

An Exploration of Quality-of-Life Surveys and Indicators in Long-Term Care Homes

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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.

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Statement of Contributions

Amanda Nova was the sole author for Chapters 1 and 6, which were written under the supervision of Prof. Dr. Anja Declercq, Dr. George Heckman, and Dr. John Hirdes and not written for publication.

This thesis also contains four manuscripts written for publication in collaboration with the dissertation committee. Exceptions to sole authorship are as follows:

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Abstract

Introduction: Residential long-term care (LTC) homes are tasked with protecting residents' health and wellbeing as well as their quality of life. However, insufficient focus on action-oriented quality-of-life monitoring may limit the scope of quality assurance activities that LTC homes engage in. With implementation guidance, subjective quality-of-life indicators could be beneficial for benchmarking, quality comparison, and evidence-informed quality improvement in the LTC sector. This dissertation explored the development, feasibility, and implementation of LTC quality-of-life surveys and indicators with a focus on the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF).

Methods: Guided by the Medical Research Council (MRC) Framework for implementing complex interventions, this dissertation included a modified Delphi study, feasibility study, and realist synthesis. First, the modified Delphi study aimed to identify important quality of life indicators through LTC resident and family member focus groups, staff and researcher surveys, and analyses of 2023 data from LTC homes in Flanders, Belgium. Second, the feasibility study used North American SQOL-LTCF data to explore possibilities for risk-adjusting selected quality-of-life indicators. We examined data availability, characteristics, and variability between selected candidate indicators and performed multilevel binary logistic regression modelling to determine whether risk-adjustors would influence LTC home rankings. Third, the realist synthesis examined the implementation of quality of life surveys in LTC homes through a systematic search of academic literature and key stakeholder consultation.

Results: The modified Delphi study identified 10 candidate quality of life indicators for the SQOL-LTCF using importance data from 151 research participants and 417 LTC residents.

Qualitative and quantitative data determined that, across 11 quality of life domains, respect and safety tend to be relatively more important than personal relationships with other residents and staff. In the feasibility study, an analysis of data from 16,141 LTC residents across 236 LTC homes demonstrated the feasibility of between-home quality comparisons using the SQOL-LTCF. The study also suggested that risk-adjustment based on age or self-rated health could support quality-of-life benchmarking between North American LTC homes. Finally, the realist synthesis found that supportive and empowering contexts, trustworthy data sources, and meaningful stakeholder engagement can support the implementation of quality of life surveys for care planning, quality improvement, and information sharing.

Conclusion: Quality of life surveys and indicators show promise for promoting quality assurance activities such as quality monitoring, benchmarking, and comparison. However, individual, organizational, and regulatory contexts can serve as barriers or facilitators. Social desirability biases, workforce shortages, instrument development considerations, privacy-related barriers to data collection, and the quality of interorganizational relationships each have important implications for quality of life monitoring.

Ethics: This study has received ethics clearance through the University of Waterloo Research Ethics Board (#45825, #45826) and Social and Societal Ethics Committee of KU Leuven (G-2023-6931-R3(MAR)).

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Dedication

In memory of my late grandfather, Joaquim Nova. I miss you and hope to honour your example of integrity, patience, and quality of life.

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List of Abbreviations

ADL	Activity of Daily Living
ADLH	Activities of Daily Living Hierarchy Scale
AIRE	Appraisal of Indicators through Research and Evaluation
ASCOT	Adult Social Care Outcomes Toolkit
CHESS	Changes in Health, End-Stage Disease, and Symptoms
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CMO	Context + Mechanism = Outcome
CPS	Cognitive Performance Scale
CREDES	Conducting and REporting of DElphi Studies
DRS	Depression Rating Scale
EQ-5D	EuroQoL-5 Dimensions
ICECAP-O	ICEpop CAPability measure for Older people
iNICA	interRAI Network for Integrated Care in Aging
interRAI LTCF	interRAI Assessment for Long-Term Care Facilities
interRAI MDS	interRAI Minimum Data Set
LTC	Long-Term Care
MDS	Minimum Data Set
MRC Framework	Medical Research Council Framework
NLM	National Library of Medicine
OECD	Organization for Economic Cooperation and Development
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QOL	Quality of Life
QOL.SRI	Quality of Life Structured Resident Interview
QUALIDEM	Quality of Life Dementia Scale
RE-AIM	Reach, Effectiveness, Adoption, Implementation, Maintenance
RISE	Revised Index of Social Engagement
SAS	Statistical Analysis System
SQLI	Senior's Quality Leap Initiative
SQOL-LTCF	Quality of Life Survey for Long-Term Care Facilities
VIKZ	Vlaams Instituut voor Kwaliteit van Zorg (Flemish Institute for Care Quality)
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life Tool

Chapter 1: Introduction

1.1. Quality of Life in Long Term Care

All people want to experience a good quality of life, regardless of age, geography, or health status. Quality of life is subjective, evolves over time, and is distinct from health status or happiness¹. While it can be defined in different ways, the World Health Organization (WHO) defines quality of life as an “individuals' 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”². As a residential care setting with distinct culture and value systems, long-term care (LTC) homes play a large role in shaping residents' quality of life. Quality of life in LTC encompasses several domains including comfort, dignity, security, autonomy, functional status, privacy, relationships, meaningful activities, enjoyment, food and meals, and spiritual well-being^{3,4}. By facilitating positive experiences and minimizing negative experiences in each of these domains, LTC homes can help residents live an excellent quality of life or better quality of life compared to living in a private home⁵. This dissertation will explore quality of life in LTC homes and how it can be measured for quality improvement purposes, with an emphasis on Canadian and Flemish (Belgian) contexts.

Residential LTC homes provide a wide array of medical, personal, and social care services to help individuals who can no longer live safely on their own due to physical and/or cognitive impairments⁶. LTC is unique from other services like complex continuing care, which also provides room and board over an extended period of time but generally requires more skilled, technology-based care to be provided in a hospital-based setting⁷. In Belgium, the LTC system is managed non-hierarchically by one federal government and five federated entities⁸. Each region in Belgium -- Flanders, Wallonia, and Brussels-Capital -- organizes their own LTC

systems. In contrast, the Canadian health system is hierarchical and more decentralized. In each Canadian province, regional health authorities manage LTC, while provincial ministries provide overarching policies and standards⁹. Both Belgium and Canada offer ‘free choice’ to individuals seeking LTC, but this choice is restricted by wait times, bed availability, location, and care needs^{8,9}.

Despite medical, personal, and social care needs, most individuals would prefer to live their final years in their own home and avoid or delay admission into a LTC home¹⁰. In 2021, 5.7% of Belgian individuals aged 65 or older lived in a LTC home (5.3% in Flanders, 6.1% in Wallonia, and 7.6% in Brussels)¹¹. This was higher than in neighboring countries like Germany, the Netherlands, and France with proportions around 4% on average^{12,13}. In North America, 1.7% of Americans¹³ and 6.8% of Canadians aged 65 and older lived in an LTC home in 2020 and 2016, respectively¹⁴. While LTC residents make up a small proportion of older adult populations, they usually have a high degree of health and social needs. Table 1.1. summarizes some key differences between LTC residents in Canada and Flanders, Belgium according to four validated measures created by interRAI.

Table 1.1. Characteristics of LTC residents in Canada and Belgium

	Canada (2023-2024, n=180,261)¹⁵	Flanders, Belgium (2023- 2025, n=84,764)
Mood symptoms indicating presence of a major or minor depressive disorder (<i>Score of 3+ on the interRAI Depression Rating Scale [DRS]</i> ¹⁶)	22%	33%
Severe cognitive impairment (<i>Score of 4+ on interRAI Cognitive Performance Scale</i> ¹⁷)	33%	20%
Extensive to total dependence in activities of daily living (<i>Score of 3+ on the interRAI Activities of Daily Living Hierarchy [ADLH] Scale</i> ¹⁸)	84%	62%
Low levels of social engagement (<i>Score of <3 on the interRAI Revised Index of Social Engagement [RISE]</i> ¹⁹)	43%	29%

interRAI is an international research network in over 35 countries that aims to improve healthcare systems with the development of integrated assessments, screening instruments, and other tools for evidence-informed decision making, like quality indicators and scales²⁰. interRAI scales can be used to summarize population characteristics in LTC, as shown in Table 1.1., and to support LTC resident care planning. For example, the interRAI Depression Rating Scale (DRS) is used for clinical depression screening and scored on a scale from zero to 14 with higher scores indicating more frequent and severe mood symptoms¹⁶. These mood symptoms include feeling of sadness or being depressed, persistent anger, expressions of unrealistic fears, repetitive health complaints, repetitive anxious complaints, sad or worried facial expressions, and tearfulness. The Cognitive Performance Scale (CPS) describes resident cognitive status and is scored from zero to six with higher scores indicating more severe cognitive impairment¹⁷. It is calculated based on impairment in short-term memory recall, cognitive skills for daily decision-making, ability to make yourself understood, and eating impairment. The Activities of Daily Living (ADL) Hierarchy Scale (ADLH), also scored from zero to six, summarizes performance on late-loss ADLs (i.e., personal hygiene, toilet use, locomotion, and eating) with higher scores indicating greater decline of ADL performance¹⁸. Finally, the Revised Index of Social Engagement (RISE) is used to describe a resident's sense of being socially engaged at the LTC home in which they live, and is scored from zero to six with higher scores indicating more social engagement¹⁹. Mood symptoms, cognitive impairment, independence in ADLs, and social engagement can each play a role in how an individual resident experiences quality of life in an LTC home.

1.2. Quality Improvement and Quality Assurance

Improving patient experiences is a key priority for health system transformation within the quintuple aim, a widely accepted framework developed by the Institute for Healthcare

Improvement²¹. Researchers have investigated a wide array of quality improvement interventions^{22,23} and person-centered models of care to improve resident experiences of the LTC system, such as through interactions with staff or the LTC environment. Person-centered care is the philosophy and practice of providing health care that supports shared control and decision-making while acknowledging patient individuality²⁴. In contrast with task-focused care, an emphasis on person-centered care in LTC has been shown to promote social engagement and reduce agitation among residents with dementia²⁵, as well as reduce pain, behavioural challenges, antipsychotic use, and infection transmission²⁶. Additionally, LTC homes with ‘fully implemented’ person-centered care are shown to have higher resident satisfaction, quality of life, and quality of care compared to homes with partial implementation²⁷. Examples such as Green House²⁸, Dementia Villages²⁹, Wellspring³⁰, and the Eden Alternative³¹ that emphasize individuality and autonomy, collaborative decision-making, and quality monitoring, have shown promise thus far. There have been many calls and initiatives to improve quality of life in LTC systems around the world³².

However, the public reputation of LTC has not been very positive, especially after the COVID-19 pandemic led to devastating effects on resident health and wellbeing³². On an individual level, admission to LTC is often a stressful experience, characterized by feelings of uncertainty, loss, and disempowerment^{33,34}. Residents may endure a myriad of existential challenges that cause suffering before, during, or after admission to a LTC home, such as death anxiety or grief³⁵. While they can be supported through challenging emotions with support and compassion from family and care providers, these challenges are complex, difficult, and time consuming to ameliorate³⁵. On a broader scale, LTC sectors are faced with a multitude of challenges related to health care quality, such as LTC home underfunding, challenges with

meeting regulatory demands, and outdated infrastructure. These challenges can translate to constraints and negatively impact quality in LTC homes, particularly residents' experiences and quality of life³⁶. There are also major staffing crises in the LTC sectors of most Organization for Economic Cooperation and Development (OECD) countries, which have resulted from a combination of population aging, low job satisfaction, and insufficient recruitment and retention of skilled LTC staff³⁷. Canada has about 29 LTC beds per 1000 older adults aged 65 or older³⁸, while the United states has 30³⁹. In Belgium, there are about 65 LTC beds per 1000 older adults aged 65 or older¹¹, as well as increasing clinical complexity among residents requiring more specialized and multifaceted care compared to previous generations³⁷. To summarize, there are a multitude of challenges and barriers to improving quality of life in LTC.

The process of improving quality is one that has been highly investigated by researchers within and outside of health care. For example, hiring more staff to work in LTC homes is a quality improvement strategy that has been widely promoted, and researchers have suggested that better gerontological expertise among LTC staff could improve resident outcomes⁴⁰. Given the diversity of LTC homes, residents, and resource availability, a one-size-fits-all quality improvement intervention is unlikely to be fully effective. Understanding the needs of LTC homes on an individual level can support targeted intervention, such as the types of staff (e.g., social workers, food service staff, personal support workers) or types of expertise (i.e., geriatric psychiatry, rehabilitation) needed to address salient quality of life concerns. Quality assurance, defined as a systematic process aiming to establish, defend, and promote quality through an array of activities (e.g., goal setting, community consultation, monitoring, education, and system redesign)⁴¹, can facilitate targeted quality improvement in LTC homes. To illustrate, there are several groups currently employing quality assurance to support improvements in quality of life,

such as the Canadian Translating Research in Elder Care (TREC) Program⁴². Through partnership with policy-makers, lay individuals, researchers, and dozens of LTC homes, TREC has produced research and shared best-practices in a way that has led to measurable improvements to quality of care and quality of life for residents⁴².

1.3. Measuring Quality of Life with Surveys

Quality measurement is foundational for quality assurance, as understanding the current state can help with goal setting and determine whether an intervention led to observable changes. There are many ways to measure quality of life in LTC homes. While self-report is the ‘gold-standard’ for measuring quality of life³, proxy-reporting from family members, caregivers, and staff is also common practice. One 2021 systematic review of self-report quality of life surveys identified 29 diverse quality of life measurement instruments, of which 12 were designed to be completed by residents independently, 14 were administered by interviewers, and 3 were proxy-reported⁴³. The surveys ranged in length from 5 to 57 items⁴³. Popular examples of self-reported quality of life surveys include the EuroQoL-5 Dimensions (EQ-5D)⁴⁴, World Health Organization Quality of Life Tool (WHOQOL-BREF)⁴⁵, and the Adult Social Care Outcomes Toolkit (ASCOT)⁴⁶.

Self-report surveys are less feasible for individuals with severe cognitive impairment, and direct observation may be necessary to gather information on quality of life³. There are many dementia-specific quality of life measurement tools and the majority are observation- or proxy-based, like Dementia Care Mapping⁴⁷ or the Quality of Life for People with Dementia (QUALIDEM) instrument⁴⁸. The focus of this dissertation is on the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF), but a comparison of several quality of life surveys is included in Table 1.2.

Table 1.2. Comparison of Quality of Life Surveys

Survey Name	Data Collection	Length	Duration	Domains
The Quality of Life Structured Resident Interview and Care Plan (QOL.SRI/CP) ⁴⁹	- Interviewer-led, resident self-report - Resident asked yes / no question, then frequency question and (if negative) importance question - Open-ended probes for five top-ranking items - Excludes residents with severe dementia	69 items	30 minutes	Comfort, security, food enjoyment, privacy, meaningful activities, religious practices, relationships, functional competence, dignity, individuality, autonomy, and spiritual well-being
interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF) ⁴	- Interviewer-led, resident self-report or family proxy-report - 5-point frequency scale for ratings - Excludes residents with severe dementia	50 items	30 minutes	Safety and security, autonomy, respect, staff responsiveness, food and meals, personal relationships, comfort and environment, privacy, staff-resident bonding, and activities
World Health Organization Quality of Life Tool (WHOQOL-BREF) ^{2,50}	- Self-administered, interviewer-assisted, or interview-administered - 5-point scale with a variety of response options (e.g., satisfaction, frequency, amount) - Includes residents with mild to moderate cognitive impairment	26 items	30 minutes	Physical health, psychological, social relationships, environment
Nottingham Health Profile (NHP) ^{51,52}	- Resident self-report - Yes / no response, then importance score from 0 to 100 - Includes residents with mild to moderate cognitive impairment	38 items	12 to 40 minutes	Physical mobility, pain, sleep, social isolation, emotional reaction, energy level
Quality of Life for People with Dementia (QUALIDEM) ⁵³	- Proxy-report by direct care staff with close relationship to resident - 4-point scale including “never”, “rarely”, “sometimes”, and “frequently” - Survey is dementia-specific	18 to 37 items	15 minutes	Care relationships, positive and negative affect, restless tense behaviour, self-image, social relations and isolation, feeling at home, and having something to do

Quality of Life - Alzheimer's Disease (QOL-AD) ⁵⁴	- Resident or staff self-report - 4-point scale from “poor” to “excellent” - Survey is dementia-specific	15 items	15 to 20 minutes	Physical, energy, mood, living, memory, family, staff, friends, personality, busy, fun, life, care for self, live with others, choices
Dementia Quality of Life Instrument – Care Homes (DEMQOL-CH) ⁵⁵	- Proxy-report by direct care staff - 4-point scale from “a lot” to “not at all” on how worried the resident has been or how the resident has felt - Survey is dementia-specific	31 items	5 minutes	Feelings, memory, everyday life, and overall quality of life
EuroQoL-5 Dimensions (EQ-5D) ^{44,56}	- Self-administered, interviewer-administered, or proxy-reported - 5-point scale from “no problems” to “extreme problems/unable to” and visual analogue scale from 0 to 100 on self-rated health - Includes residents with mild to moderate cognitive impairment	5 items	A few minutes	Mobility, self-care, usual activities, pain / discomfort, and anxiety / depression
Adult social care outcomes toolkit for Care Homes (ASCOT CH4-HL) ⁴⁶	- Interviews with residents, staff, and family members, and structured observations - 3-point scale including “no needs”, “some needs”, or “high needs” - Includes residents with dementia	8 items	2 hour observation, unknown interview duration	Control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort, dignity
Dementia Care Mapping (DCM) ⁵⁷	- Multicomponent observational method - Five people with dementia observed over representative time period in communal areas, documentation of behaviours every 5 minutes - Tool is dementia-specific	24 behaviour codes	6 hour observation	Social engagement, activities (e.g., walking, performing work or work-like activity, sleeping), caregiver interactions, distress
Note: This is not a complete list of quality of life surveys available for LTC. These surveys were selected based on demonstrated popularity and recurrent presence in literature reviews, interviews, and informal conversations conducted for this dissertation.				

The SQOL-LTCF is a survey that was developed by interRAI in 2009 to evaluate quality of life. It has moderate test-retest reliability, adequate content validity, good internal consistency, and good convergent validity for assessing quality of life among care recipients in LTC homes, including those with mild-to-moderate cognitive impairment (CPS $\geq$ 4, with residents scoring CPS = 4 included based on clinical judgement)^{58,59}. Administered by trained assessors, the SQOL-LTCF assesses the perspectives of consenting LTC residents across 50 items related to privacy, food and meals, safety and security, comfort, autonomy, respect, staff responsiveness, staff-resident bonding, activities, and personal relationships. A supplementary or proxy-reported SQOL-LTCF survey can also be administered to obtain the perspectives of family members or other informal caregivers. The SQOL-LTCF can be used to generate five validated summary scales, covering social life, personal control, food, caring staff, and staff responsiveness⁵⁹. It is a relatively comprehensive quality of life survey and covers a greater number of topics than many other quality of life surveys designed for LTC homes. Similar interRAI quality of life surveys with common survey items also exist in the independent living, assisted living, home and continuing care, and mental health and addictions sectors⁴. Thus, the SQOL-LTCF may support quality comparisons between different care settings. A table describing the domains of the SQOL-LTCF is included in Appendix A.

There is work in progress on implementing and further developing the SQOL-LTCF. The SQOL-LTCF has been piloted or implemented in several countries internationally, but implementation is most mature in Belgium (Flanders) and Canada, in addition to the United States (east and mid-west)⁵⁹. We have recently begun to use SQOL-LTCF data from these locations to develop a quality of life composite measure. A SQOL-LTCF composite measure would offer a simple and easy to understand summary of LTC home performance in quality of

life based on performance in the SQOL-LTCF summary scales and preference weights from LTC residents, care partners, staff, and researchers. While composite measures are highly effective for benchmarking and summarizing complex information, they are less useful for flagging specific quality issues⁶⁰.

1.4. Introduction to Quality of Life Indicators

Quality indicators are quantitative measures based on standards of care that are intended to capture specific issues in structures, processes, or outcomes^{41,61}. Structures are the circumstances in which care is offered, processes are observable care activities, and outcomes are changes attributable to care⁶². According to a 2025 review paper, Belgium currently monitors 15 indicators in their home care and residential LTC system with data gathered by several institutions under the authority of the Health System Performance Assessment framework⁶³. On the other hand, Canada monitors 40 indicators in their home care and residential LTC system with data gathered via interRAI instruments under the authority of the Canadian Institute of Health Information (CIHI)⁶³. An ideal quality indicator should be valid, reliable, specific, sensitive, relevant, and based upon clear and agreed-upon definitions⁶¹. They can be sub-categorized in many ways, including by their target area. For example, quality-of-life indicators are quality indicators that flag issues pertaining to quality of life.

To account for differences in population characteristics that may bias quality indicators, many are risk-adjusted⁶⁴. For example, the interRAI LTCF quality indicator for potentially inappropriate use of antipsychotics in LTC is risk-adjusted for individual covariates, including long-term memory problems or dementia diagnoses, because organizations with a higher number of residents with these conditions are more likely to prescribe antipsychotics for behaviour management. In this sense, quality indicators ‘level the playing field’. The statistical process of

risk-adjustment is commonly used for the purpose of setting payment schemes, enhancing quality comparison, and supporting fair public reporting⁶⁵. Good risk adjustment variables are generally those that are reliable, valid, and resistant to manipulation⁶⁶. They are also correlated with the quality indicators of interest, vary between organizations, and do not change based on the actual care provided^{67,68}.

Demographic (e.g., age, gender), functional (e.g., activities of daily living (ADLs), cognitive impairment), and health-related (e.g., Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS)) variables are commonly used for the risk-adjustment of clinical quality indicators⁶⁵. A small pool of research suggests that these variables may also be promising for risk-adjusting quality-of-life indicators. A doctoral thesis by Kehyayan on the SQOL-LTCF reported that non-modifiable individual characteristics may explain about 20% of the variation in LTC resident quality of life reporting⁶⁹. They found relationships between multiple quality of life domains and religiosity, age group, cognitive impairment, and marital status⁶⁹. Additionally, research has shown that individuals who are older, have lower educational attainment, or have better self-rated health tend to rate care more positively on self-report surveys compared to individuals who are younger, have higher educational attainment, or have worse self-rated health^{64,70}.

While data suggests that some demographic, functional, and clinical variables could be useful for risk-adjusting quality of life indicators, risk-adjustment decision-making should not be solely data-driven. Choosing a set of appropriate risk-adjustment variables requires careful consideration of feasibility, context, and equity⁶⁵. Regarding the latter, some sources of difference between populations tend to be seen as fair or “allowable” for adjustment due to their non-modifiability, such as age, sex, and (in some cases) clinical status⁷¹. On the other hand, some

would argue that societal responses to an innate characteristic, such as ageism, represent an unjust disparity that is amenable to intervention and, therefore, “non-allowable”⁷¹. Whether or not a variable is defined as allowable for risk adjustment has important implications⁷¹.

Depending on the context of interest, risk-adjustment by certain variables may reveal disparities, mask them, or even amplify them⁷¹.

1.5. Audit, Feedback, and Benchmarking

It is also vital to consider the role of contextual factors in whether an LTC home uses quality indicator data and best practices in a meaningful way^{72,73}. As a quality assurance intervention, research suggests that audit and feedback can lead to improved practice among health care providers⁷⁴. However, feedback is generally more effective if it offers specific goals and actions for improvement, focuses on decreasing negative behaviours, and is provided frequently and in multiple formats by a respected individual in a leadership position⁷⁴. Other important considerations include whether an organization has staff with sufficient analytical skills, experience, and resources for working with datasets⁷², and whether the performance data are publicly reported. One realist synthesis stated that when performance data is privately reported, care providers are more likely to ignore or dismiss it⁷⁵. In contrast, when data are publicly reported, some organizations may choose to manipulate or misrepresent their data to improve their ratings, or overemphasize the measured quality area at the expense of other areas (i.e., tunnel vision)⁷⁵. While there is uncertainty around how the effectiveness of audit and feedback varies between contexts, context clearly plays a pivotal role in how information is received.

Context is also important when it comes to interorganizational comparisons. Benchmarking is a specific feedback process used across health care that involves

interorganizational comparisons on quality indicator performance⁷⁶. It has been shown to have a positive association with quality, especially when combined with other interventions (e.g., financial incentives)⁷⁶. Usually a voluntary process applied on a national or regional level, the goal of benchmarking is to identify top-performers and motivate organizations to learn from one another to improve quality⁷⁶. This process can be competitive or collaborative. When there are a large number of partners, frequent meetings between them, and longstanding relationships, benchmarking is more likely to be collaborative than competitive⁷⁵. Communities of practice, like the Senior's Quality Leap Initiative (SQLI) in LTC, aim to engage in collaborative benchmarking. The SQLI in particular uses quality of life measures from the SQOL-LTCF to enhance their collective quality improvement efforts⁷⁷. Some strengths of communities of practice include collaborative planning, knowledge mobilization, capacity-building, and relationship-building⁷⁸.

1.6. Dissertation Overview

1.6.1. Dissertation Rationale and Purpose

There are numerous studies available establishing the validity of quality of life surveys in the LTC sector^{43,48} and many interventions exist to improve quality of life in LTC homes²². However, to our knowledge, there is a lack of research on the development of quality of life indicators to support quality comparisons, benchmarking, and collaboration between LTC homes. This quality assurance 'bridge' between collecting quality of life survey data and taking action with quality improvement initiatives is complex, has important implications, and should not be overlooked. The purpose of this dissertation is to explore the development of quality of life indicators for LTC homes and how they can be harnessed to support quality improvement.

1.6.2. Theoretical Framework

Quality of life indicators for LTC would be considered a complex intervention due to the wide range of domains that make up quality of life⁷⁹. A commonly used tool for developing and evaluating complex interventions, the Medical Research Council (MRC) Framework outlines four phases to follow in complex intervention research: (1) developing or identifying the intervention, (2) testing feasibility in content and delivery, (3) mixed-methods evaluation, and (4) flexible implementation. The MRC Framework also highlights that context, program theory (i.e., how an innovation works and in what circumstances), perspectives, uncertainties, refinement, and cost-effectiveness are core elements that should be considered early in the research process⁷⁹. The MRC framework was originally developed in 2000 and last updated in 2021. We used the most recent iteration of the MRC framework, specifically phases 1, 2, and 4 and the core elements, to guide the planning and conduct of this dissertation. The following section will describe each of the chapters in this dissertation.

1.6.3. Dissertation Outline

Chapter 2 provides a research protocol for this dissertation and highlights our rationale, aims, and research methods. The protocol is followed by three research chapters that will be submitted for publication in peer-reviewed journals. Chapter 3, a modified Delphi study, addresses Phase 1 from the MRC Framework with an emphasis on stakeholder engagement and intervention refinement. The study was conducted to gather importance ratings and perspectives from LTC residents, family members, staff, and researchers on the SQOL-LTCF. A primary objective was to identify a set of candidate quality of life indicators that would be explored further in Chapter 4. Chapter 4, a feasibility study, addresses questions for Phase 2 from the MRC Framework while highlighting intervention refinement and key uncertainties. This

quantitative study explored seven candidate quality of life indicators and whether they would be feasible and appropriate for risk-adjustment using demographic and health-related covariates. Chapter 5, a realist synthesis, supported Phase 4 from the MRC framework with an emphasis on context and refining program theory. The study took a broader perspective on quality of life measurement by examining the implementation of subjective quality of life surveys in LTC homes. Finally, Chapter 6 presents a synthesis of results from the three research studies and how they are situated in the existing literature, identifies implications and recommendations, and describes the strengths and limitations of this dissertation.

Chapter 2: Exploring subjective quality-of-life indicators in long-term care facilities: A mixed-methods research protocol

This chapter has been submitted as:

Nova, A. A., Declercq, A., Heckman, G. A., Hirdes, J. P., McAiney, C., & Lepeleire, J. D. (2024). Exploring subjective quality-of-life indicators in long-term care facilities: A mixed-methods research protocol. *BMJ Open*, 14(7), e087380. <https://doi.org/10.1136/bmjopen-2024-087380>

Abstract

Introduction: Improving quality of life has become a priority in the long-term care (LTC) sector internationally. With development and implementation guidance, standardized quality-of-life monitoring tools based on valid, self-report surveys could be used more effectively to benefit LTC residents, families, and organizations. This research will explore the potential for subjective quality-of-life indicators in the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF).

Methods and analysis: Guided by the Medical Research Council Framework, this research will entail a (1) modified Delphi study, (2) feasibility study, and (3) realist synthesis. In study 1, we will evaluate the importance of statements and scales in the QoL-LTCF by administering Delphi surveys and focus groups to purposively recruited resident and family advisors, interRAI researchers, and LTC clinicians, staff, and leadership from international quality improvement organizations. In study 2, we will critically examine the feasibility and implications of risk-adjusting subjective quality of life indicators. Specifically, we will collect expert stakeholder perspectives with interviews and apply a risk-adjustment methodology to SQOL-LTCF data. In study 3, we will iteratively review and synthesize literature and consult with expert stakeholders to explore the implementation of quality-of-life indicators.

Ethics and dissemination: This study has received approval through a University of Waterloo Research Ethics Board and the Social and Societal Ethics Committee of KU Leuven. We will disseminate our findings in conferences, journal article publications, and presentations for a variety of stakeholders.

Article Summary

Strengths and limitations of this study:

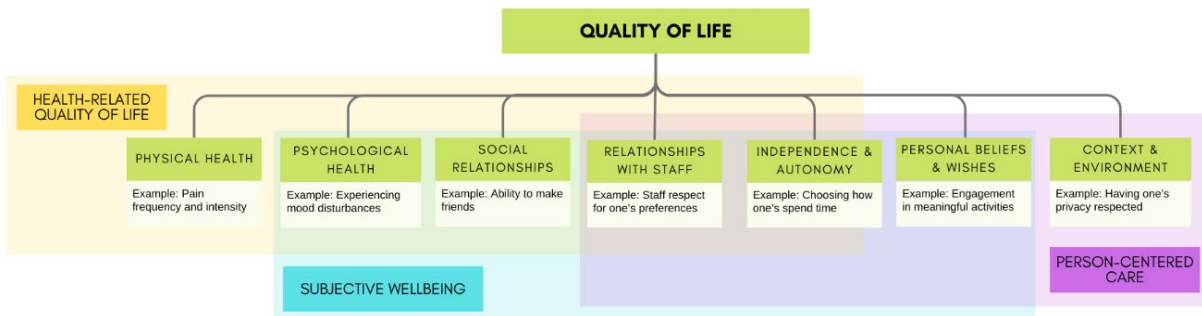
- For our first study, we will recruit a variety of LTC ‘insiders’, including residents and family members, interRAI researchers, and leadership for a modified Delphi study.
- A limitation of the first study is the exclusion of residents living with moderate-to-severe cognitive impairment, which represent a large proportion of the long-term care population.
- Our second study will use a comprehensive, linked dataset that includes the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF) and the interRAI Minimum Data Set (interRAI MDS).
- A major strength of study three is the use of a review methodology that is proven useful for unpacking complex interventions in a pragmatic manner. Researcher biases will be identified and mitigated throughout data collection and analysis with investigator triangulation, member checking, and checklists.

2.1. Introduction

2.1.1. Background

Quality of life can be defined as how an individual perceives their life in relation to their culture, values, expectations, and concerns². Understanding quality of life is especially important in the long-term care (LTC) system. LTC is facing high rates of age-related chronic disease and pressure to maximize value²⁶. As a highly-controlled residential institution⁸⁰, LTC is also held responsible for maintaining resident quality of life by providing person-centered care and supporting physical and psychological health²⁶. Quality of life overlaps conceptually with health-related quality of life, subjective wellbeing, and social care-related quality of life^{1,2,81}. It is also a broad term, incorporating subjective, objective, personal, and organizational elements¹. Therefore, it is unsurprising that quality of life is understood differently by different players in the LTC system⁸², and can be easily oversimplified or equated to happiness, quality of care, or satisfaction². Figure 2.1. shows a concept map describing the multiple dimensions of quality of life².

Figure 2.1. Quality of Life Concept Map



Our ability to describe and compare quality of life in LTC, identify challenges, and evaluate solutions is strengthened by quantitative measurement⁷². While listening to residents one-on-one plays an important role in care⁸³, collecting, analyzing, and discussing performance

related to modifiable challenges, like staff responsiveness in supporting activities of daily living (ADLs), allows care providers and care organizations to make evidence-informed decisions and hold themselves more accountable for enhancing quality of life^{72,84}. Additionally, monitoring residents' quality of life may enable organizations to address challenges more cost effectively. To illustrate, decision-makers can determine whether to invest in recreation programs, food services, or clinical programs based on the expressed needs of residents rather than professional judgement alone⁷². Measuring quality of life to identify resident needs may also help with addressing quality of life disparities⁸⁵. Since patient experience, health care spending, and equity are each priorities for health care quality improvement within the Quintuple Aim Framework²¹, quality of life monitoring is an important component of a LTC quality improvement strategy.

There are many ways to measure LTC residents' quality of life, including family member reports, staff reports, and direct observation. Proxy reports can provide information about externally observable aspects of quality of life, and may be necessary to evaluate quality of life for residents living with more severe levels of physical or cognitive impairment³. However, proxy-reporting should not be used as a substitute when self-reporting is possible. Self-report is the gold standard for assessing quality of life among LTC residents, even for those living with mild-to-moderate cognitive impairment^{58,59}. Several self-reported quality of life surveys exist, including the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF)^{4,82} which will be the focus of this research.

interRAI is an international research network that aims to improve the healthcare system by creating high-quality integrated assessments and screening instruments to support evidence-informed decision making²⁰. The SQOL-LTCF is a reliable and valid survey that was developed by interRAI in 2009, piloted, and implemented in several countries for assessing subjective

quality of life among LTC care recipients^{58,59}. It is administered by trained assessors not providing direct care to respondents. While the SQOL-LTCF is not appropriate for assessing quality of life among residents living with severe levels of cognitive impairment, it has been used and researched among residents living with mild-to-moderate cognitive impairment⁸². To complete the survey, LTC residents are asked to rate their experience on 50 statements, and report how often each is true for them on a 5-point Likert scale from never to always. The quality-of-life domains in the SQOL-LTCF are listed with examples in Table 2.1. The SQOL-LTCF also calculates five summary scales, covering social life, personal control, food, caring staff, and staff responsiveness⁵⁹. Depending on which country the survey is being implemented, it also collects demographic information on couple status, gender, age, self-rated health, and length of time living in the LTC home⁴.

Table 2.1. Quality of life domains in the interRAI quality of life survey for long-term care facilities (SQOL-LTCF) with example statements

Quality of Life Domains	Example Statements (<i>Adapted</i>)
Privacy	Alone when wish
Food and Meals	Get favorite foods
Safety and Security	Possessions secure
Comfort	Feels like home
Daily Decisions (Autonomy)	Decide when to go to bed
Respect by Staff	Treated with respect by staff
Staff Responsiveness	Staff act on resident suggestions
Staff-Resident Bonding	Staff know resident life story
Activities	Has meaningful activities
Personal Relationships	Resident is close friend

The SQOL-LTCF has several advantages. Compared to other surveys, like the Adult Social Care Outcomes Toolkit (ASCOT)⁸¹, the SQOL-LTCF may be better suited for LTC homes that have already implemented other interRAI assessments^{20,86,87}. Integrated assessment systems can better support health system integration⁸⁸. For example, the interRAI Assessment for Long-

Term Care Facilities (interRAI LTCF) and, its predecessor, the interRAI Minimum Data Set (interRAI MDS) are instruments for comprehensive geriatric assessment that have been mandated in several countries for examining resident health and functional status^{89,90}. The SQOL-LTCF can be integrated with the interRAI LTCF and MDS. On the other hand, many countries that have not implemented interRAI assessments, and may prefer to use different tools, like the minimum data set in England⁹¹.

Another advantage of most interRAI assessments, including the interRAI LTCF, is that they can be used to generate risk adjusted quality indicators. Quality indicators are quantitative measures based on standards of care that capture issues in quality⁶¹ and quality-of-life indicators are a type of quality indicator that captures issues in quality of life. Quality indicators can support research, program evaluation, decision-making, and public reporting⁹². To be useful, quality indicators should be actionable⁹³, acceptable to stakeholders, easy to interpret, sensitive to change, specific, reliable, valid⁹², harmless to vulnerable groups, and resistant to manipulation⁶⁶. Additionally, to ensure fair quality comparisons, quality indicators are often risk-adjusted⁷⁶. Risk-adjustment is a process that accounts for differences in resident populations.

There are arguments for and against risk-adjusting subjective quality of life indicators. Proponents argue that some individuals systematically rate their care as better or worse than others⁶⁸. For example, compared to people with intact cognition, persons with moderate cognitive impairment rate the quality of food and meals better, and their experience with autonomy, feeling respected, and staff-resident bonding as worse⁶⁹. Non-modifiable individual characteristics, like cognitive impairment, have been reported to explain about 20% of the variation in LTC resident quality of life reporting⁶⁹. Risk-adjusting quality-of-life indicators could improve the fairness of quality comparisons for LTC decision-making and public

reporting^{64,69}. However, the chosen risk adjustment variables should be correlated with the quality indicator of interest, should not be indicators of good or poor quality of care themselves, should vary between organizations, and should be unaffected by related care processes^{67,68}.

In contrast, concerns have been raised about risk-adjusting subjective quality-of-life indicators. First, if risk-adjustment is done poorly, important differences in quality could be negated or exaggerated⁹⁴. Specifically, under adjustment (i.e., adjusting by too few covariates) has been reported to make LTC homes with “good” quality look mediocre while overadjustment (i.e., adjusting by too many covariates) could make LTC homes with “bad” quality look mediocre⁹⁴. Second, because of the risk-adjustment process, there is concern that the voices of some residents could be misrepresented as ‘more important’ than others, leading to unequal treatment⁶⁸. For instance, “adjusting away” differences or disparities in care, such as those related to race or cognitive impairment, would mask differences in quality that should instead be amplified⁷¹. Third, some clinical factors, like depression or pain, could affect subjective quality of life ratings but would not be appropriate risk adjusters because they are themselves important indicators of subjective quality of life. Finally, due to the complex and subjective nature of quality of life, incorrect assumptions could be made regarding the relationships between resident characteristics and quality of life outcomes. Thus, it is important to not overextend the conclusions that can be drawn from risk-adjusted quality indicators or misuse them as a means to describe quality in a single LTC home. There is no gold standard to establish the validity of a quality of life monitoring system, so some researchers recommend opting for simpler quality measurement approaches that highlight LTC homes with the poorest quality⁹⁴.

2.1.2. Rationale

While there is a large amount of research on quality of life in LTC⁹⁵, there are gaps when it comes to LTC quality of life indicators. Most research on quality indicators thus far has focused on technical, medical, and observable elements of care⁹³. This may be due, in part, to the lack of focus on subjective quality of life in earlier versions of the interRAI-LTCF or MDS assessment⁹³. However, technical and medical indicators only represent a small part of what makes a LTC home high-quality⁹³. While the interRAI LTCF offers quality of life indicators related to objective or observable issues, such as pain, mood, or behaviour symptoms, it has a limited focus on subjective quality of life. Some research has investigated quality of life indicators in long-term care^{81,96}. For example, The ASCOT was developed to measure social care-related quality of life, a concept that overlaps with quality of life for social care services more broadly⁸¹. Although it has been proven useful in several countries, it is not integrated in the interRAI suite of assessments. The SQOL-LTCF may be a good candidate for subjective quality-of-life indicators, but it is still unclear which statements and scales on the survey are the most important to stakeholders, whether risk adjusting subjective quality of life indicators is feasible or appropriate⁹⁷, and if and how subjective quality of life indicators could be best implemented to improve the lives of LTC residents⁹².

2.2. Aims and Objectives

The purpose of this research is to explore the development and implementation of LTC quality-of-life indicators for the SQOL-LTCF. This study will address the following research objectives and questions:

2.2.1. Research Objectives

1. Engage with stakeholders to evaluate the importance of statements and scales related to LTC resident quality of life in the SQOL-LTCF.

2. Critically examine and test the feasibility of risk-adjusting quality-of-life indicators for the SQOL-LTCF.
3. Explore the potential for quality-of-life indicators in LTC homes and how they could be implemented to encourage quality improvement.

2.2.2. Research Questions

- A. What statements and scales in the SQOL-LTCF do resident and family advisors, interRAI researchers, and leadership from LTC organizations consider important indicators of quality of life in LTC?
- B. Is it appropriate and feasible to risk-adjust quality of life indicators for the SQOL-LTCF? If so, what implications should researchers consider?
- C. How, for whom, in what circumstances, and why should quality-of-life indicators be implemented or not in LTC homes?

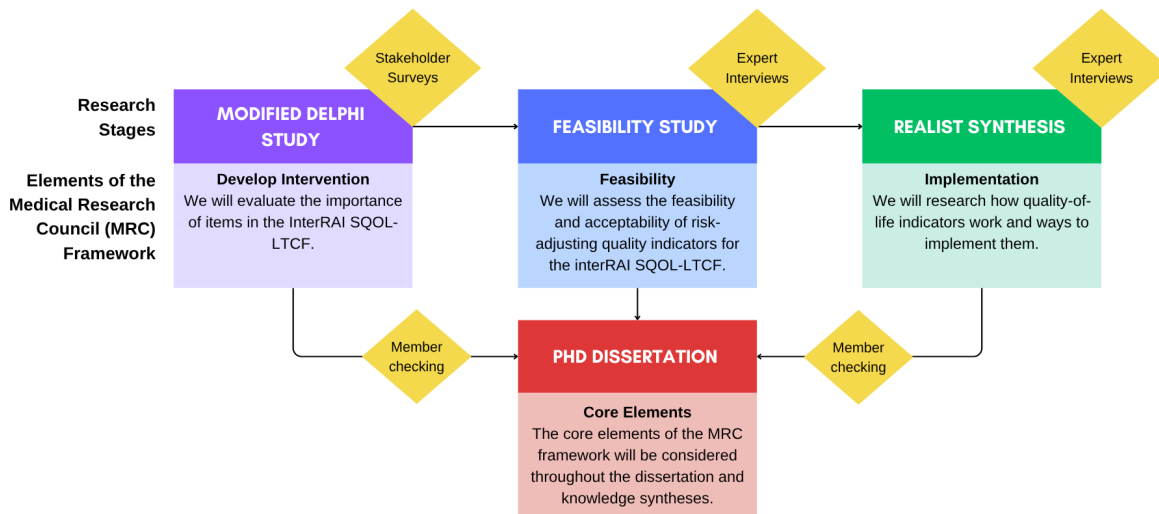
We hypothesize that participants will identify several statements as important indicators of quality of life in LTC, including staff respect and responsiveness⁹⁶. Of this list, we expect that there will be at least three statements which can be further evaluated in study 2 for feasibility and appropriateness, and that complex implications and additional questions will be discussed that challenge assumptions around quality of life in long-term care. Finally, we hypothesize that we will be able to generate implementation recommendations for quality-of-life indicators in LTC.

2.3. Methods and analysis

This mixed-methods research will contribute to a PhD dissertation and will be conducted for about 8 months beginning in January 2024. It includes three related studies: a modified Delphi study to address objective 1 and research question A, a feasibility study to address

objective 2 and research question B, and a realist synthesis to address objective 3 and research question C. A workflow diagram describing the research is shown in Figure 2.2.

Figure 2.2. Project Workflow Diagram



SQOL-LTCF, Self-reported Quality of Life Survey for Long-Term Care Facilities

2.3.1. Study 1: Insider perspectives on quality-of-life indicators for the interRAI SQOL-LTCF: A modified Delphi study.

Study Design

To begin, we will conduct a modified Delphi study to evaluate the importance of different outcome measures related to quality-of-life. This study is considered ‘modified’ because the first round of surveys will not entail open brainstorming, but instead evaluate a fixed set of statements and scales from the SQOL-LTCF surveys. We will also deviate from the traditional Delphi approach by collecting data with focus groups⁹⁸. Data collection and analysis will occur from February to May 2024.

Sampling and Recruitment

We aim to recruit about 100 individuals from LTC-related organizations in Canada, the United States, and Flanders, Belgium using purposive sampling. We will categorize participants into two panels:

1. **Professional Experience Panel:** This panel will include about 40 individuals who are engaged in LTC quality improvement networks. We will email members of the interRAI research network to participate as many are familiar with the SQOL-LTCF and motivated to participate in interRAI-related research. We will also recruit individuals from organizations like the Senior's Quality Leap Initiative (SQLI), a community of practice of 14 LTC organizations aiming to improve quality of life and quality of care for residents⁹⁹.
2. **Lived Experience Panel:** This panel will be composed of about 60 LTC residents and care partners engaged in LTC resident and family advisory councils or committees across the SQLI¹⁰⁰. We will include individuals who report having the time and ability to participate and sufficient cognitive and communication skills to provide informed consent.

Individuals under the age of 18 or not fluent in English, French, or Flemish will be excluded.

Recruitment will end once we meet or exceed the target sample size.

Data Collection and Analysis

Before collecting data, we will obtain approval from all research ethics boards necessary and informed consent from panelists. The data will be collected in one of two ways:

1. **Asynchronous:** For the professional experience panel, data will be collected electronically with 20-minute, quasi-anonymous Qualtrics surveys. There will be three survey rounds, each open for three weeks. To maintain panelists' motivation, we will send

reminder emails three business days before survey closing¹⁰¹. Detail on our asynchronous data collection and analysis plan is shown in Table 2.2.

Table 2.2. Data collection and analysis for the asynchronous Delphi surveys

	Survey 1	Survey 2	Survey 3
Goals	Narrow down a list of important candidate quality indicators for measuring quality of life in LTC and analyze the demographic data.	Narrow down a list of important candidate quality indicators for measuring quality of life in LTC.	Evaluate a set of candidate quality indicators for content coverage, proportional representation, and possible contamination ¹⁰² .
Pre-survey preparation	Distribute the Qualtrics link via email and employ informed consent procedures.	Provide plain-language group feedback on the synthesized results of Survey 1 and distribute the Qualtrics link via email.	Provide plain-language group feedback on the synthesized results of Survey 2 and distribute the Qualtrics link via email.
Response format	Quantitative: Demographic questions (i.e., name, role, and country) and feedback collected on a list of statements and scales according to a 11-point Likert scale from least to most important. Qualitative: Opportunity to suggest changes, express ideas, provide explanations, and ask questions in free text boxes.	Quantitative: Feedback collected on a list of statements and scales that have not yet achieved consensus according to a 11-point Likert scale from least to most important. Qualitative: Opportunity to suggest changes, express ideas, provide explanations, and ask questions in free text boxes.	Quantitative: Feedback collected on a list of statements and scales according to a 11-point Likert scale from complete disagreement to complete agreement on whether the indicator set has (1) covers the right items, (2) is an acceptable size, and (3) does not include items considered irrelevant or misleading. Qualitative: Opportunity to suggest changes, express ideas, provide explanations, and ask questions in free text boxes.
Post-survey follow-up	Share a summary of individual responses and appreciation email; develop survey 2 and group feedback document.	Share a summary of individual responses and appreciation email; develop survey 3 and group feedback document.	Share a summary of individual responses, group feedback document, and appreciation emails.

2. **Synchronous:** For the lived experience panel, data will be collected through focus groups.

The focus groups will employ discussions for consensus-building around the importance of statements and scales on the SQOL-LTCF⁹⁸. In each LTC home, the survey will be

administered using flexible methods by webinar-trained staff not providing direct care to participants. One or more focus group sessions may be needed depending on the preferences of the group. The focus groups may also be audio recorded if participants agree to it beforehand. To begin, the focus group facilitator will present the first section of statements from the focus group survey. Then, the resident or family advisor group will discuss and rate the importance of each statement to LTC resident quality of life on a scale from 0 (extremely unimportant) to 10 (extremely important). While importance is seen as a subjective concept in the study, ‘important’ was defined to facilitators and focus group participants as ‘needed for a good quality of life’ and ‘without it, residents would be worse off’. ‘Unimportant’ was defined as ‘unnecessary, irrelevant, frivolous’ and ‘neutral’ was defined as ‘important to some but not others’. Once all of the statements and scales have been discussed and rated as a group, the facilitator will ask the group what they believe are the five most and least important quality of life statements in the survey. Relevant comments will be noted by the facilitator, then they will return the surveys via email to the PhD researcher for analysis.

Once the Delphi and focus groups surveys are submitted, we will listen to all of the focus group audio recordings, take notes on key points of conversation, and synthesize the data into a single Excel file. Then, we will ensure the data are stratified by role (i.e., resident, researcher, etc.) and perform frequency analysis of the importance scores. We will select our candidate quality indicators for Study 2 from the list of statements where 70% of the professional and lived experience panels agreed that the item was important or extremely important. Statements that do not reach 70% consensus will still be reported on but will not be considered suitable for quality indicator development, as in previous research¹⁰³. Comments and notes from the surveys and

audio-recordings will be examined using content analysis, then grouped into themes while staying as true to the original wording as possible. The themes should contextualize the importance scores, justify quality indicator selection, and provide additional depth for the discussion. A summary of the responses will be shared back to participants in May 2024 for member checking.

2.3.2. Study 2: Exploring quality of life indicator risk adjustment: A feasibility study.

Study Design

In our second study, we will explore the feasibility of risk-adjusting of quality-of-life indicators. As part of this effort, we will test a risk adjustment procedure using observational data from SQOL-LTCF datasets, including a Canadian dataset that links SQOL-LTCF and interRAI MDS assessment results, and consult with expert stakeholders. Data preparation and analysis will occur from May to July 2024 and expert consultation will occur from July to August 2024.

Data Sources

We currently have access to data that was collected from January 2015 to December 2016 (n=331) and June 2011 to August 2013 (n=662) across 10 LTC homes in Ontario, Canada. Trained volunteers, peer support staff, or staff not providing direct care to respondents administered the SQOL-LTCF on paper or electronically, and trained assessors administered the interRAI MDS. Once the data were submitted to interRAI Canada, they were linked by an interRAI data manager. More details on the target populations, recruitment, and data collection can be found in the relevant user manuals^{4,90}.

Variables

Three variables of interest will be selected as candidate quality indicators for this study based on the quantitative and qualitative findings of the modified Delphi study, degree of variation between homes, and whether they represent distinct concepts. While more than three variables could serve as candidate quality indicators in the future, the Medical Research Council (MRC) framework states that exploring feasibility on a smaller scale can support decision-making about future larger-scale evaluations and implementation initiatives⁷⁹. We will also identify useful risk-adjustment variables from the demographic variables in the SQOL-LTCF and from the wider range of demographic variables, summary scales, and health-related variables (e.g., impairment in ADLs, cognitive impairment, and disease diagnoses) in the interRAI MDS. As mentioned previously, risk adjustment variables should be correlated with the quality indicator of interest, should not be indicators of good or poor quality of care themselves, should vary between organizations, and should be unaffected by related care processes^{67,68}.

Data Analysis

We will begin analysis by ensuring the data are clean, excluding missing values, and performing exploratory analyses. We will exclude new admissions with a length of stay of under three months since their experiences may overly reflect the stress and uncertainty associated with relocation, termed ‘relocation stress syndrome’^{33,34}. Observations with missing length of stay data will also be excluded. Preliminary analysis will entail creating frequency tables and conducting chi-square tests for each candidate indicator. To ensure that the indicators are relevant, candidate indicators with a prevalence of less than 3% will not be considered for risk adjustment (e.g., if less than 3% of residents in the entire sample agree that “Bothered by noise”, it will no longer be considered as a candidate quality indicator for the present study)¹⁰³.

Then, we will apply risk-adjustment methods adapted from Jones et al¹⁰⁴. The first step will involve stratifying the data for each quality-of-life indicator into high-, medium-, and low-risk groups, divided at the 20th and 80th percentile of a relevant risk adjustment variable, such as the Resource Utilization Groups (RUG-III) case mix algorithm¹⁰⁴, cognitive performance, or age group. In each stratum, we will generate observed indicator scores for the individual LTC homes and the organization-wide reference population. Risk adjustment will then proceed for each indicator using at least one of two methods described in Table 2.3.

Table 2.3. Risk Adjustment Methods

Method	Steps	Relevant formulas
Indirect Standardization: Uses multivariable logistic regression to adjust for clinically relevant covariates (e.g., age, RUG-III) and produces three scores adjusted at the resident-level.	1. Calculate expected indicator scores within each risk group (high-, medium, and low-risk) using data from the population of interest and Formula A. 2. Generate three performance ratios by dividing observed indicator scores over expected indicator scores. 3. Multiply the performance ratios by the observed indicator scores for the reference population. 4. Transform using the logit function.	Formula A: $y_{RL} = \frac{e^{\beta_0 + \beta_1 c_1 + \beta_2 c_2 \dots + \beta_n c_n}}{1 + e^{\beta_0 + \beta_1 c_1 + \beta_2 c_2 \dots + \beta_n c_n}}$ Where, y_{RL} is the expected indicator score for the risk level of interest. β_0 is the fixed, unknown intercept. $\beta_1 \dots \beta_n$ are the fixed, unknown regression coefficients corresponding to each covariate. $c_1 \dots c_n$ are the mean covariate values.
Direct Standardization: applies standard population weights to adjusted indicator scores, yielding a single composite score adjusted at the facility level.	1. Multiply the resident-adjusted scores for each risk group by the reference population weights (i.e., proportion in strata). 2. Sum into a single composite score, as shown in Formula B.	Formula B: $S_{adj} = \Sigma(S_{RL} \times P_{RL})$ Where, S_{adj} is the composite indicator score. S_{RL} is the adjusted indicator score for each risk level. P_{RL} is the proportion in strata for each risk group, calculated by dividing the size of the risk group over the size of the reference population.

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Finally, we will appraise the risk adjusted quality of life indicators using the Appraisal of Indicators through Research and Evaluation (AIRE) Instrument and informally consult with up to 10 expert stakeholders for feedback on the findings. The stakeholder group will be composed of English-speaking representatives from the SQLI, Flemish Institute for Care Quality, and/or interRAI that were recruited for the Delphi study and have experience using or developing quality indicators. To consult the stakeholders, we will ask the question “do you have any thoughts you would like to share about risk-adjusting quality of life indicators?” and additional prompts as needed. Once stakeholder comments have been collected and reviewed by the research team, we will meet to further discuss the feasibility and appropriateness of risk-adjusting quality-of-life indicators. Specifically, we will weigh the ethical, methodological, and practical implications of developing a set of quality-of-life indicators, including concerns about utility, data availability, cultural differences, and privacy.

2.3.3. Study 3: Exploring the implementation of quality-of-life indicators in LTC homes: A realist synthesis.

Study Design

Our final study will be a realist synthesis, scheduled from May to August 2024. Realist syntheses are less rigid than systematic reviews¹⁰⁵ but still useful for synthesizing several sources of information. Our aim will not be to evaluate the effectiveness or efficiency of quality-of-life indicators. Instead, realist syntheses unpack the ‘black box’ of complex interventions by producing two types of theory¹⁰⁶: (1) Middle-range theories provide structured explanations of social phenomena using context + mechanism = outcome (CMO) configurations, and (2) programme theories explain how and why specific programmes yield different outcomes in different contexts¹⁰⁷. By combining middle-range and programme theories, we aim to explain if

and how quality of life indicators could be implemented to promote quality improvement in LTC homes, for whom, in what circumstances, and why. We will perform the realist synthesis in six iterative steps.

Step 1: Scoping the Literature

First, we will informally scope the literature on quality-of-life indicators in LTC within two relevant bodies of literature, gathering key references from PubMed, Google Scholar, and Connected Papers. To facilitate knowledge synthesis, we will compile all references in a Zotero reference management software library and note relevant concepts from abstracts and figures in an Excel spreadsheet.

Step 2: Stakeholder Interviews

Next, we will recruit and conduct informal, virtual interviews with up to 10 stakeholders that were previously engaged in the Delphi study. Engaging subject matter experts can improve the efficiency of reviews¹⁰⁸. Therefore, we aim to include researchers and health care leaders with experience using quality indicators. We will exclude individuals who do not speak English or do not have access to a computer. Stakeholders will be asked the following interview questions:

1. In your opinion, are quality of life indicators useful (or could they be useful) for quality improvement in LTC homes? Why or why not?

PROMPT 1: Who would benefit or not from quality-of-life indicators if they were implemented in LTC?

PROMPT 2: How could quality of life indicators be implemented? Are there circumstances that would make them easier or harder to implement in LTC?

2. What theories, papers, practice guidelines or other resources do you know of that could help with implementing quality of life indicators in LTC?
3. Are you interested in being sent the results of this study or being personally acknowledged in the final publication?

The interviews should take about 30 minutes to complete and will be audio recorded to facilitate notetaking. Any resources identified by the stakeholders will be searched for and added to the reference library.

Step 3: Searching Process

We will formally search white and grey literature for additional references. In collaboration with a university librarian, we will compile a list of search terms related to “quality of life”, “quality indicators”, “implementation”, and “long-term care”. To identify relevant white literature, we will search PubMed via the National Library of Medicine (NLM), Scopus, and CINAHL via EBSCOhost, with the search terms while restricting the search to papers in English. For the grey literature search, we will use the Trip Database and Google Search, screening titles and summaries in the first five pages of the searches for government reports and documents from credible organizations. We will prioritize case studies, qualitative research, and reports from reputable sources, and exclude unpublished manuscripts and conference abstracts.

Step 4: Document Selection and Appraisal

Two researchers will then independently screen titles and abstracts from the collected literature using Covidence review management software¹⁰⁹. After removing duplicates, we will screen the full texts and appraise them using questions adapted from Pawson’s ‘fitness-for-purpose’ criteria¹¹⁰: (1) ‘what were the findings? Is the study design suited to make those

claims?’, and (2) ‘do the findings build on or challenge the emerging pattern? Is a shift in scope needed?’. Disagreements between reviewers will be resolved through discussions with the research team.

Step 5: Data Extraction

Once the papers have been reviewed, we will extract and analyze relevant information using a realist lens. Specifically, we will label the text with the theory-driven codes *context*, *mechanism*, and *outcome* to separate relevant aspects of each article. Then, we will apply data-driven sub-codes. Using modified thematic analysis, the sub-codes will be listed and organized into themes based on their frequency and contributions to the emerging theory¹¹¹.

Step 6: Analysis and Synthesis

Finally, we will synthesize the codes, structure them into themes, incorporate insights from the stakeholder interviews, and develop middle-range and programme theories. We will primarily employ mind-mapping to generate theory by arranging the ‘pieces of the puzzle’ into charts and figures. The interview participants will then be invited to approve or reject a one-page summary of the research findings via email. The steps of the realist synthesis will be iteratively repeated as needed, and the study will conclude when our themes meet the conceptual depth criteria of range, complexity, subtlety, resonance, and validity¹¹².

2.3.4. Patient and Public Involvement

Patients and the public were not involved in designing the research protocol or determining the aims and objectives. However, in study 1, we will involve LTC residents and care partners in focus groups to gather their perspectives on quality of life in LTC, which inform parts of Study 2 and 3. We will also disseminate our results to all interested participants.

2.4. Discussion

2.4.1. Summary of Expected Outcomes

This research will contribute to the growing body of literature on quality-of-life indicators. We expect to evaluate the importance of several quality-of-life statements and scales, examine the feasibility of risk-adjusting quality-of-life indicators for the SQOL-LTCF, and describe if and how LTC quality-of-life indicators could be best implemented.

2.4.2. Limitations

This research may be affected by some limitations. First, no financial compensation is available for participants due to resource constraints. Instead, we will express our gratitude with appreciation letters. Second, participant biases may limit the generalizability of this research. For example, the Delphi study may be susceptible to selection bias since we will only recruit individuals connected to large organizations committed to quality improvement, such as the SQLI and interRAI. While purposeful sampling offers advantages, like the efficient recruitment of information-rich cases¹¹³, individuals who are not part of these groups may have different perspectives around quality of life. Another limitation is that we have also chosen to exclude residents with moderate to severe dementia from the focus groups as they cannot provide their own informed consent. These residents represent a large proportion of the LTC population and may have different experiences around quality of life that are better captured with proxy-reported instruments¹¹⁴. Finally, the focus groups may be susceptible to social desirability bias and groupthink¹¹⁵. Running separate focus groups at multiple LTC homes may reduce the effect of this bias on the results. We will employ investigator triangulation, member checking, and checklists (e.g., AIRE) to minimize bias throughout our research¹¹⁶.

2.4.3. Strengths and contributions

This research also has several strengths, including our mixed methods approach, stakeholder engagement, and use of the SQOL-LTCF. First, we will use quantitative and qualitative research methods, including surveys, focus groups, interviews, secondary data analysis, and literature searches to obtain and describe multiple perspectives related to quality of life in LTC. Some researchers have suggested that applying mixed methods and combining subjective and objective data supports the development of more trustworthy and useful quality indicators¹¹⁷. Specifically, the Delphi technique is widely seen as valuable for selecting candidate quality indicators¹¹⁸. Second, this study will engage a diverse array of stakeholders, including LTC residents, care partners, researchers, and organizational leaders. Participant triangulation can improve the trustworthiness of research¹¹⁹ since different stakeholders have unique perspectives on quality of life in LTC⁸². Third, using the SQOL-LTCF offers several advantages. The SQOL-LTCF is a robust, reliable, and valid survey for evaluating subjective quality of life among LTC residents^{58,59}. Since it is part of an international third generation assessment system²⁰, it can be linked to other robust, reliable, and valid measurement instruments such as the interRAI LTCF. Therefore, the SQOL-LTCF is well-positioned to streamline the piloting and implementation of quality indicators, a task rarely performed by other researchers¹²⁰.

Finally, the present research may offer several research and practice contributions. Depending on our findings, quality indicators developed from this study could facilitate benchmarking and comparisons between quality of life in LTC and other outcomes, such as decline in mood, worsening pain, decline in ADLs, and more. Researchers using interRAI data could also be enabled to highlight gaps in care, advocate for more proactive quality evaluation, and support approaches that enhance resident quality of life like person-centered or relationship-

centered care. Our findings could also open avenues for exploring relatively new research methodologies like multi-attribute utility analysis, which optimizes decision-making with composite measures based on preference-weighted sources of information¹²¹. Regarding practice contributions, we expect that evaluating the statements and scales in the SQOL-LTCF will improve its utility for supporting LTC residents without dementia or mild-to-moderate dementia. Moreover, the knowledge we generate on risk-adjusting and implementing quality of life indicators, could be valuable for organizations hoping to measure, benchmark, and compare their performance with others.

2.4.4. Ethics and dissemination

This research and all relevant materials were reviewed and approved by a University of Waterloo Research Ethics Board (#45825, #45826, #45956) and Social and Societal Ethics Committee of KU Leuven (G-2023-6931-R3). There are no known or anticipated risks to the participants of this study, who will be required to provide informed consent. We will inform participants that their responses are confidential, they can withdraw from the study at any time up until the results are submitted for publication, and their data will be erased if they choose to withdraw. All primary data will be securely stored and retained by the LTC organizations and/or researchers for five years following the conclusion of the study.

Beyond academic publications and conference presentations, we plan to present our research findings with several stakeholder groups, such as the SQLI. Our dissemination strategies will be informed by research best-practices^{122,123}.

Author contributions: All authors contributed to conceptualization, developing the methodology, and reviewing, revising, and approving the final draft of this research protocol. In

addition, AN wrote the original draft and created figures and tables, AD, GH, and JH were responsible for supervision, providing resources, and connecting with stakeholders from participating organizations, and CM and JDL provided supervision. AD and JH are co-guarantors for this publication.

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Competing interests statement: AD, GH, and JH are interRAI research fellows. The authors have no additional competing interests to declare.

Chapter 3: Insider perspectives on the interRAI quality of life survey for long term care facilities: A modified Delphi study

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Insider perspectives on the interRAI quality of life survey for long term care facilities: A modified Delphi study.

3.1. Introduction

Subjective quality of life is a person's perception of their life and its alignment with their goals and expectations in the context of their culture and value systems². For residents of long-term care (LTC) homes, subjective quality of life encompasses several domains, including privacy, food and meals, safety and security, comfort, autonomy, staff respect and responsiveness, staff-resident bonding, activities, and personal relationships⁴. Currently, many LTC homes around the world are being confronted with complex staffing and management challenges³⁶. These challenges, among others, have contributed to dissatisfaction, stress, and instability within the LTC system, and raised quality of life in LTC as a priority on institutional agendas³⁶.

interRAI is an international research network that develops and refines standardized assessment instruments to support evidence-informed decision making in the care of individuals living with a disability or medical complexity²⁰. Due to growing interest in measuring, monitoring, and improving quality of life¹²⁴, interRAI developed the interRAI Self-Reported and Proxy-Reported Quality of Life Surveys for Long-Term Care Facilities (SQOL-LTCF)^{4,82}. The self-report SQOL-LTCF has 50 items and 5 scales related to quality of life^{4,59}. It validated for use with residents who are cognitively intact or live with mild-to-moderate impairment, and is administered by interviewers who do not provide direct care to respondents but are trained to capture residents' perspectives on their quality of life^{4,82}. A supplementary or proxy-reported survey can also be administered to obtain the perspectives of family members. Other self-reported quality of life surveys exist, but the SQOL-LTCF is commonly used⁴³, and has been piloted and implemented in several countries internationally⁵⁹.

There is an opportunity for interRAI to improve the utility of the SQOL-LTCF. Quality indicators are quantitative measures based on standards of care that flag challenges and support benchmarking, quality comparison, and quality improvement⁶¹. Most research on quality indicators thus far has focused on technical, medical, and observable elements of care^{3,93,125}, but quality of care does not necessarily reflect quality of life in LTC¹²⁵. Researchers have recommended the development of quality of life indicators based on self-report assessments^{3,126}. Quality of life indicators could better position the SQOL-LTCF as a quality improvement tool within the interRAI suite and support LTC leaders in their pursuit of the quintuple aim^{21,127}.

One of the first steps towards potentially developing quality-of-life indicators for LTC is to ask experts by profession and by experience (i.e., insiders) which items represent acceptable quality improvement priorities⁹². Thus, our objective was to engage with LTC residents, family members, staff, and researchers to evaluate the importance of statements and scales in the SQOL-LTCF.

3.2. Methods

4.2.1. Study design

A modified Delphi study was conducted from January to June 2024. The Delphi method is a qualitative research technique that usually incorporates five elements: (1) groups of ‘expert’ panelists, (2) anonymity between panelists to minimize social pressure, (3) iterative data collection over several rounds of surveys, (4) controlled feedback between survey rounds, and (5) the application of feedback in subsequent rounds^{101,128}. The present study is considered a modified Delphi study as we deviated from traditional Delphi standards in three ways. First, we did not employ an initial round of open brainstorming because the SQOL-LTCF is made up of

fixed statements and scales. Second, in addition to employing iterative researcher and staff surveys, we used focus groups to gather consensus from LTC resident and family member participants, as has been done in previous research^{98,118}, to answer participant questions, facilitate discussions, and offer participants with supportive resources (e.g., mental health supports) if any serious concerns were raised around their wellbeing. Third, we incorporated a secondary data analysis of importance scores from Flemish LTC homes. These data on the importance of statements in the Flemish SQOL-LTCF were collected by the Flemish Institute for Care Quality from three LTC homes in Flanders during a 2023 survey pilot. To collect the data for each statement, a trained interviewer asked individual residents to rate performance on a 4-point scale from “never” to “always”. Immediately after each importance score was reported, the interviewer asked whether that was important to them with three possible response options (i.e., “not important”, “neutral” or “important”. These data were collected anonymously within LTC homes, and LTC home names were pseudonymized before being shared with the researchers for this study.

This study was part of a larger research project exploring the development and implementation of LTC quality-of-life indicators¹²⁹. Ethics approval for this study was obtained from a University of Waterloo Research Ethics Board, the Social and Societal Ethics Committee of KU Leuven, and several LTC research ethics boards. Our study is reported in alignment with the Conducting and REporting of DElphi Studies (CREDES) checklist included in Appendix B¹²⁸.

3.2.2. Sampling and Recruitment

We aimed to purposively recruit approximately 100 LTC insiders, including individuals with professional or lived expertise in the LTC sector. We included individuals who were

motivated to participate, had the time and ability to participate, and who could provide informed consent, and excluded individuals under the age of 18, persons not fluent in English, French, Flemish, or Dutch, and residents living with moderate to severe cognitive or communication impairments. Recruitment efforts were primarily focused on Canada, Belgium, and the United States, but we did not set exclusion criteria based on geography.

To reach prospective participants, the research team emailed and met virtually with individuals from LTC quality improvement networks, including the Senior's Quality Leap Initiative (SQLI)⁹⁹, the interRAI Network of Integrated Care and Aging (iNICA), the Flemish Institute for Care Quality (VIKZ), and two university research groups. We also provided a recruitment flyer to LTC organizations to distribute among resident and family advisory committees. Recruitment ended once we were set to meet or exceed the target sample size with sufficient representation from each insider group.

3.2.3. Primary Data Collection

To collect data, we developed a questionnaire adapted from the resident and family versions of the interRAI SQOL-LTCF. The English version of the questionnaire has been included in Appendix C. All of the original survey questions were reworded to evaluate importance rather than frequency, then revised based on early feedback from initial focus groups and facilitator training sessions. We asked participants to rate the importance of 62 statements on an 11-point scale from extremely unimportant to extremely important, then evaluate five quality of life scales⁵⁹, identify the five most and least important statements on the survey, and share additional comments.

We employed the questionnaire in face-to-face or zoom focus groups with LTC residents and family members, and in electronic surveys with LTC staff and researchers.

Focus groups. We employed flexible methods for the focus groups because each facility had unique rules, requirements, and constraints (e.g., ethics procedures, staff availability, council membership and experience level). The focus groups were led by at least one webinar-trained staff member not providing direct care to participants. Facilitators were provided with information and consent forms, resident-facing and facilitator versions of the survey, a large-font 11-point rating scale, a focus group introduction video and ‘facilitation cheat sheet’ (included in Appendix B), and an appreciation letter to print and distribute. Several of the materials used to support focus group facilitators in included in Appendix D. After collecting informed consent, facilitators read each question aloud, prompted participants to share their importance ratings, and guided discussions to support consensus-building. If consensus was achieved by the group, the facilitator recorded the group importance score, and if consensus was not achieved, they noted individual importance scores which would be averaged by the research team. We instructed facilitators to audio-record the session(s) if participants consented to it and run multiple focus groups sessions if needed. Additionally, half of the focus groups were completed the survey in reverse.

Electronic surveys. Survey participants were asked the same set of questions as focus group participants via Qualtrics surveys distributed by email. Each Delphi round took three to four weeks to complete, including one week for analysis between rounds. In round one, participants completed the questionnaire and reported their email address, role, and organization. The second round was individualized and began with a list of statements that achieved consensus for inclusion and exclusion. Each section was prefaced by round-one average importance scores

from staff or researchers (depending on which group the participant pertained to) as well as a comment summary. Individual first-round responses, including scores and comments, were pre-populated for each item. In the third round, we provided participants with average importance scores from the second Delphi round, average scores from the resident and family focus groups, and individual scores. We then asked participants to determine which ‘most important’ statements would make good quality-of-life indicators for LTC out of the 40 statements that had reached consensus or were near reaching consensus in the first two rounds. This selection was made in two stages, where participants were told to choose generously first, then selecting a top 10 from those. Each participant then proceeded to evaluate their top 10 by responding yes, maybe, or no to the following criteria and providing optional comments:

1. whether the statement represents a specific challenge in LTC (specificity),
2. whether they would expect residents without significant cognitive impairment to understand what the statement means (understandability),
3. whether improvement pertaining to the indicator would be realistic (actionability),
4. whether improvement would be good for all residents (including residents living with cognitive impairment, mobility challenges, etc.) (equity),
5. whether they would expect scores to be sensitive to change (sensitivity to change), and
6. an overall evaluation on whether the statement could become a good quality indicator on the above criteria

Following evaluations, participants were given the choice to re-consider their “top 10” quality indicator set and evaluate their set based on breadth and whether irrelevant statements were present.

We shared the final results with all participants for voluntary member checking within a 6-page plain-language research summary and appreciation letter.

3.2.4. Analysis

For the quantitative data gathered in the surveys and focus groups, we calculated average importance scores and performed frequency analyses stratified by role (i.e., resident, family, researcher, or staff). For the Delphi surveys, when 70% of participants agreed on an importance rating of 9 to 10 or 70% agreed that the importance rating was not 9 or 10¹⁰³, the statement met the ‘consensus cutoff’ for inclusion or exclusion in the final candidate QI list presented in Delphi round three. For qualitative analysis, we reviewed each available audio recording twice and took notes on key points of conversation. We compiled and organized all notes and comments into a single file, stratified by role, then coded and summarized the data for each questionnaire item using content analysis. Then, we summarized the codes and summaries into themes for each section of the SQOL-LTCF and generated overall themes with mind-mapping. Finally, we analyzed the secondary data from Flemish residents which were securely transferred to AN and securely stored on a KU Leuven server. Using RStudio¹³⁰, we first applied numeric scores to the individual level importance score data, where unimportant was assigned a score of 0, neutral was assigned a score of 5, and important was assigned a score of 10. Then, we calculated mean importance scores by individual questions on the SQOL-LTCF and for each domain with confidence intervals to determine if scores for the different items were significantly different. Finally, we tabulated the results to perform side-by-side comparisons with the primary data collected. Our final recommendations were reviewed by multiple interRAI fellows to enhance alignment with organizational priorities.

3.3. Results

3.3.1. Participants

We recruited 151 unique participants, including 65 LTC residents across 14 focus groups, 39 family members across 10 focus groups, 23 researchers, and 24 staff. The residents and family members were all members of a resident and/or family advisory group within a large urban LTC home. Focus groups took place in the United States (Florida, Massachusetts, and California) and Canada (Ontario, Nova Scotia, and Manitoba). For the Delphi surveys, participants were primarily from North America and Europe, with some representation from Africa and Asia. Most of the researcher participants were interRAI fellows and most of the staff participants were from SQLI member organizations. Additional detail on participant characteristics is included in Table 3.1.

Table 3.1. Participant Characteristics

Data Collection Modalities	n	%
Focus Groups (residents and care partners)	24 focus groups	4.4%
<i>Audio recording and importance scores</i>	9	37.5%
<i>Detailed notes and importance scores</i>	12	50.0%
<i>Importance scores only</i>	3	12.5%
Surveys (staff and researchers)	109 surveys	19.8%
<i>Round 1</i>	40	36.7%
<i>Round 2</i>	36	33.0%
<i>Round 3</i>	33	30.3%
Secondary Data (residents only)	417 observations	75.8%
Primary Data – Participant Characteristics	n	%
Participant Type		
<i>Residents</i>	65	43.0%
<i>Care partners and family members</i>	39	25.8%
<i>Staff</i>	24	15.9%
<i>Researchers</i>	23	15.2%
Country / Continent		
Canada	100	66.2%
<i>Focus Group Participants</i>	75	
<i>Survey Participants</i>	25	
United States of America	34	22.5%
<i>Focus Group Participants</i>	29	

<i>Survey Participants</i>	5	
Europe, Australia, or New Zealand (<i>Survey Only</i>)	11	7.2%
Asia or Africa (<i>Survey Only</i>)	4	2.6%
Unknown	2	1.3%
Secondary Data – Participant Characteristics		
Gender		
Women	312	74.8%
Men	105	25.2%
Age Group		
Under 75	23	5.5%
75 to 85	87	29.9%
85 to 95	238	57.1%
Over 95	52	12.5%
Prefer to not respond	17	4.1%

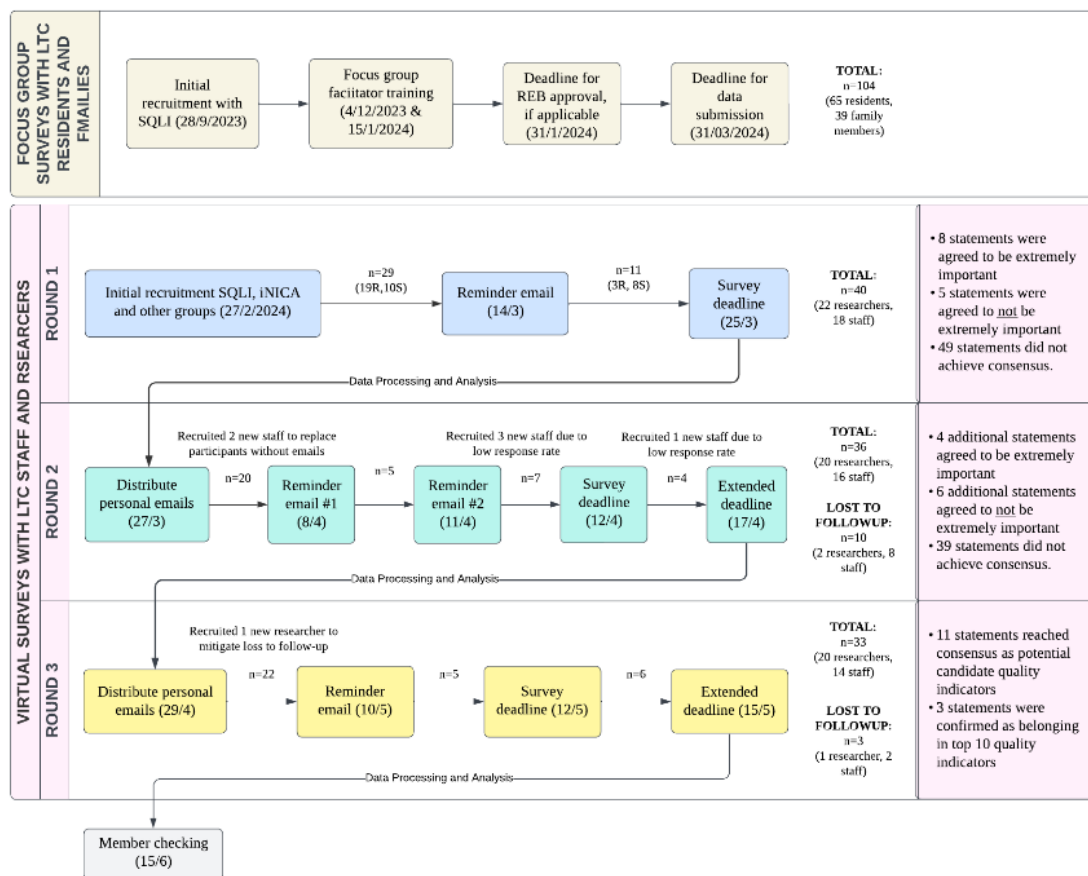
Of the 151 participants, eight residents did not complete the entire focus group, and 4 researchers and 16 staff did not complete all three Delphi surveys. Drop out during the focus group was attributed to fatigue or scheduling conflicts (i.e., able to attend for only the first hour). Reasons for not completing all three surveys included loss to follow-up, drop out, or being recruited partway through data collection. Round 2 of the Delphi survey had a 75% response rate and round 3 had a 93% response rate. Since these rates were lower than expected, we approved late enrollment for 7 individuals by request. Including the late addition participants had a minimal effect on the final importance scores and did not change our conclusions. A flowchart with detail on recruitment, participation, and data collection been included Figure 3.1.

3.3.2. Outcome Data

In round one of the virtual surveys, 8 statements reached consensus as extremely important and 5 reached consensus as less important. In round two, staff and researchers evaluated 49 statements, from which two additional statements reached consensus as extremely important and seven as less important. In round three, three out of 40 evaluated statements

reached consensus and were identified as ideal candidate quality-of-life indicators, and eight statements reached consensus as potential quality-of-life indicators. One out of the eleven confirmed and potential indicators (“Family knows contact when concerned”) was dropped from the final list due to limited inclusion in participants’ final list of candidate quality of life indicators, leaving ten candidate quality of life indicators remaining. The frequency of importance scores assigned in Delphi round one, additional detail on results for each Delphi round and the focus groups have been included in Appendices E, F, and G.

Figure 3.1. Data Collection Flowchart



3.3.3. Main Results

3.3.3.1. Importance of quality of life elements

All of the quality of life items on the SQOL-LTCF were rated as important, but some were significantly more important than others. According to the secondary Flemish data, the most important quality of life domains were safety and security (mean = 8.88, 95% CI = [8.73, 9.04]) and respect (mean=8.64, 95% CI = [8.50, 8.79]). The second most important domains were responsiveness (mean = 8.29, 95% CI = [8.16, 8.41]), food (mean = 8.10, 95% CI=[7.95, 8.24]), autonomy (mean = 8.01, 95% CI=[7.89, 8.13]), and privacy (7.92, 95% CI=[7.67, 8.16]). The third most important domains were comfort (mean=6.75, 95% CI=[6.56, 6.94]) and staff-resident bonding (mean = 6.70, 95% CI=[6.55, 6.84]). The least important domains were activities (mean = 6.14, 95% CI=[5.99, 6.28]) and personal relationships (mean = 6.03, 95% CI=[5.87, 6.19]).

The following sections describe the results from the first two rounds of the Delphi survey, focus groups, and Flemish secondary data in greater detail. During primary data collection, every statement received a score of 10 (extremely important) from at minimum two researcher or staff participants and at least one focus group (with several individuals assigning a 10 prior to consensus-building). Average importance scores for each statement on the SQOL-LTCF is included in Table 3.2.

Table 3.2. Average Importance Scores by Data Source

Category	#	Statement	Secondary Data	Delphi Study			
			Flemish Residents	Residents	Family	Researcher	Staff
Privacy	A1	Alone when wish	7.56 (7.21, 7.91)	7.9	7.9	8.0	8.1
	A2	Privacy respected during care	8.28 (7.95, 8.61)	8.6	N/A	9.3	9.7
Food & Meals	B1	Get favourite foods	9.05 (8.80, 9.30)	8.1	N/A	7.7	7.6
	B2	Eat when want	6.27 (5.93, 6.61)	5.0	N/A	7.1	7.2
	B3	Enough meal variety	8.40 (8.09, 8.71)	7.3	8.1	7.8	8.4
	B4	Enjoy meal times	8.00 (7.67, 8.34)	7.7	8.9	8.6	9.0
	B5	Food is right temperature	8.76 (8.48, 9.03)	8.8	N/A	7.9	9.4
Safety & Security	C1	Can get help right away	9.01 (8.74, 9.27)	9.2	9.8	9.4	9.2
	C2	Possessions secure	8.74 (8.45, 9.03)	9.1	8.5	8.3	9.1

	C3	Feel safe alone	8.91 (8.64, 9.18)	9.2	9.9	9.4	9.4
Comfort	D1	Get other needed services	9.35 (9.14, 9.57)	8.8	9.7	8.8	7.9
	D2	Would recommend to others	<i>No data</i>	8.7	6.8	7.2	7.7
	D3	Feels like home	8.73 (8.44, 9.02)	6.5	<i>N/A</i>	8.5	7.4
	D4	Easily go outdoors	8.18 (7.86, 8.50)	7.8	<i>N/A</i>	8.4	6.6
	D5	Bothered by noise	7.47 (7.12, 7.82)	8.1	<i>N/A</i>	8.0	7.6
	D6	Clean and pleasant environment	<i>No data</i>	9.3	9.8	9.1	9.2
	D7	Best place for meeting needs	<i>No data</i>	9.1	9.4	7.5	7.8
Autonomy	E1	Bath/shower as often as wish	7.04 (6.69, 7.38)	8.3	<i>N/A</i>	7.7	7.8
	E2	Decide when to get up	7.67 (7.33, 8.01)	8.3	<i>N/A</i>	7.8	8.5
	E3	Decide when to go to bed	8.43 (8.11, 8.74)	9.2	<i>N/A</i>	8.1	8.4
	E4	Go on spur of moment	7.93 (7.59, 8.27)	7.9	<i>N/A</i>	7.0	7.0
	E5	Control who comes in room	7.44 (7.09, 7.80)	7.8	<i>N/A</i>	8.6	8.3
	E6	Decide clothes to wear	8.74 (8.46, 9.01)	8.9	<i>N/A</i>	8.1	8.3
	E7	Decide how to spend time	8.83 (8.55, 9.10)	9.4	<i>N/A</i>	8.8	9.1
Staff Respect	F1	Treated with respect by staff	9.55 (9.37, 9.73)	9.5	9.9	9.6	9.6
	F2	Family treated with respect by staff	<i>No data</i>	9.7	8.8	9.1	9.4
	F3	Staff pay attention	8.82 (8.54, 9.10)	9.0	9.7	9.0	8.9
	F4	Can express my opinion	8.41 (8.10, 8.73)	9.3	<i>N/A</i>	9.2	9.3
	F5	Staff respect likes/dislikes	7.79 (7.43, 8.15)	9.1	<i>N/A</i>	8.8	9.4
Staff Responsiveness	G1	Staff help me live my life	8.32 (7.99, 8.66)	8.9	<i>N/A</i>	8.5	8.4
	G2	Staff respond quickly	8.98 (8.72, 9.24)	8.9	8.8	8.6	8.8
	G3	Staff act on resident suggestions	6.54 (6.13, 6.95)	6.8	<i>N/A</i>	7.9	8.1
	G4	Get needed health services	9.21 (8.97, 9.45)	9.0	<i>N/A</i>	8.8	8.4
	G5	Staff have enough time	8.33 (8.01, 8.65)	8.6	<i>N/A</i>	8.8	8.6
	G6	Staff know what doing	8.62 (8.32, 8.93)	9.0	<i>N/A</i>	9.1	9.1
	G7	Serviced delivered when wanted	8.01 (7.67, 8.35)	7.6	<i>N/A</i>	7.9	7.8
	G8	Home well managed	<i>No data</i>	8.7	9.6	8.3	7.9
	G9	Family trusts staff to provide care	<i>No data</i>	8.1	9.8	8.5	8.8
	G10	Family trusts information from staff	<i>No data</i>	8.6	9.7	8.4	8.6
Staff-Resident Bonding	H1	Staff know resident life story	6.24 (5.89, 6.59)	7.9	<i>N/A</i>	7.3	7.9
	H2	Staff member a friend	6.74 (6.39, 7.10)	8.3	<i>N/A</i>	6.3	7.2
	H3	Have special relationship with staff	6.21 (5.86, 6.56)	6.7	<i>N/A</i>	6.7	7.0
	H4	Friendly conversation with staff	7.38 (7.00, 7.75)	8.5	<i>N/A</i>	8.5	8.9
	H5	Staff ask how to meet needs	7.82 (7.48, 8.15)	8.6	<i>N/A</i>	8.7	8.9
	H6	Have same nurse assistant	5.79 (5.44, 6.14)	7.9	<i>N/A</i>	7.9	8.0
Activities	I1	Enjoyable things on weekends	5.82 (5.48, 6.17)	7.8	<i>N/A</i>	8.1	8.2
	I2	Enjoyable things on evenings	5.31 (5.01, 5.61)	6.8	<i>N/A</i>	8.0	8.1
	I3	Has meaningful activities	6.79 (6.44, 7.15)	9.0	8.8	8.5	8.8
	I4	Can participate in religion	6.77 (6.44, 7.10)	8.4	<i>N/A</i>	7.2	8.8
	I5	Time with like-minded residents	6.84 (6.47, 7.21)	7.4	<i>N/A</i>	8.1	8.4
	I6	Explores new interests	5.28 (4.93, 5.63)	7.9	<i>N/A</i>	6.7	7.9
Personal Relationships	J1	Resident is close friend	6.97 (6.63, 7.32)	6.8	5.6	8.0	7.5
	J2	Asked for help/advice	5.71 (5.36, 6.05)	6.4	<i>N/A</i>	6.5	6.9
	J3	Affection/romance opportunities	5.35 (5.01, 5.70)	4.5	<i>N/A</i>	7.2	6.9
	J4	Easy to make friends here	6.67 (6.31, 7.04)	7.2	<i>N/A</i>	8.0	7.5
	J5	People to do things with	5.42 (5.05, 5.80)	7.5	<i>N/A</i>	8.0	7.8
	J6	Family can visit when they want	<i>No data</i>	9.1	9.4	9.1	8.9

	J7	Comfortable visiting places	<i>No data</i>	8.8	7.6	8.7	8.6
Family Communication and Engagement	K1	Family has needed health information	<i>No data</i>	9.2	9.8	8.4	8.7
	K2	Family knows contact when concerned	<i>No data</i>	9.1	9.2	8.7	8.9
	K3	Family participates in decision-making	<i>No data</i>	8.1	9.5	8.6	9.1
	K4	Family consulted about care plan changes	<i>No data</i>	7.2	9.6	8.6	8.8
Scales	L1	Social Life	<i>No data</i>	6.8	8.5	8.6	8.4
	L2	Personal Control	<i>No data</i>	8.5	8.5	9.2	9.2
	L3	Food	<i>No data</i>	9.0	8.7	8.0	8.9
	L4	Caring Staff	<i>No data</i>	8.7	9.8	9.0	9.2
	L5	Staff Responsiveness	<i>No data</i>	8.7	9.8	8.9	9.3

For the statements around privacy, several participants stressed the value of alone time for rest and relaxation. However, some participants expressed that not all residents can or should be alone when they wish due to space limitations (e.g., shared rooms) and safety concerns related to dementia. Respect for privacy in particular was described as extremely important for maintaining resident dignity. According to the Flemish resident data, respect for privacy (mean = 8.28, 95% CI=[7.95, 8.61]) was significantly more important than getting to be alone when one wishes (mean = 7.56, 95% CI=[7.21, 7.91]) .

Getting well-cooked, quality food at the right temperature was also important for quality of life. The secondary data analysis determined that eating when one wishes was significantly less important than the other items in the food domain (mean = 6.27, 95% CI=[5.93, 6.61]). During qualitative data collection, participants in all groups expressed that mealtimes can be a great source of enjoyment, but loud or crowded dining rooms, dietary restrictions (e.g., vegetarian diet, thickened fluids diet), keeping food at the right temperature, and poor staff cooking skills were obstacles to enjoyable food and meals. Facilitators to good food and meals

included having family that bring in favourite foods, buying their own food when the option was available, and ongoing quality improvement initiatives.

In the section on safety and security, good communication and staff responsiveness (i.e., responding to emergencies and call bells) were valued for providing a sense of physical and psychological safety, particularly considering that LTC residents experience high rates of ADL impairment. When it came to possessions, multiple focus groups mentioned that it can be upsetting when things go missing. In response, some reported that they avoid keeping valuables in their LTC home. According to the Flemish residents, the statements in this domain were equally important.

Participants expressed that LTC homes should be welcoming, clean, and feel less ‘institutional’, but some items in the section on comfort spurred debate among participants. For example, some resident participants indicated that their LTC home would never truly feel like a home. Similarly, distinguishing between what services residents *need* versus what they *want* was an important distinction raised in the context of staffing shortages. According to the Flemish sample, ‘get other needed services’ (mean = 9.35, 95% CI=[9.14, 9.57]) was significantly more important than ‘feels like home’ (mean = 8.73, 95% CI=[8.44, 9.02])

Most participants emphasized that resident autonomy should be respected, and that they should be empowered to make their own choices in alignment with their habits and preferences. Deciding how to spend one’s time (mean = 8.83, 95% CI=[8.55, 9.10]) was among the most important statements in this domain. However, understaffing or insufficient time among staff members and staff shortages were raised as key barriers. For instance, ‘Go on spur of moment’ was described as less feasible for residents with mobility impairments who depended on staff to be available. Additionally, multiple resident focus groups explained that the statement

‘Bath/shower as often as wish’ as ‘extremely important, yet extremely impossible’ due to understaffing or insufficient time among staff members. One resident explained that they use wet wipes between showers to overcome this challenge.

Participants agreed that respect should be shared between residents, families, and staff as a ‘pillar of civilized society’. The statement ‘treated with respect by staff’ (mean = 9.55, 95% CI=[9.37, 9.73]) was considered the most important statement in respect domain. Half of the family member focus groups rated respect for the resident as more important than respect for the family member. Other important elements of respect that were discussed included respectful communication and opportunities for residents to provide confidential and constructive feedback.

In terms of the staff responsiveness and trust section, access to health services, trained staff, and timely care were listed as key reasons why several participants accessed LTC in the first place. Thus, there was broad agreement on the high importance of this section. In the Flemish dataset, getting needed health services (mean = 9.21, 95% CI=[8.97, 9.45]) was significantly more important than the other statements in the responsiveness section, with the exception of ‘staff respond quickly’ (mean = 8.98, 95% CI=[8.72, 9.24]). The key themes identified in this section were that some needs are more urgent than others (e.g., health emergencies), different residents have different expectations around what services they need, and some residents cannot speak for themselves to ask for help or change.

Staff-resident bonding (or having friendly relationships with staff who ask about and anticipate resident needs) was considered important as it shows when staff are motivated, trustworthy, and caring. However, this section was described as somewhat less important by some participants, particularly the first three statements on personal relationships with staff (mean = 6.24, 95% CI=[5.89, 6.59]; mean = 6.74, 95% CI=[6.39, 7.10]; (mean = 6.21, 95%

CI=[5.86, 6.56]), which were significantly less important than how often staff ask how the resident's needs can be met (mean = 7.82, 95% CI=[7.48, 8.15]) in the secondary data. For example, 'Have special relationship with staff' was misinterpreted by several residents as a romantic relationship and multiple staff participants raised conversations about professional boundaries.

Engaging in meaningful activities was described as uplifting, with positive effects that linger. One focus group stated that 'Can participate in religion' was a basic human right. The meaningful activities (mean = 6.79, 95% CI=[6.44, 7.15]) and religious activities statements (mean = 6.77, 95% CI=[6.44, 7.10]) were significantly more important than having enjoyable things to do on evenings (mean = 5.79, 95% CI=[5.44, 6.14]) and weekends (mean = 5.82, 95% CI=[5.48, 6.17]) according to the Flemish sample. Participants shared several examples of meaningful activities, including singing, painting, exercising, playing games, going to the library, going out, spending time with family or alone, spending time in the garden, and learning new things.

The section on personal relationships was described as somewhat less important to participants as well and somewhat outside of staff control. Multiple family member participants described cognitive impairment as hindering their loved one's capability of building close friendships. Similarly, multiple resident groups described building a close friendship as 'unlikely', 'impossible', or unwanted due to limited opportunities or having had close friends pass away. In the Flemish data, 'Resident is close friend' had greater importance (mean = 6.97, 95% CI=[6.63, 7.32]) compared to other statements, like opportunities for affection and romance (mean = 5.35, 95% CI=[5.01, 5.70]). The statement 'Family can visit when they want' raised

intense emotions for resident participants without close family, and some refused to rate the statement altogether.

Family communication and engagement was a high priority for most participants, especially the participating family members as many mentioned having loved ones with dementia and being highly involved in their care (e.g., through power of attorney). The residents who participated were often capable of making decisions independently and noted that different changes and decisions needed different levels of family involvement or no family involvement at all.

3.3.3.2. Candidate quality-of-life indicators

When choosing their “top 10” set of candidate quality indicators, over 70% of staff and researcher participants voted to include the statements ‘I am treated with respect by staff’ and ‘has meaningful activities’ in their final set of 10 candidate QIs. When asked to choose generously, over 70% of participants selected an additional 9 ‘most important’ statements could be good quality-of-life indicators for LTC. The 10 statements with the best potential to be candidate quality of life indicators are listed below, with additional detail included in Appendix G. Frequency of inclusion in participants’ final QI set included in brackets:

1. Treated with respect by staff (n=25, 76%)*
2. Has meaningful activities (n=24, 73%)
3. Privacy respected during care (n=21, 64%)
4. Clean and pleasant environment (n=16, 48%)
5. Decide how to spend time (n=15, 45%)*
6. Enjoy mealtimes (n=14, 42%)
7. Feel safe alone (n=13, 39%)*
8. Can get help right away (n=13, 39%)*
9. Family can visit when they want (n=13, 39%)
10. Staff respond quickly (n=11, 33%)*

Half of the above statements are within the top 10 ranking statements in the SQOL-LTCF according to the Flemish data (indicated with an asterisk), and two were not ranked as they are collected in the family-facing version of the SQOL-LTCF (#4 and #9). ‘Privacy respected during care’ ranked 20th in the Flemish data (though it was not significantly less important than statements in the 8th, 9th, and 10th position), and ‘Enjoy mealtimes’ ranked 23rd. More detail on the number of votes for 40 statements in Delphi round three is attached in Appendix G.

3.3.4. Secondary Results

Descriptive bar charts illustrating how each of the final candidate QIs were evaluated for specificity, understandability, actionability, equitability, and sensitivity to change is included in Appendix H. Only one (3%) participant believed that their final selected QI set was not broad enough to capture most important issues around quality of life in LTC, and 11 (34.4%) responded that their set was maybe not broad enough. In addition, one (3%) participant believed that their final set contained statements that were irrelevant to quality of life in LTC, and 6 (18.8%) responded that their list of statements was ‘maybe irrelevant’.

3.4. Discussion

3.4.1. Key Results and Interpretations

Our findings align with current knowledge by demonstrating that all of the statements on the SQOL-LTCF are considered important to LTC resident quality of life^{4,82,131}. We found that statements around respect and safety were described as most important overall, but there were differences in perspectives between participant groups and within each group, similar to previous research¹³². Personal relationships with other residents and staff were described as relatively less important. The final list of 10 QIs included one statement per quality of life category (with the

exception of safety and security, from which there were two statements, and staff-resident bonding and family communication and engagement, from which there were no statements).

The present study aligns with and adds to existing literature in a variety of ways. First, our findings suggested that ‘what matters most’ to LTC insiders appears to align with the areas in which LTC homes perform relatively well. A large 2018 study by Morris et al concluded that performance on statements regarding respect and responsiveness was better than performance on most caring staff and social life-related statements in the SQOL-LTCF⁵⁹. Second, we found that the relationships between quality of life domains can be interconnected and influenced by a variety of factors, such as social dynamics. For instance, the staff-resident bond was considered important for creating a homelike environment¹³³, but institutional norms and tensions between maintaining professionalism and emotional involvement may cause some staff to distance themselves¹³⁴. Third, our qualitative findings suggest that residents’ quality of life *expectations* are influenced by social and contextual factors, like staffing shortages. Previous research has suggested that residents may revise their expectations around quality of life in light of their experiences in LTC¹³⁵. Reasons for a possible social desirability bias among LTC residents completing quality of life surveys may include avoiding reinforcing ageist stereotypes (e.g., being overly demanding), and avoiding negatively impacting the staff-resident bond¹³⁶. Longitudinal research investigating how quality of life importance scores change from LTC admission over time would be valuable to further test this hypothesis.

One unplanned finding from this study was related to how insiders may hold different quality of life expectations for residents living with and without dementia, especially around the domains of autonomy and social life. This finding aligns with previous research. In a 2005 study, cognitively intact residents, family members, and health providers tended to rate several quality

of life domains as less important for LTC residents living with cognitive impairment compared to those without cognitive impairment¹³⁷. Although many underestimate the capabilities of individuals living with dementia¹³⁸, most people living with dementia can retain autonomy over their lives with support^{139,140} and are capable of understanding and developing friendships (though ties may be weaker or expressed differently with increasing dementia severity¹⁴¹). While implicit biases around dementia was not a primary focus of this research, the finding that dementia-related biases extend to quality of life expectations points to the importance of using self-reported quality of life measures where possible. It also points to the need for continued collaboration between researchers, health professionals, family members, and residents to explore and dispel misconceptions around the capabilities of people living with dementia.

Finally, the present study identified several instances where improvement was described as impossible by insiders, regardless of importance level. First, “Bath/shower as often as wish” was seen as extremely important, but extremely impossible. Research shows compared to the other statements on autonomy, residents are about 20% less likely to report that they can have a bath or shower as often as they wish most of the time or always^{58,59}. While challenges in the quality of bathing attributed to inadequate training may be addressed at the LTC home level¹⁴², staff availability and physical infrastructure challenges exist at a systemic level and are most effectively improved upon at a policy-level rather than home-level. Second, the present study suggested that “feels like home” may not be an ideal overall measure of personal quality of life as it could be an unattainable goal influenced more by factors outside of staff control (e.g., duration of stay, personal definitions of home) than factors within staff control (e.g., creating a comfortable and welcoming environment). Other research has suggested that the term ‘home’ may be overly idealistic¹³³. Third, several statements on social life were rated as impossible for

some, outside of staff control, and as relatively less important for quality of life in long-term care. The death of a close friend or resident introversion are generally outside of staff control. However, research shows that staff can directly or indirectly encourage relationship-building between residents by offering meaningful activities³ and, in turn, improve quality of life¹³¹. In a person-centered LTC system, decision makers should strive to align their quality improvement efforts with what matters most to resident quality of life despite ongoing barriers. This will take creative thinking and collaboration between LTC home residents, leaders, funders, and policy makers.

3.4.2. Strengths and Limitations

This study had several strengths and limitations. In terms of strengths, we recruited a large number of residents and family members to participate. We collaborated with many motivated and knowledgeable individuals and organizations who supported data collection. In contrast, because we employed flexible methods, the focus group data were sometimes collected inconsistently. To illustrate, some facilitators opted to audio-record the focus groups, while others took detailed notes or only recorded numerical scores. Therefore, the perspective of some focus groups was represented more than others in the qualitative data. Second, some focus group participants expressed dissatisfaction or confusion around the wording, structure, and length of the survey. Previous research has found that some LTC residents struggle with distinguishing between different points on a scale related to importance¹⁴³, and challenges around fatigue may worsen this issue. This, in addition to higher loss to follow-up in round two of the virtual Delphi survey may have negatively impacted data quality. Finally, the recruitment strategy used led to the inclusion of individuals from primarily North America and Europe and from organizations with more experience in quality assurance (i.e., SQLI, interRAI). Persons from other continents

(i.e., Africa, Asia, South America) or individuals with less experience in quality assurance may have different perspectives.

3.4.3. Publication and dissemination

The results of this study have been shared with participants in an individualized 6-page summary report and in presentations at an SQLI meeting, an interRAI network meeting, and multiple academic conferences. The further development of the identified candidate quality of life indicators will be explored in future research.

3.5. Conclusions

This modified Delphi study engaged LTC residents, family members, staff, and researchers to evaluate the importance of statements and scales in the SQOL-LTCF. Ten highly important statements covering a range of quality-of-life domains were identified as having good potential for development in future research. While professional judgement and consultation with resident and family advisors is invaluable, and consensus does not guarantee the ‘correct’ answer. It is important to reflect on how quality of life can be measured in an accurate way while considering individual values, beliefs, circumstances, and expectations. Quality indicators are a relatively inexpensive and convenient way to monitor quality of life¹³¹, but it is essential that LTC homes balance the feasibility of quality of life monitoring with an appreciation of complexity. This study strengthens the idea that quality of life surveys like the SQOL-LTCF can measure concepts that are important to the quality of life of LTC residents, and points to domains that may be deserving of special attention from researchers and LTC leadership.

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Chapter 4: Exploring quality indicators and risk adjustment for the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF): A feasibility study

This chapter will be submitted as:

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Exploring Quality Indicators and Risk Adjustment for the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities: A Feasibility Study

4.1. Introduction

4.1.1. Background

Quality indicators are quantitative measures based on standards of care that aim to identify issues in quality⁶¹. When designed carefully and with end-users in mind, they can be a trusted source of information for quality comparisons and benchmarking^{61,76,99,144}, and can be complemented by narrative data to inform quality improvement initiatives^{83,94}. Clinical quality indicators are commonly used in the long-term care (LTC) system, and extremely important for identifying the needs of complex residents. However, LTC homes are also responsible for ensuring that residents experience good quality of life, defined as how a person perceives their own life in the context of their beliefs and expectations².

interRAI, an international research network and non-profit organization, has been a major influence in development of LTC quality measures globally¹⁴⁵. In addition to developing systems for monitoring observable, medical issues in care^{3,36,126}, interRAI has developed a survey called the interRAI Self-Reported Quality of Life Survey for Long-Term Care Facilities (SQOL-LTCF). The SQOL-LTCF is a voluntary, self-report survey within a broad suite of interRAI instruments⁴. It was designed and validated for gathering the perspectives LTC residents with intact cognition or mild to moderate cognitive impairment (Cognitive Performance Scale (CPS) ≤ 4)^{59,82}, and is administered by a trained surveyor, such as a volunteer or LTC staff member, who does not provide direct care or services to the respondent⁴. When completing the survey, respondents rate their quality of life on a 5-point scale from never (0) to always (4) on over 50 quality of life items across 10 domains^{4,59}. The quality of life domains in the SQOL-LTCF include privacy, food and meals, safety and security, comfort, autonomy, respect by staff, staff responsiveness, staff-resident bonding, activities, and personal relationships. The SQOL-LTCF can also be used

to calculate five summary scales, encompassing social life, personal control, food, caring staff, and staff responsiveness. The scales are used by LTC organizations for broad evaluations of quality⁵⁹.

The SQOL-LTCF is reliable and valid for measuring quality of life in residents with intact cognition or mild to moderate cognitive impairment^{59,82}. However, the potential for the SQOL-LTCF to support quality improvement initiatives has been underexplored in the published literature thus far. The Institute for Healthcare Improvement include improving resident experience as a priority goal of the health system²¹, so research aiming to develop subjective quality of life indicators for benchmarking would be valuable²¹. A good quality indicator is clearly defined, based on high-quality data, valid and reliable, variable between organizations, and sensitive to change^{61,146}.

Several challenges to developing quality indicators exist. For instance, data source concerns can arise, such as low response rates, unevenly distributed missingness, risks to confidentiality, and high data collection costs¹⁴⁶. Additionally, differences between resident populations can bias unadjusted quality indicators and hinder their potential for quality benchmarking. Intrinsic resident characteristics, such as age, education, race, income, and functioning in activities of daily living (ADLs), may explain up to 20% of variation in LTC quality of life reporting^{64,69}. If the aim of a quality indicator is to compare LTC homes on their facility attributes alone, then one must account for differences in intrinsic population characteristics to avoid providing misleading information. Failing to adjust for population differences could lead LTC homes to distrust or dismiss a quality indicator, or avoid ‘higher-risk’ clients who would make them look relatively worse¹⁴⁶.

Risk adjustment is a statistical process that aims to improve the fairness of quality comparisons by accounting for differences in risk profiles between populations⁶⁴. Risk adjustment variables, defined as the differences one would adjust for, should be known sources of bias in a quality indicator⁶⁴. They should be clearly defined, should be associated with the quality indicator of interest, and should not be adverse events, causes of quality issues, or outcomes of care^{64,147}. Choosing a set of risk-adjustment variables also involves a consideration of social context, including values, beliefs, and unintended consequences⁷¹. While certain sociodemographic variables like age and sex are commonly used as risk adjustment variables due to their limited modifiability⁷¹, health status variables have been described as stronger for risk adjustment due to their more direct link with quality of life issues¹⁴⁸. There is also conflicting evidence on the relationship between quality of life and age, gender, and length of stay^{64,69}, while the relationships between quality of life and self-rated health², ADL impairment⁶⁹, urinary incontinence¹⁴⁹, and bowel incontinence^{150,151} are more clearly established. Thus, risk adjustment choices should be made carefully in order for improved fairness to be realized.

Moreover, different data sources, variable specifications, and weighting techniques for risk-adjustment can also produce different conclusions regarding organizational performance¹⁴⁶. Table 4.1. describes several risk-adjustment methods. For example, stratification is an easy-to-understand method but may not provide adequate risk differentiation. In contrast, the ‘third generation method’ (which combines stratification with indirect and direct standardization¹⁰⁴) is a more sophisticated method despite being more complex and challenging to understand¹⁵².

Table 4.1. Example risk-adjustment methods

Method	Description
Exclusion / restriction	The process of excluding individuals from the denominator of a quality indicator if they fall within a specific category of resident ¹⁵² . For example, an individual with

	end-stage disease may be excluded from a quality indicator calculation due to different needs and expectations.
Stratification	The process of dividing a population into different subgroups so that the differences between them are more easily ascertained. Stratification is useful when the a population characteristic is ‘policy-sensitive’ (e.g., race), but less useful when multiple population characteristics need to be accounted for and when residual confounding is a concern ^{104,146} .
Indirect Standardization	The process of using linear, logistic, or hierarchical regression modelling to account for clinically and statistically relevant characteristics in a population ^{104,146} . Population differences are accounted for in indirect standardization by comparing observed with expected indicator rates (calculated based on a reference population) ¹⁰⁴ .
Direct Standardization	The process of accounting for organization-level differences by applying standard population weights to sub-group specific indicator scores, then combining them into a single composite score ¹⁰⁴ .

Concerns have been raised about the appropriateness of risk-adjusting subjective quality of life indicators, including potential misuse, oversimplification of adjusted scores, and risks of obscuring real differences in quality^{85,152}. Given a paucity of peer-reviewed research available on risk-adjusting subjective quality of life indicators for LTC, there is a need to determine whether such an approach would be appropriate or feasible before proceeding with formal risk-adjustment.

4.1.2. Aims and Objectives

The primary aim of this study was to explore the feasibility of risk-adjusting subjective quality-of-life indicators calculated using North American SQOL-LTCF data. Our research objectives were to:

1. Describe a set of candidate quality of life indicators and risk-adjustment variables calculated from the SQOL-LTCF.
2. Determine if risk-adjusting candidate quality of life indicators could influence quality benchmarking between North American LTC homes (i.e., in Canada and the United States (USA)).

This study is part of a large dissertation project that aims to explore the development and implementation of quality of life indicators in LTC homes¹²⁹.

4.2. Methods

4.2.1. Study design

Feasibility studies aim to assess innovations or research approaches for acceptability and scalability^{79,153}. Feasibility studies can have different areas of focus, such as integration, demand, and practicality¹⁵³. While each type of feasibility could be explored in detail, we determined that a feasibility study with a narrow focus on implementation would be valuable to perform on the risk-adjustment of quality of life indicators for the SQOL-LTCF. In this study, implementation feasibility was defined as the extent to which a process can be delivered in a defined context¹⁵³.

The present feasibility study analyzed secondary data to describe a set of candidate quality of life indicators for the SQOL-LTCF and explore a narrow set of risk-adjustment variables. The candidate indicators were identified based on perceived importance and face validity by content experts (i.e., LTC residents, family members, staff, and researchers) in a modified Delphi study¹⁵⁴. The design, conduct, and reporting of this study was overseen by interRAI research fellows and inspired by relevant domains in the Appraisal of Indicators through Research and Evaluation (AIRE) Instrument¹⁵⁵.

4.2.2. Data sources

Our co-primary data sources were cross-sectional datasets representing five independent survey initiatives with the SQOL-LTCF. Initiatives included multi-province data collection from a single LTC organization, a single-province data collection initiative for all LTC homes, and data from small pilot studies using the SQOL-LTCF. These datasets represented the most recent

available SQOL-LTCF data available in the data repository for interRAI Canada. The Canadian data were collected in Alberta (2016/17 and 2023), Manitoba (2016/17 and 2023), Ontario (2016/17 and 2023), British Columbia (2022/23), Quebec (2023), New Brunswick (2019 to 2020), Yukon (2020), and Saskatchewan (2016 to 2017). The USA data (from Massachusetts, Florida, and California) and South African data were gathered in 2023. These initiatives captured the perspectives of over 16,000 LTC residents across 221 LTC homes and 15 large LTC organizations in Canada, the USA, and South Africa. To simplify, we will refer to the 236 LTC homes and organizations in the dataset as ‘LTC homes’.

We also analyzed a smaller, linked dataset to examine specific variables related to late-loss ADLs) and incontinence as candidate risk-adjustment variables. The linked dataset combined data from the SQOL-LTCF and interRAI MDS and held about 1400 LTC resident observations from 10 LTC homes across one Ontario LTC organization. The data were collected from 2014 to 2015 and linking was performed by an interRAI data manager.

4.2.3. Variables

The present study explored seven candidate quality of life indicators, five quality of life scales, three sociodemographic variables, and seven variables pertaining to resident health and functional status (i.e., independence in ADLs and incontinence).

4.2.3.1. Candidate Quality of Life Indicators

Described in Table 4.2., seven candidate quality of life variables were analyzed as binary variables and as the primary outcome variables of interest. The seven candidate quality of life indicators were identified from a list of ten recommended SQOL-LTCF items in a modified Delphi study¹⁵⁴. Two survey items that were only present on the proxy-reported SQOL-LTCF

were excluded from our analyses (i.e., “Clean and pleasant environment”, “Family visit when they want”). A third item (i.e., “Can get help right away”) was also excluded due to its similarity with “Staff respond quickly”.

Table 4.2. Candidate Quality of Life Indicators

Short Name[‡]	Proposed quality indicator name	Numerator^{‡‡}	Denominator	Quality Domain on SQOL-LTCF
Low privacy	Percentage of residents expressing low or no respect for privacy in care	Number of residents responding negatively to “A2. Privacy respected during care”	Number of survey respondents	Privacy
Poor mealtimes	Percentage of residents expressing low or no mealtime enjoyment	Number of residents responding negatively to “B4. Enjoy meal times”	Number of survey respondents	Food and meals
Feels unsafe	Percentage of residents who are feeling unsafe alone	Number of residents responding negatively to “C3. Feel safe alone”	Number of survey respondents	Safety and security
Low time autonomy	Percentage of residents expressing that they infrequently or never decide how to spend their time	Number of residents responding negatively to “E7. Decide how to spend time”	Number of survey respondents	Daily decisions
Low respect	Percentage of residents expressing low respect by staff	Number of residents responding negatively to “F1. Treated with respect by staff”	Number of survey respondents	Respect by staff
Slow response	Percentage of residents with negative ratings of staff response times	Number of residents responding negatively to “G2. Staff respond quickly”	Number of survey respondents	Staff responsiveness
Low meaning	Percentage of residents expressing low or no participation in meaningful activities	Number of residents responding negatively to “I3. Has meaningful activities”	Number of survey respondents	Activities

[‡]Short names were not selected in consultation with important stakeholders and are only used for the purposes of simplifying reporting within the present study

^{‡‡}Responding ‘negatively’ is defined as responding “sometimes”, “rarely”, or “never” to a survey item.

We defined the numerator as the number of residents responding “sometimes”, “rarely”, or “never” to each survey item, since indicators are usually intended to flag problems in care rather than strengths⁶¹. We defined the denominators as the total number of survey respondents. We opted to not exclude any group of residents from the denominator because all

residents capable of responding to the SQOL-LTCF could have had a negative experience in any of the measures.

4.2.3.2. interRAI Scales

We also compared valid and reliable scales from the SQOL-LTCF with the candidate quality of life indicators with a side-by-side table. However, the scales are currently used by several LTC homes and organizations to guide their quality of life improvement efforts. Therefore, the SQOL-LTCF scales were the ideal comparator for candidate indicators, and any selected candidate indicators would ideally be equal to or better than the scales for supporting quality comparisons. The SQOL-LTCF offers five scales: the social life scale (scored from 0 to 30), personal control scale (scored from 0 to 24), food scale (scored from 0 to 9), caring staff scale (scored from 0 to 15), and staff responsiveness scale (scored from 0 to 24)⁵⁹. Higher scale scores indicate better quality of life, and high scores across all five measures suggest that an LTC home has a more home-like environment⁵⁹.

4.2.3.3. Candidate Risk Adjustment Variables (sociodemographic and health status variables)

Finally, we investigated several candidate risk adjustment variables, including three sociodemographic variables and several health and functional status variables. The sociodemographic variables (gender, age, and length of stay) and self-rated health were collected with the SQOL-LTCF. The additional health status variables included four late-loss ADLs (transfer, bed mobility, eating, toileting¹⁵⁶), bladder incontinence, and bowel incontinence. These health status variables were collected with the interRAI-MDS and were, therefore, only available in the linked dataset.

Within the sociodemographic variables, we combined the ‘female’ and ‘other’ groups for gender and ‘under 45’, ‘45 to 64’, and ‘65 to 74’ groups for age. We collapsed these categories because there were too few ‘other’, ‘under 45’, and ‘45 to 64’ responses to support meaningful analysis. Similarly, we collapsed the ADLs and incontinence variables into binary variables due to a smaller number of observations in the linked dataset. The five levels of each ADL variable were collapsed into “independent to some assistance required” and “extensive assistance required or total dependence”. The five levels of incontinence were collapsed into “continent to occasionally incontinent” and “frequently to fully incontinent”.

4.2.4. Statistical Methods

The statistical methods of this study included a descriptive analysis of sample characteristics, descriptive and variability analysis of SQOL-LTCF candidate indicators and scales for side-by-side comparison, and multilevel logistic regression modelling. Data cleaning, organization, and exploratory data analyses for this study were performed on R version 4.3.2 (2023-10-31)¹⁵⁷. The rest of the analyses were performed with SAS Enterprise Miner 7.1¹⁵⁸.

To explore each of the datasets, we first calculated summary statistics and generated frequency tables for all variables of interest. We specifically examined data availability, population characteristics, and variability between LTC homes (via standard deviations and interquartile ranges) for the candidate quality of life indicators and SQOL-LTCF scales. Data availability, sufficient prevalence within populations, and variability between LTC homes are prerequisites for calculating a quality indicator that can describe quality and support meaningful quality comparisons between LTC homes^{61,146}. Next, we examined associations between the candidate quality of life indicators and candidate risk adjustment variables with the goal of

evaluating the appropriateness of the different candidate risk adjustment variables. Specifically, we created contingency tables, performed chi-square tests, and calculated odds ratios.

Finally, we performed multilevel binary logistic regression modelling to determine whether controlling for the candidate risk adjustment variables (i.e., self-rated health or age) would influence LTC home rankings. Multilevel modelling recognizes that observations (e.g., residents) are organized in clusters (e.g., LTC homes, LTC organizations) and have an influence upon one another¹⁵². In statistical terms, multilevel modelling was considered more appropriate for this study compared to simpler logistic regression modelling methods because multilevel models account for sources of variation at the individual level *and* between ‘clusters’¹⁵². In the present study, the regression models accounted for clustering by (1) LTC home organization or survey initiative and (2) LTC home. The modelling technique that we used was generalized linear mixed modelling (GLMM) as it can handle nested data with fixed and random effects. Fixed effects represent population-level influences that are assumed to be constant across individuals or groups (e.g., self-rated health), while random effects represents variability at the individual or cluster-level¹⁵⁹. By examining random effects estimates, we were able to compare unadjusted and adjusted ranks for LTC homes on the quality of life indicators (i.e., cluster-level variability). Moreover, we included the candidate risk adjustment variables in the models individually to maintain model simplicity and examine their individual influences on rankings. Each regression model was also examined in terms of:

- *Log-likelihood* to determine the model of best fit in terms of which predictors should be included in the models (e.g., sociodemographic and health-related variables).

- *R value* (i.e., Pearson correlation coefficient) and *R² value* (i.e., coefficient of determination) to compare the unadjusted and adjusted organizational rankings and the proportion of variance in the adjusted model that can be attributed to unadjusted ratings. Following guidance from an experienced statistician, we have selected an ideal R value for risk adjusted vs unadjusted indicators to be between 0.85 and 0.95, though 0.70 has also been cited as a cutoff indicating strong correlation¹⁶⁰. Lower R values indicate a greater discrepancy between raw and adjusted indicators¹⁶⁰.
- *Chi-square tests of cluster variance* to determine if there was statistically significant clustering of quality of life reports within LTC homes and organization / survey initiative which made multilevel modelling worthwhile.
- *Plotted distributions of LTC home rank, estimates, and random effects* to generate visualizations that would support ease of interpretation around the influence of adjustment by different variables and confidence intervals for their effect.

LTC homes that did not collect data on an adjustment variable of interest were excluded from their respective regression model.

4.2.5. Data Access and Cleaning Methods

The data supporting this study are not publicly available to maintain the privacy of LTC homes and residents. We excluded observations where data were completely missing in at least 20% of the SQL-LTCF survey items or where respondents could not, would not, or did not respond to at least 50% of the survey items. For observations that were included, missing data were reported separately. LTC homes with fewer than 30 resident observations were grouped into ‘other’ categories based on province to ensure that sufficient data were available for analysis.

4.3. Results

4.3.1. Sample Characteristics

Data from 16,141 LTC residents across 236 LTC homes were included in the primary dataset. About 96% of the primary dataset was made up of Canadian LTC residents, but there were also 61 residents in one South African LTC home and 571 USA residents from three LTC organizations. Seven LTC homes in the dataset had less than 30 observations and were grouped into multiple “other” categories based on province. The linked dataset included data from 1372 residents across 10 LTC homes within one LTC organization in Canada. Due to small sample sizes in some LTC homes from the linked dataset, seven of the LTC homes were grouped into one ‘other’ category. Table 4.3. highlights the sociodemographic characteristics, and health and functional status of the sample populations.

For both datasets, the samples were mostly female and ‘85 or older’ was the largest age group. There was a spread across the length of stay categories, with over one-third of the sample having spent two years or more living in their LTC home. For self-rated health, over half of the sample from the primary dataset rated their health as fair or poor. Similarly, the sample in the linked dataset had high proportions of residents with extensive or total dependence in transfer, mobility, and/or toileting.

Table 4.3. Participant demographic, health, and functional characteristics across two SQOL-LTCF datasets

Characteristics	Demographic characteristics by dataset			
	Primary dataset (n=16,141) [‡]		Linked dataset (n=1372)	
	n	%	n	%
Gender				
Female or other	9355	58.0%	935	68.1%
Male	5429	33.6%	437	31.9%
Missing	1357	8.4%	0	0.0%
Age Categories				

Under 45	108	0.7%	20	1.5%
45 to 64	870	5.4%	157	11.4%
65 to 74	2452	15.2%	189	13.8%
75 to 84	4786	29.7%	407	29.7%
85 and older	6813	42.2%	599	43.7%
Missing	1110	6.9%	0	0.0%
Length of Stay				
Under 1 year	4998	31.0%	420	30.6%
1 to 2 years	3953	24.5%	302	22.0%
2 years or more	5779	35.8%	617	45.0%
Missing	1411	8.7%	33	2.4%
Self-Rated Health				
<i>Fair or Poor</i>	8847	54.8%		
<i>Good or Excellent</i>	3507	21.7%		
<i>Missing</i>	3787	23.5%		
Extensive or total dependence in late loss ADLs				
<i>Transfer</i>			690	50.5%
<i>Bed mobility</i>			699	51.0%
<i>Eating</i>			93	6.7%
<i>Toileting</i>			833	60.7%
Frequent or Complete Incontinence				
<i>Bladder Incontinence</i>			635	46.3%
<i>Bowel Incontinence</i>			355	25.9%

*56 LTC homes or organizations did not collect data on self-rated health, 16 did not collect data on gender, and 4 did not collect data on age.

It is important to note that there was a high proportion of missing data for the self-rated health variable at 23.5%. When 56 LTC homes collecting no self-rated health data were excluded from the primary dataset, the rate of missing data was only 3.5%. The linked dataset did not include the self-rated health variable.

4.3.2. Main Findings

4.3.2.1. Descriptive and Variability Analysis

Table 4.4. shows average proportions for the candidate quality of life indicator rates, mean scale scores, and respective measures of variability between the LTC homes in the primary dataset. There was a strong tendency towards positive responses in all quality of life measures, with the exception of ‘Low meaning’ where the average proportion of negative responses to “Has

meaningful activities” was 62.5%. ‘Low respect’ was the candidate quality of life indicator with the lowest average prevalence (i.e., best performance), as well as the least variability between LTC homes according to standard deviation and interquartile range. The SQOL-LTCF scales showed less skewed distribution towards positive ratings, but the measures of variability were similar or lower compared to the candidate quality of life indicators.

Table 4.4. Average LTC home scores on candidate quality of life indicators and SQOL-LTCF scales

	Mean among LTC homes		Measures of variability between LTC homes	
Candidate Quality of Life Indicators	Mean % responding negatively	95% CI	Standard Deviation	Interquartile Range
Low privacy	19.2%	(18.1%, 20.3%)	8.7%	10.4%
Poor mealtimes	34.1%	(32.7%, 35.4%)	10.5%	12.3%
Feels unsafe	17.9%	(16.4%, 19.3%)	11.3%	12.8%
Low time autonomy	20.7%	(19.5%, 21.9%)	9.4%	10.6%
Low respect	15.6%	(14.5%, 16.6%)	8.0%	10.4%
Slow response	32.8%	(31.4%, 34.1%)	10.4%	15.4%
Low meaning	62.5%	(60.9%, 64.2%)	13.1%	16.1%
SQOL-LTCF Scales	Mean Scale Score	95% CI	Standard Deviation	Interquartile Range
Social Life (max = 30)	11.7	(11.5, 12.1)	2.4 (8.0%)	2.6 (8.5%)
Personal Control (max = 24)	14.6	(14.4, 14.8)	1.7 (7.2%)	2.3 (9.5%)
Food (max = 9)	4.7	(4.6, 4.8)	0.78 (8.6%)	0.80 (8.8%)
Caring Staff (max = 15)	7.2	(7.1, 7.4)	1.2 (8.1%)	1.3 (8.9%)
Staff Responsiveness (max = 24)	16.3	(16.1, 16.5)	1.7 (6.9%)	2.0 (8.3%)

4.3.2.2. Relationships between candidate quality of life indicators, candidate risk adjustment variables, and LTC home ranks

We identified unadjusted and adjusted associations between the candidate quality of life indicators and the candidate risk adjustment variables. Table 4.5. shows bivariate associations between age and most of the candidate quality of life indicators across all of the LTC homes, where residents in younger age groups had a greater odds of responding sometimes, rarely, or

never to most of the quality of life measures. The exceptions were for ‘Low time autonomy’ and ‘Low meaning’ which showed no significant association with age. Male residents had a lower odds of reporting that they sometimes, rarely, or never feel safe alone, but had greater odds of reporting that they sometimes, rarely, or never feel that their privacy is respected or engage in meaningful activities. Additionally, compared to residents with a one-to-two year length of stay, residents with a length of stay of under one year were less likely to report that they were sometimes, rarely, or never respected by staff or that staff sometimes, rarely, or never respond quickly when they ask for assistance. After excluding the 56 LTC homes or organizations that did not collect data on self-rated health, there were strong correlations between fair or poor self-rated health and all of the candidate quality of life indicators, where fair or poor self rated health increased the odds of responding negatively to the survey items. The ADL and incontinence candidate risk adjustment variables had more non-significant relationships with the quality of life measures or challenges with insufficient data.

Table 4.5. Relationship between candidate quality of life indicators and candidate risk adjustment variables while controlling for demographic characteristics, LTC organization, and other factors

	Low privacy	Poor mealtimes	Feels unsafe	Low time autonomy	Low respect	Slow response	Low meaning
Odds Ratios (95% CI)							
Age group [†]							
<45 vs. 85+	1.86 (1.13, 3.06)	1.65 (1.10, 2.47)	2.60 (1.63, 4.17)	0.88 (0.51, 1.49)	3.15 (1.97, 5.03)	2.58 (1.73, 3.85)	0.84 (0.55, 1.26)
45-64 vs. 85+	1.63 (1.34, 1.97)	1.84 (1.58, 2.15)	1.48 (1.19, 1.84)	0.87 (0.72, 1.06)	2.21 (1.81, 2.70)	1.57 (1.34, 1.84)	1.00 (0.86, 1.18)
65-74 vs. 85+	1.47 (1.29, 1.68)	1.46 (1.31, 1.61)	1.48 (1.29, 1.70)	1.10 (0.97, 1.25)	1.85 (1.60, 2.13)	1.36 (1.22, 1.52)	0.94 (0.85, 1.05)
75-84 vs. 85+	1.23 (1.10, 1.38)	1.20 (1.11, 1.31)	1.31 (1.17, 1.47)	1.03 (0.93, 1.14)	1.33 (1.18, 1.51)	1.14 (1.05, 1.25)	0.95 (0.88, 1.04)
Gender [†]							
male vs. female or other	1.16 (1.05, 1.28)	1.05 (0.97, 1.13)	0.86 (0.78, 0.95)	0.96 (0.87, 1.05)	1.05 (0.94, 1.17)	1.02 (0.94, 1.10)	1.31 (1.21, 1.41)
Length of stay [†]							

<1 year vs. 1-2 years	0.92 (0.81, 1.04)	0.94 (0.86, 1.03)	0.93 (0.82, 1.05)	1.06 (0.94, 1.18)	0.83 (0.72, 0.95)	0.86 (0.78, 0.94)	1.03 (0.94, 1.13)
>2 years vs. 1-2 years	0.91 (0.80, 1.02)	1.07 (0.98, 1.17)	0.97 (0.86, 1.09)	0.96 (0.86, 1.07)	1.02 (0.89, 1.15)	0.88 (0.80, 0.97)	0.96 (0.88, 1.05)
Health, functional status, and incontinence							
Fair or poor vs. excellent or good self-rated health [†]	1.51 (1.35, 1.69)	2.10 (1.93, 2.28)	1.62 (1.43, 1.83)	1.46 (1.32, 1.61)	1.84 (1.64, 2.07)	1.81 (1.66, 1.98)	1.74 (1.59, 1.91)
Impaired Transfer [‡]	<i>Insufficient data</i>	1.00 (0.62, 1.61)	<i>Insufficient data</i>	0.71 (0.36, 1.38)	0.90 (0.42, 1.92)	1.03 ^{††} (0.62, 1.71)	0.87 (0.56, 1.37)
Impaired Bed mobility [‡]	<i>Insufficient data</i>	1.47 (0.91, 2.36)	<i>Insufficient data</i>	1.44 (0.73, 2.85)	1.57 (0.73, 3.40)	1.16 ^{††} (0.71, 1.92)	0.89 (0.57, 1.38)
Impaired Eating [‡]	<i>Insufficient data</i>	0.76 (0.45, 1.27)	<i>Insufficient data</i>	1.94 (1.10, 3.44)	0.88 (0.43, 1.79)	0.70^{††} (1.42, 1.21)	1.60 (1.00, 2.56)
Impaired Toileting [‡]	<i>Insufficient data</i>	1.06 (0.70, 1.59)	<i>Insufficient data</i>	1.17 (0.64, 2.14)	0.60 (0.31, 1.16)	1.08 ^{††} (0.70, 1.66)	1.25 (0.86, 1.83)
Bladder Incontinence [‡]	<i>Insufficient data</i>	0.99 (0.71, 1.37)	<i>Insufficient data</i>	1.28 (0.83, 1.98)	1.36 (0.84, 2.22)	1.27 ^{††} (0.90, 1.79)	1.13 (0.82, 1.54)
Bowel Incontinence [‡]	<i>Insufficient data</i>	0.76 (0.56, 1.03)	<i>Insufficient data</i>	1.59 (1.04, 2.44)	1.35 (0.85, 2.14)	1.01 ^{††} (0.74, 1.38)	0.92 (0.70, 1.22)

Note: The candidate quality of life indicators represent the degree to which residents respond negatively to corresponding SQOL-LTCF items.

[‡] Independent variables in the regression model include demographic variables, self-rated health, organization, and region

[†] Independent variables in the regression model include age group, gender, length of stay, organization, and region

^{††} Independent variables in the regression model include age group, gender, length of stay, organization clustering, and other ADL and incontinence variables. This model was generated using variables from the linked dataset.

Due to limited data availability and weaker correlations with the candidate quality of life indicators for variables in the linked dataset (i.e., ADL variables and incontinence), logistic regression was performed with variables in the primary (non-linked) dataset only. In performing logistic regression, the best fitting models for all candidate risk adjustment variables (based on log-likelihood) included self-rated health, age group, gender, and length of stay. Risk-adjusted quality indicators often account for multiple, carefully selected resident characteristics and population-level measures¹⁰³. However, given the novelty of quality of life indicators, we decided to take a conservative approach of examining the effects of individual candidate risk adjustment variables (i.e., age or self).

Tables 4.6. provides an overview of how adjusting for age influenced LTC home rankings, and Table 4.7. provides an overview of how adjusting for self-rated health influenced LTC home rankings. We performed logistic regression analyses with data from the 180 LTC homes that collected self-rated health and 232 LTC homes that collected age. We found significant within-home clustering of responses for all variables according to Chi-square tests of cluster variance (with $p\text{-value} < 0.0001$ for all measures). Adjusting for self-rated health or age changed LTC home rankings for at least 97% of the homes across all of the quality-of-life indicators. While the majority of rank-changes were within 15 or fewer spots for self-rated health and 32 or fewer spots for age, a few homes with initially poor performance increased in rank by up to 117 spots following adjustment by self-rated health and 194 spots following adjustment by age. “Low privacy” and “Low respect” had the highest values for maximum rank change. Detailed figures showing the distributions of the LTC home ranks, estimates, and random effects are available in Appendices J and K.

Table 4.6. Overview of rank changes and quintile changes across LTC homes (n=232) following adjustment by age as a candidate risk-adjustment variable

	Rank increases				Rank decreases				# of LTC homes with rank change (%)
	Count	Mean	Median	Maximum	Count	Mean	Median	Maximum	
Low privacy	101	31.9	22	194	129	-24.9	-21	-82	230 (99%)
Poor mealtimes	99	22.1	14.5	187	131	-16.7	-14	-57	230 (99%)
Feels unsafe	88	20.5	13	126	139	-13.0	-11	-51	227 (98%)
Low time autonomy	90	26.5	16.5	163	138	-17.3	-16	-50	228 (98%)
Low respect	97	31.8	19.5	194	130	-23.7	-20	-71.5	227 (98%)
Slow response	106	23.5	15.75	159	120	-20.8	-17	-68	226 (97%)
Low meaning	97	20.6	13	181	127	-15.7	-12	-66	224 (97%)
	Quintile increases				Quintile decreases				# of LTC homes with quintile change (%)
	Count	Mean	Median	Maximum	Count	Mean	Median	Maximum	
Low privacy	47	1.4	1	4	59	-1.1	-1	-2	106 (46%)
Poor mealtimes	36	1.2	1	4	41	-1.0	-1	-1	77 (33%)
Feels unsafe	32	1.1	1	3	36	-1.0	-1	-2	68 (29%)

Low time autonomy	38	1.3	1	3	49	-1.0	-1	-1	87 (38%)
Low respect	46	1.4	1	4	62	-1.0	-1	-2	108 (47%)
Slow response	41	1.1	1	3	44	-1.0	-1	-2	85 (37%)
Low meaning	31	1.2	1	4	36	-1.0	-1	-2	67 (29%)

Table 4.7. Overview of rank changes and quintile changes across LTC homes (n=180) following adjustment by self-rated health as a candidate risk-adjustment variable

	Rank increases				Rank decreases				# of LTC homes with rank change (%)
	Count	Mean	Median	Maximum	Count	Mean	Median	Maximum	
Low privacy	82	22.4	15.5	117	95	-19.3	-20	-51	177 (98%)
Poor mealtimes	87	13.4	9.5	69.5	89	-13.1	-11	-53	176 (98%)
Feels unsafe	82	18.3	13.75	103	94	-15.9	-11	-46.5	176 (98%)
Low time autonomy	82	14.3	10	85	93	-12.6	-11	-37	175 (97%)
Low respect	78	18.7	15	112	96	-15.2	-13	-49.5	174 (97%)
Slow response	84	17.1	14	60	91	-15.8	-13	-47	175 (97%)
Low meaning	75	17.0	12.5	55	100	-12.7	-11	-45	175 (97%)
	Quintile increases				Quintile decreases				# of LTC homes with quintile change (%)
	Count	Mean	Median	Maximum	Count	Mean	Median	Maximum	
Low privacy	36	1.3	1	3	42	-1.1	-1	-2	78 (43%)
Poor mealtimes	30	1.1	1	2	33	-1.0	-1	-1	63 (35%)
Feels unsafe	29	1.3	1	3	34	-1.0	-1	-2	63 (35%)
Low time autonomy	34	1.1	1	2	36	-1.0	-1	-1	70 (39%)
Low respect	31	1.1	1	3	32	-1.0	-1	-1	63 (35%)
Slow response	34	1.1	1	2	36	-1.1	-1	-2	70 (39%)
Low meaning	33	1.0	1	2	32	-1.0	-1	-1	65 (36%)

Finally, we compared the unadjusted and adjusted models for both age and self-rated health. The R and R² values, presented in Table 4.8., determined that risk-adjustment did have an influence on both models, with differences between different candidate quality indicators and candidate risk adjustment variables. Most of the R values fell within an ideal range (0.85 to 0.95), and the proportion of variance in the adjusted models that can be attributed to unadjusted ratings ranged from 69% to 89% for age and 74% and 89% for self-rated health.

Table 4.8. Relationship between unadjusted and adjusted models (by age and self-rated health) according to R and adjusted R² values

	Age-Adjusted vs. Unadjusted Model		Self-Rated Health-Adjusted vs. Unadjusted Model	
	R	R ²	R	R ²
Low privacy	0.83	0.69	0.86	0.74
Poor mealtimes	0.91	0.83	0.94	0.89
Feels unsafe	0.94	0.89	0.90	0.81
Low time autonomy	0.89	0.80	0.94	0.89
Low respect	0.84	0.70	0.91	0.83
Slow response	0.90	0.81	0.92	0.85
Low meaning	0.93	0.86	0.93	0.87

Note: Ideal R-value is 0.85 to 0.95

4.4. Discussion

4.4.1. Results summary

The present feasibility study described candidate quality of life indicators, candidate risk adjustment variables, and their relationships with one another. Large datasets were available for analyses, suggesting data collection feasibility. On the other hand, there was missing data for sociodemographic variables and self-rated health in several LTC homes included in the study. Most of the outcome variables had a prevalence of 10% or more, indicating that they were not measuring sentinel events. The highest proportion of negative responses was found for ‘Low meaning’ (62.5%), followed by ‘Poor mealtimes’ (34.1%) and ‘Slow response’ (32.8%). Poor performance in ‘Low respect’ (15.6%) or ‘Feels unsafe’ (17.9%) was less prevalent across the LTC homes in our dataset. Variability for the candidate quality of life indicators across LTC homes was similar to or greater than for the SQOL-LTCF scales. This similarity suggests that quality comparisons between LTC homes would be possible with the candidate quality of life indicators.

This study also suggested that risk-adjustment would influence quality-of-life benchmarking between North American LTC homes. Adjusting for self-rated health or age

appears to be more feasible than adjusting for ADL impairment or incontinence because of insufficient or missing data for several variables in the linked dataset. Additionally, many of the ADL and incontinence variables were not found to be associated with candidate quality of life indicators. In contrast, self-rated health and age were correlated with all of the candidate quality of life indicators and adjusting for these variables influenced rankings for the vast majority of LTC homes. According to the R and R² values, there was an acceptable degree of variance attributable to the unadjusted model following adjustment by age or self-rated health. Thus, over-adjustment was unlikely to have occurred in either model.

4.4.2. Comparisons with existing literature

Previous research has shown the feasibility of the SQOL-LTCF in North America and Europe⁵⁹, and this study adds that acceptable prevalence and variability is present across the candidate quality of life indicators for quality comparisons¹⁰³. Research on mental health quality indicators has suggested that variability between LTC homes or organizations should be at least 10% according to interquartile range¹⁶¹. All of the candidate quality of life indicators met the suggested 10% cutoff while none of the quality-of-life scales did. Thus, the candidate quality of life indicators appeared to have sufficient variability to be useful for quality comparisons. However, when choosing quality indicators or risk-adjustment variables, feasibility is only one consideration. There is also a need to understand the appropriateness of the variables of interest within their specific social contexts to evaluate the implications of risk-adjustment⁷¹.

First, we identified challenges in feasibility related to data collection and data linking. Using linked data on late-loss ADL impairment and incontinence variables was less feasible and less appropriate for adjusting the candidate quality of life indicators compared to variables collected within the SQOL-LTCF itself. To protect sensitive resident data¹⁶², the SQOL-LTCF

does not require the collection of identifiable information that would support data linking with the interRAI MDS or LTCF⁴. Regulatory barriers can also prevent data linking, such as those set by the General Data Protection Regulation (GDPR)¹⁶³. Using self-rated health as a risk adjustment variable in North America would usually not require data linking and is therefore a more feasible alternative to the interRAI MDS functional and clinical variables. On the other hand, several LTC homes in the present study did not collect self-rated health data (n=56) or age (n=4). If risk-adjusted quality of life indicators were incorporated into the SQOL-LTCF, sociodemographic variables and self-rated health should be collected consistently where possible. Moreover, the potential benefits of data linking for informational integration raises questions around if and how data protection regulations could be modernized¹⁶⁴.

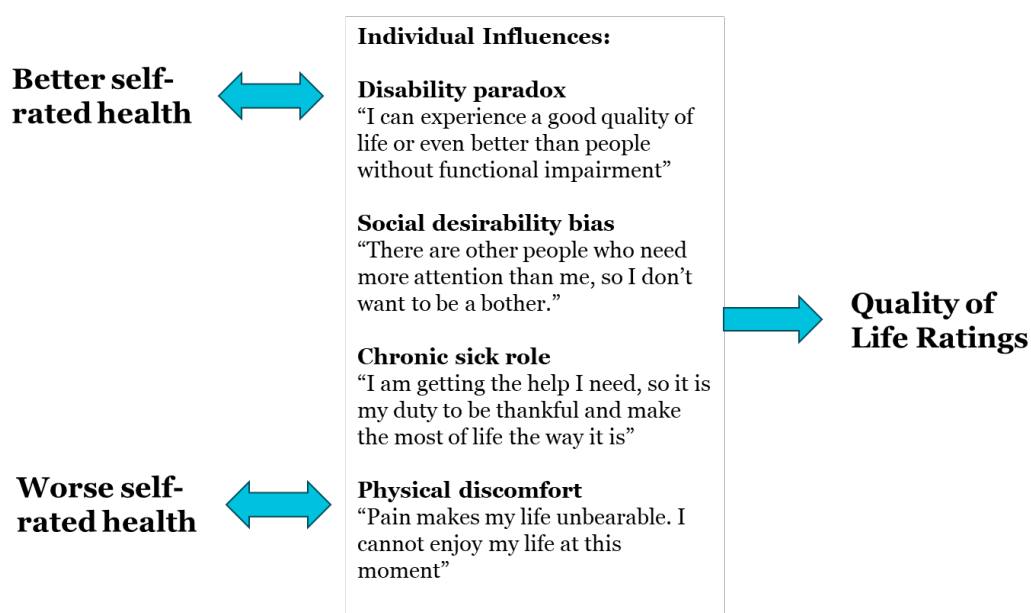
Second, all of the candidate quality of life indicators (and none of the SQOL-LTCF scales) appeared to be susceptible to ceiling effects, defined as when the proportion of respondents selecting the maximum value on a scale exceeds 15%¹⁶⁵. Ceiling effects may be attributable to social desirability bias¹⁶⁶. A 2021 paper by Timothy Schipke offers a potential explanation with the “chronic sick role”, in which individuals experiencing chronic illnesses are expected to behave in alignment with a certain set of social norms¹⁶⁷. Rather than argue, debate, or complain, individuals within the “chronic sick role” are expected to cooperate with care providers as they remain dependent on the medical system¹⁶⁷. Within this proposition, we would expect that LTC residents, who are highly dependent on care providers, would be susceptible to social desirability bias that leads them to provide more positive responses to quality of life surveys. While ceiling effects have been found in self-reported quality of life surveys beyond the SQOL-LTCF, they could decrease quality indicator feasibility by inhibiting the successful detection of changes or differences in quality of life within and between populations¹⁶⁶.

Complexities also arise in exploring age as a risk-adjustor. This study found that individuals in older age groups tended to respond more positively to the candidate quality of life indicators than younger age groups. This pattern has been documented in previous research with the SQOL-LTCF⁶⁹. It may be that younger residents are more discontent overall with living in a LTC home at that life stage. Another potential explanation is the existence of generational differences between age groups (e.g., the 1946 to 1964 “Baby Boomers” vs. the 1928 to 1945 “Silent Generation”). The ‘cohort effect’ is a phenomenon in which differences between generations result from unique historical events experienced by the group, such as war, economic crises, or social movements, during adolescence or young adulthood¹⁶⁸. To illustrate, individuals born into “The Silent Generation” have been described as more “conformist and civic-minded” compared to those in younger generations, possibly due to the influence of the Great Depression and World War II on their lives¹⁶⁸. In contrast, the “Baby Boom” cohort has been reported to have significantly worse depressive symptoms, anxiety, self-reported quality of life, and cardiac outcomes compared to the “Silent Generation” cohort¹⁶⁹. While cohort effects manifest differently across different countries¹⁷⁰, they appear to influence older adults’ perception of their lives, including self-rated health¹⁷¹, psychosocial needs¹⁷⁰, and values around physical, social, and health care environments¹⁷². The proposition that different age groups respond differently to quality of life surveys and interventions would also mean that interactions between age and health evolve over time and between populations¹⁴⁸. Thus, adjusting for age can introduce a bias known as constant risk fallacy, defined as when the effect of a risk factor is incorrectly assumed to stay consistent between populations or over time¹⁴⁸.

Using self-rated health as risk adjustor also has its challenges. Self-rated health has been recommended as a more direct measure for risk-adjustment compared to age¹⁴⁸. In the present

study, individuals with better self-rated health tended to respond more positively the quality of life measures compared to those who had worse self-rated health. However, these relationships are quite complex. Since many LTC residents live with complex and unstable health problems, an individual's health status at the time of the survey would be expected to influence how they respond. As illustrated in Figure 4.1., we propose that among individuals with good or excellent self-rated health, the disability paradox, social desirability bias, and "chronic sick role"¹⁶⁷ have a larger influence on LTC resident responses than their physical state. The disability paradox suggests that individuals living with a disease or disability can experience a good quality of life and sometimes higher quality of life than those without a disease or disability¹. For those with fair or poor self-rated health, physical discomfort may play a larger role. It may be that individuals who feel acutely ill (e.g., due to uncontrolled pain) are in a worse emotional state, less willing to engage in meaningful activities, and experiencing a worse quality of life. In these circumstances, risk-adjustment could be appropriate. On the other hand, it could also be that poor quality of life could be causing depressive symptoms and, in turn, poorer ratings of quality of

Figure 4.1. Proposed relationships between self-rated health and quality of life



life^{173,174}. Understanding that self-rated health can be influenced by extrinsic factors such as actions by an LTC home to improve quality of life (e.g., exercise programs) risk-adjustment may be less appropriate.

Another challenge with using self-rated health as a risk-adjustment variable for the SQOL-LTCF is that it is reported as a binary variable (“Excellent or Good” or “Fair or Poor”). The limited granularity of a binary measure may obscure differences between populations that would have implications for risk-adjustment precision. We would suggest that interRAI consider replacing binary self-rated health with a categorical measure (i.e., (“Excellent”, “Good”, “Fair”, “Poor”)) to enhance its performance as a risk-adjustment variable.

Given the paucity of research on developing and risk-adjusting quality of life indicators for LTC homes, we would suggest that future researchers investigate appropriateness and sensitivity to change across candidate quality of life indicators. Research shows that quality of life in LTC homes can change over time¹⁷⁵, and that responding to issues identified in LTC quality of life surveys can lead to improved quality of life scores⁴⁹. Audit and feedback have been proven effective for enhancing quality within health care practices¹⁴⁴, and well-established interventions are available for improving person-centered care^{5,176}, mealtime experiences²³, and engagement in meaningful activities¹⁷⁷. Piloting quality of life indicators could fill a gap in this research space. By investigating sensitivity to change for specific quality of life indicators, and monitoring the behaviours of LTC homes in response to the data would help establish the utility of quality of life indicators for historical comparisons⁷⁹. Future research should also be performed to explore more sophisticated methods of risk adjustment for quality of life indicators¹⁰⁴. Specifically, complex adjustment methods with models examining extrinsic variables (e.g., season, method of survey administration) could provide additional value.

4.4.3. Strengths and Limitations

The present feasibility study has several strengths. We used large datasets containing high-quality data from a valid and reliable survey to perform our analyses. We also employed several analytical methods to explore the feasibility of the candidate quality of life indicators and compared with currently used quality scales.

This study also has limitations. First, over 80% of our data were from Canadian LTC homes and over 99% were from North American LTC homes. Thus, our findings are not fully generalizable to international contexts. We also had limited data on facility characteristics to describe LTC homes (e.g., size, urban or rural, staff-to-resident ratios) and cannot claim that our findings are generalizable across these characteristics either. Second, some variables had high proportions of missing data that limited our analyses, including ‘Low privacy’ and ‘Feels unsafe’ in the linked dataset. Third, since the data were collected at different points of time and in different locations, we cannot guarantee that they were collected using consistent methods across the LTC homes. While there is a manual for using the SQOL-LTCF and we employed multilevel modeling to account for these differences, it is possible the data were not collected randomly within LTC homes.

4.5. Conclusions

A perfect quality indicator or risk-adjustment variable is unlikely to exist when it comes to quality of life given its complex and subjective nature. However, we believe that it is worthwhile to risk-adjust quality of life indicators for supporting fair benchmarking and quality comparisons as long as it is done in a careful manner. Benchmarking is a valuable tool for supporting quality improvement initiatives and must be performed fairly, without ignoring the differences between LTC resident populations that influence how they respond to subjective

surveys. Feasibility testing is an important step in the development and implementation of a complex innovation⁷⁹. The present study suggests that it would be feasible to generate useful quality of life indicators for the SQOL-LTCF. However, data collection obstacles and analytical questions related to risk-adjustment should be considered in the development of future quality of life indicators. Specifically, privacy limitations, cost of implementation, risk of bias, and sophisticated analytical processes for adjustment should be considered for the future development of quality of life indicators for the SQOL-LTCF. Further investigation is necessary for advancing our understanding of quality of life monitoring and benchmarking across LTC homes.

Chapter 5: Exploring the implementation of quality-of-life surveys in long-term care (LTC)

homes: A realist synthesis

This chapter will be submitted as:

Nova, A.A., Kroetsch, B., Heckman, G.A., Declercq, A., Leemans, K., McAiney, C., De
Lepeleire, J., Hirdes, J.P., (2025). Exploring the implementation of quality of life surveys in LTC
homes: A realist synthesis

5.1. Introduction

5.1.1. Background

Quality of life is a broad and complex concept which can be defined as a person's perception of their lives in the context of their expectations, goals, and sociocultural environment². Since long-term care (LTC) homes are intended to be a 'home-replacing environment', ensuring a good living environment is vital. Thus, LTC culture change initiatives, such as the Eden Alternative and Green House Homes¹⁷⁸, which emphasize quality of life in addition to high quality care have been growing in popularity. On a broader level, improving resident quality of life has been recognized by the Organisation for Economic Co-operation and Development (OECD) as an overarching goal of the LTC sector¹⁷⁹ and improving patient experiences has been identified as a priority for health system transformation within the Quintuple Aim Framework²¹.

High quality care is often defined and measured in terms of effectiveness, safety, and people centeredness, and encompasses processes that are delivered equitably, efficiently, and in a timely and integrated manner¹⁸⁰. Usually, health care organizations categorize quality issues in terms of structures, processes, and outcomes. Structures are the circumstances in which care is offered, processes are observable care activities, and outcomes are changes attributable to care⁶². All three categories provide important information to LTC homes including operational metrics (e.g., hours of care provided per resident per day) and quality of care. Quality monitoring strategies that cover a breadth of domains can help to minimize 'blind spots' in quality and provide opportunities for reflection, celebration, and improvement.

Surveys are a commonly used quality monitoring tool that can give LTC residents or staff a platform to express their needs, and can help LTC homes identify patterns and problems, think critically about current practices, and set evidence-informed goals¹¹⁷. Surveys can also support benchmarking, defined as a process of measuring practice quality and comparing against top performers to unveil blind spots, identify best-practices, and enhance quality improvement efforts⁷⁶. Many valid and reliable quality of life surveys exist¹⁸¹. However, it is important to note that quality measurement does not guarantee quality improvement. ‘Bridging the gap’ between measurement and action is a topic within the purview of implementation science.

Implementation is a process that aims to improve the uptake and impact of innovations and tools⁷⁹. The implementation science field recognizes that there is no ‘one-size fits all’ and offers many frameworks to enhance quality improvement efforts, such as the commonly used RE-AIM (reach, effectiveness, adoption, implementation, maintenance) framework¹⁸². Within this framework, ‘maintenance’ posits that ensuring the sustainability of an innovation requires a thorough understanding of contextual factors, stakeholder needs, and innovation characteristics (i.e., proven benefits, development potential, and fit within clinical routines)^{79,183}. The idea that context-innovation fit is important suggests that implementation strategies for quality of life surveys from other sectors may not be easily transferrable to LTC. The uniqueness and complexity of the sector, high resource needs, and resident complexity should not be overlooked⁷³. For instance, barriers to implementing evidence-based guidelines in LTC have been identified in the literature, such as resource constraints, knowledge gaps, resident complexity, reluctance to change, and impractical guidance¹⁸⁴. In contrast, adequate resources, knowledge, and collaboration, and well-designed uptake protocols can facilitate implementation¹⁸⁴.

5.1.2. Rationale

Quality of life measurement in LTC is underdeveloped and lags behind both clinical quality measurement and quality measurement of health care overall¹⁷⁹. There is no consensus on best-practice measures for quality of life in LTC homes and a limited understanding around the relevance and efficacy of quality of life measurement tools^{51,179}. There also appears to be a gap in the availability of clear and practical guidance on how quality of life surveys can be implemented in LTC homes and used to support quality improvement. Given the importance of quality of life, quality monitoring, and implementation science for improving LTC, research exploring these topics is needed.

5.1.3. Objectives

The purpose of this research was to explore the implementation of quality of life surveys in LTC homes and identify how they can be leveraged to encourage quality improvement. Our specific objectives were to:

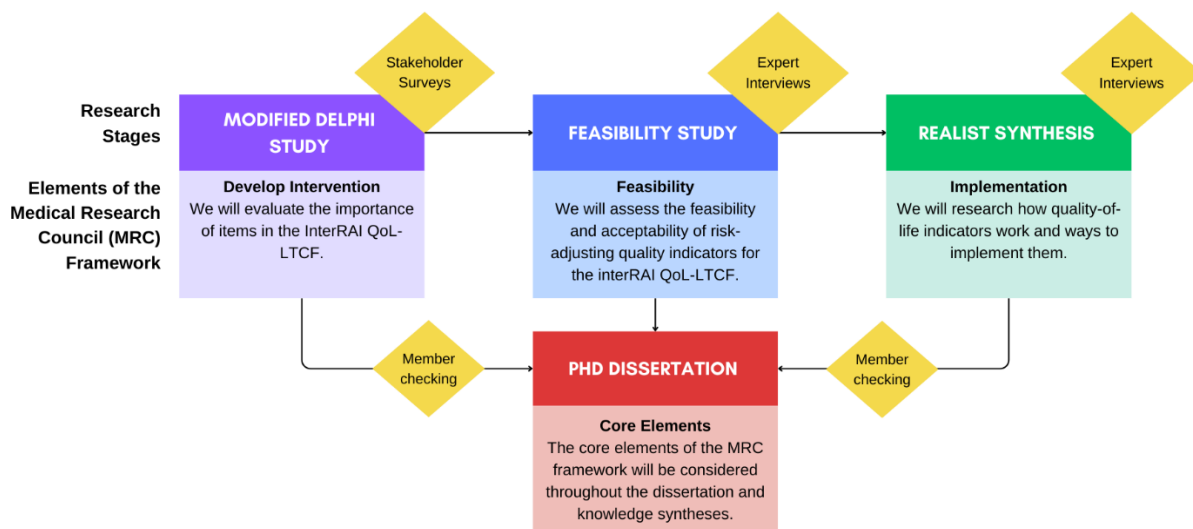
1. Identify barriers to implementing quality of life surveys in the LTC context, as well as facilitators for overcoming implementation-related challenges.
2. Identify benefits and drawbacks of implementing quality of life surveys, and who can be affected by these benefits and drawbacks.
3. Develop a middle range theory that explains how and why quality of life surveys are successfully implemented in some LTC contexts and not others.

5.2. Methods

5.2.1. Study Design, Rationale, and Changes in the Review Process

We determined that the realist synthesis methodology would be the most appropriate to achieve our research objectives. Realist syntheses are conducted iteratively, and combine systematic literature searches with meaningful stakeholder engagement¹⁰⁵. They take a flexible approach to unpacking relationships between complex contexts and innovations¹⁰⁵, and are particularly effective for describing how the policy intent of an innovation translates into real-world practice¹⁸⁵. In short, they explore ‘what works for whom, in what circumstances, and why’¹⁸⁵. This study is part of a larger project that was previously described in a research protocol¹²⁹. The research protocol has been summarized in Figure 5.1.

Figure 5.1. Project Workflow Diagram (from published protocol)



Since publishing our original protocol, we have deviated from our initial plan in three ways. First, we adapted our focus to investigate quality of life surveys rather than quality of life indicators. While scoping the literature, we found too little research on the implementation of quality of life indicators in LTC to be able to perform meaningful research. However, implementing appropriate data collection tools, like surveys, is foundational for developing and using quality indicators⁴¹. Second, we did not perform a grey literature search based upon

guidance from a university librarian and shared expertise. Third, we adapted our expert interview approach slightly by adding one interview question (“is implementing a quality of life survey different from implementing a clinical assessment?”) and performing one ‘group interview’ (i.e., focus group) by request from participants.

5.2.2. Scoping the Literature

Following consultation with a research librarian, we conducted a preliminary literature search on PubMed, Google Scholar, and the Connected Papers platform¹⁸⁶. Scoping the literature helped us to hone our objectives and identify relevant search terms, key concepts to explore further through stakeholder engagement, and several relevant research papers that served as a benchmark for subsequent searches.

5.2.3. Interviews

Interviews with researchers and managers working in an LTC organization or LTC support organization were a key source of information in this study. We aimed to recruit a maximum variation sample of 10 English-speaking individuals with a breadth of professional experiences related to quality of life surveys in LTC from Canada and Europe. We recruited from a pool of individuals who had previously engaged in a modified Delphi study¹⁵⁴. We determined that discussions with researchers and health care providers would be useful to highlight real-world implementation challenges and identify key papers, practice guidelines, and resources to inform our interpretations. Participation was voluntary and recruitment occurred at an in-person meeting for a well-established LTC community of practice and via email using a recruitment and information letter. The recruitment letter highlighted the purpose of the interviews, while the information letter provided detail on the dissertation and ethics approval.

After obtaining written informed consent, we collected data via semi-structured interviews. However, a group of three participants from one organization opted for a focus group approach (which included the same questions). The interview questions are included in Appendix L. AN conducted stakeholder interviews in 30-minute virtual meetings, which were audio-recorded and automatically transcribed verbatim with Microsoft Teams (except for the focus group, where the researcher took detailed notes instead due to participant preferences). The transcripts were reviewed alongside the audio recordings by AN to ensure accuracy. Virtual interviews were most appropriate as participants were recruited from an international pool of stakeholders. The recordings and transcripts were securely stored on a password protected computer and deidentified. Using NVivo 14 software, we then used content analysis to code the interview transcripts inductively and grouped them into three deductive themes: context, mechanism, and outcome. A codebook has been included in Appendix M. Finally, the interview data was analysed together with the data from the literature search and performed constant comparison with the original transcripts to ensure accuracy.

5.2.4. Searching Process

A systematic literature search was also performed on PubMed via MEDLINE, Scopus, and CINAHL via EBSCOhost in parallel to the qualitative interviews. The approach was developed with guidance from research librarian at the University of Waterloo. The search terms used, listed in Table 5.1., cover the topics of subjective quality of life, LTC, implementation, and surveys.

Table 5.1. Search Terms

Concepts	SUBJECTIVE QUALITY OF LIFE: How an	LONG-TERM CARE: Residential care that attempt to	IMPLEMENTATION: Deliberate efforts to increase impact, uptake, and sustainability of	SURVEY: A questionnaire that measures performance or quality for the purposes of ongoing
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	individual perceives their life in relation to their culture, values, expectations, and concerns	meet the needs of individuals with a chronic disease or disability who cannot care for themselves	health innovations within a specific context	monitoring and quality improvement.	
Author Keywords [TW]	• Quality of Life • Life Quality • QoL	• Long Term Care • LTC • Care Home* • Nursing Home* • Nursing Facilit* • Residential Care AND "Older Adult" • Residential Aged Care • Institutionalized Older Adult* • Institutionalized Elder* • Old Age Home* • Aged Care Home* • Aged Care Facilit*	• Implement* • Feasibility • Acceptability • Usefulness • Pilot* • Process Improvement • Program Evaluation • Quality Improvement • Adopt* • Routiniz* • Embed* • Scalab* • Culture Change [Tiab:~2] Survey Evaluation • Questionnaire Evaluation	• Questionnaire* • Survey* • Indicator • Indicators • Quality Measurement [Tiab:~2] • Quality Monitoring [Tiab:~2] • Performance Monitoring [Tiab:~2] • Performance Measure* • Quality Assurance • Measurement Instrument* • Process Assessment* • Instrument* • Toolkit*	• EuroQol • EQ-5D • Adult Social Care Outcomes Toolkit • ASCOT • DEMQOL • Duke Health Profile • Health Utility Index • ICECAP-O • interRAI LTCF • WHOQOL • Joy-of-Life Scale • Nottingham Health Profile • Manchester Short Assessment of Quality of Life • OPQOL • QOL-AD • LTC-QOL • QUALID • QUALIDEM • SWLS
MeSH Headings [MeSH]	• Quality of Life	• Long-Term Care • Nursing Homes • Homes for the Aged		• Quality Indicators, Health Care [noexp] • Surveys and Questionnaires	

5.2.5. Document Selection

After uploading the body of literature into Covidence systematic review software, two reviewers (AN and BK) performed title and abstract screening and full-text review separately¹⁰⁹. Our selection criteria were generated to support our focus on explanation and theory generation. We included papers written in English from 2009 to 2024 that investigated subjective quality of life surveys in LTC. Our selected time period was informed by the preliminary literature search. In terms of study design, letters to the editor, commentaries, editorials, qualitative studies, pilot studies, feasibility studies, case studies, and other peer-reviewed journal articles with implementation-related content were included. Unpublished manuscripts, conference abstracts, papers with a sole focus on psychometric properties, papers that only used quality of life surveys as a research tool, and papers that only reported quantitative findings were excluded. Disagreements between the two reviewers were resolved by mutual consensus through discussions after each stage of document screening and selection.

5.2.6. Data Extraction

AN performed data extraction of each selected paper using a Covidence extraction template. This template was inspired by the Medical Research Council (MRC) Framework and gathered information from entire papers on study design, strengths and limitations, context and participant characteristics, survey(s) implemented (if any), barriers and facilitators to implementation, and benefits and drawbacks of implementation⁷⁹. Where possible, we pulled verbatim quotes from the original text to ensure accuracy of the analysis.

5.2.7. Analysis and Synthesis

Since the data gathered from the literature review and interviews were collected at the same time, we also performed data analyses in parallel. For the qualitative interviews, we deductively coded the transcripts according to their level of context (macro, meso, or micro) and

when they would generally occur in the implementation process (from development to knowledge mobilization). Then, we synthesized the codes into themes. Analyses of data from the white literature extraction was performed similarly, by labelling relevant quotes and descriptive information by context and implementation.

Next, we synthesized themes from both sources using an iterative mind-mapping process, illustrated in Appendix M. Initial maps were re-organized by theme into more coherent processes, then labelled them explicitly as a context, mechanism, or outcome. Context-Mechanism-Outcome (CMO) configurations, described in Figure 5.2., are a heuristic commonly used in realist syntheses to structure a complex phenomenon in a simple way¹⁸⁵. We tabulated a list of 21 initial CMOs, also included in Appendix M, then consolidated them into five overarching CMOs to support the development of middle-range theories as we compared, contrasted, and identified patterns and disagreements in the themes. Disagreements were particularly useful for developing programme theories. Due to the complex nature of our analysis and synthesis process, we returned to the raw data frequently to enhance the accuracy of our interpretations. Finally, we performed member checking and obtained detailed feedback on our interpretations from one Canadian and two European interview participants.

Figure 5.2. Key definitions for realist syntheses

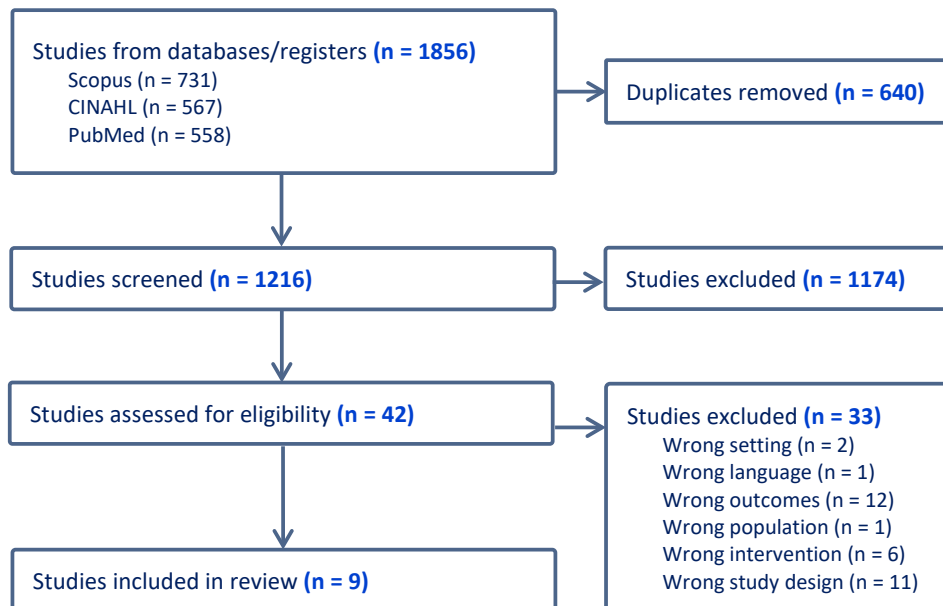
Middle-range theories: Formal propositional statements that explain dynamic and complex social phenomena.

Context-Mechanism-Outcome Configurations (CMOs): A heuristic device (i.e., simplification strategy) for describing middle-range theories. CMOs illustrate how underlying mechanisms work as forces, interactions, feedback, or feedforward processes and interact with a context (material, individual, group, or institutional) to cause an outcome. Observing outcomes lets researchers deduce the underlying causes of systemic change.

Programme theories: Explain how and why a specific programme will produce different outcomes in different contexts

5.3. Results

We identified nine studies from our review and conducted five individual interviews and one focus group with three individuals (eight participants in total). Table 5.1. highlights the key characteristics of our sample. Figure 5.3. shows a PRISMA flow diagram outlining our screening and review process, including document uploading, duplicate deletion, title and abstract screening, full text screening, and extraction. Appendix N presents the full results of our data extraction from the literature. The following sections will describe our evidence synthesis into 5



overarching CMO configurations. Each CMO describes LTC contexts and how they can trigger varying mechanisms that influence different implementation-related outcomes.

Figure 5.3. PRISMA Flow Diagram

Table 5.2. Participant Characteristics

Pseudonyms	Description
Participant 1	Long-Term Care Clinician and Medical Director in Canada
Participant 2	Researcher in a European Quality Improvement Organization

Participant 3	Manager for a Canadian Long-Term Care Organization
Participant 4	European University Researcher involved in Health System Research
Participant 5	Leader in a Large Canadian Quality Improvement Organization
Focus Group	Three staff in a Canadian Resident Advocacy Organization

5.3.1. CMO #1: Government involvement (C) → Motivation (M) → Decision-Making (O)

Government and other regulatory bodies responsible for developing, informing, or enforcing rules in LTC (e.g., policies, decrees, laws) can influence the implementation of quality of life surveys across homes. These ‘external powers’ usually take one of two approaches to quality of life survey implementation. First, they may recommend quality of life monitoring without specific guidelines (C). For example, policy makers and regulatory bodies in the UK do not provide specific guidelines, policies, or procedures that the LTC sector must follow related to implementing quality of life surveys¹⁸⁷. Consequently, implementation depends on the intrinsic motivation of one or more LTC staff members, who must choose to prioritize quality of life monitoring despite competing priorities (M), fill their own knowledge gaps, and initiate ‘bottom-up’ implementation. Much of the LTC sector in the UK chooses not to implement routine quality of life surveys (O), in part because many LTC homes are “inherently busy and time poor”¹⁸⁷. Additionally, staff turnover can halt a survey initiative if a staff member champion leaves the LTC home. According to our qualitative focus group, “unless it’s an expectation that inspectors are looking for, [LTC] homes won’t do it”.

In other settings, governments have chosen the approach of mandating quality of life surveys using top-down enforcement. However, they often do not share recommendations on which survey to implement, how to implement it, or what to do with the results (C). For example, our focus group discussion suggested we look at Ontario, Canada’s 2021 ‘Fixing LTC

Act' which states that LTC home licensees must ensure annual resident and family experience surveys¹⁸⁸. The mechanism of action for an act such as this is extrinsic motivation (M) and leads to more LTC homes deciding to implement a survey (O). However, LTC homes must also decide which quality of life survey to implement, and how they will approach implementation.

Participant 3 described their experience with choosing a survey:

"I was looking for... a research validated tool and I couldn't find anything... I think we're using our best judgement and obviously expertise that we have to bring it to a certain level, but the resources aren't quite the same [as in the acute care sector]" – Participant

3

Information on the validity and reliability of quality of life surveys can be difficult to find and interpret⁵¹. In the absence of standardization (C), survey decisions are often made on an individual home or organization level based on intuition, attainability, and sometimes guidance from general literature or resident councils (M). In turn, poor standardization can cause different LTC homes to approach survey implementation differently and be a source of inconsistency and error for those attempting to use quality of life surveys (O)¹⁸⁹.

Finally, conflicting laws (C) can be difficult for LTC leadership to navigate (M). While rules are generally well intended, participants in this study and in one journal article reported a challenge with risk-aversion (O) that leadership faces with responding to resident needs when they conflict with legislation¹⁹⁰:

"Legislation has requirements -- requiring a survey, council, and quality reports are all great -- but [in the LTC sector] we're all highly regulated, so we can't make changes. When the compliance officers come in, how are they going to look at the home? [LTC

leaders think] 'Are we going to get in trouble because we got food from farmers market instead of from a pre-packaged pre-approved sterile facility?'" – Focus Group

5.3.2. CMO #2: Resident and staff involvement (C) → Outcome Expectations (M) → Implementation Quality and Scope (O)

Power imbalances can also exist *within* LTC that influence how residents and staff are involved in quality of life survey initiatives. For instance, residents can sometimes be treated like passive care recipients (C) and not be engaged in improving their own quality of life (M):

"Residents say that they feel there's a power imbalance in long term care... I feel that the long-term care environment takes away some of their autonomy ... staff maybe treat them in too much of a systematic or organizational way" – Participant 1

In turn, the scope of approaches to quality improvement may be limited to those identified by staff (O). The language used by some articles implied a top down approach and that resident quality of life was the responsibility of staff alone rather than shared^{54,187}:

*"Staff... often struggled to identify actions that could be taken to help improve residents' quality of life, even though the residents defined aspects of their life that were lacking... While it was hoped that resident feedback could motivate staff to implement individually tailored interventions to improve residents' quality of life, the responses tended to re-assure staff that there was no need for action"*⁵⁴

"In the hospital system, patients have rights and responsibilities. So, I was looking for the responsibilities on the resident side and they're not published, you know." – Participant 3

LTC staff may also feel a power imbalance (C). Fear of reprisal (M) was an important mechanism identified in the literature and interviews. A 2015 study by Towers et al reported that

the LTC staff who participated in the study had concerns and anxiety around “culpability and reliability” when it came to implementing a quality of life survey in their LTC home⁴⁶. This could have consequences for the quality of survey recruitment (O):

“When people talk to me about this, they tell me the resident refused to do the survey and I'll say no. They have a choice. They decline... I think [LTC staff are] worried that they're going to get in trouble if they don't make sure all the residents do a survey.” – Participant

3

In contrast, many LTC homes are moving towards a context of resident and staff empowerment with the support of committed, consistent, confident, supportive, and knowledgeable leadership (C)^{54,190}. These organizations tend to choose language that puts residents ‘in control’⁴⁶ and involve staff in quality improvement initiatives by way of regular communication, training, time, and resources (M)¹⁸⁷. In turn, a shared sense of purpose and accountability can be established across the LTC home, leading to a more successful implementation process (O):

“We found it very important that everyone is involved in the project from cleaners to people who work in the kitchen, the hairdresser. Then of course the residents themselves. The next of kin... and that you communicate very clearly about a project and very regularly. So not just once, but in many different moments, in very different ways... If the personnel is aware of the project, they can answer the questions... we try to really encourage the nursing homes to get all these context factors into place just to make the project more successful” – Participant 2

5.3.3. CMO #3: Chosen Feedback Sources (C) → Response Biases (M) → Trustworthiness of Findings (O)

A key purpose of quality of life surveys is to gather feedback. We found three approaches to collecting feedback. The first approach was to obtain direct care staff perspectives on resident quality of life using dementia-specific surveys such as the ‘Quality of Life for People with Dementia’ (QUALIDEM) instrument and ‘Dementia Quality of Life Instrument for Care Homes’ (DEMQOL-CH) (C)^{53,55,187}. There was disagreement in the literature around whether dementia-specific surveys are appropriate to implement in a whole-home approach (for residents living with and without dementia). Of the three collected papers that used a proxy-report strategy, one author argued that proxy-rated quality of life was a feasible way for organizations to compare quality of life across an entire LTC home population⁵⁵. The other two found limited confidence or knowledge among staff participants to speak on behalf of residents (M)^{53,187}.

“Many participants, when asked if they feel confident in their ability to measure resident QoL, displayed some uncertainty. A number of participants, however, described feeling confident. On further exploration, however, many explained that they believe they should feel confident because of the amount of time that they have worked in the care home”¹⁸⁷

“[Carer] focus group participants... noted that they would only consider the ratings trustworthy if provided by an independent organization or if they represented the views of relatives and those who had stayed in the home. Ratings based on first-hand experience were considered more reliable than judgements made by health and social care professionals, who they felt might have ‘an agenda’ based on making cost-savings”⁴⁶

One commentary paper strongly discouraged the whole-home use of dementia-specific surveys claiming that the approach could lead to observer bias, reinforce implicit biases (i.e., expecting dementia in all LTC residents), and lower trustworthiness of survey results (O)¹⁸⁹.

A second approach to gathering feedback was resident self-report with support from an external interviewer (C)^{49,51}. While this approach could be susceptible to recall bias (M) and decrease the trustworthiness of the results (O)¹⁹⁰, it also allows for improved confidentiality (M) and minimizes social desirability bias by helping residents feel more comfortable with discussing their problems (O)⁴⁹.

The third approach identified was to draw upon multiple sources of feedback, including a resident-reported quality of life survey (C)^{46,54,190}. All the interview participants discussed collecting multiple sources of feedback to provide additional explanation and clarify conflicting information (M). In turn, they hypothesized that they could gather a more holistic picture of quality of life in the LTC home (O):

“To me it means nothing unless there's an explanation... Part of the answer may be in any sort of in narrative section where people are invited to comment on or maybe it's something to bring back to a group like the Resident's Council” – Participant 1

“There can be a lot of conflicting information in surveys, and it's only as good as the questions you ask and the responses you get. So, it's a starting point...It's important to do, but I think it should not be... your only source for figuring out...opportunities to improve” - Participant 5

5.3.4. CMO #4: Opportunities for Reflection (C) → Quality of Engagement (M) → Quality of Life Changes (or not) and Reinforced Culture (O)

Once the data are collected from proxy-reports, self-reports, and/or other sources, the LTC home should usually attempt to generate solutions. Many LTC organizations use quality of life surveys in a context with time constraints and competing priorities (C). For these organizations, shorter quality of life surveys are commonly selected due to their high feasibility (e.g., under 5-minute completion time for the DEMQOL-CH). On the other hand, shorter surveys generally offer less detail to support meaningful engagement with the results:

“When I joined there was [about 70] questions and we went down to 40. Now we’re at [about 25] and some people would say we only need 10 but I don’t know about that because then we end up doing another survey to find out why they scored it” – Participant 3

Competing priorities may also mean that fewer resources are leveraged for generating solutions. For example, one study implemented a 15-item dementia-specific survey that asks residents how they feel about several aspects of their lives⁵⁴. Residents and staff were invited to generate solutions to identified quality problems but struggled to do so (M). They expressed apathy and resignation, and questioned the usefulness of the quality of life survey (despite it having good psychometric properties) (O)¹⁹¹:

“Few residents were able to identify ways that the aged care facility could assist them to address problems or improve their quality of life (with the exception of addressing food issues)... Resignation regarding quality of life issues was a common sentiment among residents, often expressed as ‘That’s just the way it is’... Staff expressed a range of reservations about the usefulness of measuring resident’s quality of life: ‘How can I improve someone’s quality of life? You can’t make someone have a good quality of life’... ‘we can’t do anything to fix that, so what’s the point?’”⁵⁴

Conversely, an environment where information and resources (i.e., collaboration, accountability, leadership support) are available to support residents and staff with generating solutions together (C) may facilitate shared priorities and engagement (M):

“Communication. I think that's the most important thing. Just getting people with the noses in the same direction, not always on the same path, but in the same direction. It's a good start.” – Participant 2

Improved engagement can manifest as improved care planning (M). For example, we identified a randomized controlled trial and pilot study of a 69-item survey intended to support care planning:

“The assessor used the residents’ responses to the open ended component of the QOL.SRI to develop a draft QOL care plan task... that identified the issue of concern, the goal in terms of resident QOL, the staff involved, and the frequency with which the task should be accomplished... Care was taken to develop tasks that were practical and feasible... The draft care plan task was brought to the unit manager and the appropriate department head (i.e., if a task involved activities or dietary staff, the corresponding person was involved) for their review and approval...the QOL care plan task was placed at the same level of accountability as other orders”⁴⁹

The authors found that residents assigned to the group that received the care planning intervention, which provided staff with dedicated time to generate and address solutions, had better quality of life scores at 90 and 180 days after baseline (O), while quality of life in the control group did not change⁴⁹. When repeated, this type of supportive context could reinforce a positive evaluation culture (O), as reported by Participant 4:

“If those reflections are being done, not once but repeatedly, then it becomes a habit. And when it's a habit and it becomes a culture and when it's a culture, then it becomes just the identity of the nursing home... That a little drop of having one question, but repeatedly and then having reflections around it...a nursing home can change its identity over time.”

– Participant 4

Other reported outcomes of implementing a quality-of-life survey were empowering residents (Participant 1), decision-making around contracts, scheduling, and service provision (Participant 3), and supporting conversations around taboo topics (Participant 4) (O). Additional benefits and drawbacks are listed in Appendix L.

5.3.5. CMO #5: Purpose of Information Sharing (C) → External Influence (M) → Attitudes and Actions (O)

The final identified theme was related to information sharing and public reporting. When the perceived purpose of an external body is to publicly judge or evaluate a LTC home without offering support for improvement (C), individuals working within LTC homes may feel pressure, worry, or mistrust (M). One interview participant and author described this pattern and concerns around unhealthy competition and damaging positive relationships (O):

“But if it becomes publicly available, it can become an aspect of consequence...it can become competition” – Participant 4

“[LTC managers] said their ratings should not be made publicly available. There seemed to be two interrelated reasons for this: firstly, many local authorities wanted to work in partnership with providers to improve quality and publishing ratings was seen as

potentially damaging to positive relationships (echoing the view that providers are generally against the publication of what is considered 'performance data') ”⁴⁶

An alternative context is information sharing between organizations with the purpose of offering support (C). When trust and transparency are encouraged in this type of relationship (M), LTC leaders may be more inclined to leverage supports for benchmarking, quality comparison, and quality improvement (O)^{46,49}. Participant 5 explained this relationship as a staff member in a supportive external organization:

“We'd try and support homes to use our data and facilities to support their own quality improvement. I think a lot of times there's a richness of data that people don't know how to use it... I think having suggestions – tangible, not prescriptive necessarily - but examples about what the data could imply or could point you to, and what might be an opportunity... we're not going to make a judgement necessarily... people want to know, ok, 'how am I doing?', 'how do I do compare to my peers?', and 'what are the trends telling me?'” – Participant 5

5.4. Discussion

5.4.1. Summary of Findings

The present study explored the implementation of quality of life surveys, specifically how LTC contexts can influence decisions, beliefs, and attitudes, and result in different implementation outcomes. We found that supportive and empowering contexts that foster engagement of all LTC players (including residents living with and without dementia) (CMO 1, 2, and 5) can improve the quality of data collection and scope of solutions identified in a LTC home (CMO 3 and 4). The overarching goals and benefits of quality of life surveys were (1)

positive changes to resident quality of life (e.g., via individualized care planning), (2) reinforced evaluation culture, (3) information sharing for collaboration, and (4) quality improvement across LTC homes. Successful implementation of quality of life surveys in LTC is possible, but the complexity management involved cannot be overstated. Limitations caused by policies, beliefs, resources (e.g., staff availability or financial resources), engagement choices, and external organizations can be barriers to successful implementation. As barriers, they can lead to frustration and apathy among LTC staff and residents, competition and distrust between LTC organizations, and less successful quality improvement overall. In contrast, policies, resource availability, meaningful resident and staff engagement, and supportive organizations can facilitate implementation. The five CMO configurations identified are included in Figure 5.4.

Figure 5.4. Context Mechanism Outcome (CMO) Configurations

1. Government involvement → Motivation → Decision-Making
2. Resident and staff involvement → Outcome Expectations → Implementation Quality and Scope
3. Chosen Feedback Sources → Response Biases → Trustworthiness of Findings
4. Opportunities for Reflection → Quality of Engagement → Quality of Life Changes and Reinforced Culture
5. Purpose of Information Sharing → External Influence → Attitudes and Actions

5.4.2. Comparison with Existing Literature

Multiple published review papers aim to list, evaluate, and recommend specific quality of life surveys. Aspden et al evaluated 13 surveys, Santana-Berlanga et al evaluated 24 surveys, and Makai et al evaluated 34 surveys^{48,181,192}. All reviews came to different conclusions and recommendations, despite an overlap in identified surveys. Additionally, none of the reviews suggested that dementia-specific tools should be used to measure the quality of life of entire LTC home populations (unless that LTC home only serves people living with moderate to severe

dementia). Our findings emphasize that survey feasibility and validity do not guarantee successful or sustainable implementation in real-world LTC homes. Several core elements from the MRC Framework were present in the results of this study that point to considerations for successful implementation, including context, stakeholder engagement, key uncertainties, and intervention refinement⁷⁹. While shorter surveys may be more feasible to implement, they may also produce results that are more difficult to act upon. In measuring quality of life, we recommend that LTC homes choose a comprehensive, action-oriented, and self-report survey that captures individual resident preferences¹⁹³. Self-report surveys have been reported to empower residents and are often feasible for use in residents with mild-to-moderate dementia^{3,58}. Additionally, survey data should be complemented with narrative care partner, staff, and resident perspectives and initiatives to ensure that LTC home partners feel prepared to engage in quality improvement initiatives¹⁹⁴.

Many of the context-related barriers to implementing quality of life surveys identified in this study have also been identified in previous research. Lack of time is a widely discussed problem across the LTC system, and greater management and direct care staff hours are significantly associated with better resident quality of life⁹⁷. Moreover, studies have identified that residents and staff may avoid expressing their opinions due to social solidarity or social desirability within LTC homes, fear of consequences (e.g., damaging relationships), or both^{195,196}. An ethnography by DeForge et al described a LTC home with an especially large perceived power imbalance, where the role of government and compliance officers was seen as surveillance, enforcement, and control¹⁹⁷. They determined that these dynamics could unintentionally push a ‘culture of compliance’, restrict individualized care, and limit quality of life (e.g., not allowing open windows or knitting due to safety concerns)¹⁹⁷. Social complexities

in LTC homes that limit honest data collection allude to the importance of confidentiality when administering quality of life surveys. In addition, conflicts between restrictive policies and quality of life raise the question of whether government, regulatory agencies, and external organizations should also take accountability over resident quality of life and contribute to quality improvement through empowerment and support rather than control. Shared ownership is key for ensuring the sustainability of any quality assurance strategy¹⁸³, and several organizations have demonstrated the feasibility of collaborative quality improvement work^{198,199}.

Finally, when aggregate performance data is publicly reported, the issues raised are less likely to be ignored and more likely to lead to quality improvement⁷⁵. However, this is only the case if care providers feel a sense of ownership over the data and perceive the data as credible, timely, specific to clinically important issues, and shared for the purpose of improving patient care⁷⁵. Similarly, information sharing between organizations can foster collaboration rather than competition in supportive contexts. For example, the Seniors Quality Leap Initiative, a LTC community of practice, has actively shared quality of life survey data with each other for over a decade with the intention of collaboration and knowledge exchange⁷⁷. In these types of initiatives, it is important to not expect immediate success and recognize that quality improvement is a long and continuous learning journey that is highly influenced by context and external pressures¹⁹⁹.

5.4.3. Strengths and Limitations

This study possesses several strengths and limitations. A primary strength was the informational triangulation we were able to achieve. Mixed-methods can improve problem identification as it mirrors how people naturally gather information²⁰⁰. Expert involvement was especially helpful in enhancing the relevancy of our findings. We obtained perspectives from

individuals who had engaged in implementing a quality of life survey, in LTC quality improvement, and/or in a well-established LTC community of practice. While this expertise is not common throughout the LTC sector, it proved valuable for collecting rich and pragmatic qualitative data. Second, two reviewers independently screened and selected the articles for the literature review using a systematic and organized approach, thus increasing the quality of our review process. Finally, the methods we chose for the realist synthesis were flexible to better capture complexity in the implementation processes and LTC. We believe that our findings clarified some key questions that stakeholders have about conducting quality of life surveys in LTC homes, thus filling a research gap.

Limitations were also present. First, only one reviewer analyzed the qualitative data and performed the literature review extraction due to time and resource constraints. Therefore, this study may still be susceptible to researcher bias. Second, this was a relatively small realist synthesis, and we decided to not include grey literature in the review or perspectives from LTC residents, family members, or direct care staff. Grey literature and the perspectives of individuals with different lived experiences could have provided additional insights that were not present in the interviews or selected literature. However, we determined that peer-reviewed literature and professional stakeholder perspectives would provide more valid, relevant, and useful information to achieve our objectives. Third, our data only captured perspectives from European and North American stakeholders in the interviews and extracted literature. Given the importance of culture in our findings, our findings are therefore not transferable to LTC sectors (e.g., Africa, Asia, or South America). in other countries. Finally, we did not perform an in-depth quality appraisal of the articles included in the review due to time and resource constraints, and because it was not

needed to achieve our objective of theory generation. We used the Pawson's 'fitness-for-purpose' criteria instead, which was quicker to apply than other available appraisal frameworks¹¹⁰.

5.5. Conclusions and Recommendations

Quality of life is complex, with controllable and uncontrollable factors², but seeking to improve quality of life in LTC is undoubtedly worth pursuing. Given the findings of this realist synthesis, we would recommend that governments in North America and Europe incentivize quality of life monitoring while acknowledging that implementation at the individual LTC home level can be challenging, disorienting, and resource intensive²⁰¹. Thus, they should support LTC home efforts through balanced and actionable measures, clear recommendations and reporting structures, and aligned financial and organizational incentives²⁰¹. LTC organizations, researchers, and government bodies should also collaborate to develop evidence-informed guidelines and standards for implementing quality of life surveys in LTC, as well as identify policies and structures that may inhibit progress and innovation in improving quality of life. For example, strict safety regulations -- enforced with inspections and punishment -- often take precedent over quality of life, which can limit residents' 'dignity of risk' (i.e., allowing a person to take risks that would enhance quality of life) and the ability for LTC homes to take reasonable risks for the benefit of their resident population²⁰². Additionally, government and external organizations should use aggregated results from quality of life surveys at a macro level to inform planning, benchmarking, quality improvement, and policies and enable supportive contexts. We would also encourage researchers to continue studying the implementation of quality of life surveys and quality indicators in LTC using pragmatic methods that meaningfully engage LTC residents, care partners, staff, and other LTC stakeholders²⁰³. For example, it could be valuable to examine 'high-performers' who have implemented person-centered LTC models and explore which

resources and organizational characteristics could be harnessed more broadly for evidence-informed quality improvement. Finally, we would recommend that LTC leaders implementing quality of life surveys plan their approach carefully, ensuring that they choose action-oriented surveys, only use dementia-specific surveys for residents with dementia, empower residents and staff to engage in solution generation, and continue to take important steps towards quality improvement. Effective collaboration with LTC support organizations and within communities of practices can facilitate these efforts⁷⁸.

Chapter 6: General discussion

6.1. Summary of Key Findings

This dissertation explored the important topic of quality of life in LTC homes. For the small proportion of older adults who live in a LTC home as well as their caregivers^{11,14}, quality of life is of critical importance. Physical health challenges, complex care needs, and difficult life transitions can place LTC residents at risk for lower quality of life². Many LTC homes show remarkable expertise in applying evidence to create environments that foster excellent quality of life for residents. In a supportive context, formal interventions like subjective quality of life surveys and indicators can support care planning, improvement, and benchmarking, while positioning quality of life as a priority. However, these are not easy tasks.

As the theoretical foundation for this dissertation, the 2021 Medical Research Council (MRC) Framework⁷⁹ for developing and evaluating complex interventions was effective in setting our research directions. We made progress in three out of the four phases and several core elements from the framework, including identifying the intervention (i.e., candidate quality of life indicators for the interRAI SQOL-LTCF), testing implementation feasibility in content and delivery with a focus on risk-adjustment, and the identification of core elements for the flexible implementation of quality of life surveys.

In Chapter 3, we used Flemish LTC home data, engaged with residents and family members in focus groups, and surveyed staff and researchers to find that the domains, statements, and scales in the SQOL-LTCF were all important for resident quality of life to different degrees. The most important quality of life domains identified were respect, safety, and security, followed by responsiveness, food, autonomy, and privacy, then comfort and staff-

resident bonding, and, finally, activities and personal relationships. Our analyses of the qualitative data determined that social complexity within LTC homes may influence LTC resident expectations about autonomy and staff responsiveness, beliefs about friendship and other social relationships, and responses to quality of life surveys in general. As a primary deliverable, we also identified 10 candidate quality of life indicators based on their importance to LTC resident quality of life.

1. Treated with respect by staff
2. Has meaningful activities
3. Privacy respected during care
4. Clean and pleasant environment (family survey only)
5. Decide how to spend time
6. Enjoy mealtimes
7. Feel safe when alone
8. Can get help right away
9. Family can visit when they want (family survey only)
10. Staff respond quickly

Chapter 4 investigated the feasibility of calculating and risk adjusting a sub-set of seven candidate quality of life indicators, excluding those only in the family survey and the item “staff respond quickly” due to its similarity with “can get help right away”. After examining their prevalence, variability, and relationships with key demographic and health-related variables, we found a tendency towards positive responses in most of the candidate indicators. We also found that (A) younger age groups and those with worse self-rated health tended to report worse quality of life, (B) compared to female residents, male residents felt safer alone but less that their privacy is respected or that they engage in meaningful activities, and (3) compared to residents with longer length of stays, residents who had lived in a home for under a year reported more respect and better responsiveness from staff. Finally, we found that adjusting for self-rated health or age changed LTC home rankings to an acceptable degree, but that ceiling effects, data linking

and privacy challenges, cohort differences, data collection challenges, and beliefs about the modifiability of population differences or disparities may pose challenges to the feasibility of risk-adjustment.

Data collection and contextual barriers were further explored in Chapter 5, with a specific focus on the implementation of quality of life surveys in LTC homes. We identified five contextual influences and related mechanisms for implementation success including (1) the role of external bodies (e.g., government) as a motivator or guiding force for implementing quality of life surveys, (2) power dynamics within an LTC home and their role in shaping resident and staff involvement and outcome expectations, (3) choices around feedback sources (e.g., resident self-report, proxy-report) and the extent to which these provide trustworthy data, (4) opportunities (e.g., time and space) for residents, staff, and others to reflect on quality issues and engage in generating effective solutions, and (5) information sharing requirements and the ways in which external bodies (e.g., quality organizations) are expected to judge or support an LTC home. We also described implementation outcomes, such as changing resident quality of life, reinforcing evaluation cultures, and enhancing or deterring collaboration. Possible drawbacks of implementing quality of life surveys included costs, potential inconvenience, resident stress from being observed or interviewed, and challenges with obtaining the perspectives of residents living with moderate to severe dementia.

6.2. Research Contributions

This dissertation represents the most comprehensive research exploring subjective quality of life indicators for LTC homes. A 2024 scoping review by Loureiro and Martin on quality indicators in LTC highlighted a major gap in quality-of-life-specific measures²⁰⁴. They found that only four studies out of 110 presented indicators of resident and family satisfaction²⁰⁴. In these

four studies, one explored nutritional care indicators alone²⁰⁵, two reported domain-level quality of life indicators (e.g., care delivery, wellbeing)^{206,207}, and three calculated global resident and/or family satisfaction scores^{207–209}. This quality measurement disparity is reflected in health systems around the world. A 2025 literature review and expert consultation by Poldrugovac et al searched for LTC performance indicators across 43 high- and middle-income countries⁶³. They also found an emphasis of medical or health-related aspects of care over social care⁶³. Within the 29 national and subnational jurisdictions where performance monitoring was identified, the most widely adopted quality LTC performance indicators were pressure ulcers (present in 16 jurisdictions), followed by falls (12 jurisdictions), and restraint use (nine jurisdictions)⁶³. The most prevalent patient reported experience measure was overall satisfaction (present in five jurisdictions), with quality of life being less commonly reported (four jurisdictions)⁶³.

This dissertation also found that LTC resident expectations and reports on care can be influenced by their personal context, relationships with staff members, physical health status, and beliefs about what is within their scope of control. The presence of these complexities suggest that satisfaction or global quality of life measures alone offer insufficient detail for evidence-informed quality improvement. Satisfaction, for instance, describes whether a resident's experience of care met their expectations, and not whether care was delivered according to evidence-based standards²¹⁰. Patient reported experience measures (PREMs), like satisfaction, can capture important issues in quality across different domains²¹⁰. However, they may miss quality of life domains that could be improved upon but are not believed to be within staff control, such as psychological wellbeing and social relationships. The quality of life survey and candidate indicators examined in this research may show promise due to their specific focus, coverage of a breadth of domains, and feasibility.

The modified Delphi study in Chapter 3 confirmed that the SQOL-LTCF is a valid survey covering important aspects of quality of life. It also identified which domains are considered most important. This contribution has implications for research. The body of research on social interventions for LTC residents appears to be large and growing more rapidly than research focusing on other quality of life domains²¹¹. However, we found that safety and security, respect, staff responsiveness, food, autonomy, privacy, and comfort are all significantly more important than social life for LTC resident quality of life. We also described complexity in the social relationships and preferences of LTC residents, which could partially explain the mixed acceptability of social interventions, like Artificial intelligence (AI)-driven social robots, for LTC resident engagement²¹². Our findings could support LTC leaders and researchers make better use of their limited time and financial resources by identifying priorities and challenges in improving resident quality of life.

Next, the quantitative feasibility study in Chapter 4 contributed to the emergent field of subjective quality of life indicator risk adjustment for LTC. Though other studies have identified relationships between demographic or clinical variables and quality of life in LTC²¹³, Chapter 4 showed that these predictors can influence how an LTC organization ranks compared to others. At present, literature on subjective quality of life indicator risk-adjustment is sparse. To our knowledge, only one other study has examined the influence of resident demographic and clinical characteristics on organizational quality of life rankings²¹⁴. This 2004 landmark study by Kane et al was the first to suggest that the risk adjustment of quality of life measures could be valuable for interorganizational quality comparisons²¹⁴. However, their work was focused on domain-level and overall quality of life²¹⁴. Chapter 4 was unique in that it focused on flagging specific quality of life issues for targeted quality improvement. We found that the SQOL-LTCF is

a feasible tool for quality of life indicator risk adjustment in many North American LTC homes and identified acceptability-related considerations for future research.

Finally, the realist synthesis in Chapter 5 provided a model for quality of life survey implementation emphasizing the importance of context, actionability, and comprehensiveness. Research thus far has established that some quality of life surveys are better than others⁴³, but psychometric properties appear to have been overemphasized in the debate. Chapter 5 adds that, regardless of validity, not all LTC contexts are equally prepared to choose, administer, and action quality of life surveys. Several challenges can hinder a productive context-survey match, such as power imbalances, lack of time and resources, and limited support from external organizations. Chapter 5 also emphasises the importance of choosing appropriate and actionable feedback sources and offering time and space for residents, staff, leaders, and external organizations to collaboratively address quality of life challenges. This ‘shared accountability’ approach can help to reinforce a positive evaluation culture rather than a culture where quality of life surveys are received with apathy or frustration. Finally, Chapter 5 proposed that it is inappropriate to implement proxy-reported surveys to measure the quality of life of residents without cognitive impairment as part of a ‘whole home’ monitoring approach. The appropriateness of proxy reports in measuring quality of life is an ongoing debate with important practice implications.

6.3. Implications and Recommendations for Research, Practice, and Policy

The following section will highlight overarching research implications along with key recommendations for SQOL-LTCF development, future research, LTC practice, and policy. A list of recommendations is summarized in Table 6.1.

Table 6.1. Summary of Recommendations

Source	Recommendations	Expected Effort
Chapter 3	Research: Longitudinal research investigating how quality of life importance scores change from admission over time should be performed to examine how residents may revise their quality of life expectations (page 52)	Moderate
	Research: Researchers should collaborate with health professionals, family members, and residents to explore and dispel misconceptions around the capabilities of people living with dementia (page 53)	Moderate
	Practice and policy: In a person-centered LTC system, decision makers should strive to align quality improvement with what matters most to resident quality of life despite ongoing barriers (page 54)	Moderate
Chapter 4	Policy: Governmental organizations should critically examine data protection laws and opportunities for modernization, and evaluate whether the risks associated with linking or collecting sociodemographic with quality of life data outweigh the benefits (page 78)	Moderate
	Research: interRAI should consider replacing binary self-rated health with categorical self-rated health to enhance its performance as a risk-adjustment variable (page 81)	Low
	Research: Researchers should investigate appropriateness, sensitivity to change, and methods of risk adjustment of quality of life indicators, such as those discussed in this research (page 81)	Moderate
Chapter 5	Practice: LTC homes should collect self-reported quality of life survey data on an ongoing basis along with narrative care partner, staff, and resident perspectives on quality of life problems and solutions (page 106)	Low
	Practice: Organizations should incentivize quality of life monitoring while acknowledging that implementation can be challenging and resource intensive and supporting LTC home efforts (page 109)	Moderate
	Policy: LTC organizations, researchers, and government bodies should collaborate to develop implementation guidelines and standards, and identify policies and structures that may inhibit innovation (page 109)	High
	Policy: Government and external organizations should use LTC-home level results from quality of life surveys to inform planning, benchmarking, quality improvement, and policies and enable supportive contexts (page 109)	High
	Research: Researchers should continue studying the implementation of quality of life surveys in LTC using pragmatic research methods and meaningful resident, care partner, staff, and leadership engagement (page 109)	Moderate
	Practice: LTC homes should plan their quality of life data collection approach carefully, ensuring that they choose surveys that are action-oriented, not dementia-specific (unless appropriate for the individual resident), comprehensive, and empowering to residents and family members (page 110)	Low
Overall	Research: Survey developers should continue expanding the spread and functionalities of quality of life surveys with quality of life indicators (page 119)	Low
	Research: Researchers should examine the ethical implications of risk-adjusting quality of life indicators, ideal methodological approaches for adjustment, and the acceptability of different risk-adjustment variable choices (page 120)	Moderate

	Research: Researchers should explore quality of life surveys utility for care planning and weigh benefits against risks (e.g., privacy) (page 120)	Moderate
	Research: Researchers should examine opportunities to shorten quality of life surveys by considering the exclusion of items identified as less important by LTC residents, frequently misunderstood, or repetitive (page 121)	Low
	Research: Researchers should compare the usefulness and actionability of the many quality of life surveys available (page 122)	Low
	Practice: LTC homes should implement a broad and multidimensional quality assurance strategy that uses quality of life indicators and narrative feedback to address resident concerns. (page 123)	Moderate
	Practice: Canadian LTC homes should formally shift the language of LTC to highlight ‘living’ as equally important to care (page 124)	Low
	Practice: LTC homes should engage in opportunities for interorganizational collaboration, such as through a LTC community of practice (page 124)	Moderate
	Policy: International organizations, such as the World Health Organization, should encourage collaboration between international governments by advocating for or building a balanced quality indicator standard that incorporates quality of life measures (page 125)	High
	Policy: Governments should critically evaluate existing LTC policies that may hinder quality of life improvement and revise accordingly (page 126)	Moderate
	Policy: Governments and funders should provide LTC homes with adequate resources (including funds and staffing) to collect and act upon quality of life data (page 127)	High
Note: Expected effort was determined based on the interpretations, experiences, and individual expertise of AN for illustrative purposes only. These may not align with the experience and expertise of others and should not be represented as an objective truth.		

6.3.1. Recommendations for Researchers and Quality-of-Life Survey Developers

First, this work has demonstrated many benefits of implementing quality of life surveys and indicators, such as bringing attention to LTC resident priorities. The emphasis of medical and health-related quality measures over quality-of-life measures appears to be reflected in both research and health systems^{63,204}. Efforts from researchers to add to the functionalities of quality of life surveys is an important first step towards offering more balanced health system performance measures. In the introduction chapter, we discussed the SQOL-LTCF quality of life composite measure, a preference-weighted global score with the potential to support interorganizational quality comparisons. Quality of life indicators would support quality comparisons in a similar way but target specific quality of life concerns, like whether residents

feel safe when they are alone. Items from the SQOL-LTCF are already being used as quality indicators by Health Quality Ontario^{215,216} and within the Senior's Quality Leap Initiative⁷⁷, but interRAI has not formally endorsed quality indicators for the SQOL-LTCF thus far.

***Recommendation #1:* We suggest that LTC survey developers, including interRAI, continue expanding the spread and functionalities of quality of life surveys by offering quality indicators. We recommend endorsing indicators that have been established as priorities for LTC resident quality of life and that appear to be less susceptible to ceiling effects, such as:**

- **I participate in meaningful activities**
- **I decide how to spend my time**
- **I enjoy mealtimes**
- **I feel safe when I am alone**
- **If I need help right away, I can get it**

This dissertation also brought attention to the topic of quality-of-life indicator risk adjustment, a challenge that had previously been under explored. It is highly likely that inherent, non-modifiable differences between residents influence how they respond to quality of life surveys. For instance, Chapter 3 highlighted resident characteristics, such as cognitive impairment, that could influence quality of life expectations and reporting. As a result of population-level differences, LTC leaders may see quality of life indicators as less credible and, in turn, dismiss potentially valuable insights. Risk-adjustment shows promise in improving indicator fairness for quality benchmarking and 'level the playing field' for collaboration. However, determining which risk-adjustment methodologies are ideal, which risk-adjustment variables should be selected, and how to manage ethical implications remain unclear.

Recommendation #2: Researchers should examine the ethical implications of risk-adjusting quality of life indicators, ideal methodological approaches for adjustment, and the acceptability of different risk-adjustment variable choices. This work should include engagement with LTC home leaders, statisticians, and supportive organizations.

Next, care planning was identified as a potential application of quality of life surveys in Chapter 6. Care planning was the only application represented within the literature that resulted in statistically significant improvements in quality of life scores among LTC residents. However, the importance of resident confidentiality means that care planning is a more challenging survey application to consider. Chapter 4 discussed strict privacy regulations that are imposed to protect the anonymity of quality of life survey respondents. Additionally, data available to the researchers indicated that about 20% of North American and Flemish residents report that they can sometimes, rarely, or never express their opinions without fear of consequences. Residents may adjust how they respond to quality of life surveys to protect staff members and themselves from negative consequences.

Recommendation #3: LTC researchers should further explore the utility of quality of life surveys as a tool to support care planning, and weigh potential benefits against privacy-related drawbacks and unintended consequences.

Moreover, Chapter 3 generated secondary findings that may be pertinent to interRAI and LTC researchers in general. While collecting data for this modified Delphi study, we received feedback from several residents on the content and length of the SQOL-LTCF. For instance, some items were described as irrelevant, repetitive, or confusing by resident focus groups. While the study did administer a lengthened and adapted survey based on all possible SQOL-LTCF items, Chapter 5 also highlighted the improved feasibility of shorter LTC quality of life surveys

due to time and resource constraints. While we could consider the SQOL-LTCF a strong quality of life survey due to the importance and actionability of the items within it and breadth of domains covered, ongoing development and responsiveness to the needs of end-user populations is an important part of ensuring instrument sustainability¹⁸³.

Recommendation #4: If shortening a quality of life survey, like the SQOL-LTCF, we would suggest that survey developers consider excluding items identified as less important by LTC residents, frequently misunderstood, or seen as repetitive. Opportunities for items to exclude in the SQOL-LTCF, for example, include:

- **I can eat when I want (less important)**
- **People ask for my help or advice (less important)**
- **Some of the staff know the story of my life (less important)**
- **I have a special relationship with a staff member (misunderstood)**
- **ONE OF: “Enjoyable things on weekends” OR “Enjoyable things on evenings” (repetitive and less important)**
- **ONE OF: “Get needed health services” OR “Get other needed services” (repetitive)**
- **ONE OF: “Staff respond quickly” OR “Can get help right away” (repetitive)**

Beyond advancing the development of quality of life surveys themselves, this dissertation also highlighted the importance of quality of life survey actionability. In Chapter 5, it was not uncommon that when a valid survey was implemented by researchers, it was unsuccessful in leading to measurable changes. Explanations around why were usually limited. It seems as though psychometric testing, which offers limited implementation advice, is more popular in quality of life survey research than utility and usability testing. This imbalance can have

unintended consequences. For example, LTC leaders may erroneously equate validity with usefulness in a specific context, and overlook comprehensiveness and actionability. We would suggest that validity and reliability are a minimum, and that comprehensiveness and actionability should be prioritized in survey quality evaluations.

Recommendation #5: Primary and secondary research should be performed that compares the usefulness and actionability of the many quality of life surveys currently available. A primary purpose of this activity would be to facilitate survey decision-making for LTC home leaders.

6.3.2. Recommendations for Long-Term Care Practice

Many LTC staff and leaders, including those who contributed to this dissertation, are well-intentioned and motivated to support resident quality of life. However, attempting to implement and use the results of a quality of life survey in LTC is not an easy task. It requires knowledge, resources, and perseverance. Chapter 5 offered several LTC-home level recommendations for implementation, such as choosing a survey instrument that is comprehensive and relevant. The SQOL-LTCF appears to meet these requirements, but there are other tools with value for collecting quality of life data from LTC residents^{48,181,192}. Regardless of which survey or set of surveys is most appropriate for a LTC home, collecting self-reported data and narrative feedback from residents should be pursued where possible. Quality of life surveys like the DEMQOL-CH that only collect data based on staff interpretations of outward expressions of poor quality of life (e.g., crying, tearfulness) or surveys like the EQ-5D that lack focus on subjective quality of life domains (i.e., using physical health or functional status as a measure of quality of life) may offer insufficient or unhelpful information for meaningful quality assurance. While it could be argued that short measures such as these have the advantage of feasibility, other ways to enhance

feasibility may be more helpful. For instance, volunteers could support the administration of a more comprehensive quality of life survey and data could be collected annually from a representative random sample of residents rather than all residents in a LTC home.

Recommendation #6: LTC homes should implement a broad and ongoing quality assurance strategy that incorporates quality of life surveys, indicators, and narrative feedback from multiple groups (including residents with and without cognitive impairment, family members, and staff). Several characteristics can support the success of a quality assurance strategy such as alignment with organizational priorities, collaboration, and a positive evaluation culture.

Quality of life in LTC is important to measure because it cannot be guaranteed. Due to a historical emphasis of the biomedical model of care, physical health and safety often take precedence over quality of life. A recent example comes from the COVID-19 pandemic, when public health measures and lockdown protocols severely limited the activities of LTC residents in Canada³². There are, however, many exceptions to the overemphasis of physical health and safety. For instance, in Flanders, Belgium, government decrees and a shift in terminology from “verpleeghuizen” (nursing homes) to “woonzorgcentra” (living care centers) have demonstrated a shift towards recognizing social and psychological well being as fundamental to LTC. Other shifts in the language of LTC include referring to “LTC units” as “neighbourhoods” or “facilities” as “homes”. Person-centered language, as well as person-centered changes to LTC home mission and value statements, are low-effort actions intended to set the stage for shifts in culture towards person-centered care.

Recommendation #7: Similar to LTC homes in Flanders, Canadian LTC homes should consider formally shifting the language of LTC to highlight ‘living’ as equally important to care.

In moving towards person-centered care, LTC homes may find it easier to address quality of life concerns if working alongside organizations that have experienced similar challenges. The Senior’s Quality Leap Initiative (SQLI) is a community of practice that uses data and knowledge, including quality of life measures from the SQOL-LTCF, to enhance their collective quality improvement efforts⁷⁷. This dissertation, which was aided by several SQLI members, reported that information sharing for the purpose of gaining support instead of competition is a facilitator for quality of life survey implementation. Other research in LTC contexts confirms that communities of practice can be effective for collaborative problem-solving, building professional relationships, social learning, and addressing complex challenges⁷⁸. Chapter 3 highlighted one very complex challenge, improving quality of life within a health care staffing crisis. Creative solutions will be needed to overcome this worsening systemic challenge²¹⁷, and protectiveness over silos does not foster creativity.

Recommendation #8: LTC homes should engage in opportunities for interorganizational collaboration with other LTC homes and organizations, such as through communities of practice.

6.3.3. Recommendations for Policymakers and Supportive Organizations

Collaboration and learning between countries may also facilitate quality improvement. As demonstrated throughout this dissertation, there is much to learn from comparing the structures, processes, challenges, and successes of different health systems. Canada and Flanders, Belgium

were the primary contexts for this work due to advanced SQOL-LTCF adoption in both countries. The use of a single instrument across multiple countries made this work more feasible. However, different contexts often use different instruments to measure the same concept⁶³. Where feasible, instruments that can transcend borders across care settings, populations, and countries should be selected¹⁷. A common survey language and a consistent standard allows for comparison and collaboration between settings, organizations, and countries.

Recommendation #9: International organizations, such as the World Health Organization (WHO), should encourage collaboration between international governments by advocating for or building a balanced quality indicator standard. This standard should incorporate quality of life measures.

When it comes to individual LTC homes, this dissertation found a multitude of influences on resident quality of life that are largely outside of resident, staff, and leadership control, such as physical infrastructure and inspection criteria. LTC homes operate with competing priorities and tight constraints, including human resource, budgetary, and policy constraints, which may act as barriers to improving resident quality of life. With this in mind, it is clear that movement towards prioritizing quality of life must occur on a larger scale, within government and regulatory structures. Several regulatory structures in North America appear to be ineffective for improving quality of life in LTC homes and may even be detrimental²¹⁸. For example, in Ontario, Canada inspection and enforcement activities exist, but non-compliance appears to have no consequences²¹⁹. On the other hand, with stricter enforcement of standards, there is the risk of introducing ‘tunnel vision’ or defensive decision-making among LTC leaders (as opposed to decision-making based on what LTC residents want or need). Research on regulatory enforcement provides some guidance on how these structures could be improved. For example,

the reimagined roles of quality inspectors could include education, persuasion, praise, or collaboration to correct a quality problem in addition to traditional enforcement measures²¹⁸.

Recommendation #10: Governments should collaborate with residents, staff, leaders, researchers, and supportive organizations to critically identify, evaluate, and adapt LTC policies that hinder quality improvement in quality of life. Examples of policies to explore include overly strict privacy and safety regulations (e.g., food temperature laws).

In addition to addressing barriers, appropriate facilitators should be put in place to improve LTC resident quality of life. Research has described an inequitable distribution of financial resources across the health system that favours acute care⁴⁰. As a result of limited resources, LTC managers may make trade-offs, such as choosing a quality of life survey for feasibility rather than comprehensiveness or putting more effort into collecting quality of life data than fixing problems raised within the data. While published Canadian and Belgian standards of care offer recommendations on implementing quality of life surveys, guidance has been somewhat vague and, therefore, followed inconsistently^{220,221}. We believe that it is insufficient to collect global satisfaction measures or information on only a select few quality of life domains in lieu of a comprehensive quality of life survey. Attempts to replace a full clinical health assessment with a four-point self-rated health measure would be faced with strong pushback. Similarly, it would be seen as inappropriate for a LTC home to only collect data on a handful of physical health domains (i.e., only asking about falls and pressure ulcers). In contrast, it not uncommon in quality of life measurement for these types of oversimplification to be suggested. However, quality of life is complex, multifaceted, and equally deserving of attention.

Additionally, the rigorous collection and analysis of quality of life data in LTC can be resource intensive. High-quality communities of practice in LTC can offer more specific

guidance on how to act on the findings of a quality of life survey, but participation can be unaffordable for many LTC homes. Even if an LTC home were able to collect high quality data and identify potential solutions, the improvement interventions themselves may also be expensive. For instance, updates to physical infrastructure may greatly benefit residents, but infrastructure changes are not always feasible⁴⁰.

Recommendation #11: Governments and funders should provide LTC homes with sufficient resources and incentives to collect and act upon comprehensive quality of life data.

Examples of resources may include:

- **Funding surveyors and/or consultants to administer LTC quality of life surveys, disseminate findings, and support solution generation**
- **Providing quality of life dashboards and technology to support survey analysis and interpretation**

6.4. Strengths and Limitations

Each of the research papers in this dissertation has their own strengths and limitations. The following section will describe the strengths and limitations of this dissertation overall.

There are several notable strengths in this dissertation. Each of the projects we performed were large and based on multiple sources of data (i.e., participant groups, datasets, and information sources). Informational triangulation is encouraged by pragmatism and social complexity theory as it can enhance our understanding of complex phenomena as opposed to pursuing methodological purity²²². Additionally, the National Academies of Science and Medicine has stated that the perspectives of LTC residents and their families are underutilized in quality measurement and improvement work²²³. This dissertation gained first-hand perspectives

from LTC residents, family members, and staff from large LTC organizations. We also used international data, with sources from Canada, Belgium, and the United States. Given that the SQOL-LTCF is most mature in these locations⁵⁹, we believe that this was an appropriate geographic spread. Use of the SQOL-LTCF was another strength of this study, as it is a valid, reliable, and comprehensive survey. There are large communities of practice⁷⁷ and reputable organizations²²⁴ that depend on the SQOL-LTCF, suggesting that the present research is relevant to many LTC homes. Another strength of this research was the use of the MRC framework⁷⁹. The framework enhanced our ability to examine the development and feasibility of implementing candidate quality of life indicators for the SQOL-LTCF, as well as the implementation of LTC quality of life surveys in general⁴¹. It also helped us to embrace complexity in the LTC system and maximize our ability to contribute to health system improvement with this work⁷⁹.

In contrast, this dissertation possesses several limitations. First, this research was performed with time and resource constraints. We were unfortunately unable to provide honoraria to participants, the involvement of resident, family member, and staff participants for member checking was limited, and only one researcher performed data analyses. Regarding the latter, using multiple coders for qualitative data analysis is generally recommended to boost research credibility and appreciation of depth and nuance²²⁵. Second, we had access to limited resident demographic characteristics and descriptive LTC home data. Information on resident race and ethnicity, cognition, educational status, staff-to-resident ratios, and whether a home was urban or rural could have been valuable for this research given their relationships with quality of life and LTC home quality. Finally, though the flexibility of the methodology was positive in some respects, it also created more room for error. For example, in the Chapter 3 focus groups,

there was inconsistency in which data were collected and how they were collected. Thus, it is possible that some of the data used in this study were susceptible to social desirability bias.

6.5. Conclusions

The gap between quality of life data collection and action has been historically overlooked in LTC research. This dissertation highlighted that this gap holds much complexity, and that bridging it will require ongoing commitment from a multitude of stakeholders. Quality of life indicators can offer valuable information on specific challenges that are important to residents and to those who care for them. Much work remains to establish quality of life measurement and related quality assurance as a norm in the LTC system. Therefore, we encourage and deeply appreciate the continued efforts of those working towards improving quality of life in LTC homes and LTC systems around the world.

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**Appendix A: Domains of the interRAI Self-Reported Quality of Life Survey for Long-Term
Care Facilities (SQOL-LTCF)**

Quality of Life Domains	Example Statements (<i>Adapted</i>)
Privacy	Alone when wish
Food and Meals	Get favorite foods
Safety and Security	Possessions secure
Comfort	Feels like home
Daily Decisions (Autonomy)	Decide when to go to bed
Respect by Staff	Treated with respect by staff
Staff Responsiveness	Staff act on resident suggestions
Staff-Resident Bonding	Staff know resident life story
Activities	Has meaningful activities
Personal Relationships	Resident is close friend

Appendix B: Conducting and REporting of DELphi Studies (CREDES) checklist¹²⁸

Title	Description	Page #
Rationale for the choice of the Delphi technique		
1. Justification	The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature	35
Planning and Design		
Planning and Process	The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously	35-36
Definition of Consensus		
Definition of consensus	Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations	39
Study Conduct		
4. Informational input	All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias	37-38
5. Prevention of bias	Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable	37-38
6. Interpretation	Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question	54
7. External validation and processing of results.	It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before publication and dissemination	39
Reporting		
8. Purpose and rationale	The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided	35
9. Expert panel	Criteria for the selection of experts and transparent information on recruitment of the expert panel, socio-demographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported	36-37, 40, 42

10. Description of the methods	The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process	35-39
11. Procedure	Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps	42, Appendix
12. Definition and attainment of consensus	It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus	39, 42
13. Results	Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds	41-50, Appendix
14. Discussion of limitations.	Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance	53-54
15. Adequacy of conclusions.	The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance	50-54
16. Publication and dissemination.	The resulting guidance on good practice in palliative care should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process (e.g. persistent disagreement and controversy on certain issues)). A dissemination plan should include endorsement of the guidance by professional associations and health care authorities to facilitate implementation	54

Appendix C: Delphi questionnaires

FOCUS GROUP SURVEY AND ROUND 1 SURVEY

Insider Perspectives on Quality-of-Life Indicators for Long-Term Care:

Resident Survey

This focus group will focus on residents' beliefs about quality of life in long-term care homes. The group will be asked to rate the importance of several items related to quality of life. There are no right or wrong answers. If someone is unsure, they can choose not to respond.

For each statement, please answer on a scale of 0 to 10:

0	1	2	3	4	5	6	7	8	9	10
Extremely Unimportant		Unimportant		Neutral		Important		Extremely Important		

Important note for focus group facilitators: If the group cannot agree on one score, make a note indicating how many participants chose each value.

NOTE: The interRAI SQOL-LTCF survey items are excluded from this publication due to copyright restrictions.

The original survey items were adapted for this questionnaire. The statement "alone when with" was adapted to "how important is it that long-term care residents can be alone when they wish".

M. Most and Least Important Items

M1. What are the 5 most important items in the quality of life survey? (Write below)

M2. What are the 5 least important items in the quality of life survey? (Write below)

N. Other

N1. How many long-term care resident(s) participated in your focus group? _____

N2. What organization or long-term care home are you associated with? (Write below)

N3. Do you have additional comments you'd like to share? (Write below)

INSIDER PERSPECTIVES ON QUALITY OF LIFE INDICATORS FOR LONG-TERM CARE: ROUND #3

Welcome back!

LAST SURVEY: You rated the importance of 48 statements on a scale from 0 to 10. From surveys 1 to 2, average importance scores increased for 3 statements and decreased for 34 statements.

- 8 statements were confirmed as extremely important & 2 new statements reached consensus.
- 5 statements were confirmed as not extremely important & 7 new statements reached consensus.
- 39 statements did not meet the 70% agreement cutoff.

With this information -- and data from long-term care resident and family focus groups -- we compiled a list of importance scores for a quality-of-life composite scoring system. However, we need more feedback before choosing a set of candidate quality-of-life indicators.

The researchers may send me the next Delphi survey and inform me about the results of this survey using the following e-mail address (*type below*):

THIS SURVEY: You will be asked to...

1. Carefully review the top statements, comment summaries, and average importance scores from researchers, staff, care partners and residents.
2. Build your ideal candidate quality indicator from a set of 40 possible candidate quality indicators.
3. Evaluate each chosen candidate quality indicator.
4. Confirm and evaluate your ideal quality indicator set.

This survey should take about 20 minutes to complete.

PART 1: REVIEW RESULTS

Below are the average importance scores gathered across resident and family focus groups and the first two rounds of the Delphi study:

Would you like to see the importance ratings you shared in previous survey rounds?

☐ Yes (*Note: We will not ask you to re-rate your importance scores*)

☐ No

Individual Responses

YOUR RESPONSES FROM PREVIOUS ROUNDS (OPTIONAL)

The scores below are for your review only. You do not need to change your ratings.

PART 2: NARROW DOWN

A quality indicator is an evidence-based quantitative (#) way to measure health care quality for a set population (e.g., a long-term care home). The goal of a quality indicator is to help flag when issues in quality arise and support quality improvement initiatives.

We used the importance scores from residents, families, staff, and researchers to narrow down the full list of statements from the survey to 40 'most important' statements.

**Survey items have been excluded
due to copyright restrictions**

Which of the following 'most important' statements from the interRAI quality of life survey do you think could be a good quality indicator in long-term care? (*Choose at least 10; you will be asked to narrow down further in the next question*)

PART 3: EVALUATE EACH STATEMENT

Imagine you are the quality improvement lead of a typical long-term care home.

You plan to ask resident or family members to rate the statement "\${lm://Field/1}" on a scale from never to always to support a quality improvement initiative. To be a good quality indicator, the statement needs to be specific, understandable, actionable, equitable, and sensitive to change.

Does "\${lm://Field/1}" represent a specific challenge in long-term care?

- ☐ Yes - the statement represents a specific challenge
 - ☐ No - The statement is neither specific nor broad. It's somewhere in the middle.
 - ☐ No - the statement is broad (it can be influenced by several underlying issues)
-

Would you expect residents (*without significant cognitive impairment*) to understand what you mean by "\${lm://Field/1}"?

- ☐ Yes - it should be easy for residents to understand
 - ☐ Maybe
 - ☐ No - residents may find it ambiguous or confusing
-

If most residents in your long-term care home said "\${lm://Field/1}" rarely or never, would it be realistic for staff and leadership to try to improve?

- ☐ Yes - quality improvement in this area is a realistic goal
 - ☐ Maybe - I'm not confident in our ability to change things
 - ☐ No - it would not be a realistic goal to try and improve
-

Would improving your performance on "\${lm://Field/1}" be good for everyone living in your long-term care home (including individuals living with cognitive impairment, mobility challenges, etc.)?

- ☐ Yes - improving would be good for all residents
 - ☐ Somewhat - improving would be good for most residents, but may not impact some
 - ☐ No - improving could cause harm to some residents
-

If you tried to improve performance around "\${lm://Field/1}", would you expect resident survey scores to reflect this improvement?

- ☐ Yes - residents would notice improvements and score the item more positively
- ☐ Maybe - some residents would notice improvements and others would not
- ☐ No - I would not expect residents to notice quality improvements in this area

Overall evaluation: With the above in mind, do you still think the statement "\${lm://Field/1}" could be a good quality indicator?

- ☐ Yes
- ☐ Maybe
- ☐ No

Please include any comments below on the suitability of "\${lm://Field/1}" as a quality indicator:

PART 4: EVALUATE THE SET

You initially selected the following statements as the most important: \${q://QID49/ChoiceGroup/SelectedChoices}

Now that you have evaluated each item, would you like to re-consider any of the statements from your initial set of indicators?

- ☐ Yes
- ☐ No

You selected the following statements as the most important: \${q://QID49/
ChoiceGroup/SelectedChoices}

Is your quality indicator set broad enough to capture the important issues around
quality of life in long-term care?

- ☐ Yes
- ☐ Maybe
- ☐ No

Does your quality indicator set contain statements that are irrelevant to quality of life
in long-term care homes?

- ☐ No
- ☐ Maybe
- ☐ Yes

Conclusion

If you have any additional comments, please write them below:

Thank you for participating!

We will send you a summary of the final results in early June.

Appendix D: Materials to support focus group facilitation

Video Script for Focus Group Communication

Hi everyone. My name is Amanda and I'm a PhD researcher at the University of Waterloo and KU Leuven. Welcome and thanks so much for joining today. In this video, I'll be telling you a bit about my research, what to expect from this focus group, and a bit about your rights and responsibilities as a participant.

First off, quality of life is complex. There are a lot of different things that might impact your quality of life, like how you spend your time, who you spend your time with, how you feel about your environment and more. We have invited you to participate in this focus group because you have experience living in a long-term care home or you are the family member of someone living in long-term care home.

Now, this is not going to be a typical focus group. In this session, your focus group leader will ask you a list of questions. Each question will tackle something different that may or may not impact your quality of life. Your goal is to rate how important each of these things are.

For example, your focus group leader might ask, "how important is it that you or your loved one enjoys mealtimes?". Take a second to think, then point to what number best represents your opinion on the scale in front of you. If you think mealtimes are extremely important point to 10. If you think they're not important at all, point to 0. If everyone votes the same, you can move onto the next question. If not, your job is to work as a team to agree on one importance rating.

Few things you should know:

1. Your voice matters individually and as a group → There might be moments that you disagree with each other and that's okay. Please keep the conversation respectful, try your best to stay focused, and know that your individual comments are just as important as the numbers you come up with in the end. You can agree to disagree, and the focus group leader will note that down. If you choose to, you can also fill out an individual survey to keep track of your own opinions separately from the opinions of the group.
2. The questions you'll be asked came from a survey that LTC homes around the world, including yours, are already using to improve care. That being said, there might be some questions that throw you off for different reasons. Do your best think about the big picture of what each question is really asking you, rather than getting into the weeds about the wording or structure of the survey.
3. We don't want to make any assumptions on what's important to you. Because of this, the survey is long! → Your focus group leader has been given a few tools to help you along the way but try your best stay on topic so that you can keep things moving.
4. By agreeing to participate in this focus group you have a few rights and responsibilities:

- You have the right to stop participating at any time. There will be no consequences for choosing to skip a question or leaving early.
- You also have the right to privacy and to have your information protected. Your identity will be kept confidential by the focus group leader and your feedback will be stored in a safe place.
 - This also means that you have the responsibility to protect the privacy of everyone in this focus group. Please keep everything that's said here confidential.

More detail on how your data will be collected, used and stored is outlined in the information and consent form that was given to you by your focus group leader. Feel free to ask them any questions you have or you can reach out to me directly.

Finally, I want to thank you and your focus group leader for taking the time to be a part of this study. Knowing how important each of these things are will help researchers like myself, decision-makers and long-term care leaders understand what really matters.

So, best of luck and I look forward to hearing your opinions on what's important for quality of life in long-term care!

FOCUS GROUP CHEAT SHEET

Insider Perspectives on the InterRAI Quality of Life Survey for Long-Term Care Facilities

Background

“Improving resident quality of life is a priority. In long-term care, many different experiences can impact quality of life, like physical and mental health, social life, and the ability to live with comfort, independence, and respect.

You may have recently done a survey asking about your quality of life. The goal of this focus group is to **rate the importance of each statement in the survey, then list the 5 most and 5 least important ones**. This way, we can understand what matters most to residents and create tools for summarizing quality.”

Preparing the Room

For the day of the focus group:

- ☐ Consent forms with facilitator info
- ☐ Family / resident focus group survey
- ☐ Printed scales (or another visual aid)
- ☐ Private comfortable room with chairs
- ☐ Clock, watch, or timer
- ☐ Pens and paper
- ☐ Laptop or survey for taking notes.
- ☐ Audio-recording device
- ☐ Appreciation letters with contact info for ‘go-to’ person.

Summary of Information and Consent Form

We encourage the facilitator to read the consent form out loud. Summary below:

“This study collects personal data. We will do our best to protect your privacy and ask that you respect each other’s privacy by not sharing what is said in the focus group. You have the right to stop participating at any time and ask questions about the study.”

Step-by-Step

1. Introduce the study and explain the information and consent form.
2. Collect signed consent forms.
3. Discuss ground rules.
4. Start the survey.
5. Introduce the section topic and statements.
6. Individual reflection (~30s)
7. Group vote and discussion (using printed rating scale).
8. Ask for final rating.
9. Move onto the next section and repeat step 5 to 8 until finished.
10. Ask for final thoughts, thank participants.
11. Provide appreciation letter.
12. Store consent forms safely.

Important Definitions

Unimportant: Unnecessary, irrelevant, frivolous

Neutral: Important to some but not others.

Important: Needed for a good quality of life.

Without it, residents would be worse off.

Tips for Participants

- Try to stay on topic and come to an agreement as quickly as possible.
- Keep distractions to a minimum and avoid interruptions (i.e., silence phones)
- Give everyone a chance to participate.
- Listen, ask questions, and be open.

Tips for Facilitators

- Note how long you want to spend on each section and **stick to your timeline**. You may want to complete survey over 2 sessions.
- Bring **visual aids** to support the discussion.
- Run resident/family focus groups separately.
- Stay neutral, encourage participation.
- Listen and look for non-verbal cues.
- Understand your organizational protocols if sensitive or concerning info is revealed.
- **Email the completed group survey to aanova@uwaterloo.ca by March 31st.**

Appendix E: Frequency of importance scores assigned in Delphi round one

	Rating	Count	Percent
Missing		12	0.5%
Less Important (11.1%)	0	11	0.4%
	1	9	0.3%
	2	4	0.2%
	3	12	0.5%
	4	32	1.2%
	5	85	3.2%
	6	141	5.3%
Important (34.4%)	7	276	10.4%
	8	633	24.0%
Very Important (53.6%)	9	568	21.5%
	10	849	32.1%
Total		2642	99.7%

Total count and percentage of importance scores assigned to all statements and scales in round 1 of the virtual Delphi survey

Appendix F: Progression of consensus-building

Category	#	All statements	% rating 9 or 10 importance			% selected as QI
			Focus group	Round 1	Round 2	Round 3
			62 evaluated	62 evaluated	48 evaluated	40 evaluated
Privacy	A1	Alone when wish	43%	43%	31%	48%
	A2	Privacy respected during care	77%	88%	N/E	97%
Food & Meals	B1	Get favourite foods	23%	28%	17%	N/E
	B2	Eat when want	8%	30%	22%	N/E
	B3	Enough meal variety	39%	45%	44%	N/E
	B4	Enjoy meal times	52%	68%	69%	76%
	B5	Food is right temperature	54%	60%	56%	42%
Safety & Security	C1	Can get help right away	83%	73%	83%	73%
	C2	Possessions secure	65%	58%	61%	45%
	C3	Feel safe alone	87%	83%	N/E	79%
Comfort	D1	Get other needed services	71%	53%	44%	55%
	D2	Would recommend to others	38%	55%	47%	42%
	D3	Feels like home	29%	50%	39%	N/E
	D4	Easily go outdoors	29%	55%	42%	N/E
	D5	Bothered by noise	43%	55%	39%	30%
	D6	Clean and pleasant environment	83%	78%	N/E	91%
	D7	Best place for meeting needs	79%	53%	47%	58%
Autonomy	E1	Bath/shower as often as wish	38%	35%	28%	N/E
	E2	Decide when to get up	43%	45%	36%	N/E
	E3	Decide when to go to bed	71%	45%	39%	64%
	E4	Go on spur of moment	38%	23%	N/E	N/E
	E5	Control who comes in room	50%	63%	58%	61%
	E6	Decide clothes to wear	64%	58%	50%	36%
	E7	Decide how to spend time	64%	63%	64%	82%
Staff Respect	F1	Treated with respect by staff	83%	90%	N/E	91%
	F2	Family treated with respect by staff	79%	79%	N/E	61%
	F3	Staff pay attention	75%	72%	N/E	45%
	F4	Can express my opinion	71%	79%	N/E	61%
	F5	Staff respect likes/dislikes	71%	79%	N/E	61%
Staff Responsiveness	G1	Staff help me live my life	50%	56%	58%	52%
	G2	Staff respond quickly	67%	67%	64%	73%
	G3	Staff act on resident suggestions	21%	41%	33%	N/E
	G4	Get needed health services	57%	64%	56%	52%
	G5	Staff have enough time	54%	59%	61%	58%
	G6	Staff know what doing	64%	77%	83%	61%
	G7	Serviced delivered when wanted	29%	31%	19%	N/E
	G8	Home well managed	83%	49%	53%	N/E
	G9	Family trusts staff to provide care	70%	51%	50%	52%
	G10	Family trusts information from staff	65%	51%	47%	42%
Staff-Resident Bonding	H1	Staff know resident life story	46%	36%	28%	N/E
	H2	Staff member a friend	36%	18%	N/E	N/E

	H3	Have special relationship with staff	21%	19%	N/E	N/E
	H4	Friendly conversation with staff	43%	61%	56%	58%
	H5	Staff ask how to meet needs	64%	64%	67%	67%
	H6	Have same nurse assistant	29%	38%	31%	N/E
Activities	I1	Enjoyable things on weekends	36%	51%	44%	N/E
	I2	Enjoyable things on evenings	36%	47%	42%	N/E
	I3	Has meaningful activities	50%	56%	64%	94%
	I4	Can participate in religion	57%	51%	42%	30%
	I5	Time with like-minded residents	21%	51%	39%	39%
	I6	Explores new interests	43%	33%	22%	N/E
Personal Relationships	J1	Resident is close friend	25%	35%	28%	N/E
	J2	Asked for help/advice	21%	15%	N/E	N/E
	J3	Affection/romance opportunities	15%	28%	N/E	N/E
	J4	Easy to make friends here	17%	38%	31%	N/E
	J5	People to do things with	23%	35%	36%	39%
	J6	Family can visit when they want	78%	70%	69%	76%
	J7	Comfortable visiting places	39%	65%	58%	52%
Family Communication and Engagement	K1	Family has needed health information	78%	58%	56%	58%
	K2	Family knows contact when concerned	65%	67%	64%	79%
	K3	Family participates in decision-making	57%	64%	69%	61%
	K4	Family consulted about care plan changes	59%	62%	61%	61%

Note: Statement numbers in purple indicate those pulled from the family-facing SQOL-LTCF without an equivalent in the resident-facing version

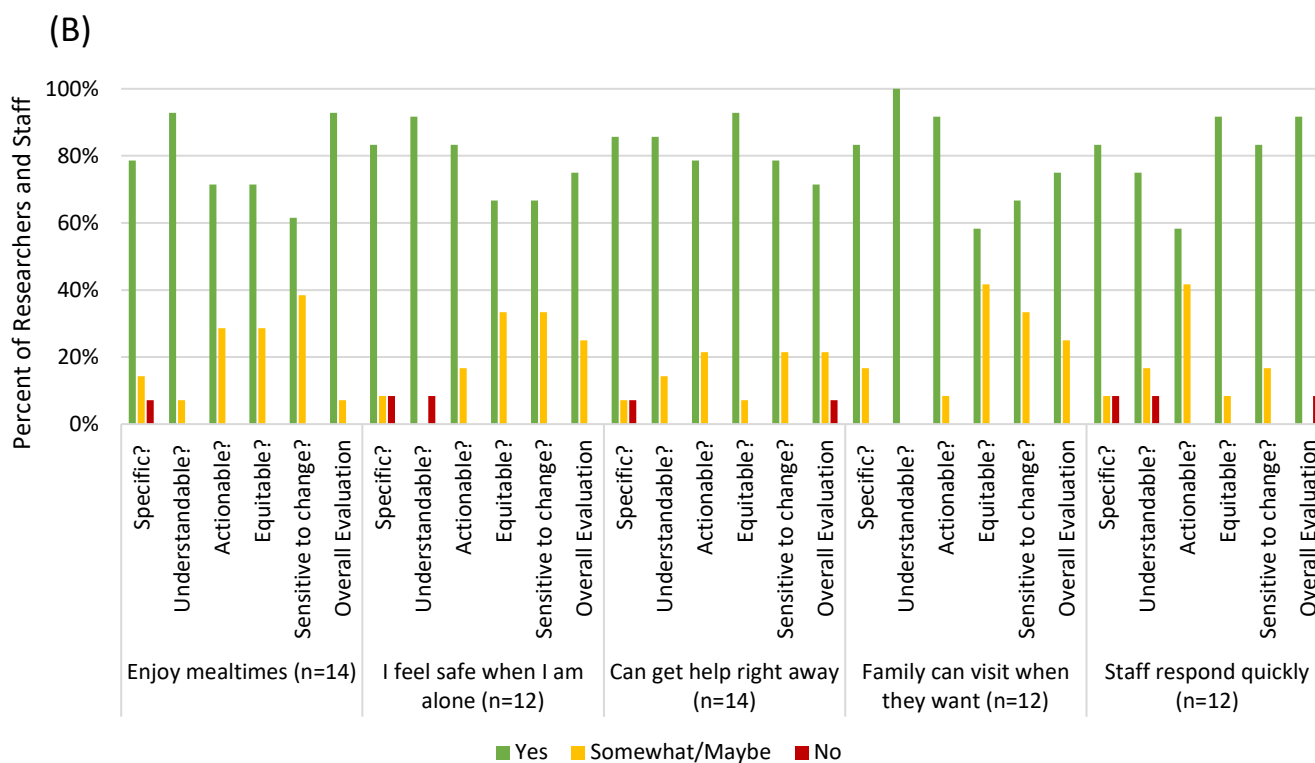
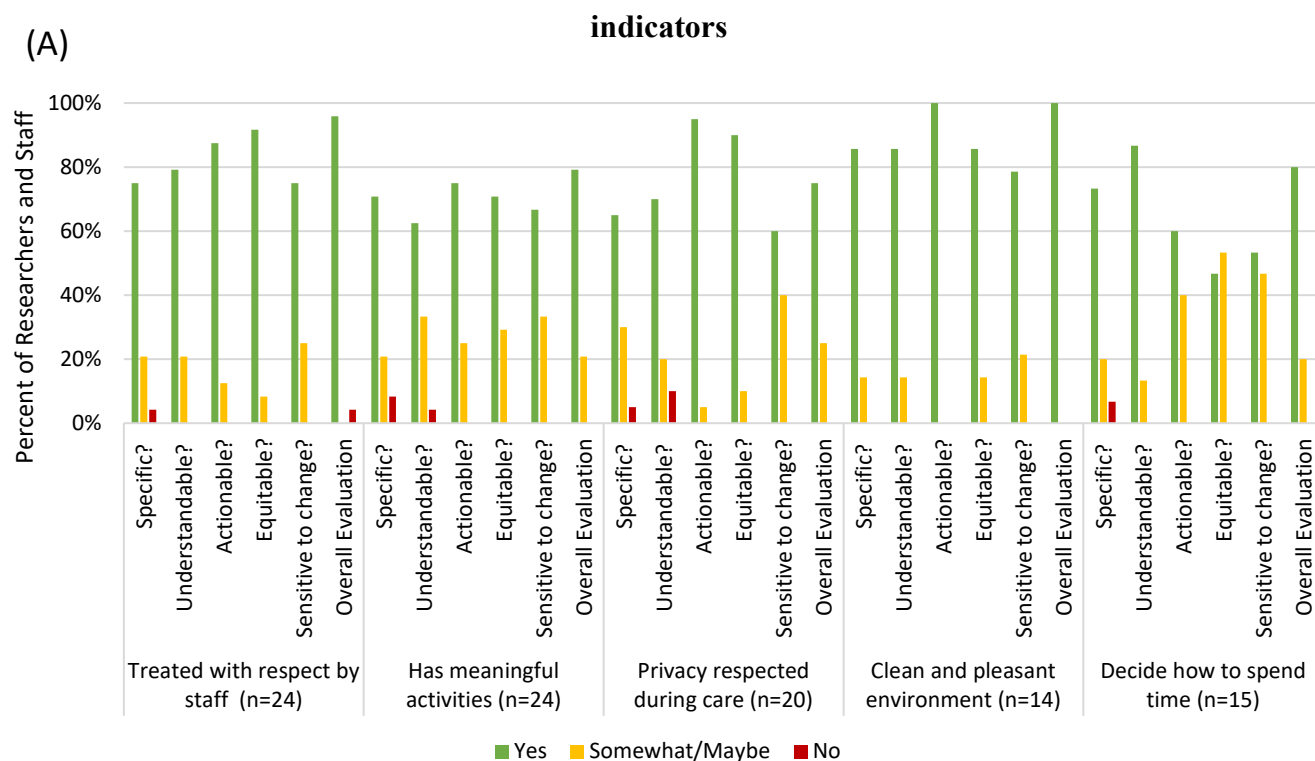
N/E indicates statements that were not evaluated in the round specified (i.e., removed from the survey based on results from the previous round)

Appendix G: Frequency of votes for the top candidate quality indicators

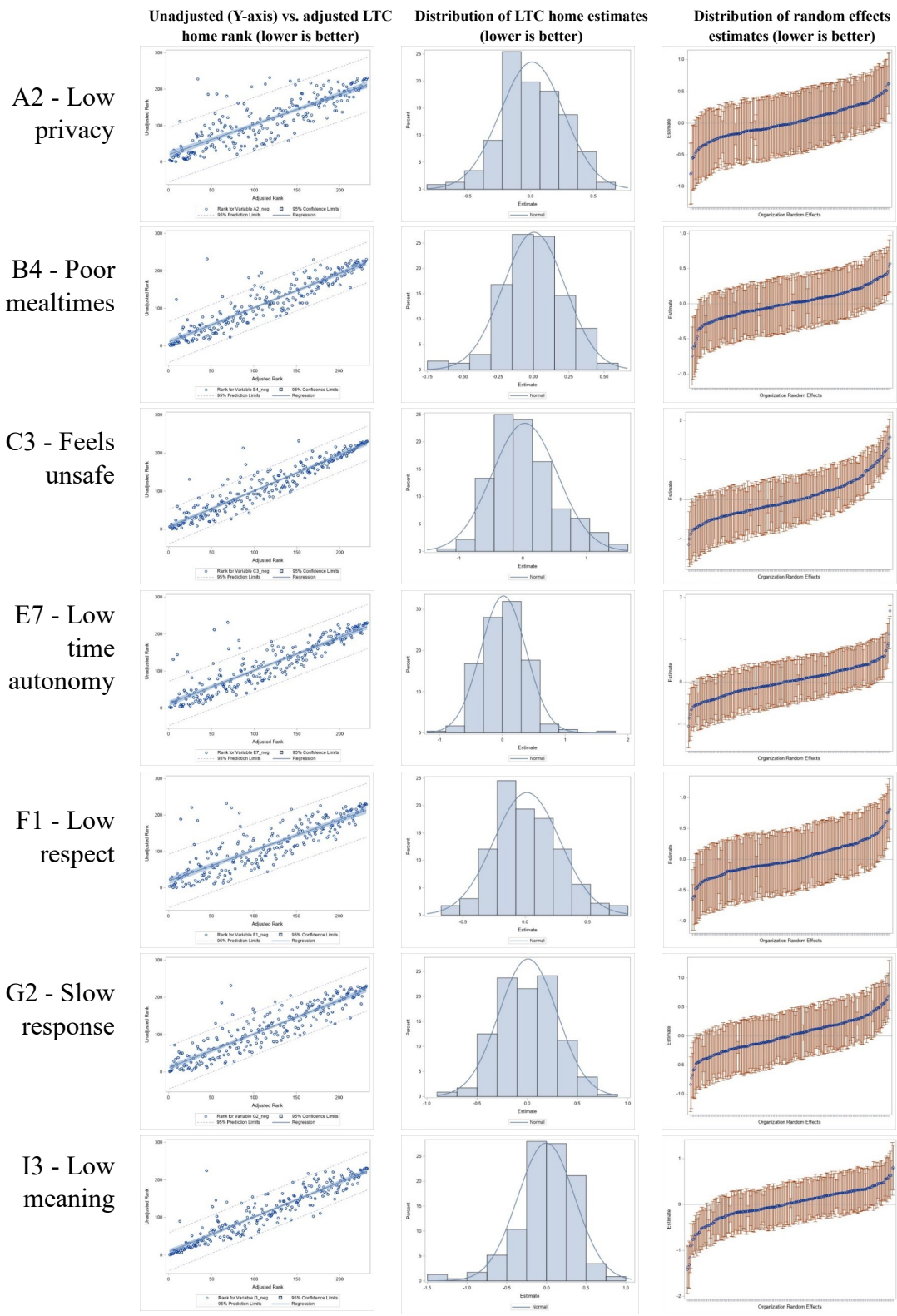
Statements	Candidate QIs (choosing generously)	Initial Candidate QIs (top 10)	Final Candidate QIs (top 10)
1. Treated with respect by staff	30	25	25
2. Has meaningful activities	31	24	24
3. Privacy respected during care	32	21	21
4. Clean and pleasant environment	30	16	16
5. Decide how to spend time	27	15	15
6. Enjoy meal times	25	14	14
7. Feel safe alone	26	13	13
8. Can get help right away	24	14	13
9. Family can visit when they want	25	12	13
10. Staff respond quickly	24	12	11
11. Can express my opinion	20	12	11
12. Family participates in decision-making	20	11	11
13. Staff help me live my life	17	11	11
14. Get other needed services	18	9	10
15. Family treated with respect by staff	20	10	10
16. Staff ask how to meet needs	22	9	9
17. Best place for meeting needs	19	9	9
18. Staff have enough time	19	8	8
19. Get needed health services	17	8	7
20. Staff respect likes/dislikes	20	7	7
21. Food is right temperature	14	5	6
22. Friendly conversation with staff	19	5	6
23. Family knows contact when concerned	26	5	5
24. Alone when wish	16	4	4
25. Would recommend to others	14	4	4
26. Staff know what doing	20	5	4
27. Staff pay attention	15	4	4
28. Control who comes in room	20	2	3
29. Decide when to go to bed	21	3	3
30. Possessions secure	15	3	3
31. Can participate in religion	10	3	3
32. Family has needed health information	19	3	3
33. Family consulted about care plan changes	20	3	3
34. Family trusts staff to provide care	17	3	3
35. Comfortable visiting places	17	3	3
36. Bothered by noise	10	2	2
37. People to do things with	13	3	2
38. Decide clothes to wear	12	0	0
39. Time with like-minded residents	13	0	0
40. Family trusts information from staff	14	0	0

NOTE: The survey had 33 respondents, so the 70% consensus cutoff is at 23 and 10 votes. Participants selected candidate quality of life indicators in a three-step approach. First, they were told to choose generously from the list of statements that had received consensus for inclusion or no consensus. Second, they narrowed their choices to a top 10. Prior to completing the survey, participants were given the choice to revise their “top 10” list.

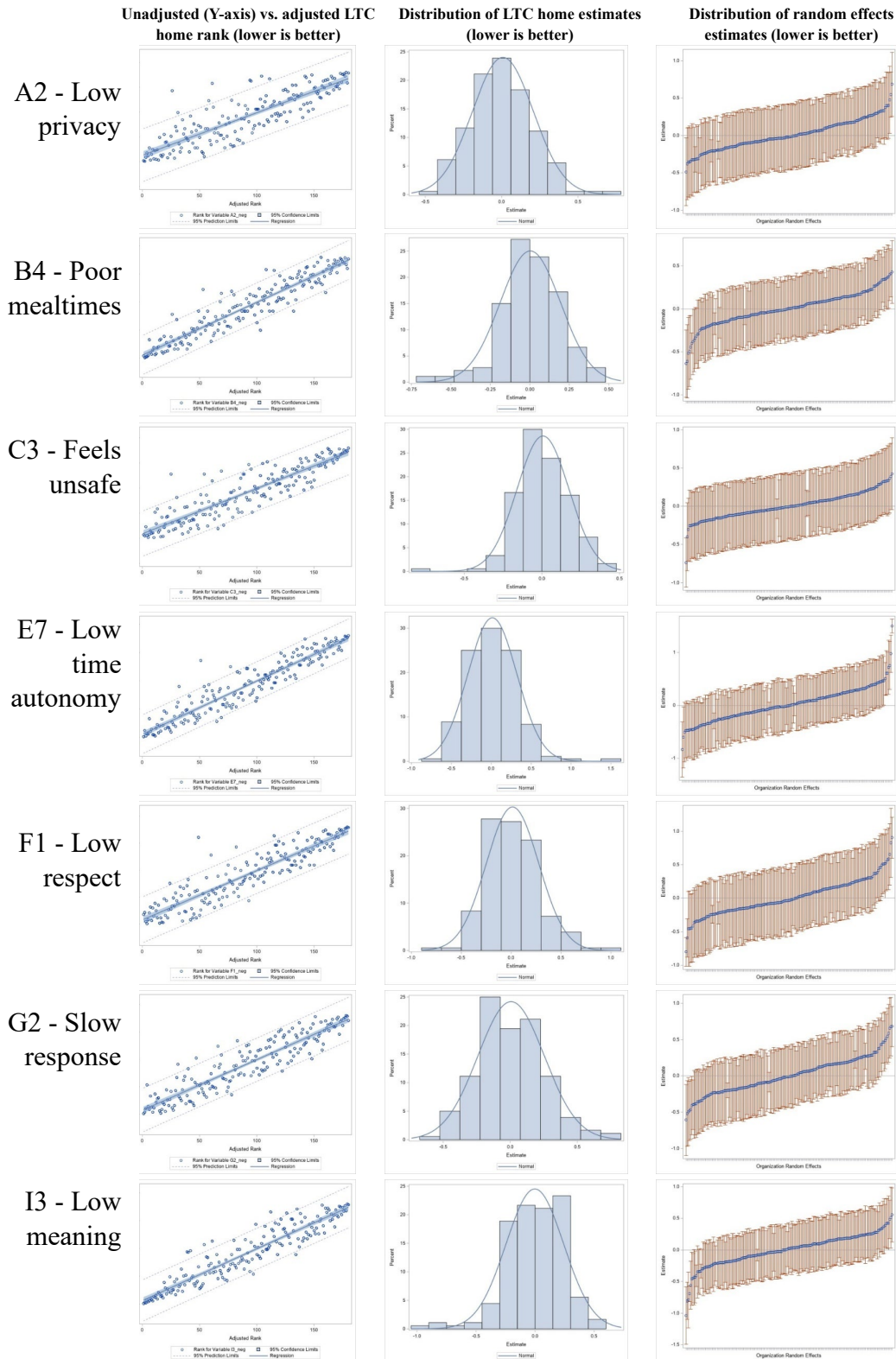
Appendix H: Researcher and staff evaluations of selected candidate quality of life



Appendix J: Distributions of LTC home rank, estimates, and random effects adjusting by age



Appendix K: Distributions of LTC home rank, estimates and random effects adjusting by self-rated health



Appendix L: Interview Questions

1. In your opinion, are quality of life surveys useful for quality improvement in LTC homes? Why or why not?
 - a. PROMPT 1: Who would quality of life surveys impact if implemented in LTC?
 - b. PROMPT 2: Are the specific circumstances that would make quality of life surveys easier or harder to use for quality improvement?
2. Is implementing a QoL survey or indicator any different from implementing a clinical assessment?
3. Do you know of any theories, papers, practice guidelines, or other resources that could help with implementing quality of life surveys in LTC?
4. Are you interested in being sent the results of this study or being personally acknowledged in the final publication?

**Appendix M: Codebook from transcript, images from the Physical Mind-Mapping Process,
and preliminary CMO configurations**

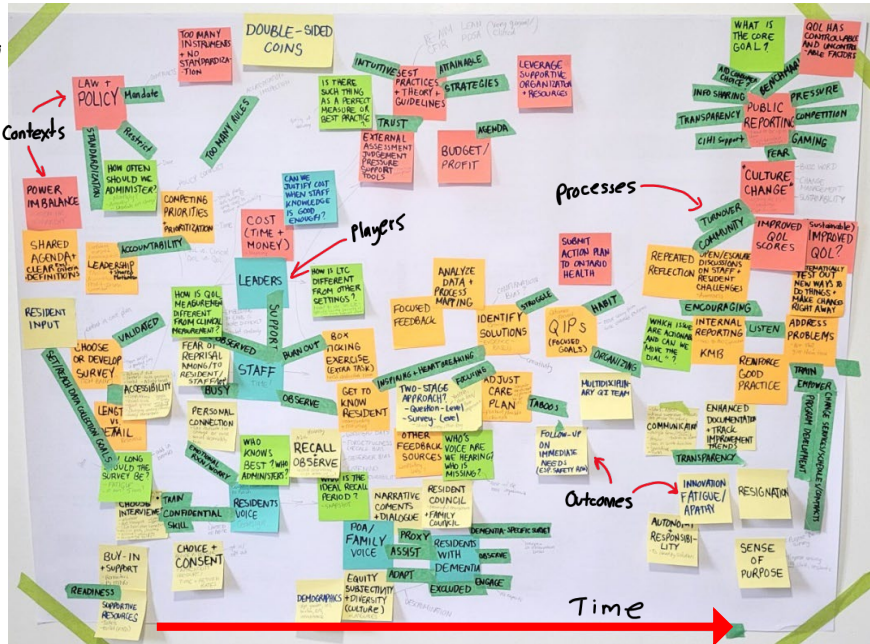
Interview Codes

Actioning survey (Outcome)		
Attaching best-practice recommendations	2	3
Feedback to focus improvement	5	16
Identifying trends	1	2
Outcomes of implementing a QoL survey	4	9
Sustainability	4	9
Context		
Cognitive impairment	3	3
Evaluation Culture	3	10
Financial resources	2	2
Having enough time	4	7
Including Family	2	2
Including Residents	5	22
Including Staff	5	16
Law and policy	5	10
Power imbalance in LTC	2	2
Strong and honest leadership	5	9
Theory and guidelines	3	6
Process (Mechanism)		
Choosing interviewers	1	8
Communication and transparency	6	11
Confidentiality	2	4
Considering resident culture	1	1
Developing surveys	2	4
Implementation	3	7
Multiple forms of feedback	1	1
Rating scale	1	1
Survey Accessibility	1	3

Macro

Meso

Micro



Regroup + Label as CMOCs



CONTEXT	MECHANISM	OUTCOME
Government recommends quality of life survey, but does not mandate	Internal motivation among LTC leaders	LTC homes can choose if they want to implement a quality of life survey, but assessment is less prevalent
Government mandates annual quality of life survey, but does provide implementation recommendations, guidance on managing dementia, or a survey standard	External (and internal) motivation among LTC leaders to administer an annual survey Lack of clear guidelines on which survey to choose	LTC homes expected to choose and/or develop procedures for implementing a quality of life survey and administer at the minimum frequency; Decisions based on intuition, attainability, and general guidance; potential for unintentionally excluding some voices
Government enforces rules in LTC that emphasize clinical quality (inspection and accreditation)	Leaders manage competing priorities that may conflict with quality of life	LTC home adopts 'safer' changes
Leaders are consistent, confident, knowledgeable, and committed to investing in resident quality of life in a collaborative manner with clearly defined shared agenda	Stakeholders feel a sense of direction and accountability; higher transparency of processes / greater sense of evaluation culture	Greater buy-in and support for quality of life survey
Residents seen as passive care recipients	Top-down improvement approaches to improving quality of life are selected	Narrower scope of quality of life challenges can be addressed; lack of 'resident responsibilities'
Power imbalance between leaders, staff, and residents	Fear of reprisal caused by quality-of-life survey; Pressure to have high return rates	Social desirability bias in responses; discounting, pushing back on, or ignoring results; Questionable consent processes and authenticity of responses
Empowerment of leaders staff, and residents	Sense of shared purpose caused by quality-of-life survey	Motivation to collaborate and improve
A population of staff with high turnover rates who are very busy are asked to administer or respond to the quality of life survey	Competing priorities (especially if it is resource intensive); Survey seen as a box-ticking activity / extra task Limited time to get to know residents	Shorter QoL surveys are chosen and applied with a smaller number of residents; quality of life survey is deprioritized Low knowledge of resident quality of life
Staff have time and space to get to know residents and obtain focused feedback from residents <u>and</u> quality of life surveys are embedded in staff routines	Feelings of inspiration / heartbreak; personal connection with residents Increased understanding of patient needs and repeated reflection on those needs	Higher motivation to improve; sense of purpose Greater capacity to adjust resident care plan and address resident immediate needs; Movement towards incremental, sustainable culture change
Staff are asked to rate resident quality of life as a proxy	Potentially limited confidence or knowledge to speak on behalf of the resident (especially in high turnover environments)	Results susceptible to observer bias and confirmation bias; Notion that residents are unable to speak for themselves is reinforced
Residents are asked about their quality of life by trained external assessors (e.g., volunteers)	Potential recall bias or forgetfulness from respondents with mild to moderate dementia	Potential for lower trustworthiness of responses from some residents, but lower social desirability bias and greater comfort among residents

Feedback is gathered with accessibility, confidentiality, and flexibility in mind (can this be combined with staff have time and space?)	Less fatigue and confusion, and more comfort among respondents	Improved success of survey initiative, greater honesty from respondents, better reliability of results Potentially lower validity of responses if questions are re-worded
Multiple sources of feedback are drawn upon (e.g., resident council)	Commitment to a complex approach to quality of life	More complete picture of resident quality of life is obtained (fewer missing voices)
Leaders provide supportive resources, such as training, time, and a multidisciplinary team (opposite of busy staff / staff told to generate solutions)	Improves readiness	Reduced challenges with data collection; enhanced documentation
High quality data analysis and process mapping approaches are harnessed	Enhanced capacity to track trends in improvement	More focused and specific quality improvement plans can be generated
Results of the survey are communicated in multiple formats using language and formatting appropriate to the target audiences (e.g., residents, staff)	Stakeholders feel that the survey has a purpose	Stakeholders are encouraged to participate in future surveys
Organizations implement evidence-informed changes (e.g., new programs, changes to schedules or contracts) in a timely manner with a focus on sustainability and routinization (“just implementing an assessment won’t make a difference”). Immediate interventions without the expectation of immediate changes to QoL scores)	Incremental culture change and reinforced good practice	Improved quality of life scores reflecting improved quality of life over the long term
Residents <u>or</u> staff told to generate solutions to potential issues in quality of life with minimal support	Greater struggle to identify meaningful solutions; Innovation fatigue	Apathy and resignation (“it’s impossible to improve this”, “it’s out of our control”)
Residents <u>and</u> staff are engaged in a dialogue on QoL as experts and invited to generate solutions to specific quality of life challenges with access to time, space, funds, leadership, and information, as appropriate	Sense of purpose / motivation	More creative and person-centered solutions are generated; opportunity for awareness and bottom-up change
External evaluation or public reporting of quality of life without support	Sense of external judgement	Sense of competition, gaming, fear, mistrust, and pressure drives improvement or apathy
Information sharing and benchmarking with supportive external organizations	Mutual support, trust, and transparency	LTC leaders leverage supports (tools, strategies, and reports) to improve

Appendix N: Extraction Table

STUDY ID	TITLE	STUDY AIM	COUNTRY	DESIGN	MRC
Magennis 2009	How can we improve residents' quality of life? Assessing the value and practicality of routine quality of life measurement in a residential aged care facility.	To understand issues impacting resident's quality of life and assess the potential benefits and practicality of routine quality of life measurement.	Australia	Qualitative; Pilot / feasibility	Feasibility; Implementation
Madsø 2021	Implementation of quality of life assessment in long-term care.	To express need for securing validity of quality of life surveys for residents with dementia.	Not reported	Opinion paper	Development
Dichter 2011	Validity, reliability, and feasibility of a quality of life questionnaire for people with dementia.	To evaluate the construct validity, reliability (internal consistency), and feasibility of the German version of the QUALIDEM survey.	Germany	Cross-sectional; Qualitative; Secondary data analysis	Feasibility
Simon 2013	Quality of life in nursing homes following the group-living principle: a pilot study measuring the quality of life from the subjective perspective of dependent-living elderly.	To understand quality of care in group-living LTC homes (vs. independently living older adults) and analyze and validate the usability of implemented measures.	Germany	Cross-sectional; Pilot / feasibility	Feasibility
Degenholtz 2014	Improving quality of life in nursing homes: the structured resident interview approach.	To develop, implement, and evaluate an assessment and care planning tool for improving resident quality of life of residents over 180 days.	United States	Randomized controlled trial; Pilot / feasibility	Development; Feasibility
Towers 2015	Adapting the adult social care outcomes toolkit (ASCOT) for use in care home quality monitoring: conceptual development and testing.	To explore how the ASCOT care homes toolkit may be adapted for use as a quality indicator and carry out preliminary testing.	UK	Qualitative; Pilot / feasibility	Development; Feasibility; Implementation
Towers 2016	The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes.	To design, pilot, and test the acceptability of a feedback intervention based on the ASCOT-CH3.	UK	Qualitative; Pilot / feasibility	Implementation ; Evaluation
Hoben 2022	Feasibility of Routine Quality of Life Measurement for People Living With Dementia in Long-Term Care.	To assess the feasibility of the DEMQOL-CH for assessing the quality of life in LTC and assisted living residents with dementia	Canada	Cross-sectional; Pilot / feasibility	Feasibility
Hughes 2022	Care home staff perceptions of implementing a quality of life instrument into routine care practice: A qualitative study.	To understand the views of LTC staff about using a quality-of-life instrument as a part of routine care and support implementation.	UK	Cohort study; Qualitative	Feasibility; Implementation

STUDY ID	# OF LTCH	ABOUT LTCH	PARTICIPANTS	INCLUSION / EXCLUSION CRITERIA	SAMPLE SIZE	STRENGTHS	LIMITATIONS	APPROPRIATE METHODS FOR CLAIMS?
Magennis 2009	1	Urban; Large pop.; Low-care setting	Residents; PSWs; Nurses; Admin	EXCL: Residents with MMSE < 10 or on palliative care	43 residents; 26 staff	Mixed-methods	Small study	Yes
Madsø 2021	N/A	N/A	None	N/A	N/A	N/A	N/A	N/A
Dichter 2011	34	Urban	Residents; Nurses	INCL: MMSE < 24, Stay > 2-4 weeks / EXCL: Residents with schizophrenia/ psychotic disorder	486 residents; 4 raters	Rater statements were consistent	Thin description	Maybe - appropriate to claim validity, limited evidence for feasibility claims.
Simon 2013	7	'Group Living Model'	Residents	INCL: Stay > 3 months, Residents > 75 willing and able to participate	145 residents	Broad inclusion criteria, novel research	Convenience sample	No - No qualitative data to back up implementation-related discussion.
Degenholtz 2014	3	Urban; Suburban Large pop.; Not-for-profit	Residents	EXCL: Residents on hospice / rehab, young, do not speak English, under quarantine, or in dementia unit	64 (39 intervention/ 25 control)	Comparison group	Small sample; Limited time for follow-up	Yes
Towers 2015	2	Small pop.	Families; Admin	INCL: Professional members of ASCOT mailing list, potential lay users (relatives / carers)	17 in focus group; 28 in workshop	Multiple methods; clear definitions	Sample not representative; limited detail in methods	Yes
Towers 2016	4	Large & Small pop.; Private; Public; 2 Female only	Residents; Family; PSWs; Nurses; Admin	EXCL: Residents on respite / short-term care or in hospital	58 residents	Partnership with LTC homes	Small sample, no control group	Yes
Hoben 2022	5	Large pop.; Private; Public; Not-for-profit	PSWs; Nurses	INCL: Staff employment > 3 mo. and had cared for residents for 3+ shifts over previous week; Residents 65+, CPS 2+, Stay > 3 mo.	42 staff (21 LTC staff assessed 183 residents)	Collaborative study design; anonymous questionnaire	No on-site data collection; convenience sample	Maybe - No resident engagement; Limited reporting of results
Hughes 2022	3	Small pop.; Private; Not-for-profit; 1 dementia-specific	Admin	EXCL: agency staff and casual workers on zero-hour contracts	35 in interviews; 4 in focus groups	Inductive approach; Included care staff	Limited night staff; presenting DEMQOL-proxy before may have caused bias	Yes

STUDY ID	SURVEY	PURPOSE	PERSPECTIVE	ADMINISTERED BY	LENGTH	DURATION	DEMENTIA
Magennis 2009	QoL - Alzheimer's Disease (QOL-AD)	Quality improvement	Residents; Staff	Research staff	15 items	15 - 20 minutes	Survey is dementia-specific
Madsø 2021	None	N/A	N/A	N/A	N/A	N/A	N/A
Dichter 2011	QUALIDEM	Research; Validation	Staff	Trained nurses with close relationship to resident	37 items	10 minutes	Survey is dementia-specific
Simon 2013	Nottingham Health Profile (NHP)	Research	Residents	Interviewer	38 items	40 minutes	Survey includes residents with and without dementia
Degenholtz 2014	The QoL Structured Resident Interview and Care Plan (QOL.SRI/CP)	Care planning; Quality improvement	Residents	Former director of social service and social work graduate	69 items + open-ended follow-up questions	30 minutes	Survey excludes residents with severe dementia
Towers 2015	Adult social care outcomes toolkit (ASCOT)	Quality improvement	Residents; Staff; Observer	Multi-method approach administered by rater pairs	8 - 32 items	1 day for rating whole home	Survey includes residents with and without dementia
Towers 2016	ASCOT CH3	Quality improvement	Residents; Other: Observer	ASCOT trainers	Not reported	5 days of observation	Survey includes residents with and without dementia
Hoben 2022	DEMQOL-CH	Research	Staff	Direct care staff employed for at least 3 months	31 items	< 5 minutes	Survey is dementia-specific
Hughes 2022	DEMQOL-Proxy	Example of a survey that can be implemented	Staff	Care staff	31 items	Not reported	Survey includes residents with and without dementia

STUDY ID	BARRIERS TO IMPLEMENTATION	FACILITATORS FOR IMPLEMENTATION
Magennis 2009	MICRO: Residents and staff struggled with identifying solutions to QoL issues (with exception of food issues) and expressed resignation (i.e., "that's just the way it is") MESO: Staff overrate mood and underrate relationship with friends; staff may be skeptical about usefulness of measuring QoL (i.e., "we can't fix it"); When residents expressed satisfaction, it re-assured staff that there was no need for action MACRO: QoL measures have controllable and uncontrollable factors	MESO: Hiring more (consistent) staff; management support and resources; committed leadership
Madsø 2021	MICRO: Recall bias (current emotional state can influence responses) MACRO: Lack of validated QoL surveys for residents with dementia; lack of standardized QoL measurement and too many instruments to choose from	MICRO: Proper recall period for interview-based survey MACRO: Lessons from care settings outside of LTC; including residents with dementia as experts in survey development
Dichter 2011	MICRO: Hard for proxy raters (nurses) to judge how residents with dementia expressed satisfaction, what they enjoy, and if social withdrawal was due to physical limitations or intentional; Hard for nurses to limit observation to 2 weeks MESO: Poor language skills for some raters (e.g., understanding 'restlessness')	MICRO: Short administration period (10 minutes); Survey seen as applicable, practical, logical, and sensible with easy to use and understand response categories MESO: Inclusion and exclusion criteria for nurse proxy raters to those with sufficient language skills MACRO: Survey validity and reliability
Simon 2013	MICRO: Strong emotional reactions for some questions and worry caused by negatively formulated statements	MICRO: Interviewer reading question aloud was beneficial due to poor vision/hearing/concentration in some residents; Not having staff administer the surveys minimized social desirability bias
Degenholtz 2014	MESO: Time and resource constraints	MICRO: Residents asked yes / no question, then frequency question to reduce cognitive burden; residents indicating poor QoL rated importance to ensure focus on care planning MESO: Solutions ensured to be practical and feasible for staff to execute within constraints; non-staff member conducted surveys so residents felt more comfortable discussing issues; care plan at same level of accountability as other orders; Electronic point-of-care systems for nurse aides; reminder in a voice-activated system; description of care plan tasks on kiosk; leadership approval of care plans
Towers 2015	MICRO: Long interview and poor availability of staff and relatives MESO: Decisions on who will collect data, how to communicate findings (e.g., "A, B, C, D", traffic light, stars) and, choosing the right language (i.e., avoid suggesting that residents are passive recipients); lack of time; rater (staff) anxiety around culpability and reliability; determining responsibility for collecting / publishing data MACRO: Financial barriers; Poor information sharing between LTC organizations; Concern that publicly available data could damage positive relationships	MICRO: If ratings were provided by independent organization or self-reported by persons with first-hand experience (i.e. residents / families) rather than staff who may have 'an agenda' based on cost-savings; tone and warmth of communication; two reviewers MESO: Clear definitions; fit with existing quality monitoring activities; rater training; sharing family surveys in advance; collective accountability MACRO: Local authorities must review quality at service level; Portal with info on the quality / effectiveness of individual homes to support comparison / improvement; outcomes-focused survey
Towers 2016	MICRO: Challenges of collecting self-report data with residents and obtaining consent from POAs; residents have good and bad days; possibly extra agitation among residents with severe dementia MESO: Lack of staff time to participate in interviews on resident QoL; Observations of practice initially perceived as threatening by staff MACRO: Organizational culture, insufficient time for staff to improve QoL; inconsistent management	MICRO: Outside assessors meant no disruption to home activities; staff training on how to improve QoL; family support of the project MESO: Management support; sensitive feedback delivery; welcoming, cooperative, and engaged staff; attendance at feedback sessions; care home culture; skills and commitment from management; Integrating outcome measurement into care planning
Hoben 2022	MESO: Staff time constraints	MICRO: Brief survey with acceptable reliability designed to work across dementia severity; staff perceived acceptable completion time, understandability, relevance, and value MESO: Survey completed by direct care staff to minimize resident burden / costs (does not require external assessors); no licencing costs
Hughes 2022	MICRO: Challenges with resident communication and expression MESO: Staff uncertainty in rating resident QoL (insufficient time with specific residents to rate their QoL); lack of extra time for staff to complete survey	MICRO: Survey ease of use and simplicity MESO: Measure monthly or more for residents they have concerns about (e.g., changing care needs); instrument fit within existing practices; Staff training, confidence, and empowerment to make changes; raters allowed to opt-out if feel they cannot speak on behalf of the resident.

STUDY ID	DRAWBACKS OF IMPLEMENTING QOL SURVEY	BENEFITS OF IMPLEMENTING QOL SURVEY
Magennis 2009	SHORT TERM: Information on issues alone is likely not a sufficient catalyst for improvement; Difficult to justify cost / inconvenience of conducting resident surveys when staff demonstrate good knowledge of resident issues; may be easier to address known QoL issues with proven models of care rather than implementing routine QoL measurement that requires staff problem-solving skills	IMMEDIATE: Give residents a say; Staff may learn something new about a resident SHORT TERM: Resident interviews could motivate staff to address issues
Madsø 2021	LONG TERM: Discourage using dementia-specific instruments for whole population in LTC as it would lead to implicit attitudes of expecting cognitive impairment in residents living there for other reasons.	
Dichter 2011		
Simon 2013		IMMEDIATE: Identify residents' views on care
Degenholtz 2014		IMMEDIATE: Identify actionable care planning items SHORT TERM: Significant improvement in QoL scores across most domains at 90-days (p=0.14) and 180 days (p=0.346) after baseline LONG TERM: Improved accountability within LTC management to improve QoL; data aggregated can be used to track performance, benchmark, and support improvement
Towers 2015	IMMEDIATE: Resident concern over why raters were observing them SHORT TERM: QoL surveys do not usually represent the views of residents with the most impairment LONG TERM: Decision to move into LTC often made at a time of crisis and constrained bed availability; greater weight given to word of mouth or reviews	SHORT TERM: Piloting measures with local authorities (scalability) LONG TERM: Public reporting may help people choose a LTC home, may drive up quality by focusing home on monitoring and improving QoL outcomes
Towers 2016	IMMEDIATE: Potential resident stress from researchers being present in the LTC home. SHORT TERM: Hard to know if there is a real impact of survey on residents (no measurable improvement, only anecdotal evidence) LONG TERM: Difficult to maintain measurable improvements in QoL	SHORT TERM: Staff interviews allowed staff to discuss their own challenges in supporting resident QoL and have that info escalated in hierarchy LONG TERM: Manager was able to change the workday setup so that staff have more time with residents to provide QoL
Hoben 2022	LONG TERM: No reports on how survey contributes to better resident QoL	IMMEDIATE: Organized data collection
Hughes 2022		IMMEDIATE: Opportunity for staff to learn about residents SHORT TERM: Opportunity for staff increase awareness around QoL; Tools can be linked and embedded into routine practice LONG TERM: Improvements in resident QoL; enhancing documentation to incorporate QoL; move away from task-oriented routines; demonstrating / reinforcing good practice; ability to report QoL to governing bodies; ability to track improvements over time