staff contact lists already maintained in the home. Only the resident and family member responses are used in this paper's analysis.

Study #2- Ontario

In 2017, several Ontario-based LTC homes across multiple operating providers took part in an additional pilot study of the Version 1 Family QoL instrument, along with gathering resident responses using the self-report tool. A total of 3,301 family member responses and 3,620 resident responses were gathered. Ninety LTC homes participated, and these data have not previously been published.

Study #3- British Columbia

The BC Office of the Seniors Advocate conducted a survey in 2016, using the interRAI resident self-report and Version 1 family QoL instruments (BC Office of the Seniors Advocate, 2017). Based on a review of the evidence, the survey administrators added approximately 50 additional items to the survey, but only the core interRAI items are included in this analysis. This study yielded 9,531 family member responses and 9,214 resident responses. Residents had to have been at the home for at least one month to participate and family members were defined as the "most frequent visitor" in the home, as identified by facility administrators.

Ethics

This study received ethics approval from the University of Waterloo (ORE #42872).

Measures

The interRAI Resident Self-report QoL instrument and Version 1 Family QoL instruments were used in all three studies. These instruments contain the same items, which had been reworded slightly to reference the family member's perspective (for example. "I can bath/shower when I want" reworded to "my family member can bath/shower when they want"). In total, 48 parallel core items were captured across all three studies. Residents with cognitive performance scores between 0 (intact) to 3 (moderate impairment) were eligible to self report in all studies. Consistent with other studies using the interRAI QoL instruments, any records with either missing or non-response values on greater than 50 percent of items, were deleted from the data set (Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V., 2015).

Response options in both instruments ranged from 0 "never" to 4 "always" and in most studies, respondents had the option to skip questions, or rate them with a non-response option (don't know, prefer not to answer, not applicable). Skipped and non-response scores were totaled to calculate the missing/non-response rates by item and respondent group. When comparing across studies, this becomes problematic as non-response is not handled consistently across the 3 studies. In the NS study, both family and resident respondents have all 3 non-response options. In the BC study, residents may skip questions or use any of the 3 non-response options. Family members can skip questions but do not have the additional non-response options. In the ON study, both respondent groups were not able to skip questions but had the 3 non-response options.

When assessing agreement in ratings, this study used the positive response rate which is a combination of “most of the time” and “always” responses. This is also a consistent measure in other studies using the interRAI QoL instruments (Kehyayan V., 2015; Morris, et al., 2018).

Other measurements included in this analysis are missing and non-response rates, and specifically, the rates of the non-repsonse option “don’t know”. Within each summary scale, item ratings between residents and families were examined by reviewing the rank order of items, absolute and relative differences. To calculate absolute differences, the difference between resident and family member respective positive response rates was calculated at the item level. Relative differences within an item considered the family positive response rate as a percentage of the resident’s positive response rate. Absolute and relative variances for all items are provided in these appendices and reported below in the results by exception (>1.5).

Results

Analysis of non-response rates were performed by study, by respondent group and by item after combining the results from the three included studies. These results are presented in Table 4.1 and Figure 4.1. Rates of positive responses and agreement in those rates between resident and family members were examined on the combined data set within each of the five domain scales. Three of those scales pertain to a resident or family member’s perspective on personal aspects of quality of life (Social Life, Personal Control and Food) and the remaining two pertain to aspects of care and services (Caring Staff and Staff Responsiveness). Figures 4.1- 4.5 display the positive response rate (“most of the time” and “always” responses combined) for the items in each domain scale, by respondent group.

Rates of Non-Response Among Residents and Family

Table 4.1 displays the mean non-response rate by respondent group, in each of the three included studies. In the combined study data set, resident respondent groups had a mean non-response rate of 7.6% and family members 5.5%. Family members had a higher non-response rate than residents in two of the three included studies, with the highest non-response in the Nova Scotia study (17.4%). In the British Columbia study, residents were given the option to skip questions, or respond with three available non-responses; "don't know", "prefer not to say" or "not applicable". In that same study, family members were only able to skip questions and did not have the additional non-response options.

Table 4.1. Summary of Item Non-Response Rates by Study and Respondent Group

Study	Respondent	N	Mean Item Non-Response %	St.Dev	Min	Max
Nova Scotia	Family	364	17.4%	11.6	0.0	47.9
	Resident	315	6.3%	6.3	0.0	31.3
Ontario	Family	3,301	4.5%	6.5	2.0	47.9
	Resident	3,620	2.5%	5.5	0.0	47.9
British Columbia	Family	9,531	5.4%	9.7	0.0	47.9
	Resident	9,214	9.6%	10.2	0.0	47.9
Total	Family	13,196	5.5%	9.3	0.0	47.9
	Resident	13,149	7.6%	9.6	0.0	47.9

Figure 4.1 displays the non-response rates by item, shown for both residents and family members. Of the 15 items with the highest non-response rates for residents, nine were items from the Social Life Scale, two were from the Caring Staff Scale and four were standalone items

(staff know what they are doing, staff have time for me, there are enjoyable things to do on the weekend and having a special relationship with staff). Eleven of those items were also the highest non-response items for family member respondents. Items with high non-response rates for family included being able to express opinions without fear, being able to bath/shower when preferred, people asking for their help, and favorite foods being offered here. Residents and family members had the lowest non-response rates in the Staff Responsiveness Scale items. The correlation between non-response rates between these groups was moderate to strong (r=0.60).

Figure 4.2 looks specifically at the non-response code of “don’t know” across the 2 studies that included this as a response option for both residents and family members (Nova Scotia and Ontario). In the Resident Self-report instrument, these responses are typically viewed as ambivalent responses from residents and are scored with the middle value “sometimes”. This may not be an appropriate interpretation for family members and could inform future items on a family instrument. Many of the highest “don’t know” rated items among family members (> 10%), are subjective in nature and may be difficult for the family member to observe or experience themselves (e.g., opportunities for affection and romance, staff know what they are doing).

Figure 4.1. Combined Missing and Non-response rates by Item and Respondent Group in three Canadian Provinces (Family N=13,196; Resident N= 13,149)

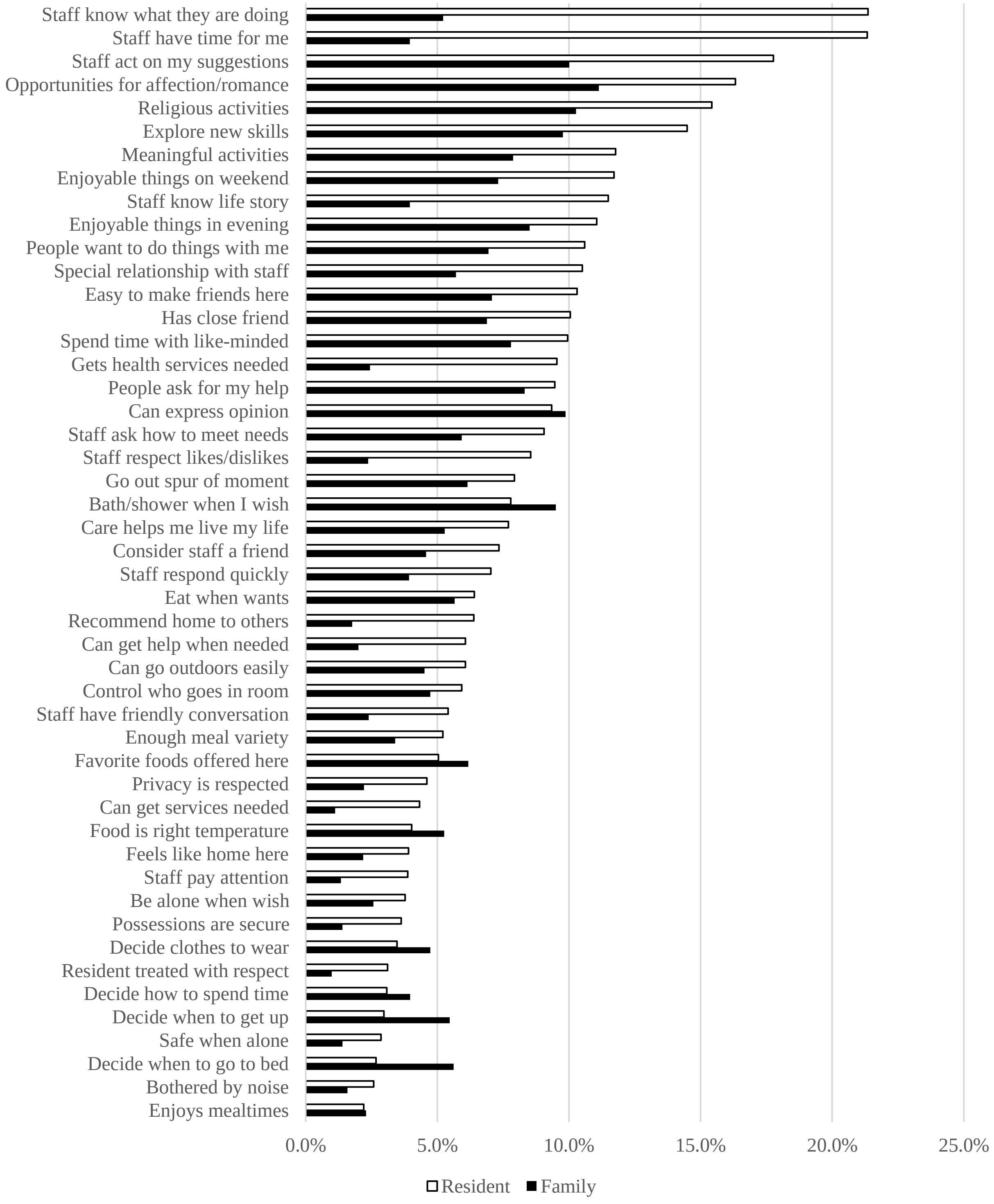
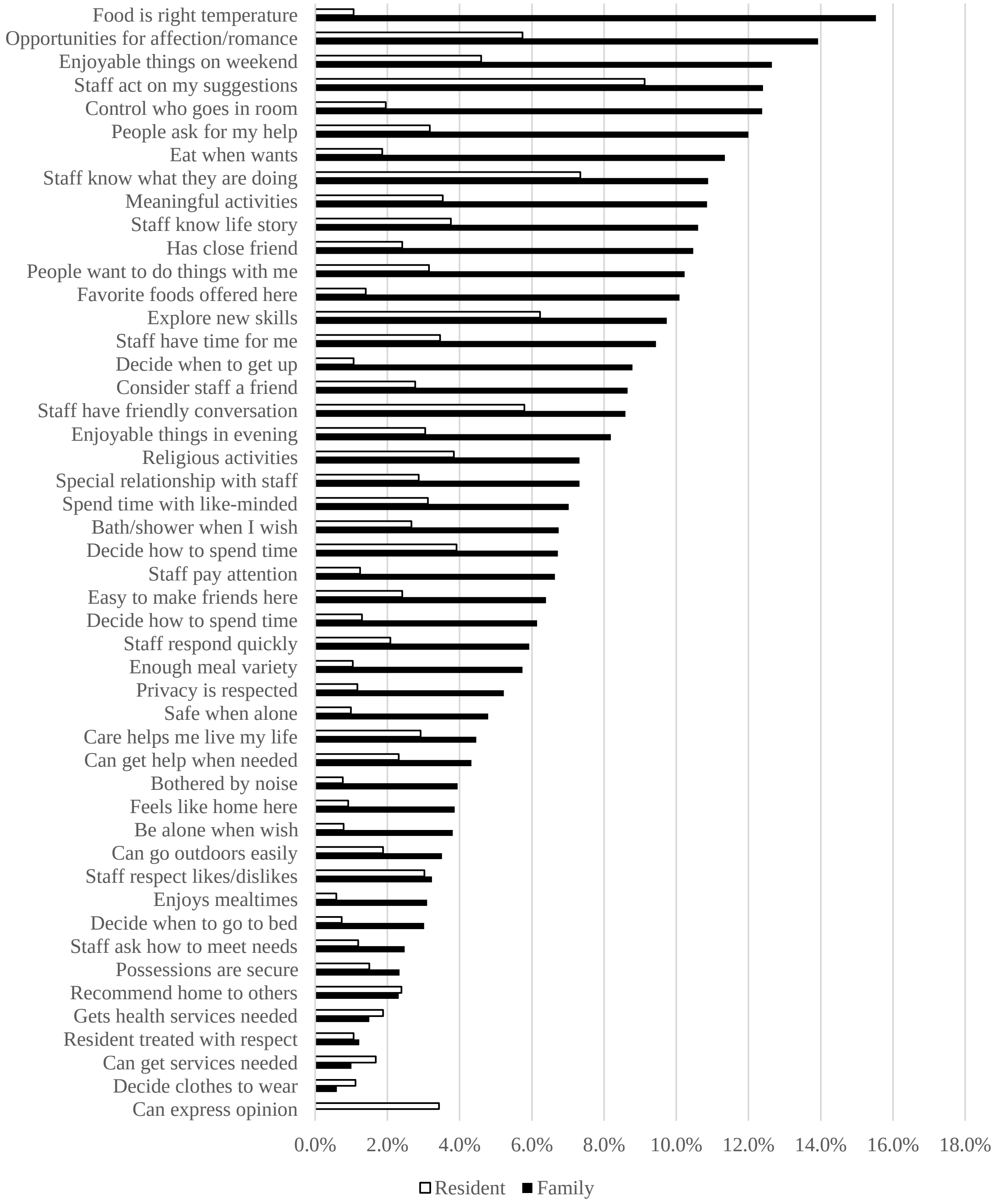


Figure 4.2. "Don't Know" Response Rates by Item and Respondent Group in Nova Scotia and Ontario (Family N=3,676; Resident N= 3,935)



Positive Response Rates Among Residents and Family Members

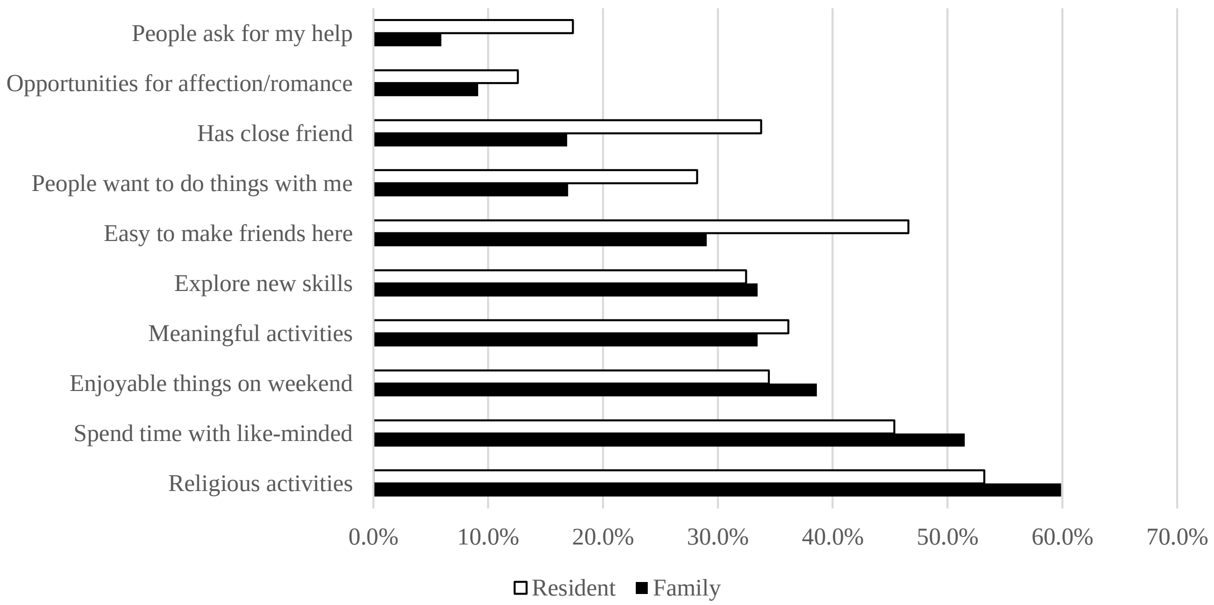
Positive Response Rates- Social Life Scale

Figure 4.3 describes the 10 items included in the Social Life Scale, which includes statements regarding participation in available activities in the home, engagement with others and exploring new skills. Among resident respondents, at least one third reported these statements as true “most of the time” or “always” on six of these 10 items. Family members also rated six of 10 items with one third or higher rating “most of the time” or “always”. Family member ratings were higher than resident ratings on two of the 10 items, lower than resident ratings on four items and within +/- 5% on four items. The items with the highest absolute variance were also among those with higher relative variance. For example, enjoyable things to do on the weekend had the highest relative variance between residents and family ratings, at 1.22. Social Life is the lowest rated scale among both residents and family members.

When rating whether they found it easy to make friends in the home and whether they had a close friend in the home, residents responded positively more often than family members did. These two items reported the largest variances between resident and family ratings in the Social Life Scale, with differences between their ratings of 17.6% and 16.9%, respectively. Residents also reported higher scores than family members regarding their opportunities for affection and romance in the home although this was the lowest scoring question in the Social Life Scale for both respondent groups. Residents also reported higher positive responses on whether others in the home ask them for help and people wanting to do things with them.

Residents scored slightly lower on whether they were able to explore new skills (32.5%) than family members did (33.5%) and this item had the smallest gap between residents and family members. Compared with family, residents also rated less positively their ability to participate in religious activities although this was the highest rated item for both respondent groups in the Social Life Scale. They also scored lower than family members on spending time with like-minded individuals and having enjoyable things to do on the weekend.

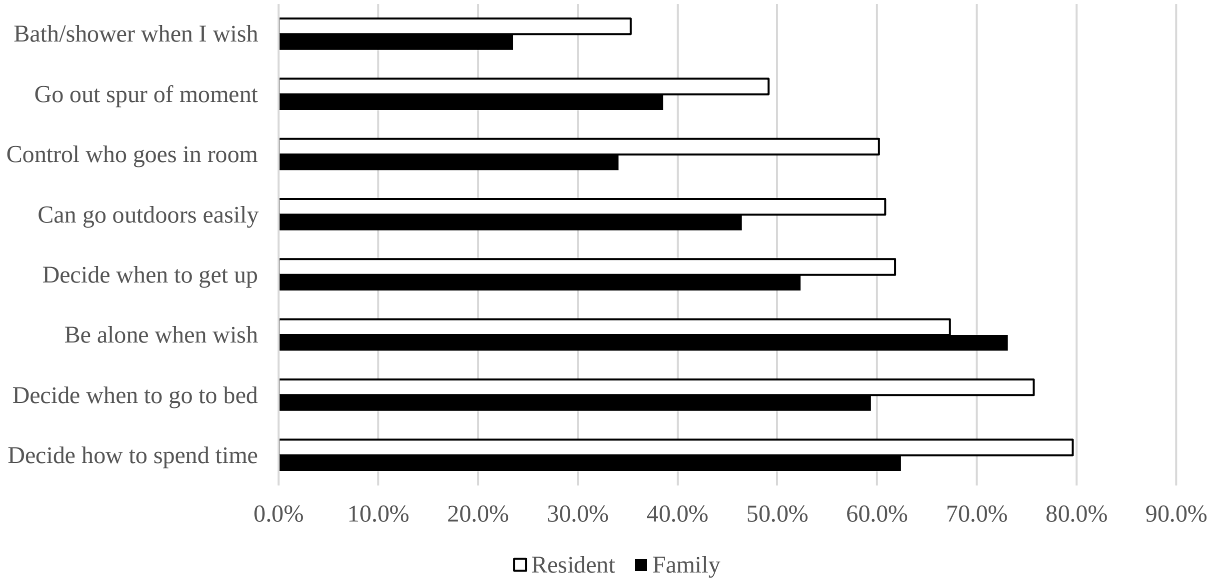
Figure 4.3 Social Life Scale: Percentage of Residents and Family respondents reporting statements to be true "most of the time" or "always" in in three Canadian Provinces (Family N=13,196; Resident N= 13,149)



Positive Response Rates – Personal Control Scale

The Personal Control Scale includes eight items that describe choices residents make without the assistance of others and their level of control over how they spend their time or move about the facility. Figure 4.4 displays these items. Family members had lower rates of positive response ("most of the time" or "always") than residents on all but one of these items (be alone when wish). For that item, residents rated positively 67.3% of the time and family members 73.1%- over a third of family members (34.7%) said the resident could "always" be alone when they wish. This item had the smallest gap between resident and family positive ratings and is the highest rated items from family respondents. In terms of relative variance, all items in this scale were below 1.5.

Figure 4.4. Personal Control Scale: Percentage of Residents and Family respondents reporting statements to be true "most of the time" or "always" in three Canadian Provinces (Family N=13,196; Resident N= 13,149)



Six of the personal control scale items had resident positive scores of greater than 50% and four had positive scores above 50% among family members. The greatest difference between resident and family positive response rates was regarding whether the resident had control over who came in their room. Residents responded most positively to whether they decide how to spend their time, at 79.6%. Family members responded positively to that statement 62.4% of the time. Similarly, when asked if they decide when to go to bed, residents responded positively 75.7% of the time and family members 59.4%. While residents felt they had autonomy at bedtime, they felt less so regarding their morning routine. 61.8% responded positively to whether they decided when they got up and 52.3% of family members.

The three items with lowest positive ratings in this scale were regarding whether the resident could easily go outdoors, and whether they could go out on the “spur of the moment”. The lowest rated item for both resident (35.3%) and family (23.5%) respondents was regarding having a bath or shower when they wanted.

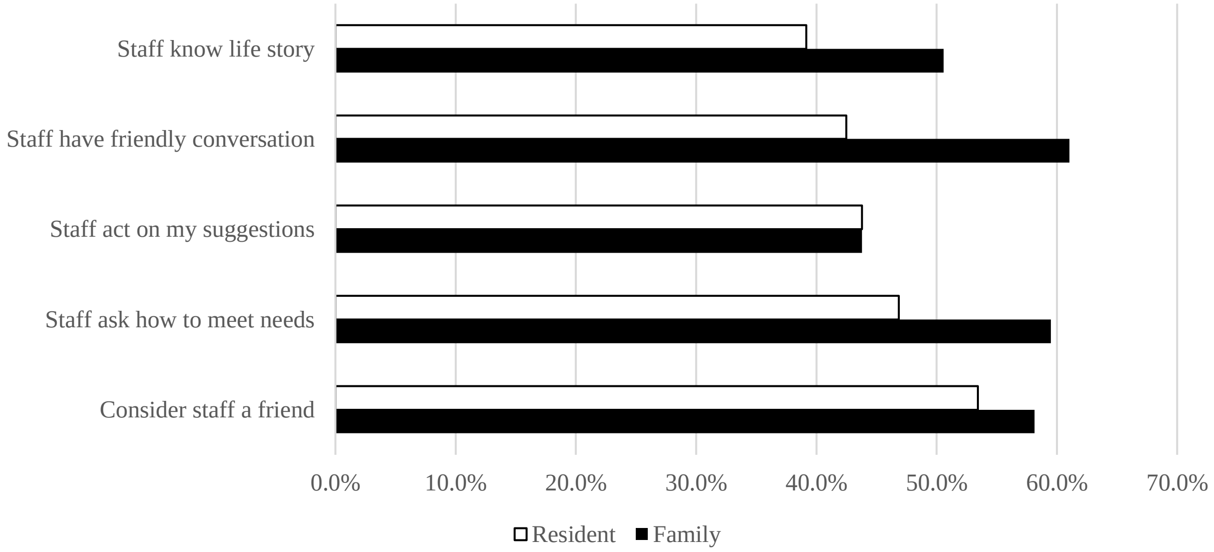
Positive Response Rates - Caring Staff Scale

The Caring Staff Scale includes five items regarding the resident’s relationships and interactions with the staff in the home. Figure 4.5 displays the percentage of positive responses to those five items, among resident and family members. Family members responded more positively than residents on three of these items and were within +/-5% of resident responses on the other two. There was marked agreement between residents and family members on whether the staff acted on their suggestions. Each responded positively 43.8% of the time, with a similar distribution of “most of the time” and “always” responses. All items in this scale had a relative variance over > 1.0, with ‘staff have friendly conversations’ having the highest at 1.44. This is a lower rated item among both groups.

The highest rated item among family members was regarding having friendly conversations with staff. Family members responded positively to this item 61.1% of the time, while residents responded positively 42.5%. The highest rated item among resident responses was “I consider a staff member a close friend”. 53.4% of residents responded positively to that statement, and family members mostly agreed, with 58.1% responding positively.

There 46.9% of residents who responded positively regarding whether staff asked them how best to meet their needs, while 59.5% of family members said the same. The lowest rated item among resident respondent, was regarding the staff knowing the resident's life story. Only 39.2% of residents responded positively to that item and just slightly over half of family members (50.6%).

Figure 4.5. Caring Staff Scale: Percentage of Residents and Family respondents reporting statements to be true "most of the time" or "always" in three Canadian Provinces (Family N=13,196; Resident N= 13,149)



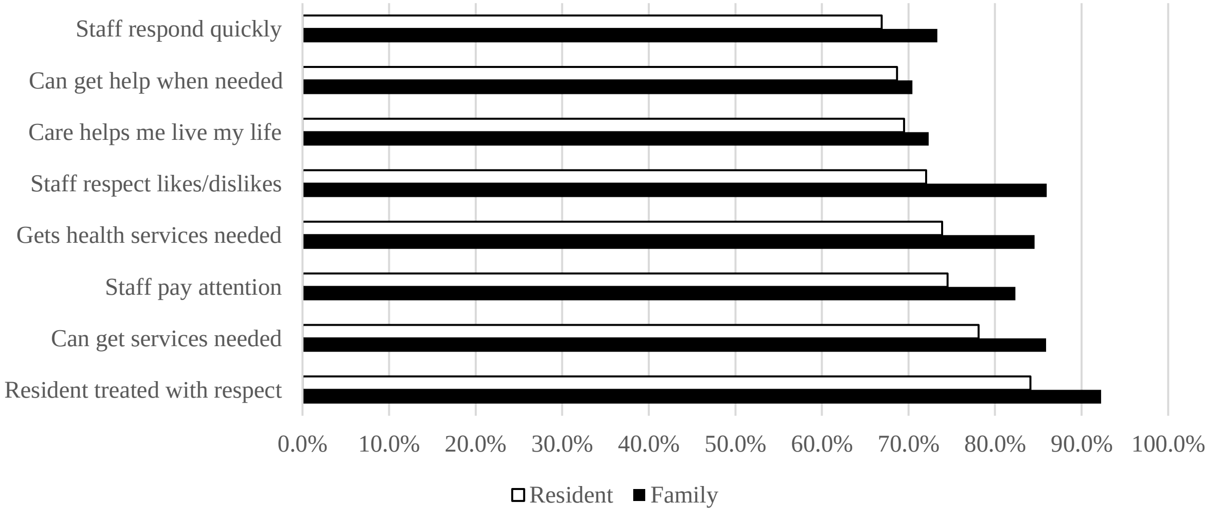
Positive Response Rates - Staff Responsiveness Scale

Of the five scales in this instrument, the Staff Responsiveness Scale has the highest ratings among both residents and family members. Across all eight of its items, residents have lower positive rates than family members at an average difference of 7.4% less. More than 70% of family members responded positively, on all eight items and more than 70% of residents scored positively on five of them. Family members scored within +/-5% of residents on two of the eight items. The items in this scale and their rates for positive responses, are shown in Figure 4.6.

The top two rated items were the same for both residents and their family members- the resident being treated with respect by staff and getting the services they needed there. Responses from both residents and family members also indicated that staff pay attention to the residents, respect their likes and dislikes and that they can get the health services they need there. All eight items in this scale had a relative variance over > 1.0 but none exceeded 1.5.

The lowest scoring items were regarding the timeliness of help and care provided in the home. Residents and family members responded similarly regarding whether the care provided helps them live their best life (69.5% and 72.3% respectively), that they can get help when they need it (69.5% and 72.3% respectively) and that staff respond quickly when they need help (66.9% and 73.3% respectively).

Figure 4.6. Staff Responsiveness Scale: Percentage of Residents and Family respondents reporting statements to be true "most of the time" or "always" in three Canadian Provinces (Family N=13,196; Resident N= 13,149)

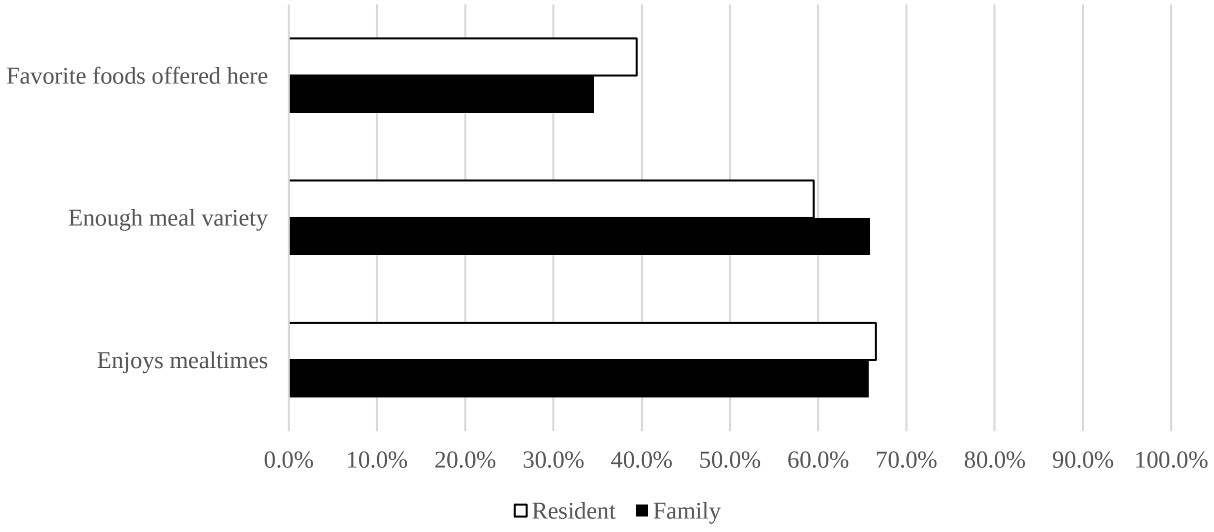


Positive Response Rates – Food Scale

There are three items comprising the Food Scale, which explore quality of life related to food services in the home. Figure 4.7 shows the percentage of “most of the time” and “always” responses to these items, for residents and family members. Both residents and family members responded more positively about enjoying mealtimes, with 28% of residents stating that was “always” true for them. Family members responded more positively about meal variety at 65.9%, than residents did at 59.5%. None of the three items in this scale had a relative variance of > 1.5.

The lowest rated item for both residents and family members were about their favorite foods being offered at the home. Less than 40% of both respondent groups responded positively to that statement. Of the three items, family members scored higher than residents on one item, lower than residents on one item and were within +-5% on the remaining item.

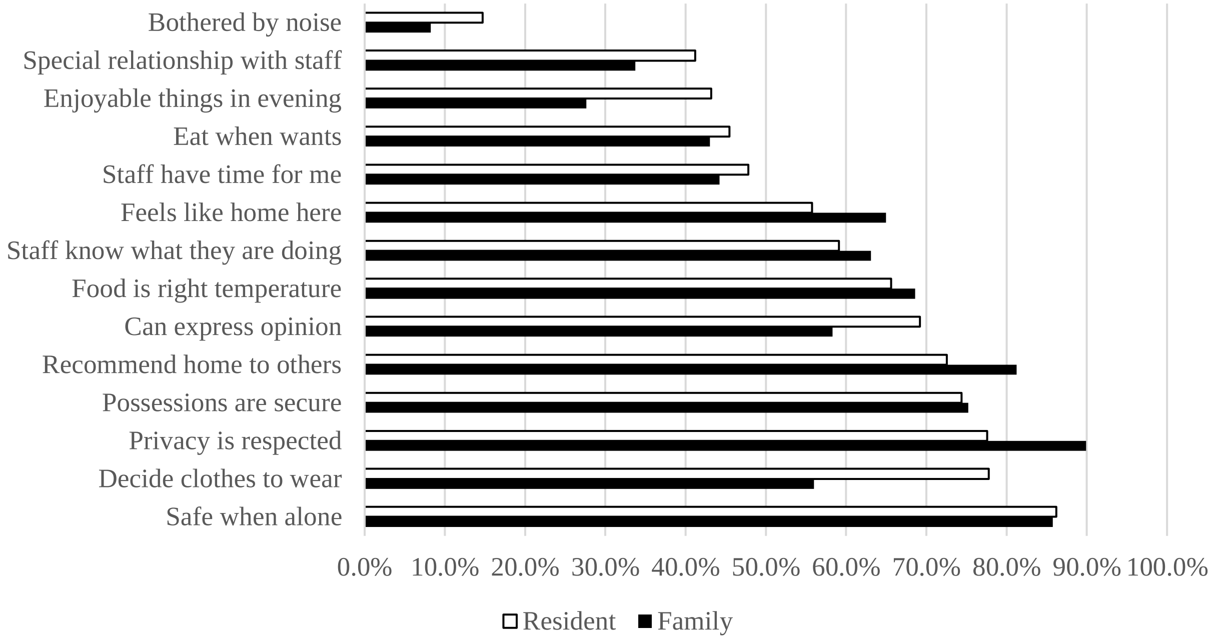
Figure 4.7. Food Scale: Percentage of Residents and Family respondents reporting statements to be true “most of the time” or “always” in three Canadian Provinces (Family N=13,196; Resident N= 13,149)



Positive Response Rates- Standalone Items

There are 14 ‘standalone’ items that are not included in one of the six summary scales of the Version 1 interRAI Family QoL-LTCF instrument, as shown in Figure 4.8. These items span multiple areas of Quality of Life, including aspects of the living environment (e.g., safety and security, noise), relationships with staff and autonomy. The four items with the highest positive rating scores related to safety and security (safe when alone, possessions are secure), autonomy (decide clothes to wear, privacy is respected). Lower rated items related to social life in the home (enjoyable things to do in the weekend), food (eat when wants) and aspects relating to staffing (staff have time for me, special relationship with staff). This is somewhat consistent with how the summary scales performed, with the food and social life scales performing lower than the autonomy scale. The item ‘bothered by noise here’ has the lowest positive score, which is desirable (less people rated that statement as true). Through that lens, this is the highest rated item in this group.

Figure 4.8. Standalone Items: Percentage of Residents and Family respondents reporting statements to be true "most of the time" or "always" in three Canadian Provinces (Family N=13,196; Resident N= 13,149)



Unsurprisingly, the group of standalone items had a larger range of variation in positive response rates between resident and family member respondents, ranging from a difference of -12.3% (privacy is respected), to 21.8% (decide which clothes to wear). Items that had the most agreement between groups were: safe when alone (0.4% difference), possessions are secure (-0.8%), eat when wants (2.4%) and, food is right temperature (-3.0%). Residents scored higher than family members on items including: decide which clothes to wear (21.8% positive difference); can express opinion (10.9%) and; enjoyable things in the evening (15.6%). Areas where residents scored lower than family members included: privacy is respected (12.3% negative difference); feels like home here (10.9%), and I would recommend this home to others (8.7%).

Summary of Results

Resident and family responses to similar items were examined both in terms of their rates of missing/non-responses and rates of positive responses. Missing/non-response rates are difficult to compare across studies, as response options were handled different in each. Resident rates ranged from 2.5% to 9.6% and family members ranged from 4.5% to 17.4%. The overall missing/non-response rate across all 3 studies for residents was 7.6% and 5.5% for family members. Both respondent groups had the highest rates of missing/non-response on items on the areas of social activities and staff relationships. While residents and families tended to have the highest total missing/non-response on the same items, their rates of responding with “don’t know” were different by item. This may indicate a different interpretation and meaning to that response for family members.

When responding to items, there is variation in positive response rates between residents and family members with their rates agreeing within plus or minus five percent of each other on only 16 of the 48 items. Both groups had the highest positive response rates in the area of staff responsiveness and the lowest rates in social activities. While they had the same highest and lowest scoring areas, family members tended to respond more positively than residents about staff responsiveness. In social activities, the opposite is true: residents respond more positively to these items than family members do.

Discussion

The levels of agreement seen among LTC residents and family members to the quality of life items, support previous findings that these groups bring different perspectives and place different levels of importance on the various domains in resident quality of life (Pickard & Knight, 2005; Godin, Keefe, Kelloway, & Hirdes, 2015). Only one-third of the 48 items had a difference within +/- 5% between the resident rate and family members. Assuming equivalence between the groups is not appropriate. Relying on the family member to act as a proxy for the resident living in the nursing home is not a recommended practice to approximate the resident's perceptions (Kane, et al., 2005; Kothari & Kirschner, 2006).

Family members can, however, provide unique and valuable contributions based on their own perceptions and experiences in the home. Family members can and do advocate for residents and influence quality of care (Legault & Ducharme, 2009; Baumbusch & Phinney, 2014). Their experiences in the home, relationships with staff and own views of resident experiences, can provide valuable input and a more comprehensive view on quality of life in the home. The unique perspectives of family members provide important additional information that broadens the capacity to evaluate facility performance.

Residents and family members tended to have similar ratings on items that are less subjective in nature, or observable by others. Of the 16 items with agreement within +/- 5%, the majority were lower scoring items, with less "always" responses across both respondent groups. 11 of the 16 items had a percentage of "always" responses that was less than the mean "always" rate for residents. Residents may be more likely to discuss dissatisfaction or concerns about specific areas with their family members, creating alignment in their perspectives. Family members may also observe or experience these areas of opportunity more directly during their time and interactions with the LTC home. Conversely, the item that residents rated "always" the most on out of all 48 items, whether they feel safe when alone, had a very low variance with family member rates of 0.5%. Perhaps the items residents feel most strongly about, either positively or negatively, are the ones that they are most likely to discuss with their family members for support. These results may also be indicative of the paramount importance resident safety often has in the eyes of both the staff, the LTC home operator, the family member and resident themselves.

Family members may introduce their own bias when responding to items about the resident's quality of life. In proxy reports, families are asked to respond about the resident's quality of life as they believe the resident would. This is a complicated and troublesome request as quality of life is viewed in the context of personal values (WHO, 2023), which are difficult to set aside within ourselves, or assume correctly of others. Based on the inherent issues with that approach, the studies included in this research asked families to respond about the resident's quality of life based on their own perspective.

In addition to being informed by what they observe or discuss with the resident, family member views may also be influenced by the priorities, expectations, and experiences of the family member themselves. For example, family members largely scored the items in the Social Life domain scale lower than residents did. Family members may have different expectations and priorities around social engagement and what is meaningful, which may be reflected in their lower ratings. For example, 46.6% of residents responded positively to whether it was easy to make friends in the nursing home, while only 29% of family members did. Similarly, 33.8% of residents responded that they had a close friend in the home compared to 16.9% of family members. Family members may have different expectations of what a close friend is at their stage of life, or about what qualifies an environment as one where it is "easy" to make friends.

This study demonstrates that family members provide a unique and valuable perspective on these areas, which can help drive quality and process improvements. The three domains where residents and family member ratings were most aligned- Caring Staff, Staff Responsiveness and Food- appear often in available family-oriented surveys on quality of life in LTC (Norman, 2023). Security is another domain that is common in family-oriented surveys, and the related two items in this instrument (feels safe when alone, feels possessions are secure) had high agreement between residents and family members.

Limitations

A wide range of missing/non-response rates was found between studies and between respondent groups. Some of these findings were inconsistent with previous studies at least in part because the British Columbia study offered non-response options to residents, but not to family members. This meant that unless family members skipped a question, they provided some kind of answer. Some studies allowed respondents to skip questions, but others did not. This could potentially skew not just the non-response rates but the positive response rates as well, as family members may rate items differently (positively or negatively) if they do not feel prepared to respond.

Consistent background items were not available for each of the three studies, which limited the ability to evaluate relationships between ratings and factors that emerge in the literature as potential factors that influence family perspectives. This includes visitation frequency, relationship to the resident, and their length of stay in the home (Kehyayan V., 2016). This is an opportunity for further research and may provide some additional validity to the family instrument.

Missing responses were not included in this analysis, rather than being handled by methods such as multiple imputation or listwise deletion. Due to the high and varied rates of missing data and its importance as a variable of interest, missing data were calculated and then ignored when calculating positive response rates. This introduces some uncertainty into the findings of this analysis, as high missing rates may indicate bias in the results (Perneger, Chamot, & Bovier, 2005). Consistent with other interRAI measurement protocols, any responses where > 50% of the items have missing/non-response were deleted from the data, which may limit this potential bias.

A final limitation of this study lies in the independent nature of the data collection between residents and family members. Responses were not linked within family units, limiting any exploration or conclusions to be drawn from the quality of life perspectives within those relationships. Linking residents and families and even further, the resident's clinical assessment data, could be very informative, particularly as it relates to how the perspectives and ratings of each group vary depending on certain disease states, levels of communication, clinical complexity, and family relationships.

Conclusion

The first aim of this study was to explore rates of non-response from nursing home residents and family members responding on similar quality of life items. In two of the three studies included, family members had higher non-response rates than residents, which is consistent with previous research (Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011; Godin, Keefe, Kelloway, & Hirdes, 2015). The third study contained inconsistent handling of non-response between respondent groups, resulting in lower non-response rates among family respondents. Future instruments should handle non-response in a standardized way, supported by technology used to administer the survey. The author suggests all mandatory questions with no skipping, but consistent application of non-response options; don't know, not applicable, prefer not to answer.

Despite this inconsistency, this analysis demonstrates that some domain scales and items had consistently high rates of non-response among family members and sometimes residents themselves. For example, the high non-response rates from family members in the Social Life domain scale, combined with the consistently lower family member scores compared to residents, suggest that the perspectives family members are providing in this area may be unique and distinct from resident perspectives. This additional perspective may prove useful in exploring ways to better engage residents and their families in more meaningful social activities.

The second aim of the study was to assess quality of life ratings among residents and families, and to what extent those ratings are in agreement. This study demonstrates that residents and family members both provide valuable insight into quality of life in nursing homes. In some domain scales, such as Staff Responsiveness, residents and family members have consistently high positive rates. This may mean family members are assessing staff responsiveness similarly to residents, with similar priorities and perspectives. Alternatively, family members may be considering different perspectives and interactions when rating staff responsiveness, providing useful feedback to decision-makers about the multiple ways staff respond.

This study adds to the literature regarding family perspectives on QoL in LTC homes, as measured through a validated, internationally used instrument. Having a standardized, valid instrument to measure family perspectives will add to the feedback from residents themselves about their QoL, helping healthcare workers, administrators and policy makers make better decisions about overall quality in the home. Leveraging the relatively widely used interRAI QoL instrument in this study provides insight into which items may be most appropriate and useful as family QoL tools continue to be evolved.

Chapter Five (Manuscript #3)

Capturing the Unique Voice of Families- Developing a Quality of Life Survey for Families of Nursing Home Residents

Background

Family members of those living in long-term care facilities are increasingly recognized as valuable partners in the delivery of high quality, resident-directed care. Engaged family members are a rich and credible source of information and insight into resident care, an active contributor to resident's quality of life and are often a direct and essential provider of care and support for their loved one. Studies have upheld the consistent and important roles families play in the LTC setting (Port, et al., 2001; Baumbusch & Phinney, 2014; Chamberlain, S. A., 2023). The level of support they provide and their engagement during the resident's stay are correlated with family perspectives and engagement. Yet, the COVID-19 pandemic and ensuing restrictions and protocols hindered reliable and meaningful engagement and presence of these essential care partners in LTC. This absence left lasting effects on family members, the healthcare workers in those homes and on the quality of life and quality of care for residents (Chamberlain S. e., 2023; Cooke, Wu, Bourbonnais, & Baumbusch, 2023).

The relationship between family involvement and resident outcomes (Durkin, Shotwell, & Simmons, 2014; Li, Li, & Tang, 2016; Mukamel, Saliba, Weimer, & Ladd, 2021) points to the importance of obtaining their perspective as partners in support of LTC residents. Family members often continue their caregiving role after a resident is admitted into the LTC facility, assisting with regular caregiving tasks such as meal assistance, activities of daily living and psychosocial support (Gaulgler, 2005; Baumbusch & Phinney, 2014; Cohen, et al., 2014). As such, family members observe and participate in care delivery and often influence resident decisions or make decisions directly. Previous efforts aiming to understand and describe family engagement and perspectives in LTC have shown that family members do not always agree with resident's self-reported views on their quality of life (Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011; Godin, Keefe, Kelloway, & Hirdes, 2015; BC Office of the Seniors Advocate, 2017). Additionally, family members and residents may place different levels of importance on various aspects of quality of life. Lastly, while family members can provide reliable and meaningful perspectives on items of similar importance to residents, they also have their own perspectives on and experiences with the LTC home's services and facilities. The unique aspects of being a LTC resident's family member (e.g., visiting experience, engagement in care plan discussions) provide helpful insight into process and quality improvement opportunities, advocacy, policy change or clinical intervention. Understanding what factors influence their perspectives and having opportunities to address gaps in engaging family members is of vital importance as many LTC facilities in Canada increasingly rely on the support and presence of family members (Chamberlain S. A., 2019; Yuting, et al., 2023).

Quality of Life vs. Quality of Care

There is some debate on whether measurement of LTC family member perspectives should focus on quality of life or quality of care. There have been substantial strides forward in the objective quality indicators for LTC homes, based on standardized assessments such as the interRAI instruments (Zimmerman, DR, 2003; Morris, et al, 2019; Frijters DH., 2013). Facilities who leverage these standardized quality indicators may find that while they have an evidence-based description of quality of care in various aspects of their home, they do not capture the subjective perspectives and experience of residents and family members. The interRAI Quality of Life

Resident Self-Report for LTC Facilities captures the subjective domains that influence a resident's quality of life (e.g. satisfaction with meals, meaningful activities, feeling of belonging), beyond the quality of care they receive (Morris, et al., 2019). Given the subjective and individual nature of assessing one's perception on their own quality of life, a direct self-report from residents is the "gold standard" approach, including for LTC residents with moderate cognitive impairment. Family members are often asked to speak as a proxy for residents living with more severe cognitive impairment, but it must be recognized that many aspects of QOL are perceive in ways that are uniquely personal or idiosyncratic. Family members views are valuable in their own right with unique perspectives on the nature of the experience in LTC homes. To provide an additional consumer perspective on quality of life in LTC, the goal of this study was to develop a Version 2 of the Quality of Life Family Survey for LTC Facilities building off of the original interRAI Family QOL survey. The aim is to establish a set of core items that could be reliably used in both resident and family surveys, along with a set of additional, unique items that are of particular relevance to family members.

Previous Stages of Survey Development

The interRAI Self-Report QoL Survey instrument (Morris, 2018; Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V, 2015) was developed to collect standardized data describing resident perspectives on quality of life in LTC facilities. The Resident QoL survey has 50 items, which are grouped into 10 domains reflective of items on Maslow's hierarchy of human needs (e.g., food, safety, meaningful relations, learning). Early psychometric testing showed that this instrument could be self-reported by LTC residents, including those with moderate cognitive impairment (Kehyayan V, 2015; Kehyayan V, 2016). The interRAI Resident QoL survey has additional appeal as a companion to the integrated suite of interRAI instruments, which are widely used in LTC facilities across Canada, the United States, and internationally (Frijters DH., 2013; Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V, 2015; Morris, et al., 2018).

In their 2015 study (n=399 family responses), Godin et al. measured quality of life across the various perspectives of residents, families, and staff, using a consistent core survey (Godin, Keefe, Kelloway, & Hirdes, 2015). Using the interRAI Resident QoL instrument, the team modified items slightly to create family and staff survey versions. For example, the Resident QoL Survey item “I can get my favorite foods here” was changed to “My family member can get their favorite foods here” for the Family QoL Survey. The study showed some quality of life domains where residents, staff and families shared perspectives, but largely reiterated the different perspectives each participant group has on quality of life in the LTC home.

The modified Family QoL Survey was field tested again in 2017 as part of a broader survey distributed by the Office of the Seniors Advocate regarding Residential Care in British Columbia, Canada (BC Office of the Seniors Advocate, 2017) and in 2018 with family members in a subset of LTC homes in Ontario, Canada (unpublished results). In the 2017 BC study, the 50 items from the Family QoL instrument were administered to family members of LTC residents in the province (n=10,100) along with 50 additional items added by the committee based on a review of the evidence. Resident QoL version was administered to residents in those homes. Analyses of these studies informed the selection of core survey items that would be paralleled between the resident and family survey versions.

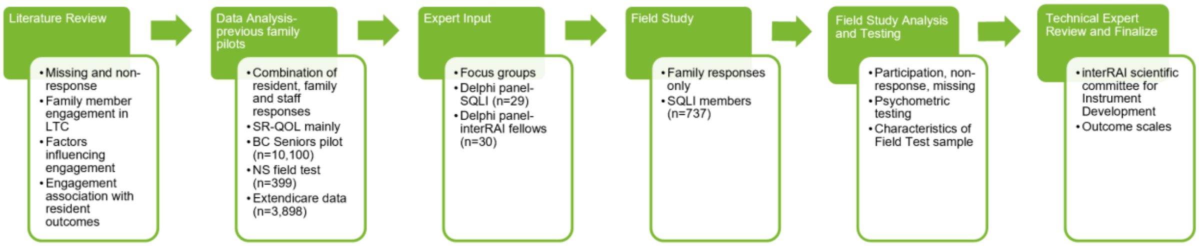
Selecting the "Family" Respondent

Similar to previous studies leveraging the previous Family QoL Survey, the new interRAI Family QoL Survey refers to 'family' but does not require that the respondent be an actual family member. The survey targets the 'family member' as being a family member, friend or socially engaged party who is most involved with the care of the resident. This person is not necessarily the person legally responsible for making healthcare decisions for a resident and is often the person who is most often present and visiting in the home. Survey administrators within the home determine, based on existing records, who the respondent is for each resident.

Design and Methods

The development of the new interRAI Family QoL Survey instrument followed a methodical process, summarized in Figure 5.1: leverage existing literature and study data to inform a draft survey; collect expert academic, sector and operational input on the draft; field test the draft survey; conduct psychometric analysis of the field test data; make adjustments to the draft; review the survey with an expert technical panel; and finalize the survey content with the interRAI Instrument and Systems Development Committee.

Figure 5.1. interRAI Family QoL Survey Development Process



Formative Research

Formative research was instrumental in developing the new interRAI Family QoL Survey. A literature review was conducted early in this study. The literature review focused on the various roles family members play in LTC homes (Friedemann, Montgomery, Rice, & Farrell, 1999; Williams, Zimmerman, & Williams, 2012; Baumbusch & Phinney, 2014), how those roles change over time or at key points during a resident's time in a LTC home (e.g. on admission, after a critical incident, during palliative care) (Gaugler, Leitsch, Zarit, & Pearlin, 2000; Sussman & Dupuis, 2012; Afram, Verbeek, Bleijlevens, & Hamers, 2015), factors that influence family engagement and experiences (Gwyther, 2001; Cohen, et al., 2014; Barken & Lowndes, 2018) and the impact that engagement and experience can have on outcomes and quality of life for residents (Durkin, Shotwell, & Simmons, 2014; Williams, Straker, & Applebaum, 2016; Kehyayan V, 2016; Li, Li, & Tang, 2016). This collective evidence formed the basis for the unique items and experiences that matter to family members, what background information should be collected about respondents, and provided insight into the expectations family members have when interacting with the LTC home.

The literature review also explored evidence related to measuring family member quality of life in LTC and associated limitations or issues. Previous studies demonstrated the value of having at least a partially equivalent tool by which to measure various quality of life perspectives in LTC (Crespo, Bernaldo de Quiros, Gomez, & Hornillos, 2011; Godin, Keefe, Kelloway, & Hirdes, 2015; Oosterveld-Vlug, Onwuteaka-Philipsen, Pasman, van Gennip, & de Vet, 2015). There is also ample evidence to warn against relying on proxy sources, including family members, to assess something as personal and subjective as ones' quality of life (Kane, et al., 2005; Pickard & Knight, 2005), which formed the core item/unique item approach taken in the development of the new Family QoL Survey.

Data Analysis- Previous Studies

Data using the Version 1 interRAI Family QOL instrument was collected in three previous studies (Godin, Keefe, Kelloway, & Hirdes, 2015; Office of the Seniors Advocate, 2017; Norman, 2023). This provided an additional data source to inform the early development of the new Survey. In total, 13,196 family responses across 48 items were collected, each with corresponding resident responses. Evaluating missing and non-response rates gave some insight into items to consider for a core item- one that is in both the Resident and Family versions of the survey. For example, an item may have had relatively low missing/no value rates in resident respondents, but relatively high missing/no response rates among family respondents. While this may not always indicate a poor item for a family survey, it was used as an indicator to consider items for appropriateness on the family survey.

To provide additional context into the results of various items across different perspectives, the variance between resident and family scoring of items was also evaluated. Using a positive percent score, meaning the percentage of respondents who answered with one of the top two possible responses (‘most of the time’ or ‘always’), items were evaluated based on the measurement equivalence between resident and family results. The analysis of missing and non-response rates, along with the variance in scores between resident and family responses, identified potential domains or items that family members may not be able to reliably assess based on their observations and experiences. For example, items or domains that rely more heavily on subjective thoughts (e.g., autonomy and control) tended to have higher missing values from family members, as well as lower scores from family members. This analysis was considered during the next step in the process, an expert review.

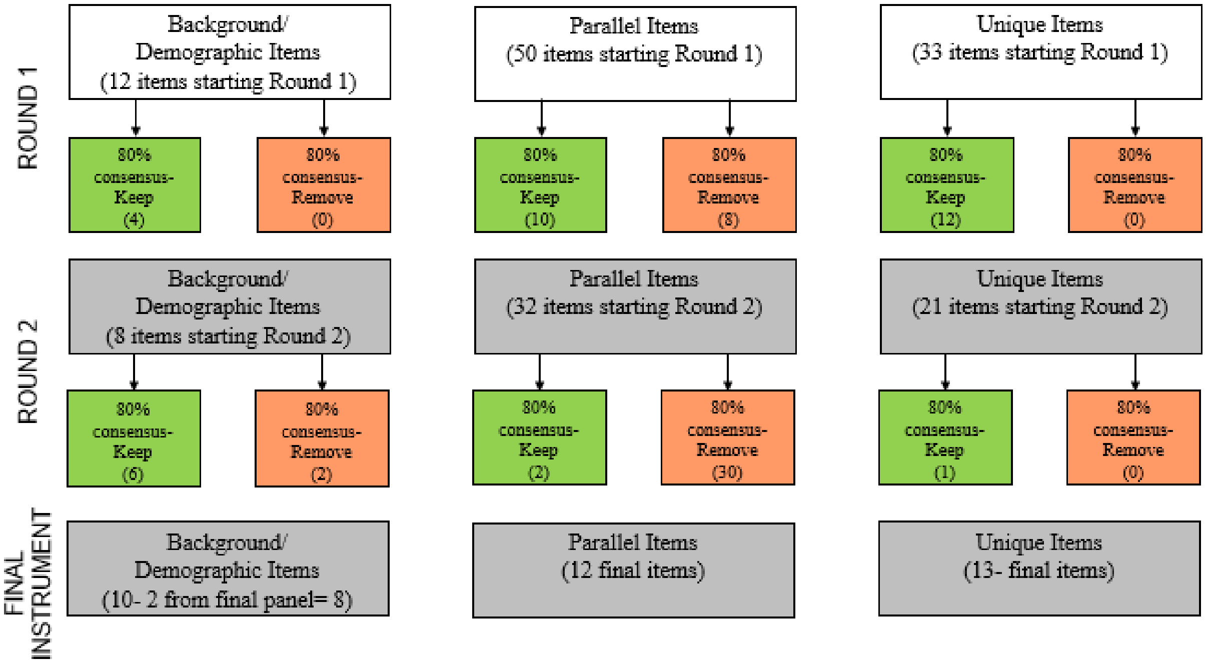
Expert Input

As a last input session before asking experts to vote on draft Family QoL Survey items, a focus group activity was conducted to gather general feedback on the previous version of the Family QoL Survey. As this work was being conducted between the initial waves of COVID-19, the project team was unable to meet with family members directly for input. A representative sample of administrators in Long Term Care facilities across Canada and the United States, made of members in the Seniors Quality Leap Initiative (Hirdes JP, 2020) participated in a focus group that gathered unstructured feedback about: any items or topic domains missing some the current version of the survey; any items in the current version of the survey that should stay but be revised; any topic or domains that should be removed from the survey and any other feedback they have about the development of the survey.

Next, the Delphi technique was used to gain consensus from an invited panel of 59 LTC experts. The Delphi technique uses structured and iterative rounds of consensus building from experts. Results from each round are summarized and used in subsequent rounds for consideration (Eubank, 2016). Responses are anonymous to allow for candid and honest feedback without pressure to conform to the group. In this process, a panel comprised of LTC professionals and clinicians (physicians, specialists), LTC and aging researchers including international interRAI fellows, LTC administrators and LTC advocacy and quality representatives was convened. Participants were existing members of Seniors Quality Leap Initiative, a consortium of high-quality and high-performing LTC and seniors care organizations in North America. This process is summarized in Figure 5.2.

In each Delphi round, panel members were presented with each item in the old Family QoL Survey, along with corresponding missing/non-response values and scores by resident and family responses. They were also given a summary of any applicable evidence or other input relevant to each item or domain. With this information and applying their own expertise, panel members were asked to vote on each item. They had the option to either: 1. Keep item, as is, 2. Keep item, with changes, or 3. Remove item. Panel members also voted on demographic and background questions to include. Respondents were then asked to rank the items they voted to keep, in order of importance and had an opportunity to provide comments on each item, including suggested wording changes. In the second round, any items with 80% consensus were modified and provided to the panel for consideration. Based on focus group feedback, another goal of the study was to narrow the family QoL Survey down to 25 items, split roughly evenly between core items that paralleled the resident survey and unique family items. This was accomplished after the second Delphi panel round, with 80% consensus from the panel. To finalize the item set, wording choices and alignment with existing interRAI instruments, a smaller panel was leveraged. The senior interRAI country fellows for Canada and the United States finalized the top 25 items in a real-time review of previous round results.

Figure 5.2. Delphi Technique Rounds and Count of Items Retained or Removed



The final items included in the new interRAI Family QoL Survey instrument are shown in Table 5.1, below. The final Delphi round with the senior interRAI fellow panel agreed on the eight displayed background items. These items are consistent with other interRAI instruments in many cases (province, couple, gender, age group, health status, length of stay) with two additions based on the literature regarding family quality of life measurements. Relation to the resident and average visits to the facility are both cited as relevant factors in the perceptions and quality of life for the resident's total circle of care (Kehyayan V, 2016; Shippee, Henning-Smith, Gaugler, Held, & Kane, 2017). This additional information about the family respondents may help inform quality improvement efforts.

Table 5.1. New interRAI Family QoL Survey Instrument Items by Item Type

Demographics/Background	Parallel Items to Resident	Unique Items to Family
Province, facility	Enjoys mealtimes	Family member is safe
Resident- part of couple	Enough variety in meals	Home is clean and pleasant
Resident/Family- gender	Possessions are secure	Best place to meet their needs
Resident/Family- age group	Can get help right away	Home is well managed
Resident- health status	Can be alone when wish	Trust staff to take good care of
Resident- length of stay	Can get services they need	Trust the info I receive from staff
Family- relationship to Resident	Would recommend site	Staff treat me with respect
Family- average monthly visits to facility	Staff pay attention	Have info needed about health
	Treated with respect	Know who to contact about care
	Staff respond quickly	Can visit when choose
	Participated in activities	Comfortable places to visit
	Has close friend	Participate in care decisions
		Consulted on changes care plan

Also consistent with other published interRAI instruments, the new interRAI Family QoL Survey instrument uses a 5-point ordinal scale with the same response categories as the Resident QoL Survey: (0) Never, (1) Rarely, (2) Sometimes, (3) Most of the time, or (4) Always. Respondents can also answer (6) Don't know or surveyors may code responses as (7) Refused or (8) No response/Cannot be coded.

Field Test Plan

To test the performance and psychometric properties of the new Family QoL instrument, a field test plan was developed. The goal was to test the new Family QoL instrument across a representative sample of LTC homes in Canada and the United States. Homes were recruited primarily through the Seniors Quality Leap Initiative (SQLI), as those members had input into the development of the new survey, were already familiar with interRAI instruments, and specifically the Resident Self Report (Hirdes JP, 2020). This familiarity reduced the learning curve for participating sites and simplified administration as many homes had existing infrastructure and mechanisms to administer an interRAI survey.

Homes were recruited to participate through an invitational letter with accompanying information. Individual home administrators selected family members to send the survey to, based on their existing distribution lists for family communication. Family members in this survey are defined as a "blood relative or other family member, close friend, substitute decision-maker or frequent visitor". In addition to the SQLI consortium, recruitment was facilitated through the Ontario LTC association, and the Francophone LTC consortium *Les Visionnaires*. This study was approved by the University of Waterloo Ethics Board (ORE # 42872) and information about consent was included in the recruitment letter. Consent was obtained during the completion of the online survey.

Results

Survey Development

The Delphi panel resulted in an instrument with 13 parallel items to the resident instrument and 12 items that are unique to the family member perspective on QoL. Several items were removed from the final instrument, including items related to autonomy and control and most items related to food and social activities. Items were added to understand the unique perspectives of family members including, items related to the visiting experience, engagement in care decisions and communication with the home.

Facility and Family, Resident Characteristics

A total of 716 family respondents from a convenience sample of 38 individual LTC homes participated in the field test. Participating homes represent four different Canadian provinces and two American states. The majority were for-profit homes (61.4%) and the number of beds ranged from 36 to 270 (mean = 87.4 beds).

Table 5.2 shows the distribution of socio-demographic characteristics for the LTC family member responses to the survey. Most respondents described their family member (referred to as “resident”) as having either fair or good health (76.8%) and 45.2% had family members who had lived at the LTC facility for longer than two years. Most of the residents were over 75 years old (84.2%) and female (60.5%). Most family member respondents were female (70.2%) and a child or child-in-law of the resident (64.2%). The imbalance of daughters carrying a heavier caretaking load for aging parents was consistent with the literature. Most of the respondents state that they visit the LTC home at least once per week (66.7%) and more than half of those (37.9%) who visit at least weekly, visit several times per week.

Table 5.2: Resident and Family socio-demographic characteristics in long-term care facilities in Canada and US (Family N=716)

Variables	**% (n)[1]**			
	Resident		**Family Member**	
Age (years)				
< 45	0.3	2	5.6	40
45 - 64	1.9	14	50.6	362
65 - 74	9.2	66	29.3	210
75 -84	25.8	185	7.8	56
85 and older	59.8	428	2.5	18
Gender				
Male	38.6	276	28.9	207
Female	61.4	440	71.1	509
Resident is part of a couple				
Yes	16.5	118		
No	83.5	598		
Resident's Health				
Fair/Poor	59.3	425		
Good/Very Good	40.7	291		
Length of Stay (years)				
< 1	28.1	201		
1 to 2	23.2	166		
More than 2	46.1	330		
Relation to Resident				
Child or child-in-law			65.5	469
Spouse			10.6	76
Sibling			6.4	46
Parent			4.9	35
Other			8.5	61
Visitation Frequency				
Daily			8.4	60
Once per week			20.9	150
Several per week			38.9	279
Several per month			9.9	71
Once per month			4.1	29
Few per year			3.1	22
Other			11.7	84

Note:

[1] Some sample sizes may not add up to the study sample (n=716) due to missing data

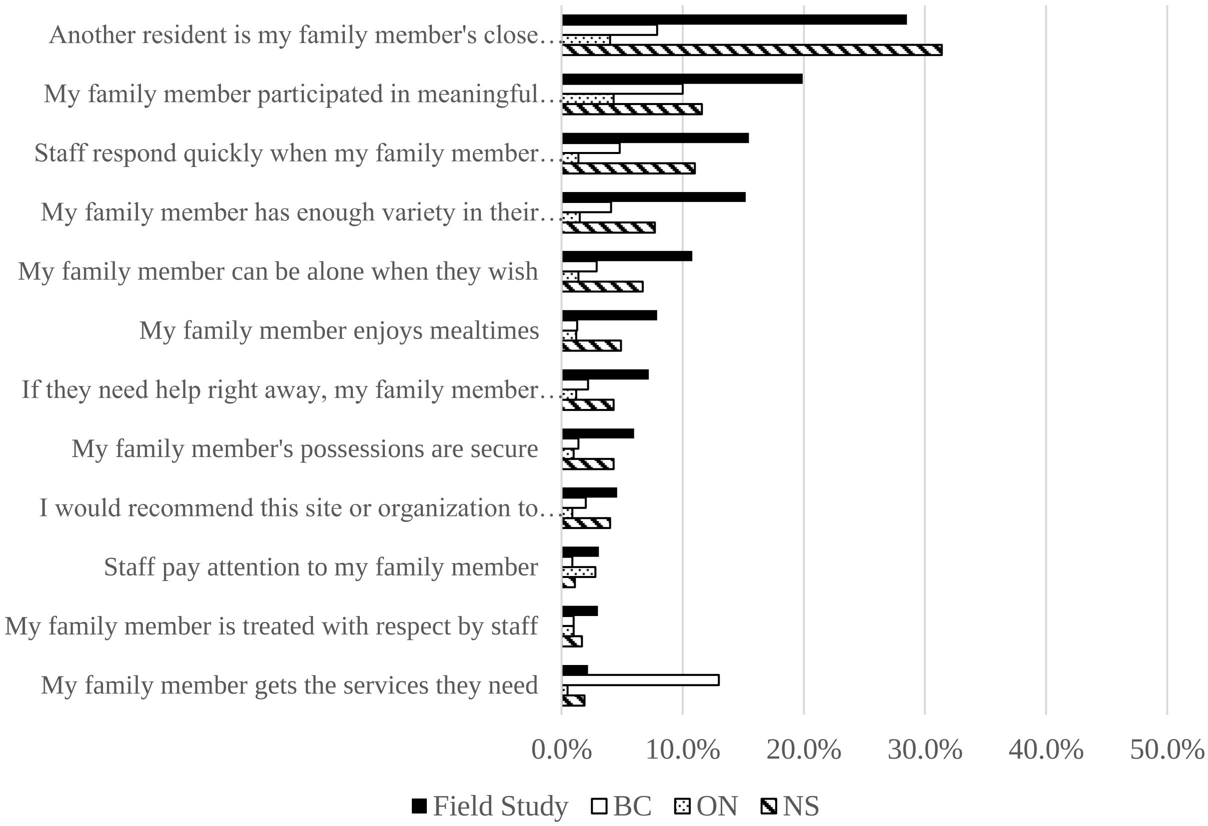
Participation

Family members were offered paper or online based methods to complete the survey. Informed consent was acquired in writing on paper-based surveys and online within the survey. A count of distributed surveys was not tracked, so it is not possible to accurately calculate participation rates. This study was conducted in between major COVID-19 waves and experienced several delays related to the pandemic.

Item Non-response and Missing Values

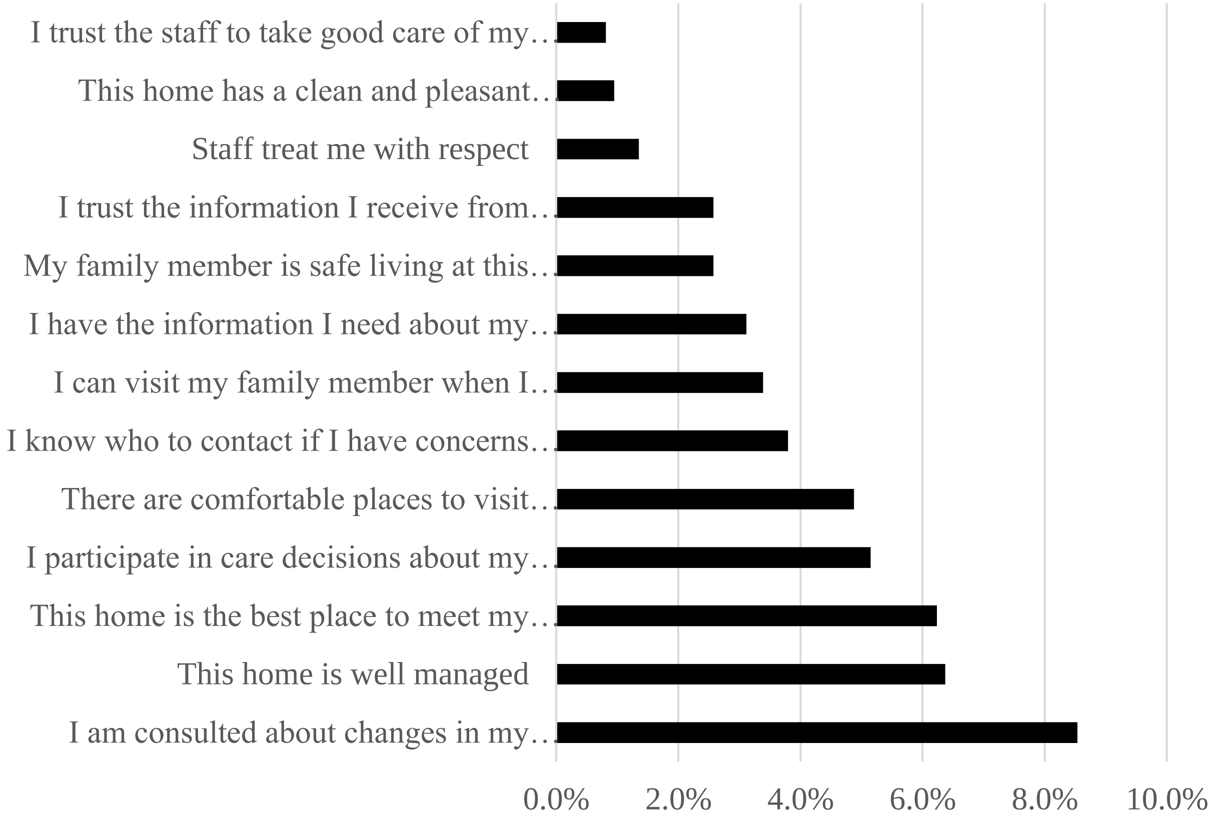
The core items that are paralleled with the Resident QoL Survey perform somewhat consistently across studies, in relation to non-response and missing value rates. Figure 5.3 illustrates the missing and non-response rates across the various studies, for those items. In 11 out of 12 items, the Field Test missing/non-response rate was higher than any previously reported result. The overall missing rate for family respondents across all parallel items for the Field Test was 10.3%, which is higher than two of three of the previous family studies using the interRAI Version 1 Family QoL instrument. The two items with the highest missing/non-response rates, “another resident is my family member’s close friend” and “my family member participated in meaningful activities”, had similarly high missing/non-response rates in the Version 1 instrument (Norman, 2023) and were later removed from the final version of the instrument.

Figure 5.3. Parallel Resident-Family QoL Item Missing and Non-Response Rates from Family Member Respondents, Across Canada and US LTC homes (Family N= 13,912)



Unique family items in the new survey performed well. The average missing/non-response rate on these items was 3.9% (low 1.2% “I trust the staff to take good care of my family member, high 8.6% “I am consulted about changes to my family member’s care plan”), compared to 10.6% for parallel items. The missing/non-response rates for all unique family member items are shown in Figure 5.4.

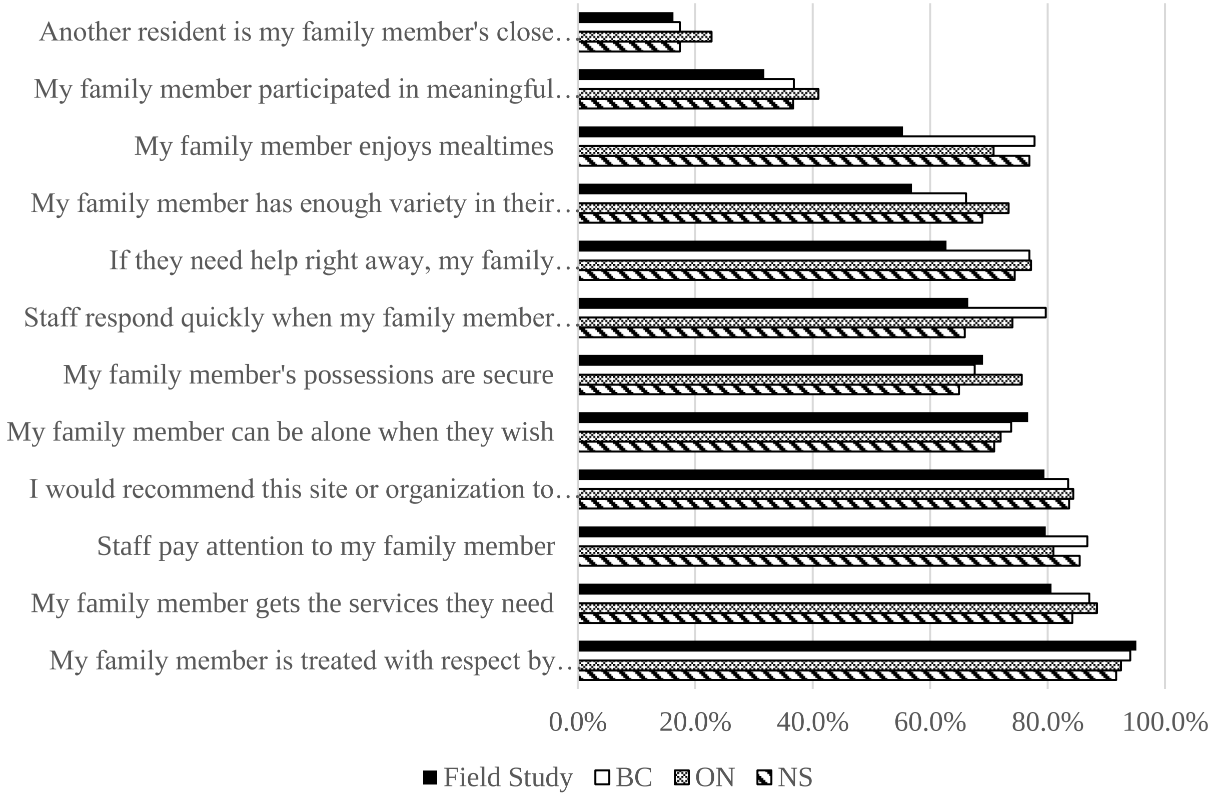
Figure 5.4. Missing and Non-Response Rates for Unique Family QoL Items, Across 38 Canada and US-based LTC homes (Family N=716)



Positive Response Rates ("Most of the Time + "Always")

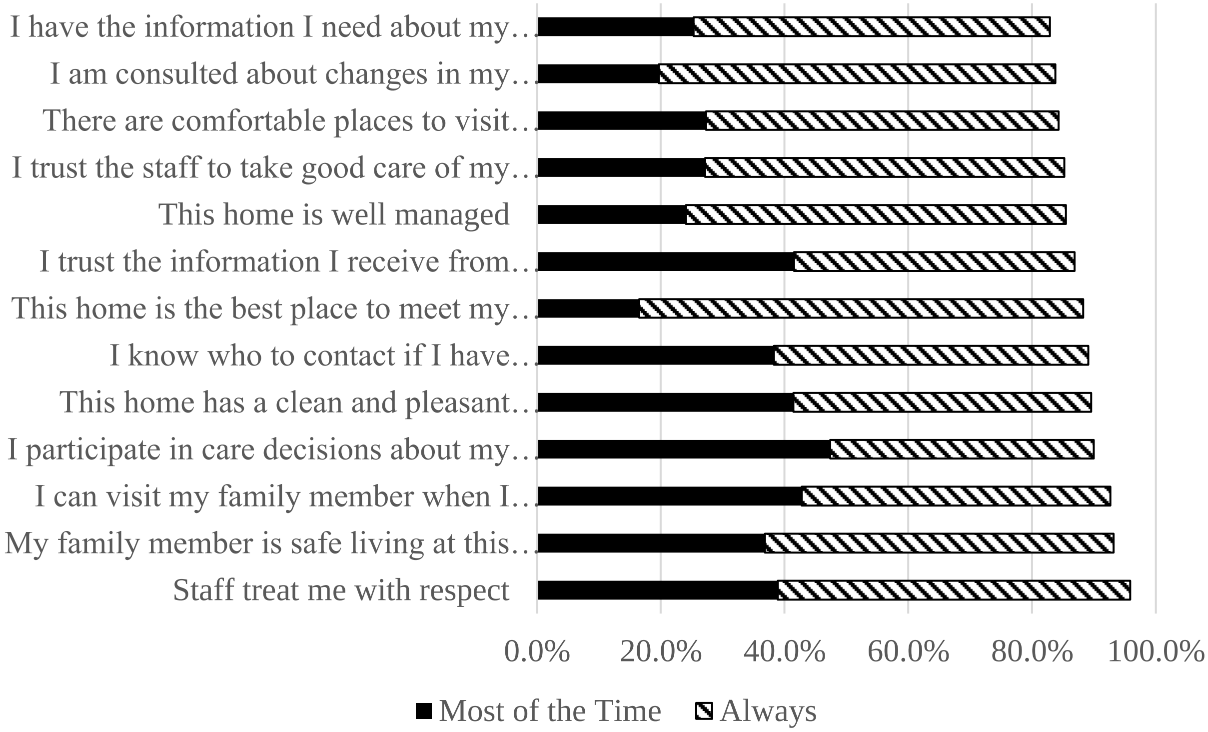
The rates of positive responses (a combination of "most of the time" and "always" responses) were lower than any other previous study result on nine of the 12 parallel items. Figure 5.5 shows the positive response rate by study, for all parallel items in the Version 2 instrument. The field study reported higher positive response rates than previous studies have on whether the resident can be alone when they wish, their possessions are secure, and they are treated with respect by staff. The two lowest scoring items in the field test, the resident considering another resident their friend and participating in meaningful activities in the past week, were also the lowest scoring two items in the previous studies. This was the same with the two highest rated items, the resident gets the services they need and are treated with respect by staff.

Figure 5.5. Parallel Resident-Family QoL Item Positive Response Rates from Family Member Respondents, Across Canada and US LTC homes (Family N= 13,912)



Among the unique family member items included in the Version 2 instrument, family member positive rates were generally high. The mean positive response rate on parallel items was 69.7%, compared to 88.2% for unique items. These results are displayed in Figure 5.6. The lowest scoring unique family member items were surrounding communication about care ("I have the information I need about my family member's health" and "I am consulted about changes in my family member's care plan"). The top-rated items were "my family member is safe living here" and "staff treat me with respect".

Figure 5.6. “Most of the Time” and “Always” Responses for Unique Family QoL Items, Across 38 Canada and US-based LTC homes (Family N=716)



Technical Expert Review

Newly developed interRAI instruments undergo a review process that includes a review of the scientific work underpinning the instrument and requires formal approval from the interRAI Instrument Standards Development (ISD) Committee. The ISD committee reviewed the scientific work of this study and approved the new interRAI Family QoL Survey instrument in May 2022.

Discussion

The objective of this study was to develop a Version 2 interRAI Family QoL Survey Instrument that reflected the evidence to date regarding family involvement, experiences, and perspectives on quality of life in LTC. The instrument developed in this study provides a tool LTC homes can use to better understand the quality experiences of residents and families, through multiple perspectives. This is a critically important need for decision-makers, as many seniors in LTC are too cognitively impaired to provide this feedback directly.

Like two of the more widely used family QoL surveys in the US (Frentzel, et al., 2012; Nwakasi, Mehri, & Parajuli, 2022), the Version 2 interRAI family QoL instrument shares a set of core items with its' companion Resident Self-Report QoL instrument. This will provide an additional perspective on items that are important to resident's quality of life, which family members are able to observe or make meaningful judgements on. Additionally, the Version 2 instrument developed in this study adds items that refer to the unique experiences of family members in LTC, such as engagement in care, visiting experiences and communication with staff. Understanding, managing, and improving these aspects of resident and family engagement are a heavy focus on new national LTC standards, along with standards published by accrediting bodies (Ontario Hospital Association, 2019; HSO, 2023).

A strength of this instrument lies in the formative research upon which it was developed. The interRAI Resident Self-report QoL is an internationally studied and validated instrument which has undergone several updates. A thorough scoping review on existing family QoL measurement instruments for LTC, informed the approach and focus of this development effort. The analysis of previously collected data using the Version 1 interRAI family instrument provided a large sample to draw inferences from. Although this data was from Canadian LTC homes only, the variety of ownership status, region and timeframe for these studies improves the generalizability of the inferences drawn. Focus groups and expert panels to further refine the tool were held through a consortium of several large, accredited, high-performing LTC organizations, along with international interRAI and LTC research fellows, bringing substantial expertise to the decision-making process.

In addition to the strong development methods applied to the Version 2 interRAI family QoL instrument, the new tool is unique in that results may be combined with the broad range of existing interRAI instruments. The LTCF and MDS2.0 used in Canadian and US-based LTC homes generates extensive quality of care indicators, along with home-based, health zone, provincial and national benchmarks. Through its' internal research agenda and partnership with SQLI, interRAI produces additional QoL benchmarks from the Resident Self-report instrument. The development of a Version 2 family QoL tool will bring homes closer to a full view of quality in homes using the interRAI suite of instruments. These homes will have benchmarks for quality of care and quality of life, from multiple perspectives, allowing them to understand and prioritize improvement, advocacy, and policy efforts more appropriately.

Limitations

Two integral voices are unfortunately missing from the early item development and Delphi process to design this instrument; that of LTC residents themselves and their family members. These processes were underway during the early stages of COVID, so SQLI representatives, LTC administrators, researchers and other stakeholders provided valuable input based on their discussions with residents and families, some through previous experiences with family surveys. As key users of the results from a family surveys, the LTC administrator group provided a valuable input informing many aspects of the Version 2 interRAI family QoL however, cannot substitute the direct perspectives of residents and their families. Ideally, these voices would have been present both during the initial development of items and during the Delphi process. Of note, understanding any shifts in priorities and perspectives of family members before, during and after COVID, may be particularly relevant in reducing bias in the instrument.

While the development of the Version 2 interRAI family QoL instrument began prior to the COVID-19 pandemic, the field study of the tool was largely conducted between the 2nd and 3rd waves experienced in North America. At the time of this writing, it is not yet fully understood the extent of impact the experiences of LTC residents and their family members during COVID. It may be reasonable to hypothesize that both residents and family members may report differently about the quality of life in LTC at that time, relative to pre-COVID. Anticipated annual administration of the Version 2 instrument through SQLI will enable further examination of its psychometric properties, with increased consideration for pandemic-related shifts.

Analysis of the psychometric properties of the Version 2 interRAI family QoL instrument will further strengthen this research area and allow for broader deployment. Additionally, to fully leverage the Version 2 tool as an integrated part of the interRAI suite of instruments for LTC, future research should be done to develop summary scales for this instrument. Summary scales provide reliable measures of key quality of life domains, providing useful ways to evaluate, interpret and communicate results and are available for interRAI's range of instruments. Testing the predictive validity of this instrument and exploring how it is associated with resident QoL ratings, quality of care outcomes and other outcomes of interest, will further improve the usefulness of this tool and evidence of quality in LTC homes. Conducting international studies using this tool will further enhance its generalizability and reflect the various cultural and regional factors that require examination.

Conclusion

The COVID-19 pandemic highlighted the critical importance not just in quality care in nursing homes, but also quality of life. Reduced visitations and social interactions among residents led to worse outcomes and continue to be felt in the sector. Family members have been increasingly recognized as a valuable and essential care partner to support residents living their best lives in LTC. The Version 2 interRAI Family QoL-LTCF instrument captures this important voice in the resident's quality of life. The initial feedback from LTC operators who participated in the field study described in this study was very positive about its appropriateness and usefulness, resulting in the SQLI consortium membership opting to adopt it as a required annual instrument for all members. This additional voice will improve our understanding of the interactions and experiences that influence quality of life in Canadian and US LTC homes, particularly for our most vulnerable residents living with severe cognitive impairment.

Chapter Six (Manuscript #4)

Assessing the Psychometric Properties of a New Instrument to Hear Family Perspectives on Quality of Life in Long-Term Care

Background

Quality of life is an important element of overall quality occurring in Long-term Care (LTC) homes. Residents of LTC homes are increasingly being admitted with severe cognitive impairment, making it difficult to capture their perspective directly (CIHI, 2023; CIHI, 2021). While the resident's self report is the ideal source, LTC homes have responded to these challenges by engaging family members in the process. Family members play a vital role in LTC homes, providing essential socio-emotional and physical support (Friedemann, Montgomery, Rice, & Farrell, 1999; Baumbusch & Phinney, 2014; Puurveen, Baumbusch, & Gandhi, 2018). Their experiences have the potential to influence resident's perceived quality of life (Roberts & Ishler, 2017) and their quality of care outcomes (Li, Li, & Tang, 2016). They also provide a unique and valuable perspective to contribute to quality in the home. Health Standards Organization and Accreditation Canada have recognized this value, as family engagement features heavily in new national standards (HSO, 2023; Accreditation Canada, 2023).

For homes to respond to national requirements regarding family engagement, they require a valid, appropriate, and valuable instrument to assess how they are performing. There are several instruments published that capture the unique perspectives of family members, but with little standardization or broad deployment that would allow for systemic analysis and initiatives (Marisetti, 2001; Ejaz, Straker, Fox, & Shobhana, 2003; Castle, 2004; Frentzel, et al., 2012; Godin, Keefe, Kelloway, & Hirdes, 2015). The interRAI V1 Family QoL instrument is based on their internationally validated and widely used Resident QoL instrument (Kehyayan V, 2015; Morris, et al., 2018; Norman, 2023). Previous work developed a second version of the interRAI Family QoL based on a review of the relevant literature, input from LTC homes and family members, analysis of V1 data across multiple studies, and the involvement of experts (Godin, Keefe, Kelloway, & Hirdes, 2015; Norman, 2023). The V2 Family QoL was deployed in a field study for primary data collection.

The V2 Family QoL instrument was designed for maximum adoption in LTC. Length was a key consideration, aiming to minimize administrative burdens associated with data collection. To optimize how managers and policy makers interpret results, summary scales are required. Summary scales combine related items under a key concept of QoL (e.g., food or social life), providing aggregate scores.

The first aim of this study was to assess the psychometric properties of a newly developed interRAI Quality of Life in LTC Family Survey and identify its underlying domains. This includes evaluation of the performance of individual items in the survey; examining performance when clustered into various domain or summary scales; and assessing how individual items and each summary scale relates to a global measurement item. The second aim of this study was to examine family members’ perspectives on Quality of Life in Long-Term Care facilities in Canada and the United States.

Methods

Design and Setting

This was a cross-sectional, descriptive study using a convenience sample of 716 family members surveyed across 38 LTC homes in Canada and the US. The homes were recruited by the researcher through their involvement in the Seniors Quality Leap Initiative (SQLI), a community of practice for LTC providers in North America (Hirdes JP, 2020; McArthur C, 2023). Homes in Nova Scotia, New Brunswick, Ontario, and British Columbia participated from Canada, along with several US homes in Massachusetts and Pennsylvania. Two of the homes were primarily French speaking, and translated French surveys were provided.

Ethics

This study received full ethics clearance from the Office of Research Ethics, University of Waterloo (REB #42872). Some participating homes also conducted their own internal ethics review for clearance or reviewed the study with resident and family councils for input.

Criteria for Inclusion of facilities and families

LTC facilities participating in this study had to be an existing user of the interRAI Resident Self-Reported Quality of Life LTC instrument for at least one year. The interRAI Quality of Life-Family instrument is part of a suite of interRAI instruments that use common operationalization of items and response sets (Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V, 2015; Kehyayan V, 2016; Morris, et al., 2018). In this study, family, and facility level familiarity with interRAI instruments was important to remove barriers to participating in the study. While participating facilities were recruited through their membership with SQLI, that membership was not a requirement to participate. Through word of mouth, several other stakeholders expressed interest in participating but were not able to collect data within the study timelines.

Consistent with the evidence regarding current methods of surveying LTC family members, participants were included using a broad definition of “family member”. Blood relatives, legal guardians/decision-makers, close friends, and other frequent visitors were able to respond if they were the person most involved in the resident's care at the home. Staff at the participating homes distributed the surveys directly based on these criteria, using their internal contact lists. Family members were sent a study recruitment letter along with a link to the electronic, web version of the survey, which captured consent. Because exact numbers of sent surveys were not tracked by each home, accurate participation rates could not be calculated. As a proxy estimate, we may assume that each bed in each participating home had an eligible family member respondent that was sent a copy of the survey. Using that method, 716 responses were received from 3,831 surveys sent, which is a participation rate of 18.7%.

Measurement of Quality of Life

The interRAI Quality of Life LTC- Family Survey consists of 25 items. Of the 25 items in the survey, 12 are parallel items from the Resident Self-Report QOL instrument and the remainder are designed to capture the unique perspectives of family members. The psychometric properties of this instrument have not been previously examined.

This instrument was chosen for several reasons. It is a companion to interRAI's broad suite of assessment instruments that, when used together, provide LTC homes with a robust health information system that includes a diverse array of performance measures. Given the lack of consistency in measuring family member perspectives, the study used a tool that would complement existing instruments used in LTC. The interRAI suite of instruments are widely used in Canada and the US, with increasing LTC adoption of the QOL instruments specifically (Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V, 2015; Kehyayan V, 2016; Morris, et al., 2018). At the home, this is helpful because their staff, residents and family members are already familiar with the interRAI scoring method and style. They also may already have technology or software that supports these tools. For researchers, this presents the potential to examine QOL from the perspectives of many stakeholders, in relation to clinical and demographic information and outcomes, or across health systems.

The interRAI QOL LTC- Family Survey instrument's content was also a consideration. Within the Family Survey, almost half of the items are based on parallel questions in the Resident Self-Report instrument. By having several parallel items, homes can consider measurement equivalency among residents and families across many items of QOL. This additional feedback is particularly valuable given the high proportion of LTC residents who do not complete the Resident Self-Report QOL survey due to their Cognitive Performance Scale (CIHI, Accessed May 14, 2023). While not a proxy for the resident's feedback on their QOL in the home, the family perspective provides additional input that may can be useful to administrators, researchers, and policy makers. The interRAI QOL LTC-Family Survey also includes a global measure for overall QOL, "I would recommend this site or organization to others", which is a useful benchmarking tool given the item's common presence in QOL instruments. The background item on family member visitation frequency may also be used as a "risk adjustor" to account for visitation frequency in QOL ratings. Finally, the interRAI QOL LTC- Family Survey was developed with input from LTC administrators, staff members, residents, and families, as well as international interRAI fellows, who provided advanced subject matter expertise and international cultural considerations.

Data Analysis

All data analyses were conducted using SAS v9.4 software (SAS Institute Inc., 2002-2003). A multi-step process was used to achieve aim one of this study and evaluate the psychometric properties of this instrument. First, to align the analytic approach with previous studies conducted on interRAI self-report and QoL instrument data, any survey responses where greater than 50% of the responses were missing were removed (Kehyayan V, 2015). The response categories in this instrument range from “never” to “always”, with the most frequent responses in the “sometimes” to “always” range. “Never” and “rarely” responses were recoded to have a value of 0, “sometimes” a value of 1, “most of the time” a value of 2 and “always” a value of 3 (Morris, et al., 2018). Responses were treated as categorical data as some were combined for later analysis (e.g. percent positive) and to be consistent with previous analysis of associated data.

Internal Reliability

Reliability of the Family QoL instrument’s reliability was assessed based on internal consistency of items with Cronbach’s alpha. This measurement tells us whether item responses are consistent within the group. Two methods were used to assess the convergent validity of the instrument. Family members who rated high in the “I would recommend this facility to others” item, would also be expected to have high scores in other domains and in the overall QoL score. This global satisfaction item is considered by some to be a proxy measure for overall QoL rating (Kehyayan V, 2015). The relationship between the global satisfaction item, domains and overall QoL, was expected to be stronger than the correlations between specific domains. Based on that underlying hypothesis, family member’s domain scores were compared with the global satisfaction rating and then with overall QoL, by calculating Pearson’s correlation coefficients.

Content Validity

A content validity was examined using a content validity matrix (Streiner, 1993; Streiner and Norman, 2008; Kehyayan V, 2015). A content validity matrix maps the instrument's items and domains against other well-established, validated instruments measuring the same topic. Two other family QoL instruments in Long-Term Care were used; the CAPHS (Frentzel, et al., 2012) and the Ohio Family Satisfaction Survey (Ejaz, Straker, Fox, & Shobhana, 2003). These were chosen based on their prevalence in the research on this topic, their strong psychometric properties and because they are both still currently in use. The CAPHS has reported Cronbach's alpha ranges from 0.75 to 0.90 (Frentzel, et al., 2012; Roberts & Ishler, 2017; Nwakasi, Mehri, & Parajuli, 2022). The Ohio Family Satisfaction survey was developed Ejaz et al. has also reported acceptable psychometric results, with Cronbach's alpha ranges above 0.66, high factor loadings and intraclass coefficients.

Exploratory and Confirmatory Factor Analysis

A multi-step process was used to develop and test the underlying domain constructs of the Family QoL instrument. Initial exploratory factor analysis was conducted to assess how the items clustered together, using a varimax rotation. After assessing Eigenvalues and factor loadings, a conceptual domain model was developed. Confirmatory factor analysis was conducted on this model to examine each scale's reliability based on their internal consistency, using the Cronbach's alpha. The minimum Cronbach's alpha for an acceptable scale is 0.70 (Streiner & Norman, 2008). Significance test results for factor loadings and various indices assessing the goodness of the model's fit, were also assessed. Lastly, the correlations of the various scales with an overall facility QoL measure were examined.

Distribution of Family Member's Quality of Life Ratings

Aim two of this study was to examine family member's perspectives on Quality of Life in LTC. Frequencies, percentages, means, and standard deviations were calculated at the item level to examine the distributional properties of all 25 items in Family QoL instrument. At the domain level, the same distributional properties were calculated and examined.

Results

LTC Family Member and Resident Characteristics

38 LTC facilities from four provinces in Canada and two states in the US, participated in the study. In the Canadian facilities, all of them were accredited, and the majority were not-for-profit (60%). All participating US LTC facilities were not-for-profit. Facility sizes ranged from 36 to 270 beds, with small homes (less than 95 beds) comprising the largest group (58%).

Both resident and family member socio-demographic characteristics were provided by family member respondents in this study and are shown in Table 6.1. Over 85 per cent of the residents were 75 years old or older and the majority (59%) rated their health as fair or poor. The majority (61%) were female, and a small percentage (17%) reported being part of a couple, which is expected given the advanced age of this population. 46 per cent of the resident sample had been living at the LTC facility for more than two years. Of the remainder, 23 percent had lived there between one and two years, and 23 percent for less than a year.

Among the family member respondents, the majority (86%) were younger than 75 years old, with half of respondents falling into the 45 to 64 age group. 71 per cent of the respondents were female and the majority (66%) reported being a child or child-in-law of the resident. Most of the sample (68%) reported visiting the LTC facility at least weekly.

Table 6.1: Resident and Family socio-demographic characteristics in long-term care facilities in Canada and US (Family N=13,912; Resident N=13,149)

Variables	**% (n)[1]**			
	Resident		**Family Member**	
Age (years)				
< 45	0.3	2	5.6	40
45 - 64	1.9	14	50.6	362
65 - 74	9.2	66	29.3	210
75 -84	25.8	185	7.8	56
85 and older	59.8	428	2.5	18
Gender				
Male	38.6	276	28.9	207
Female	61.4	440	71.1	509
Resident is part of a couple				
Yes	16.5	118		
No	83.5	598		
Resident's Health				
Fair/Poor	59.3	425		
Good/Very Good	40.7	291		
Length of Stay (years)				
< 1	28.1	201		
1 to 2	23.2	166		
More than 2	46.1	330		
Relation to Resident				
Child or child-in-law			65.5	469
Spouse			10.6	76
Sibling			6.4	46
Parent			4.9	35
Other			8.5	61
Visitation Frequency				
Daily			8.4	60
Once per week			20.9	150
Several per week			38.9	279
Several per month			9.9	71
Once per month			4.1	29
Few per year			3.1	22
Other			11.7	84

Note:

[1] Some sample sizes may not add up to the study sample (n=716) due to missing data

Table 6.2 displays the frequency and percentage of average visits to the home, by the family member's type of relation to the resident. More than three quarters of family members (76.3%) reported visiting the home at least once per week on average, reported consistently regardless of the family member's gender. Consistent with previous findings, females were disproportionately represented as the responding "family member" of LTC residents, at 74.8% of the respondents.

Table 6.2. Frequency and Percentage of Visiting Patterns to the Home, by Relationship to Resident, Across 38 Canadian and US LTC homes (Family N=716)

		Family Member's Relation to the Resident				
Average Visits		**Child**	**Spouse**	**Sibling**	**Parent**	**Other**
Daily	N	86	79	5	9	5
	Percent	8.3	36.2	4.2	10.8	3.6
Several times per Week	N	441	98	44	41	44
	Percent	42.5	45.0	37.0	49.4	31.9
Once per Week	N	265	18	30	16	37
	Percent	25.5	8.3	25.2	19.3	26.8
Several times per Month	N	100	5	18	10	23
	Percent	9.6	2.3	15.1	12.0	16.7
Once per Month	N	33	3	7	2	11
	Percent	3.2	1.4	5.9	2.4	8.0
Few Times per Year	N	49	1	7	1	7
	Percent	4.7	0.5	5.9	1.2	5.1
Other	N	64	14	8	4	11
	Percent	6.2	6.4	6.7	4.8	8.0
Column Totals	N	1,038	218	119	83	138
	Percent	100.0	100.0	100.0	100.0	100.0

Exploratory and Confirmatory Factor Analysis

The initial exploratory factor analysis of the 716 responses to the instrument identified four scales to represent the domains of family member's perspectives on quality of life in LTC. These scales did not produce a simple model structure, so a conceptual domain model was developed based on the factor analysis, investigator judgement and available evidence. Four domains were developed: Basic Needs, Respect and Trust, Visiting the Facility and Engaging in Care. A fifth domain, Global Rating, was added to the model, to evaluate how it would perform as a global measurement. Most family QoL instruments use a recommendation item as a proxy for global satisfaction (Castle, 2004; Norman, 2023); however, the investigator hypothesized that a family member's overall QoL may be influenced by other items and by their recommendation response. Adding the Global Rating domain to the model improved the psychometric properties of the model slightly.

Confirmatory factor analysis was conducted to examine the psychometric properties of these domains. The 5-factor model demonstrated good fit, with all but four of the 25 items having a factor loading of > 0.6. One of those items "my family member's possessions are safe here" was retained in the model because of its' value as a parallel item with the Resident Self-report QoL instrument. The other three low-performing items, "I can visit when I want", "there are comfortable places to visit here" and "I have opportunities to participate in care decisions", were also retained based on investigator judgement. There is a weak to moderate correlation between the visitation questions and the frequency of visitation to the facility by the respondent (0.29 for "I can visit when I want" and 0.22 for "there are comfortable places to visit", significant at 95%).

The 5-factor model had strong goodness-of-fit results with a comparative fit index (CFI) of 0.931. A CFI of > 0.90 is considered a good fit (Cheung & Rensvold, 2002).

Psychometric Properties of the interRAI Family QoL Survey for LTC

The psychometric properties of the instrument were examined by determining its internal consistency and validity, which are displayed in Table 6.3. Each of the domains in the Family QoL instrument had good Cronbach's alpha scores, ranging from 0.88 (Global Rating) to 0.92 (Engagement in Care). Values of 0.70 or higher demonstrate good internal consistency (Steiner and Norman, 2008). The overall alpha coefficient is 0.88, which is comparable to those found in other validated Family QoL LTC instruments, including the CAPHS at 0.75 to 0.90 (Frentzel, et al., 2012) and the Ohio Family Survey at 0.66 (Ejaz, Straker, Fox, & Shobhana, 2003). This demonstrates good internal consistency.

Table 6.3. Version 2 interRAI Family QoL Instrument Cronbach's Alpha and Correlation with Overall QoL and Global Rating, by Domain

interRAI_QOL items by domain	No. of Items	Cronbach's alpha (> 0.70)	Correlation with Overall QoL	Correlation with Global Rating Domain
1. Basic Needs	6	0.89	0.79	0.78
2. Respect and Trust	4	0.89	0.82	0.73
3. Visiting the Facility	3	0.91	0.64	0.56
4. Engaging in Care	4	0.92	0.59	0.51
5. Global Rating of Facility	3	0.88	0.89	1.00

Convergent Validity

On the global item "I would recommend this site or organization to others", 79.4% of family members responded positively ("most of the time" or "always"). Those family members had much higher overall QoL scores and scored more positively in each domain. Of note, in the Global Rating domain, family members who responded positively to the global recommendation item also responded positively to the items in the Global Rating domain 85.2% of the time. Those who did not respond positively to the recommendation item, only responded positively to the Global Rating domain items 35.3% of the time.

As expected, each of the five domains had moderately strong correlations with overall QoL, with r values ranging from 0.59 (Engaging in Care) to 0.89 (Global Rating). The Global Rating domain had the highest correlation with overall QoL, supporting the appropriateness of its use as a proxy for overall QoL rather than the common proxy of the “I would recommend this facility to others” item, which had a coefficient of 0.73. The Pearson’s correlation between the global recommendation item and domain-specific QoL ratings was also moderately strong, ranging from 0.43 (Engagement in Care) to 0.80 (Global Rating). As expected, the correlations between domains were not as strong as those between domains and overall QoL, ranging from 0.50 to 0.79. These results provide evidence for the convergent validity of the summary scales.

Content Validity

The interRAI LTC Family QoL instrument was compared with the CAHPS Nursing Home Survey: Family member instrument and the Ohio long-term care facilities family satisfaction scale. While underlying themes recurred across instruments, there were few similarities at the item level (see Table 6.4). The Ohio tool places more emphasis on the administrative operations and services in the facility (five items) and staff and specific functions in the home (25 items). The interRAI and CAHPS tools do not have items related to administrative functions but have six and eight questions related to staff in the home, respectively. The interRAI and CAHPS tools do not have items related to administrative functions but have six and eight questions related to staff in the home, respectively. The interRAI and CAHPS tools were relatively consistent in terms of number of domains (both have five) and number of items in the instrument (25 and 23, respectively). The Ohio instrument is longer with 13 domains and 59 items. Each of the three instruments contain at least one global satisfaction measurement but range from one to four items in that category. Based on this review and the psychometric properties of the interRAI Family QoL instrument, the tool provides an appropriate balance between content validity and length.

Table 6.4. Content validity matrix: Comparing Domains and Count of Items for interRAI Family QoL Survey to CAPHS and Ohio's LTC family survey

Domains	**interRAI Family QoL Items in Domain**	**CAHPS Nursing Home Survey: Resident and Family Member Instruments**	**Ohio long-term care facilities family satisfaction scale**
Basic Needs	6	3	8 [1]
Respect and Trust	4	5 [5]	5 [2]
Visiting the Facility	3	7 [6]	9 [3]
Engaging in Care	4	6	
Global Rating of Facility	3	1 [4]	4 [4]
Social Services			4
Meals and Dining	2 standalone items		5
Activities	1 standalone item		6
Admission			5
Choice	1 standalone item		5
Professional Nurses			2
Reception and Phone			2
Laundry			2
Therapy			2
Total Items	**25**	**23**	**59**

Notes

[1] Domain name is Direct Care and Nurses' Aides

[2] Domain name is Administration

[3] Domain name is Environment

[4] Domain name is Overall Satisfaction

[5] Domain name is Nurses' aides kindness and respect

[6] Domain name is Nursing Home Staffing, Care of Belongings, and Cleanliness

Feedback from Family Members

Residents who participated in the field study of the Version 2 interRAI Family QoL-LTCF Instrument, were invited to provide feedback on it during the survey. While very few family members took advantage of this option, of those comments provided, the majority were supportive of the instrument or reiterated the challenges in responding to some items from their vantage point. A sample of these comments are provided in this dissertation's appendices.

Non-Response Rates

The non-response rates for this study are shown in Table 6.5, summarized by domain. These rates have been explored at the item level previously (Norman, 2023). The five summary scales for this instrument had mean non-response rates ranging from 1.9% (Trust and Respect) to 6.1% (Basic Needs). Of note, the Trust and Respect domain has the highest positive response rate, and the Basic Needs domain has the lowest positive response rate.

The field study protocol for testing the Version 2 interRAI Family QoL-LTCF instrument required that all items have a response recorded and could not be skipped. Instead, family members had the option to score items with a non-response code (either "don't know", "prefer not to answer" or "not applicable"). These options are consistent with the Version 1 interRAI Family QoL-LTCF, as well as the Resident Self-Report instrument. In previous studies, missing (skipped questions) and non-response coded items have been combined when assessing missingness (Godin, Keefe, Kelloway, & Hirdes, 2015; Kehyayan V, 2015; Morris, et al., 2018; Norman, 2023).

In the 2016 survey conducted by the British Columbia's Office of the Seniors Advocate, family member respondents were not given non-response options but were able to skip questions. In the other two studies using the Version 1 instrument, family members had options both to skip and provide non-response scores. This inconsistency may be a factor in the wide range of missing/non-response rates seen between Version 1 and Version 2 for the parallel items. Slight inconsistencies in family member definitions across these studies and wording changes to items, may have also contributed to the variation in missing/non-response rates.

Table 6.5. Non-Response Rates by Scale, with Range of Non-Response for Items in Scale, in 38 Canadian and US LTC homes (Family N=716)

Summary Scale	Number of Items in Scale	N Missing	Percent Missing	Range of Non-Response % per Item
Basic Needs	6	270	6.1	(2.2 - 15.3)
Respect and Trust	4	57	1.9	(0.8 - 3.0)
Visiting the Facility	3	68	3.1	(0.9 - 4.9)
Engaging in Care	4	152	5.1	(3.1 - 8.5)
Global Rating	3	125	5.6	(4.3 - 6.4)

Of the 12 core items that are paralleled between the family and resident instruments, nine had non-response rates that were higher than were reported in previous studies of the Version 1 instrument (Godin, Keefe, Kelloway, & Hirdes, 2015; Norman, 2023). The two items with the highest non-response rates, “another resident is my family member’s close friend (28.5%) and “participated in meaningful activities in past week” (19.9%) were later removed from the instrument during expert review. After removing those items, the mean non-response rate parallel items fell to 7.5%. The reported mean missing/non-response rate for the same items in the Version 1 family instrument studies is 5.5% (Norman, 2023). Of the six parallel items that had non-response rates > 7.5%, five are standalone items. This may be further evidence of this instrument’s validity. Of the Version 2 instrument’s 13 new items that are unique to family members, the mean non-response rate was 3.8%. All unique items are associated with a summary scale for this instrument.

Distribution of Family’s QoL Ratings

The distribution of family member responses are summarized for each item in Table 6.6, using a combined positive response score (“most of the time” or “always”). Most family members responded positively to the resident’s possessions being safe there (69%), that the resident was safe living in the LTC home (90.9%), they got the services they need there (80.7%), and staff paid attention to them (79.7%). A lower percentage of family members felt that resident could get help when they need it (62.8) and that staff responded quickly to the resident (66.5%).

Table 6.6. Long-term Care family member's reported quality of life scores by domain and item from 38 Canadian and US LTC homes (Family N=716)

Domain	Item	Always/Most of the Time %, n	Sometimes %, n	Rarely/Never %, n
Basic Needs	Safety of resident's possessions	69.0 , 494	15.1 , 108	9.60 , 69
	Resident getting help when needed	62.8 , 450	22.5 , 161	7.10 , 51
	Resident is safe living here	90.9 , 651	5.6 , 40	6.00 , 43
	Resident gets the services needed	80.7 , 578	14.9 , 107	2.50 , 18
	Staff pay attention to resident	79.7 , 571	16.1 , 115	1.80 , 13
	Staff respond quickly to resident	66.5 , 476	14.5 , 104	4.60 , 33
Respect and Trust	Trust staff to take good care of resident	84.5 , 605	12.3 , 88	2.50 , 18
	Trust information received from staff	84.8 , 607	10.1 , 72	2.60 , 19
	Staff treat resident with respect	95.1 , 681	3.1 , 22	1.00 , 7
	Staff treat me with respect	90.6 , 649	6.1 , 44	0.70 , 5
Visiting the Facility	Clean and pleasant environment	88.7 , 635	9.1 , 65	1.20 , 9
	Can visit when I choose	91.1 , 652	5.9 , 42	1.30 , 9
	There are comfortable places to visit	81.6 , 584	9.5 , 68	5.60 , 40
Engaging in Care	I have info I need about resident's health	80.9 , 579	12.3 , 88	4.70 , 34
	I know who to contact about care	86.6 , 620	7.3 , 52	3.20 , 23
	I participate in care decisions	86.7 , 621	6.4 , 46	3.20 , 23
	Consulted about changes in resident's care plan	77.9 , 558	8.9 , 64	6.20 , 44
Global Rating	This is the best place to meet resident's needs	83.0 , 594	8.4 , 60	2.50 , 18
	I would recommend this facility to others	79.5 , 569	10.9 , 78	5.30 , 38
	Home is well managed	80.6 , 577	9.5 , 68	3.90 , 28
Standalone Items	Resident enjoys mealtimes	55.4 , 397	20.1 , 144	10.40 , 74
	Resident gets variety in meals	56.9 , 407	24.6 , 176	11.00 , 79
	Resident can be alone when they wish	76.7 , 549	8.0 , 57	9.80 , 70
	Resident participates in meaningful activities	31.8 , 228	24.9 , 178	25.50 , 183
	Resident has a close friend here	16.3 , 117	13.7 , 98	42.60 , 305

In the area of respect, 95.1 per cent of family members responded that staff treated the resident with respect and 90.6 per cent responded that staff treat them with respect. About 85% of family members responded positively about trusting the staff to take good care of the resident and trusting the information they receive about the resident's health. Most family members responded positively on being able to visit the facility when they choose (91.1%), having comfortable places to visit the resident (81.6%) as well as how clean and pleasant the facility environment is (88.7%).

When asked about their experiences being engaged in the resident's care, most family members responded positively. Almost 87 per cent reported that they knew who to contact at the facility about the resident's care and had been engaged in care decisions. Slightly fewer respondents reported positive scores on having the information they need about the resident's health (80.9%) and being consulted about changes to the resident's care plan (77.9%).

Most family members felt that the facility was the best place to meet the resident's needs (83%), that the facility was well managed (80.6%) and that they would recommend it as a place to live to others (79.5%). While the majority also felt that the resident was able to be alone when they wished (76.7%), a lower percentage felt that the resident enjoyed mealtimes (55.4%) or got enough variety in their meals (56.9%). The items family members reported the lowest positive response rates were whether the resident participated in meaningful activities (31.8) and if they had a close friend at the facility (16.3%). These items also had a higher per cent of "rarely" or "never" responses, at 25.5% and 42.6%, respectively.

To summarize and compare mean scores by domain, each scale is collapsed based on the count of items in the scale and the maximum score possible. This is aligned with the methodolgoy used in the development of previous interRAI Resident self-report scales. For example, the Basic Needs domain has 6 items, so the most positive score for that domain would be 18 (6 items with max score of 3 per). These were then standardized into a score out of 3. Mean scores based on this method are shown in Table 6.7. Family QoL ratings were highest in the "respect and trust" and "visiting the facility", with standardized mean scores of 2.4. Family's QoL ratings were lowest in "basic needs" where many of the safety and security items represent some of the foundational human needs in Maslow's (1962) hierarchy of needs. While there were some differences in mean QoL scores by respondent groups, none were statistically significant including: member's gender, relationship to resident, frequency of visits, resident's length of stay and resident's health status.

Table 6.7. Mean long-term care quality of life scores of family members by domain from 38 Canadian and US LTC homes (Family N=716)

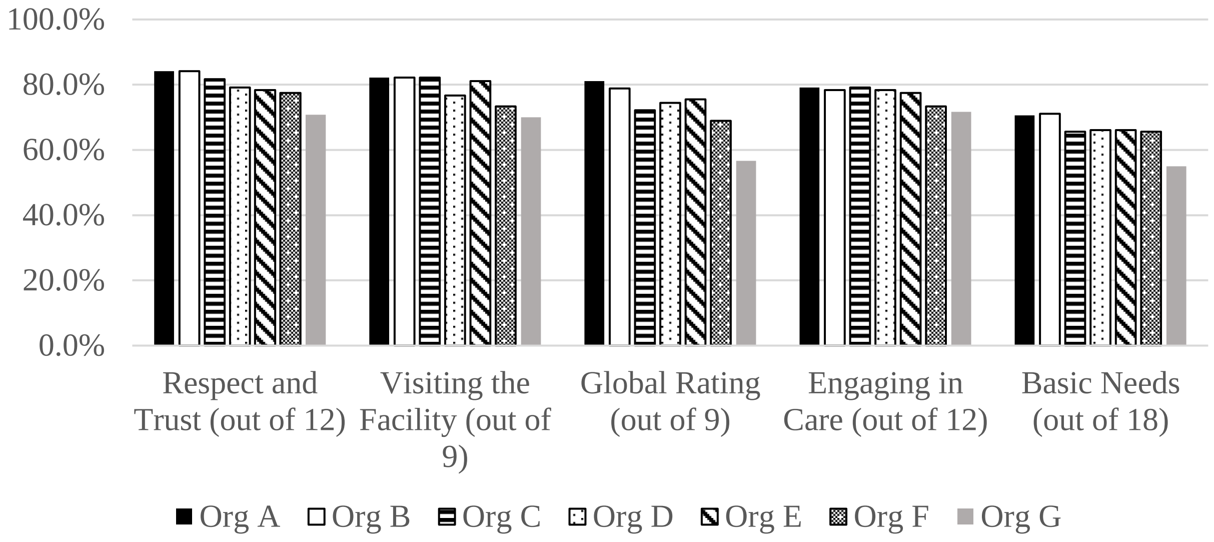
Domain (number of items)	Mean	(95% Confidence Interval)	Range of Possible Scores	Standardized Mean Percent*
Basic Needs (6)	12.2	(4.8-19.6)	0-18	67.7%
Respect and Trust (4)	9.8	(4.9-14.6)	0-12	81.7%
Visiting the Facility (3)	7.2	(3.9-10.5)	0-9	80.0%
Engaging in Care (4)	9.3	(4.0-14.6)	0-12	77.5%
Global Rating of Facility (3)	6.7	(2.1-11.2)	0-9	74.4%

*** As the items in each domain varied between 3 and 6, standardized mean QoL scores were calculated (Mean score divided by maximum range)**

38 individual LTC homes participated in this survey, across seven LTC provider organizations. Not all homes reached a minimum sample of responses to report results at the facility level however, mean scores by domain were assessed by organization, to explore the variation of results across providers by area of quality of life. These results are shown in Figure 6.1. To complete this comparison, mean scores were standardized to a percentage, based on the maximum points available in each domain. For example, the Respect and Trust scale has four items with a maximum score of three on each item, for a total of 12 maximum points. The standardized percentage is based on the mean score for those four items, as a percentage of 12 possible points.

The Global Rating domain had the widest range of scores across organizations, with a minimum standardized score of 56.7% of total possible points and a maximum score of 81.1% (range of 24.4%). Engaging in Care showed the least range in results, with a minimum of 71.7% and a maximum score of 79.2% (range of 7.5%). Visiting the Facility and Respect and Trust domains had relatively small ranges of 12.2% and 13.3%, respectively and the Basic Needs domain demonstrated a minimum of 55% and a maximum of 71.1%, for a range of 16.1%.

Figure 6.1. Mean Standardized Domain Percentages, by Participating Organization from 38 Canadian and US LTC homes (Family N=716)



Summary of Findings

The first aim of this study was to evaluate the psychometric properties of the Version 2 interRAI Family QoL instrument for LTCFs. Using a large and diverse data set collected from 38 Canadian and US-based LTC homes through a pilot study, the survey showed strong psychometric properties across the board. Internal consistency was strong, with domain-level Cronbach's alpha scores ranging from 0.88 to 0.92. Convergent validity was assessed by reviewing the correlations between domain summary scores, overall QoL ratings and the Global Satisfaction domain rating. Associations were moderate to strong, supporting the appropriateness of the items as measures of QoL. Summary scales or domains were developed using exploratory and confirmatory factor analysis. The final five-factor model had strong goodness of fit, with a CFI of 0.93.

The second aim was to explore how families rated quality of life in LTC homes with the Version 2 instrument. Using the pilot study data, item and domain level positive rating and summary scores were evaluated. Except for two items which have since been removed from the instrument, families responded positively to many areas of QoL in LTC. Consistent with previous studies on this topic, families responded most positively about the level of trust and respect they observe with staff at the home. Items about basic care needs of the resident, including items about safety and security, were the lowest scoring of the domains.

Discussion

The instrument was developed based on a review of the existing literature, analysis of previously collected data from residents and family members using a Version 1 instrument and by using a large expert panel. Due to COVID-19 related restrictions at the time of this study, the expert panel, which included many LTC home administrators, shared feedback from family members on their behalf.

The scales and associated psychometric properties reflect the validity of this instrument and its alignment with other similar tools. Summarized domains allows users of this information to quickly identify strengths and opportunities for improvement, provide an easy method to summarize results and to support quality improvement work related to these themes. The rates of missing and non-response in this study are difficult to compare to previous ones as these scoring options were not handled consistently across studies. Two items had substantially higher missing/non-response rates, which have since been removed from the instrument.

The results by domain are aligned with previous studies that showed lower family response rates in areas related to social activities, food, and basic needs. These data were collected during the

COVID-19 pandemic and may have introduced some bias in the results. The areas of safety and security, and staff responsiveness scored lower than in previous studies, which could be the result of the restrictions that were in place in many LTC homes and the substantial adverse outcomes LTC residents experienced as a result of the virus.

The feedback from families provided by the Version 2 instrument provides valuable, non-proxy information to help administrators and decision-makers better understand the quality residents experience in the home, particularly for those who cannot self report. This instrument complements the other tools in the interRAI suite, including the MDS 2.0, LTCF, associated quality indicators and outcome scales, and the Resident Self-report QoL instrument. This makes standardized benchmarking and system-wide improvement efforts possible, as researchers and managers alike can explore associations through this data. As this tool is more widely used, those associations can be shared broadly, along with additional validation studies on the scales and predictive validity of the instrument.

Limitations

The Version 2 interRAI family QoL-LTCF instrument was developed with a thorough use of the available evidence, expert knowledge and leveraging formative research. COVID-19 presented challenges in engaging with family members and residents directly on this project, relying instead on an expert panel of LTC administrators, researchers, and policy makers to speak on their behalf with the researcher. Multiple stakeholders providing input could further strengthen the validity of this instrument.

While an accurate response rate was not collected during this study, there were several participating homes that did not reach minimum sample size requirements (n=30), limiting the ability to explore organization or home level characteristics and variation. COVID-19 was ongoing during the pilot field study of this instrument, making communication and engagement with families challenging. Samples were adequate to conduct the level of testing aimed for in this study and future data sets will further enhance our understanding of family ratings.

While participating homes spanned Canadian and US provinces and states, and included several religious homes and two francophone homes, cultural aspects and ethnic diversity can be better represented in this analysis to improve generalizability and content validity. Lastly, the organizations who participated in the pilot were members of the Seniors Quality Leap Initiative, of which interRAI is a strategic partner. These member organizations use interRAI instruments regularly and may not be representative of the sector and how it would adopt such a tool. Expanded data sets can help inform the change management and implementation practices and protocols associated with this tool.

Conclusion

The Version 2 interRAI Family QoL-LTCF instrument provides additional feedback about quality of life in LTC through non-proxy family feedback on a core set of items that residents also respond to. In addition, a set of family-specific items collect feedback about family's unique perspectives and experiences in the home, in areas that are increasingly present in LTC licensing and accreditation body standards (e.g., Engagement in care, visiting experience). This feedback will supplement resident's self-reported QoL, as a companion tool, providing homes with more a more fully rounded picture of quality in the home to target interventions and improvement initiatives.

As this tool is more widely used, expanded data sets can be used to further validate summary scales and items. This will also be important as culturally diverse homes and specific-culture homes adopt the tool. Ensuring the instrument reflects the make up of the LTC homes in North America and internationally, will only increase the usefulness and validation of the tool. As jurisdictions adopt new LTC HSO standards and Accreditation Canada required organizational practices, such a tool will be a vital part of their measurement and management program for family engagement and quality of life.

Chapter Seven

Conclusion

Summary of Dissertation

The aim of this research was to explore and improve how the perspectives of family members in LTC are collected and measured, as it relates to quality of life. To reach that aim, the specific objectives of the study were to:

1. Conduct a scoping review of the current literature regarding family Quality of Life instruments in LTC, including items, measurements, and psychometric properties,
2. Examine the rates of non-response, agreement and disagreement between resident and family responses based on secondary data collected in previous studies,
3. Develop a draft version of a Quality of Life instrument for LTC family members,
4. Conduct an evaluation of the results, reliability, and convergent validity of the above tested instrument and develop summary scales.

Summary of Key Findings

In Chapter 3, a scoping review was conducted to examine existing instruments measuring family perspectives on quality of life in Long-Term Care, the measurements being used, and domains or areas included. This review revealed a limited number of instruments, and very few that were widely used in a standardized protocol. In addition, while there were a core number of domains that featured prominently across all instruments (i.e., global recommendation, basic needs being met) there were other domains that appeared less consistently across instruments (i.e., administration, therapies). The scoping review also showed that the Version 1 interRAI family instrument was among the few instruments that had been used across multiple provinces/states and had a parallel resident instrument with which it shared a set of core items.

To further examine the results obtained from the Version 1 interRAI family instrument, Chapter 4 explored secondary data that had been collected using this tool across 3 provincial studies. This analysis included reviewing rates of quality of life across various domains from the perspectives of family members, assessing those rates compared to resident ratings of the same items, and comparing rates of missing or non-response values between residents and families at the item level. Several items and domains had consistent and significant variation between family and resident responses, such as items around resident participation in social events and satisfaction with food and meals. Items surrounding trust with staff and respect in the home, performed more consistently between the groups.

Based on the results of the scoping review and secondary analysis using the Version 1 interRAI family instrument, Chapter 5 describes the development of a Version 2 interRAI family instrument. Using expert input from several Delphi panels and leveraging a large consortium of high quality LTC providers from Canada and the US, a new family QoL instrument was drafted. This instrument contained 12 core items that paralleled the resident instrument and introduced 14 new items that were unique to the family member's perspective on QOL in LTC.

In Chapter 6, the newly developed instrument was field tested and evaluated for validity and reliability. An analysis of the results from this survey, conducted across 48 LTC homes in Canada and the US, showed that family members are generally aligned with residents about QOL in the home and provided valuable input regarding their levels of engagement in care, communication with staff and the visitation experience. The Version 2 interRAI Family QoL instrument had high reliability with a Cronbach's alpha of 0.88 and strong content validity.

Factor analysis revealed five domains or summary scales within this instrument, that can help decision-makers more easily interpret, communicate, act on, and assess their results. Each of the five domains had high reliability and moderate to strong association with both overall quality of life ratings and items representing a global representation of quality of life in the home (e.g., I would recommend this home to others).

Contributions of this Research

Literature on the measurement of family member perspectives regarding Quality of Life in Long-Term Care is limited. On the broader topic of family engagement, involvement, and evaluation of Long-Term Care, previously completed reviews of the current evidence have largely excluded the topic of measurement. This study contributes a thorough analysis of the existing measurement tools in use, assessing their content, validity, and reliability. This is an important early step toward establishing a standardized instrument that can be deployed across broad health systems and inform decision-making, improvement initiatives, policies, and standards development.

The most widely used instruments in the literature; the Ohio Family Survey, CAHPS and interRAI instrument, have had limited examination of how family members and residents respond on the same or similar items (Godin, Keefe, Kelloway, & Hirdes, 2015; Williams, Straker, & Applebaum, 2016). This type of analysis can inform future standardization and refinement efforts, which would seek to limit the administrative burden surveys may introduce. The work contained in Chapter 4 contributes to this examination by incorporating multiple studies and provinces, using a tool that has been validated and implemented internationally. This improved the generalizability of the conclusions from this study. By closely examining levels of missing and non-response rates in both respondent groups, this study fills another important gap in the existing literature.

Substantively, this research responds to the call to adopt what IHI refers to as the quintuple aim framework for quality health care delivery (Berwick, et al., 2008; Bodenheimer, et al., 2014; Nundy, et al., 2022). This framework incorporates five goals: improve the patient experience of care; improve the health of populations; improve the clinician/provider experience; improve value for money and elevate health equity. In LTC specifically, the patient experience of care is challenging to capture directly, due to high rates of cognitive impairment. Along with quality-of-care indicators, resident feedback and other experience measures, the Version 2 interRAI family QoL instrument developed through this study provides an additional method for assessing quality in the home. This instrument can play a vital role in understanding quality LTC homes given its scientific rigour and relevance to quality of life.

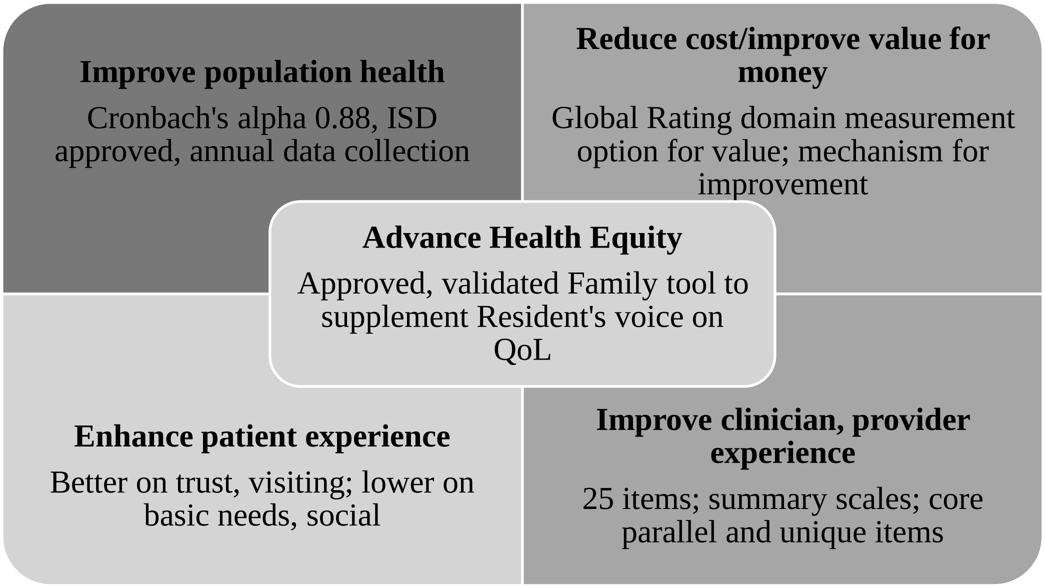
Figure 7.1 illustrates how the work of this dissertation aligns with the priorities of the Quintuple Aim (Nundy, 2022). The Version 2 interRAI Family QoL instrument's strong psychometric properties, companion resident survey and clinical assessment and existing annual deployment and data collection, make it an ideal instrument for national and international adoption. This is a necessary step toward using standardized instruments to drive health improvements at the population level. Shorter than the other widely used family surveys for LTC, this instrument captures a second perspective on QoL rather than a substitute one, allowing homes to gather valid and representative feedback irrespective of cognitive impairment. The feedback family members provide through this instrument can be a useful component of how consumers are assessing 'value for money'.

Clinicians and healthcare providers in LTC homes have demanding workloads in a challenging environment. The aim to improve their experience is met through this study by developing a shorter instrument with lower administrative burden. At 25 items, the Version 2 interRAI Family QoL is comparatively short, with easy to interpret summary scales and results that can be paralleled with resident results. Providing reliable, succinct, and meaningful feedback to LTC teams regarding QoL in their homes positions them to develop more effective action plans to drive results. Additionally, using a standardized tool to regularly collect family feedback regarding relationships with staff, communication with the home and how the family is engaged in care will position LTC teams to cultivate stronger family relationships. Mutual trust and respect among a resident's full circle of care, improves the living and working experience in the home.

Enhancing the patient experience is the goal of the Version 2 interRAI Family QoL and is met through the valuable feedback provided through this instrument. Results explored in this dissertation indicate that family members feel generally positive about the level of trust with staff in LTC homes and in the visiting experience. Studies identified opportunities to improve the patient experience around basic needs like food and meals and participating in social activities in the home. The Version 2 interRAI Family QoL also collects standard interRAI background and demographic items, plus detail regarding the family member themselves (e.g., relationship to resident, visiting frequency). This additional data will inform future analysis regarding family perspectives as they relate to resident QoL, aiming to understand and improve the levers that drive the patient experience.

Lastly and most substantively, the Version 2 interRAI Family QoL fills an important gap in how health equity in LTC homes. For the majority of LTC residents, their cognitive performance will preclude them from responding to QoL surveys directly. This has contributed to a continued practice of leveraging family members as a proxy for the resident, responding as they think the resident would. This practice clearly disadvantages the resident from having their full voice represented in the results. It may also misrepresent the resident's QoL as family members have different perspectives from residents and may not be present in the home often enough to observe quality. This dissertation assets that a validated tool to capture the family member's perspective specifically, as an additional source to inform quality rather than a replacement, will advance health equity for LTC residents, particularly those living with advanced dementia.

Figure 7.1. Dissertation Contributions Aligned with Quintuple Aim Framework for Healthcare Improvement and Advancing Health Equity



An additional contribution of this research is the development of summary scales. Summary scales are useful mechanisms for describing the various domains underlying multidimensional concepts, such as quality of life. Scales development can be relevant when assessing content validity of instruments, offering a measurement of underlying concepts and themes. The most widely used instruments reviewed in this research, provided users with performance results at the summary scale level. The work of this study included developing five summary scales for the Version 2 instrument, which were validated using the field test results. SQLI benchmarks have been developed at the summary scale level at the time of this writing, providing member organizations with evidence-informed targets for quality improvement.

The international and substantial expert and operational engagement in the development of the Version 2 instrument, and then again during field testing, has resulted in a widely accepted, validated instrument that is in a strong position for wider deployment. The SQLI consortium, which represent more than 14 LTC organizations and 4,000 long-term care beds across Canada and the US, have adopted the instrument as part of their annual data collection agreement. The scientific work produced in its development and testing has been approved by the interRAI Instrument Standards Development (ISD) Committee and the instrument is now in the publication process. This body of work produces a “ready for use” instrument available to nursing homes who aim to capture this important voice.

Implications for Policy, Practice and Research

This research has demonstrated the value of the family perspective on quality of life in nursing homes and offered a turnkey solution to standardize the collection and measurement of this important voice. As LTC organizations and providers work to meet new HSO and Accreditation standards in Canada, the family members’ voice will be increasingly sought after. Adoption of the Version 2 interRAI Family QoL instrument will help in this effort. To support the continued and broader adoption of this instrument, future research studies should include data collection from nursing homes that serve specific cultural (e.g., Chinese language, First Nations homes) or religious groups (e.g., Jewish, Catholic Sisters of Charity homes).

New national HSO standards for LTC homes include several references to family members, who are included in a stakeholder group referred to as “essential care partners”. The work of this research will support meeting and measuring compliance with many of these standards, particularly 1.1 (strategic plan is informed by needs and experiences of all stakeholders, including residents, substitute decision makers, essential care partners, etc.), and 2.3 (the home leaders and team promote the role and presence of essential care partners) which includes standards regarding communication and visiting the home. Standard 3.1.11 references the requirement of collecting and communicating the results from quality of life surveys. The standard states “for those residents unable to participate, reporting by proxy by substitute decision makers and essential care partners is encouraged” (HSO, 2023). The findings summarized in this research can inform these standards going forward, which would suggest against proxy reporting but instead, to gather additional perspectives for their own value.

In some Canadian provinces, resident and/or family quality of life surveys are completed on a mandatory basis, allowing for regional and home-level benchmarking, and sharing of results. The findings of this study support the broader adoption of Version 2 interRAI Family QoL instrument as a supplemental source of information in understanding the quality of life being experienced in a home. Homes that currently administer the interRAI resident self report QoL instrument to both residents and families, would instead administer the Version 2 interRAI family QoL instrument to all family members and administer the Self Report tool to eligible residents only, minimizing any new administrative time introduced through this survey.

At the practice level, clinicians and front-line staff should leverage the results of this research in developing family engagement strategies, inform how they engage in shared decision-making and work toward improvements together with families and residents. LTC administrators and communities of practice can share these findings with their boards, family councils, and resident council groups to discuss where their opportunities are relative to these areas of family perspectives. The evidence produced through this research may also inform advocacy efforts of those groups or other provincial and national organizations interested in quality of life in nursing homes. For example, feedback from family members regarding the visitation experience may influence future policies about the family member's vital role in the home, particularly as they are developed in a post-pandemic perspective.

One of the advantages of the interRAI QoL instruments is its inclusion in a broader system of complementary tools. Future studies should link family perspectives on QoL using the Version 2 interRAI family QoL tool, resident ratings on QoL using the interRAI Resident Self Report QoL tool (with 12 shared items between them), and quality of care indicators derived from the interRAI LTCF. Such studies should examine the predictive validity of this instrument and identify the factors associated between family perspectives and quality of care outcomes or resident QoL. Additional data that could be linked and useful in examining this topic include background and demographic resident data (e.g. diagnoses, mobility) and workforce staffing data (e.g. staffing ratios, agency or casual staff use).

Recommendations for policy, practice and research

Policy Recommendation- provinces and/or territories should adopt the Version 2 interRAI Family QoL instrument to gain family perspectives regarding quality of life in their nursing homes and support meeting national standards for Long-Term Care, in a phased approach.

Phase 1: implement the Version 2 interRAI Family QoL instrument in all New Brunswick LTC homes. New Brunswick administers the interRAI Resident Self Report QoL instrument annually, in all LTC homes, making it an ideal candidate to be an early adopter. The New Brunswick Nursing Home Association was engaged in the development of the Version 2 interRAI Family QoL tool through their engagement with SQLI.

Phase 2: implement the Version 2 interRAI Family QoL instrument and Resident Self Report QoL instruments in remaining provinces and territories, and internationally. While it is not required to administer both instruments together, the data from family members is made much more valuable and insightful when it is paired with direct input from residents themselves, with consistent measurements and shared items.

A successful implementation plan will ensure all stakeholders are informed, resources are prepared, and teams are positioned to work with the results. Below are some key items in the implementation planning of the Version 2 interRAI Family QoL instrument.

1. Stakeholder engagement:
    a. New Brunswick Nursing Home Association for endorsement of broad deployment, method or platform for data collection (i.e., Momentum, QolPro)

    b. New Brunswick Department of Social Development- conduct gap analysis of provincial licensing standards to identify any conflicting or supporting standards relative to survey items, summary scales.
    c. HSO revision- seek to revise standard reference to proxy surveys for families; seek endorsement of Version 2 interRAI Family QoL-LTCF instrument.
    d. Accreditation Canada- gain endorsement of Version 2 interRAI Family QoL-LTCF instrument as an approved instrument.
    e. interRAI and SQLI in development of manager's toolkit (see practice recommendations).
    f. CIHI- work to have Resident and Family QoL instrument results added as quality indicators in the 'Your Health System' public reporting portal.

2. Communications strategy- to be shared in family council meetings and directly with family members. Key messages include:
    a. Family members and essential care partners are vital members of the circle of care.
    b. They have unique perspectives and experiences that provide an additional source of information about quality of life in the home.
    c. This is particularly useful and necessary if your loved one has cognitive impairment and cannot respond for themselves about their QoL.
    d. The experiences of family members in our LTC homes have the potential to inform quality improvement efforts, home level decision-making and policy.
    e. This brief survey will be used in addition to the residents' self reported QoL survey results, to improve QoL.

3. Training- during phase 1, training should be minimal as these homes already use various interRAI instruments and supporting platforms. A brief webinar introducing the family survey, QoL coding, domains, and measurements will be provided to team members.
4. Data collection process- establish sampling requirements, protocols for small vs. large homes, single facility vs. multi-facility organizations, integration with existing systems (e.g., EHR systems, survey tools)
5. Strategies to promote participation and mitigate non-response rates include:
    a. Administer the survey electronically and via paper copies, offering interview approach if needed.
    b. Provide advanced notice at home level and share results from previous studies.
    c. Engage home level family councils to promote the survey.
    d. Test the survey protocol to ensure accessibility (e.g., language, font size, access).
    e. Offer small gift card draws or other incentives to encourage participation.
    f. Follow up quickly with summarized results, engage family members in action planning, share improvements broadly.
6. Sharing of results- results should be shared broadly with family members, residents, staff, and other stakeholders. A sample report for consideration is shared in Appendix 8. The following information should be included when sharing results:
    a. Participation rate- use a protocol to track the number of surveys distributed, or bed count as a proxy if distribution isn’t available. Homes require a minimum of 30 responses to the survey to generate a report of results.
    b. Missing and non-response- assuming all items are mandatory for response, even if using a ‘non-response’ code (i.e. “don’t know” or “not applicable”), this indicator

    will show the % of responses that were a non-response. This is shown at the item level.

    c. Positive response rates- this indicator includes all “most of the time” and “always” responses, as a percentage of total responses. This should be provided at the item level.
    d. Summary scales- these indicators combine several items in a related area and provide an aggregate score.
    e. Benchmarks- use current benchmarks from 2 years of data collection to illustrate how home level results compare overall and at the summary scale level.
7. International data collection- Belgium is an ideal early adopter based on their existing use of interRAI tools, the Resident Self-report, and an expressed need for a family tool. Translation and back translation of the instrument will be required.

Practice Recommendations- with family members, co-develop a toolkit that LTC home administrators, managers, staff, and family members, can use to understand, influence, and improve family perspectives on QoL, and support meeting related national standards.

1. Stakeholder engagement- engage governance boards, communities of practice and family councils to co-develop toolkits managers can use to improve results at their home, informed by family members and residents.
2. Measurement Systems- provide the context of the Version 2 interRAI Family QoL summary domains, with the interRAI Resident Self Report QoL domains and related Quality Indicators derived from the interRAI LTCF assessment.

3. Education and awareness- the toolkit should include an orientation for new LTC staff members on engaging family members:
    a. Family member experiences in LTC and their perspectives on QoL- orientation for family members, residents, and staff education.
    b. Where and when do family members engage- identify touchpoints and critical success factors for high quality experiences.
    c. Family engagement and clinical practice- engaging residents and families in shared decision-making, clinical application of results.
    d. Leading practices to improve engagement and perspectives on QoL.
4. Quality Improvement Tools- the toolkit should complement existing quality improvement methodologies or tools a LTC home has in place (e.g., Lean Six Sigma). New content to develop would be specific guidance on engaging family members in quality improvement initiatives. This includes identifying resources for support (e.g., Accreditation Canada's leading practices database).

Research Recommendations- establish a research agenda that is aligned with provincial/territorial goals regarding family member engagement and perspectives and meeting national standards for nursing homes. The agenda should be assigned to the SQLI consortium, with engagement from outside the consortium as the instrument is more widely deployed.

1. Advancing research using existing data set:
    a. Visiting LTC- an examination of the distributional properties regarding visitation frequency, correlations with family QoL ratings, resident QoL ratings and quality outcomes.

    b. Family QoL and cognitive impairment- an examination of family QoL ratings for residents based on levels of cognitive impairment, including visitation frequency.
    c. Facility characteristics and family QoL perspectives- an examination of family QoL ratings by ownership status, single home vs. multi/chain, bed count, room set up, staffing ratios.
2. Additional validation studies through broader implementation of instrument:
    a. Cultural inclusion- several upcoming opportunities may be appropriate to test, further refine and validate this instrument: newly announced African Nova Scotian-owned nursing homes in Nova Scotia; Indigenous nursing home in Eskasoni, Nova Scotia.
    b. Complete an SQLI-led study of religious vs. non-religious LTC homes to further validate the instrument.
    c. Assess content validity and predictive validity using linked interRAI LTCF assessment, resident self report QoL and family QoL results. Linked results will examine the relationships between resident and family QoL, and quality outcomes.

Limitations

This dissertation has limitations that should be acknowledged. While the foundational research conducted through this research included many international perspectives, data analysis and data collection were largely focused on Canada and the US. Additionally, data analysis and primary data collection were conducted with nursing homes that already use interRAI tools or are associated with the SQLI consortium. Studies including homes that do not currently use interRAI tools, would inform the recommended training, stakeholder and communication recommendations outlined above. Similarly, future studies conducted internationally and with a diverse range of cultures and communities, will further validate this instrument and improve the usefulness of its findings. Future studies incorporating the staff perspective on QoL would further contribute to the evidence on this topic.

The development and field testing of this instrument largely occurred during COVID, including the early waves. Restrictions in LTC made engaging residents and family members directly in this research prohibitively challenging and ethics requirements prohibited in-person research at this time. Several other stakeholder groups were leveraged based on their experiences as LTC administrators, researchers, or other interested parties on this topic. Ideally, both LTC residents and their family members would be directly engaged in the development of an instrument regarding QoL experiences in the home. These groups could inform the development of new items for family members, domains and participate in the Delphi process to finalize the instrument. The perspectives of these groups may have been influenced through experiences during the COVID-19 pandemic. Engaging these groups directly in the implementation of this instrument and future studies will be critical to its ongoing validity and usefulness in improving quality in LTC. Future work could be undertaken to obtain family member’s feedback on the content and face validity of the interRAI Family QoL survey.

The field testing of the Version 2 interRAI family QOL instrument was largely conducted during the COVID-19 pandemic, at a time when nursing homes, their residents, staff and family members were experiencing many hardships. As a cross-sectional study, aside from the secondary data analysis, this research is missing longitudinal context. As we move further post-pandemic system, future data collection will be useful in validating this tool, including matching it with resident self-reported QoL and clinical assessment outcomes. The inconsistent use of non-response variables across the secondary and primary data collection studies included in this dissertation is also a limitation. Conclusions drawn from missing and non-response rates across studies, may be biased by the approach each individual study took. Additionally, the field test did not collect information about the homes themselves (e.g., structural variables, ownership status, rural vs. city) which may provide more understanding of the factors influencing family perspectives.

Conclusion

The work of this dissertation used sound science to close important gaps in today's body of knowledge regarding family perspectives in LTC. Family members offer important functional and emotional support in our LTC homes and are part of a circle of care that is necessary to support residents living in these facilities. Family members understand the value of their input given the long histories they often have with residents, their unique perspectives and positions they are in to see things that others in the home may not observe.

Relying solely on the resident's self-reported QoL perspectives, excludes a substantial portion of LTC residents who cannot provide this information due to cognitive impairment. Family members expect to have a mechanism to provide this input and increasingly, this is being recognized by LTC standards organizations and other stakeholder groups. To meet HSO national standards and accreditation requirements, LTC homes will need an acceptable tool to fully understand the family experience. This dissertation offers a ready-to-go, appropriate, valid instrument to collect that input and move toward realizing value from standardized data collection across the larger health system.

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Chapter 1

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Appendix 1: Study recruitment letter

Capturing the Perspectives of Family Members Related to Quality of Life in Long-Term Care

Family Member Recruitment and Information Letter

To help you make an informed decision regarding your participation in this study, this letter will explain what the study is about, the possible risks and benefits, and your rights as a participant. If you do not understand something in the letter, please contact the researcher named in this letter prior to consenting to the study.

What is this study about?

interRAI is an international collaboration of researchers and healthcare practitioners who promote evidence-informed clinical practices and policy-making with aim to improve care. One way they achieve that is by standardizing clinical instruments and assessments that are used in care settings across the world. University of Waterloo researchers have partnered with interRAI to develop a survey instrument that captures family member perspectives in Long-Term Care. Family members play a critical role in resident's quality of life while living in LTC and a better understanding of those experiences can inform quality improvement initiatives, programming and family engagement strategies within a LTC home. These insights may also inform system-level policy, research and advocacy efforts.

As a valued family member of a participating LTC facility in this study, we are asking you to complete the attached survey as part of our research. This survey was developed based on existing evidence regarding family experiences in LTC, expert panel review, family member and facility input. The survey consists of questions about your perspectives on your family member's experiences in Long-term Care, as well as your own.

The information collected will be sent to the University of Waterloo to analyze but no personal identification information will be shared. We will use your submitted survey data to evaluate the performance of this survey, with an aim to standardize its' use across LTC homes. Your submitted data will be combined with other responses from your facility and then linked with de-identified clinical and demographic assessment data for your facility for additional analysis. This additional analysis will be done at the facility level and we will not be linking your specific survey results with any corresponding data related to your family member living in the home.

Is participation in the study voluntary?

Your participation in this study is voluntary. As this is an anonymous survey, in that no identifying names or IDs will be requested and the researchers have no way to identify you, you will not be able to withdraw from the study once you have submitted the survey. If you choose to complete the survey, you may skip any question you prefer not to answer.

The survey is now open through the below link. The survey will remain open to complete until January 15, 2022. We anticipate the survey will take 20-30 minutes to complete. Note that the results of your submitted survey may be used for future research therefore, you will be asked to provide informed consent to use your results for the immediate study titled "Capturing the Perspectives of Family Members Related to Quality of Life in Long-Term Care" as well as to use it for future research. You may provide consent for the current study, but choose not to consent to including your results in a dataset for future research.

Will my information be kept confidential?

This is an anonymous survey in that we will not ask for or collect names or identifying IDs at the resident level. While some demographic information will be asked of you in order to conduct analysis, the researchers will not be able to identify individual residents or family members from your responses. Facility identifiers will be provided to the researchers in order to conduct regional and facility characteristic analysis of results. Participating LTC homes will receive summary reports of their results.

Your data will be stored on a secure server located at the University of Waterloo and will be retained there for a minimum of 7 years.

When information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you. If you prefer not to participate using this online method, please contact one of the researchers so you can participate using an alternative method such as a paper-based questionnaire or telephone call. The alternate method may decrease anonymity but confidentiality will be maintained.

What are the benefits associated with the study?

Family members play a critical role in resident's quality of life while living in LTC and a better understanding of those experiences can inform quality improvement initiatives, programming and family engagement strategies within a LTC home. These insights may also inform system-level policy, research and advocacy efforts.

What are the risks associated with the study?

There are no known or anticipated risks associated with participation in this study. If you are not comfortable answering a question in the survey, you can choose not to answer. Participation in the study is voluntary.

Has the study received ethics clearance?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (File # 42872). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or oreceo@uwaterloo.ca.

Who should I contact if I have additional questions about this study?

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participating, please contact Kathleen Norman at 902-452-1955 or by email at kdedrick@uwaterloo.ca.

Are you interested in participating? If you are, please complete the survey in the below link by January 15, 2022. Participation in this study is voluntary. If you do not consent to participate, no action is required. You will be asked to provide consent within the actual survey.

By providing your consent, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Appendix 2: Version 2 interRAI Family QoL Instrument Items

Background and Demographic Items	**Core Items Paralleled with Resident Self-Report QoL Instrument**	**Items on Family QoL-LTCF Instrument Only**
Province Facility Name Unit Resident- couple? Resident- gender Resident- age group Resident- health Resident- length of stay Family- gender Family- age group Relationship to resident Visiting pattern	Enjoys mealtimes Variety in meals Possessions are secure If needs help, can get it Be alone when wish Gets services needed Would recommend to others Resident treated with respect Staff respond quickly Meaningful activities Resident has close friend	Home is well managed Staff take good care Trust info receive from staff I’m treated with respect Have info needed about health status Know who to contact about care Can visit when choose Comfortable places to visit Participate in care decisions Consulted about changes Clean and pleasant enviro Best place to meet needs Staff pay attention Safe living here

Appendix 3: Focus Group feedback template

SQLI Family QoL Task Force

Family Focus Group Questions

A few introductory talking points:

- There is a desire in many provinces and countries, to standardize feedback from residents and family members across the LTC sector regarding their quality of life in the LTC setting
- After several pilots, we’ve standardized a resident survey so we can benchmark results across organizations, provinces and countries to learn and share best practices with each other, identify sector-wide opportunities to influence policy and generate quality of life related research
- We’d now like to do the same to capture your experience as a family member
- The survey would potentially capture both your perspective of your family member’s quality of life (acting as their proxy somewhat) and your own experiences with our facility
- You may want to share the resident survey to get them thinking or give them some examples of questions

Some questions:

1. When you think about your family member who is currently living with us, what do you have the most insight into that you think impacts their quality of life?
2. What areas of your family member’s quality of life, do you not feel like you have much insight into?
3. As someone who visits our facility regularly, interacting with your own family member as well as other residents and our staff, what is important to you that you would like to have a voice in?

Appendix 4: Delphi panel survey form- Round 2

Thank you for your participation in the first round of the Delphi expert panel! In Round 1, we achieved consensus on 4 demographic/background items, 10 parallel items with the interRAI Self-Reported Quality of Life Survey and 12 new, unique items. In Round 1, respondents were asked to vote to keep, remove or change items, and then also ranked their top 20 items. Consensus was achieved if at least 80% of respondents voted to keep the item as is AND the mean ranking of the item was within the top 20 items. These 26 combined items will be included in the draft interRAI Family Member Quality of Life Survey and are listed below (Note: specific items are not reported here for copyright reasons. See www.interRAI.org for the full content of the interRAI Family Quality of Life Survey).

The remaining background, parallel and unique items for consideration on the interRAI Family Member Quality of Life Survey did not achieve consensus during Round 1. For Round 2 of the Delphi expert panel, we're asking you to review the items that did not reach consensus and vote on them again. To keep the new interRAI Family Member Quality of Life Survey at a reasonable length, we are targeting to include roughly 10-15 items from the non-consensus list.

Where applicable, we have summarized the feedback received on these items and in some cases, modified the question based on suggestions. Others may have some clarifying information that was requested during Round 1.

In this section, please vote to "keep, as is", "remove" or "keep, with changes" for each of the background/demographic items. At the end of the section, you'll be asked again to rank these items in order of priority to include on the interRAI Family Member Quality of Life Survey.

Background/Demographic Items

- Resident Health Status
- Family Member health status
- Family Member's gender
- Are you a primary caregiver (reworded to add "primary")
- Family member's race/ethnicity
- What is your highest education level
- On average, how many times do you visit this home in a month (reworded to monthly average rather than weekly)
- How close do you live to the home

In this section, please vote to “keep, as is”, “remove” or “keep, with changes” for each of the parallel items that are included in the Resident Self-Report Quality of Life survey. At the end of the section, you’ll be asked again to rank these items in order of priority to include on the interRAI Family Member Quality of Life Survey. For Round 2, please only rank your top 10 items.

Paraphrased Parallel Items

- Privacy is respected
- Get favorite foods here
- Eat when want
- Food is right temperature
- Safe when alone
- Place feels like home
- Go outdoors when want
- Bothered by noise here
- Decide when to get up
- Decide when to go to bed
- Decide how spend time
- Can go where want
- Control who comes in room
- Bath and shower when want
- Decide clothes to wear
- Express opinion
- Respect likes/dislikes
- Act on suggestions
- Can get health services needed
- Help me live life way want
- Know story of life
- Take time friendly conversation
- Ask how to meet needs
- Consider a friend
- Special relationships with staff
- Enjoyable things in evening
- Meaningful activities
- Religious activities have meaning
- Spend time like-minded
- Resident close friend
- People want do things with me
- Ask for help
- Opportunities for affection or romance

- Easy make friends

In this section, please vote to “keep, as is”, “remove” or “keep, with changes” for each item. At the end of the section, you’ll be asked again to rank these items in order of priority to include on the interRAI Family Member Quality of Life Survey. For Round 2, please only rank your top 10 items.

Potential Unique Items

- I understand how the care plan will help meet my family member's health needs
- My family member's care plan meets their health needs
- My family member's care plan meets their mental health needs
- I know how I can support my family member's health and well-being
- I have opportunities to discuss my family member's end of life preferences with the staff here (reworded to reflect opportunities to discuss)
- Staff communicate with me in a clear and understandable way
- I know who to contact about my family member's health needs
- Staff speak with me in an open and respectful manner (reworded- change to open and respectful)
- There are comfortable places to visit with my family member here
- I enjoy my visits here
- There are enjoyable things to do with my family member when I visit
- The staff know how to take care of my family member's needs (reworded to add needs)
- I have confidence in the knowledge of staff here (reworded to remove clinical)
- I am involved in the day-to-day life of my family member
- I feel like a part of this home's community
- I play a meaningful role in my family member's care
- I contribute to my family member's care
- I enjoy interacting with other residents in this home
- I feel overwhelmed by my family member's health needs
- This home is the best place to meet my family member's needs
- This home meets my family's needs
- I have enjoyable things to do here on weekends
- I have the opportunity to explore new skills and interests
- Staff take the time to have meaningful conversations with me (reworded- replaced “pleasant” with “meaningful”)
- This home respects my family member's cultural and/or religious needs (reworded to add religious need

Appendix 5: List of SQLI Member Organizations, Strategic and Academic Partners (SQLI, 2023)

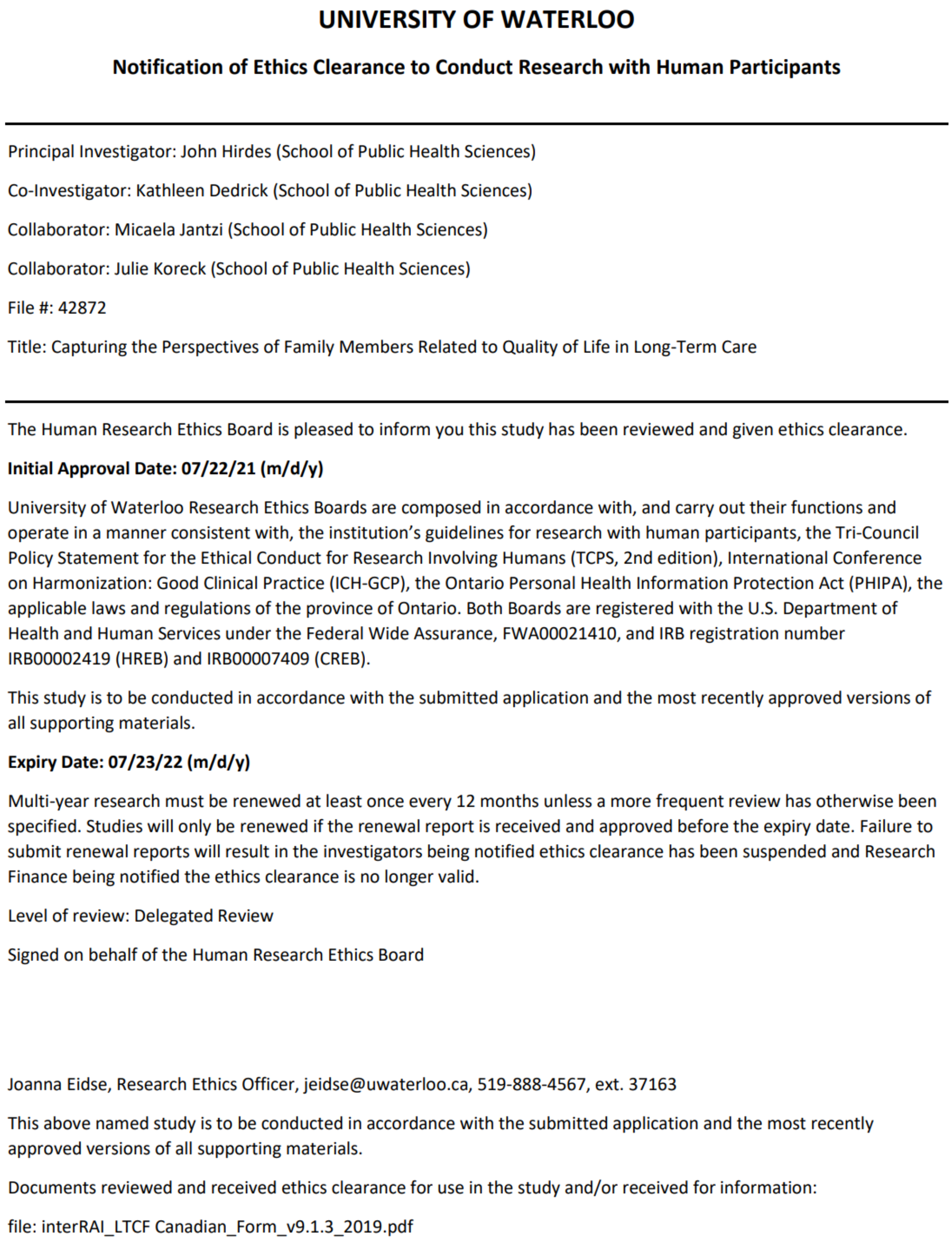
SQLI Member Organizations	Location
Canada	
Actionmarguerite	Winnipeg, MB
Baycrest Health Sciences	Toronto, ON
Bruyère Continuing Care	Ottawa, ON
Perley Health	Ottawa, ON
Providence Healthcare	Vancouver, BC
Schlegel Villages	Ontario
Shannex	Nova Scotia, New Brunswick and Ontario
Sienna Senior Living	British Columbia, Manitoba and Ontario
York Care Centre	Fredericton, NB
United States	
Hebrew SeniorLife	Boston, MA
Presbyterian Senior Living	Dillsburg, PA
San Francisco Campus for Jewish Living	San Francisco, CA
Westminster Communities of Florida	Florida

SQLI Strategic and Academic Partners
AMDA - The Society for Post-Acute and Long-Term Care Medicine
Canadian Association for Long Term Care
Canadian Institute for Health Information
Canadian Society for Long-Term Care Medicine
Centre for Aging and Brain Health Innovation
Florida State University
Healthcare Excellence Canada
LeadingAge
Marcus Institute for Aging Research
New Brunswick Association of Nursing Homes
Ontario Centres for Learning, Research & Innovation in Long-Term Care
University of Waterloo

Appendix 6: Sample of respondent comments about the survey, during the Field Study of Version 2 interRAI Family QoL-LTCF

- Surveys should be requested like this more often. This is the first one in 3.5 years of my family member living at the care home.
- It is great survey like this is being send out to families for feedback, and through these feedback BF can meet their vision and I think overall Brock Fahrni is a good care home and always looking for continuous improvement. This is another reason why BF will eventually be the leader in care home.
- the questions to the survey are difficult to answer, when a resident has dementia with limited capacity, they have no voice, deterioration has progressed very quickly, being so limited
- Number one rule - make surveys short as you will get more responses. This survey - very long.
- This question is difficult to answer as Covid has made life difficult for everyone. Pre-covid, movement inside and outdoors was very good.

Appendix 7: Ethics Clearance Letter from University of Waterloo Ethics Board



UNIVERSITY OF WATERLOO

Notification of Ethics Clearance to Conduct Research with Human Participants

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Principal Investigator: John Hirdes (School of Public Health Sciences)

Co-Investigator: Kathleen Dedrick (School of Public Health Sciences)

Collaborator: Micaela Jantzi (School of Public Health Sciences)

Collaborator: Julie Koreck (School of Public Health Sciences)

File #: 42872

Title: Capturing the Perspectives of Family Members Related to Quality of Life in Long-Term Care

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The Human Research Ethics Board is pleased to inform you this study has been reviewed and given ethics clearance.

Initial Approval Date: 07/22/21 (m/d/y)

University of Waterloo Research Ethics Boards are composed in accordance with, and carry out their functions and operate in a manner consistent with, the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS, 2nd edition), International Conference on Harmonization: Good Clinical Practice (ICH-GCP), the Ontario Personal Health Information Protection Act (PHIPA), the applicable laws and regulations of the province of Ontario. Both Boards are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (HREB) and IRB00007409 (CREB).

This study is to be conducted in accordance with the submitted application and the most recently approved versions of all supporting materials.

Expiry Date: 07/23/22 (m/d/y)

Multi-year research must be renewed at least once every 12 months unless a more frequent review has otherwise been specified. Studies will only be renewed if the renewal report is received and approved before the expiry date. Failure to submit renewal reports will result in the investigators being notified ethics clearance has been suspended and Research Finance being notified the ethics clearance is no longer valid.

Level of review: Delegated Review

Signed on behalf of the Human Research Ethics Board

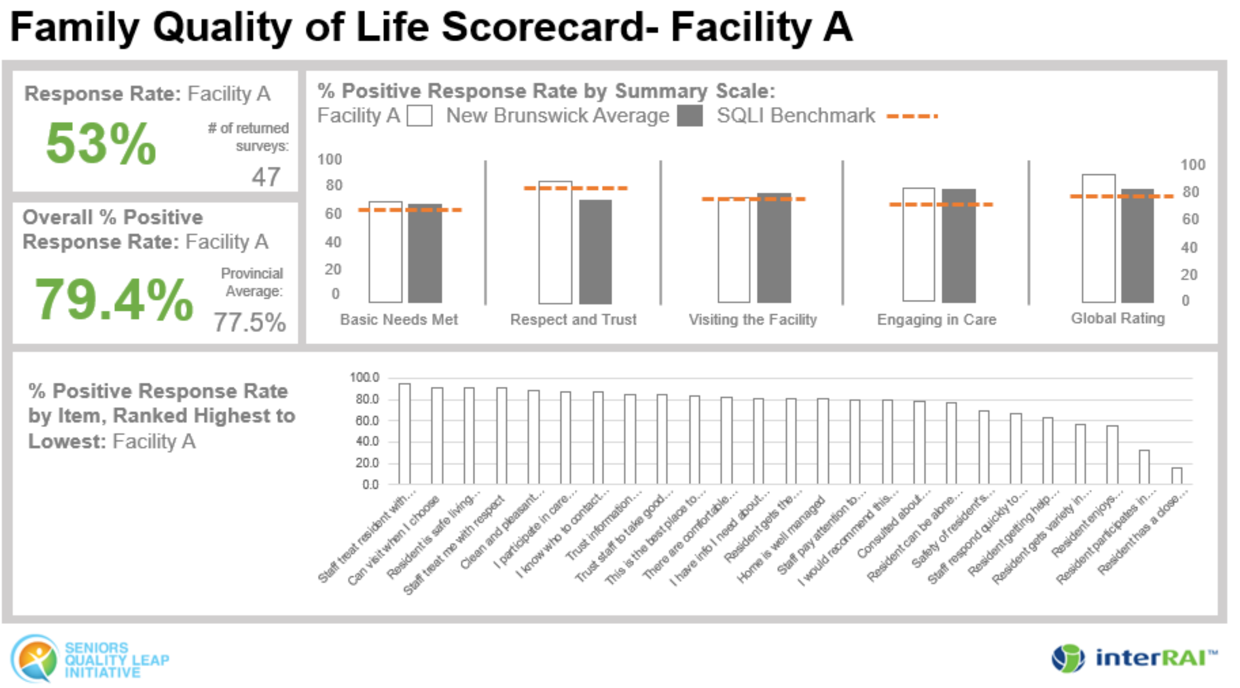
Joanna Eidse, Research Ethics Officer, jeidse@uwaterloo.ca, 519-888-4567, ext. 37163

This above named study is to be conducted in accordance with the submitted application and the most recently approved versions of all supporting materials.

Documents reviewed and received ethics clearance for use in the study and/or received for information:

file: interRAI_LTCF Canadian_Form_v9.1.3_2019.pdf

Appendix 8: Sample Family Quality of Life Facility Scorecard



Family Quality of Life Scorecard- Facility A

Response Rate: Facility A

53%

# of returned surveys:

47

Overall % Positive Response Rate: Facility A

79.4%

Provincial Average:

77.5%

% Positive Response Rate by Summary Scale:

Facility A ☐ New Brunswick Average ■ SQLI Benchmark ----

% Positive Response Rate by Item, Ranked Highest to Lowest: Facility A

SENIORS QUALITY LEAP INITIATIVE

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