Factors that Influence Quality of Life from the Perspective of People with Dementia

by

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Abstract

Background: The prevalence of dementia, a progressive and incurable condition that affects memory and daily function, is increasing worldwide. The perspective of people with dementia can be captured to better understand which factors impact quality of life for this particular population. Such factors can then be used to guide future research to improve quality of life for people with dementia, even as troubling symptoms like memory loss progress.

Purpose: The purpose of this dissertation is to identify factors that influence quality of life from the perspective of people with dementia.

Methods: The dissertation consists of four related and sequential papers: (1) a conceptual paper to assess the extent to which the perspective of people with dementia has been included to assess and conceptualize quality of life in the quantitative dementia-specific literature, (2) a systematic literature review and metasynthesis of qualitative evidence to identify factors that influence quality of life according to people with dementia, (3) a methods paper describing how metasyntheses findings were applied to design a quantitative study, and (4) a cross-sectional, quantitative, correlational study to test the association between perceived conflict and sadness (a proposed influencing factor and outcome of poor quality of life, respectively).

Findings and Conclusions: Two important limitations of previous research to understand quality of life from the perspective of people with dementia were identified. First, existing quantitative literature was inconsistent with a subjective definition of quality of life because researchers neglected to conceptualize quality of life from the perspective of people with dementia. Second, the body of existing qualitative research had not been considered collectively, nor had it informed quantitative research. In this dissertation, these limitations were addressed by applying knowledge from the body of qualitative research as a whole to design a quantitative study that was consistent with a subjective definition of quality of life.

The findings demonstrated that people with dementia could contribute meaningfully to advance knowledge about factors that impact quality of life in this population. The four factors that influenced quality of life from the perspective of people with dementia included Relationships, Sense of Place, Wellness Perspective, and Agency in Life Today. Further exploration of the Relationships factor generated evidence in support of the proposed association between conflict and sadness, and highlighted that conflict with family and friends may have a particularly negative impact on people with moderate and severe dementia living in long-term care. The factors identified in this dissertation were each complex, but potentially modifiable and useful to generate further research questions and hypotheses that reflect the priorities of people with dementia. Given these four factors, the roles and responsibilities of health care providers may need to be re-considered in order to optimize quality of life for people with dementia.

Preface

Ethics approval to conduct the study reported in chapter 5 of this dissertation was received from the University of Alberta Research Ethics Board, Project Name *"The association between sadness and relational conflict for people with dementia in long-term care"*, No. Pro00011753, June 25 2013.

A version of Chapter 2 of this dissertation was submitted to the *Journal of Advanced Nursing* (John Wiley and Sons Publications) and is currently under review as "O'Rourke HM, Fraser KD, Duggleby W. Quality of life for older adults with dementia: Where is the person". I was responsible for study conceptualization, analysis, writing the article, and responding to feedback from co-authors. KD Fraser and W Duggleby supported study conceptualization, critically reviewed manuscript drafts and provided substantive feedback. The copyright notice that appears in the Wiley publication in not yet available for inclusion here because this paper has not been accepted for publication.

A version of Chapter 3 of this dissertation was accepted for publication in the *Journal of the American Geriatrics Society* (John Wiley and Sons Publications) and is currently in press as "O'Rourke HM, Duggleby W, Fraser KD, Jerke L. Factors that affect quality of life from the perspective of people with dementia: A metasynthesis". I was responsible for study conceptualization and design, completing the search and screening, data extraction, quality appraisal, and analysis, and drafting the manuscript. W Duggleby contributed to and supported study conceptualization and design, analysis, and revision of manuscript drafts for important intellectual content. KD Fraser contributed to and supported study conceptualization and design, analysis, and revision of manuscript drafts for important intellectual content. L Jerke contributed to study conceptualization and design, tested inclusion/exclusion criteria, conducted quality appraisal of included studies, and critically reviewed manuscript drafts. The copyright notice that appears in the Wiley publication is duplicated below:

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A version of Chapter 4 of this dissertation was submitted to *Quality of Life Research* and is currently under review as "O'Rourke HM, Duggleby W, Fraser KD. Embedding the perceptions of people with dementia into quantitative research design". I was responsible for manuscript conceptualization, drafting the manuscript, and responding to feedback from co-authors. W Duggleby and KD Fraser contributed to and supported manuscript conceptualization, critically reviewed manuscript drafts, and provided substantive feedback.

Chapter 5 of this dissertation is in preparation for publication as "O'Rourke HM, Fraser KD, Duggleby W, Keating N. The association between conflict and sadness for people with moderate and severe dementia in long-term care". I was responsible for study conceptualization and design, data acquisition, conducting all analysis, and drafting the manuscript. KD Fraser, W Duggleby, and N Keating supported study conceptualization and design, analysis, and provided critical reviews of manuscript drafts and substantive feedback, contributing important intellectual content.

Dedication

To my husband D.J. O’Rourke, my parents Corrine and Rodney Jerke, and my sisters Megan McKenna and Lauren Jerke.

You have provided me with extensive encouragement and support throughout my life and also during my pursuit of a doctoral degree, creating the environment that allowed me to complete this work. You have taught me the importance of responsibility to others, the necessity of hard work, and have implored me to find my own unique way of making a positive contribution to the world. You have engaged in this work with me through many hours of discussion, thereby fuelling my mind, motivation, and passion for this research. Most importantly, you have loved me unconditionally, profoundly affecting my life and what I am capable of. This dissertation is dedicated to you.

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Chapter 1. Introducing the Problem

Dementia is a chronic and progressive disease[1,2] that is increasing in prevalence. Globally, the number of people with dementia is projected to increase from 35.6 million to 65.7 million by 2030[3]. In Canada, approximately 500,000 individuals live with dementia today[1]. Given that dementia is associated with aging[2] and the proportion of Canadians over 65 is growing[4,5], this number is projected to reach 1,100,000 within a generation[1]. Recent estimates show that dementia is particularly prevalent in Canadian long-term care settings where it is estimated that upwards of 60 % of residents have dementia[6]. As a result, meeting the needs of people with dementia is of great concern to society as a whole and for the long-term care industry, which provides housing and on-site 24 hour nursing care[7] to many older adults with dementia[1,8].

In the absence of a dementia cure, maintaining the highest possible quality of life (QOL) is a critical principle that underpins long-term care services for people with dementia[9,10]. People with dementia live with cognitive impairment and resulting dependence and thus require supportive care providers and environments to achieve QOL[11–13]. Yet, despite this emphasis, improvements to long-term care have focused primarily on a more narrow selection of clinical issues, such as improving pain management or reducing fall rates. QOL has received far less attention and dedicated resources[14–17]. Research is needed about what affects QOL for people with dementia in order to develop effective interventions that support their best possible life experience[18] while living in long-term care [12,19]. My dissertation responds to this need in order to improve understanding of QOL for people with dementia, and to identify factors that influence QOL from the perspective of people with dementia.

In this introductory chapter, I will describe key terms for my research such as QOL and dementia. I will also describe my personal impetus for conducting research in this area, as it is important for readers to understand why I was motivated to ask and respond to particular types of research questions. I will then outline the conceptual framework guiding my dissertation. I conclude the chapter with a short description of each of the four papers included in this dissertation. I describe each paper's objective(s), key content, and linkage to the other dissertation papers. I also briefly describe the methods I used for the two empirical studies, but provide further detail on study methods in Paper 2 (systematic review and metasynthesis) and Paper 4 (cross-sectional, retrospective, correlational design and logistic regression analysis).

Key Terms

Dementia: an umbrella term to describe cognitive symptoms caused by any one of several diseases, most often by Alzheimer's disease (60 to 80% of cases) or vascular dementia (20 to 30%)[20.] Symptoms include impairment to short and long-term memory, abstract thinking, and judgment, or personality changes that interfere with work, social activities, or relationships[21]. The Mini-Mental State Exam (MMSE) is a widely used tool to classify cognitive impairment as mild (MMSE=21-25), moderate (MMSE=11-20), or severe (MMSE=10 or less)[22].

Another tool, the Cognitive Performance Scale (CPS), rates the cognitive function of long-term care residents based on several items from clinical administrative data[23] . Previous work has compared CPS ratings to average MMSE scores [23, p.M179]. As per the MMSE definition and for people with a dementia diagnosis, CPS codes 0 (mean MMSE 24.9; SD 5.1) and 1 (mean MMSE 21.9; SD 5.7) capture mostly people with mild dementia; CPS codes 2 (mean MMSE 19.2; SD 5.6) and 3 (mean MMSE 15.4; SD 8.0) capture mostly people with moderate dementia;

and CPS codes 4 (mean MMSE 6.9; SD 6.9), 5 (mean MMSE 5.1; SD 5.3), and 6 (mean MMSE 0.4; SD 0.9) capture mostly people with severe dementia [23, p. M179].

People with Dementia: individuals living with the symptoms of dementia.

Long-Term Care: living accommodation and care for people who require on–site 24 hour professional health service and/or personal care[24]; also called residential care facilities or nursing homes[7].

Quality of Life (QOL): a subjective evaluation of "one's life perspective" [18, p. 186] that occurs "within the context of the culture and value systems in which (people) live and in relation to their goals, expectations, standards and concerns" [25 p. 1]. In contrast, *health-related QOL* is a narrower concept focused on how disease symptoms and treatments affect one's life[26,27]. By definition, health-related QOL worsens with increased symptom severity[28,29], which is not necessarily the case for QOL.

Researcher Motivation and Positioning

The focus of my doctoral work originated from a nursing practice problem that requires research attention: What areas should be targeted in order to support the QOL of people who live with dementia in long-term care settings? I was sensitized to this problem as a nursing student during my first clinical placement in long-term care. Working full-time alongside health care aides for a six-week rotation gave me insight into how and why work was structured in particular ways. I observed two things that have stayed with me for over a decade. First, care was frequently organized and delivered in a routine, institutionalized manner that did not seem to support the resident's best possible life experience; that is, it did not support the persons' need for QOL. Second, there were some residents with dementia who appeared to enjoy life, despite profound and advanced cognitive impairment, but in my view, these individuals were the exception instead of the norm. Care seemed more system-centred than person-centred. Despite a philosophy of care to the contrary, the actual delivery of care was focused first and foremost upon ensuring that hygiene and safety needs were efficiently met, rather than supporting the QOL for the resident with dementia. I had expected that care would have an intentional, positive and meaningful impact upon the QOL experienced by the majority of people with dementia in that setting. I was disappointed and, frankly, troubled that this was not the case.

The literature supports that my observations were not new, unique, nor isolated [14,30]. Despite increased emphasis upon QOL for people with dementia and long-term care residents, there remains a deficit of research and clinical attention in this area [15–17], whereas the well-funded, but currently unsuccessful, search for a dementia cure has continued unabated [31]. Critiques of this situation offered by two seminal dementia researchers—Tom Kitwood and Peter Whitehouse—influenced my thinking as I reflected upon my nursing experiences with people with dementia. By considering dementia as a social problem [32,33], both Kitwood and Whitehouse challenge the curative emphasis and the mainstream framing of the ‘dementia problem’ as simply an organic brain disease. These authors emphasize that dementia is not only an issue of a progressive disease that causes memory loss, but also of *our personal and societal responses to people with memory loss*.

This alternate framing greatly broadens the range of solutions that may be offered in response to the dementia problem. While preventing, curing or slowing dementia progression in an individual are the only solutions for an organic brain disease, there are opportunities for intervention at many other levels if dementia is considered as a social problem. For example, we could change how we relate to the person with dementia, or the value we place on people with progressive cognitive impairment and increasing levels of functional dependence[32,33]. It was in this particular frame of mind that I approached and appraised the dementia-specific QOL literature.

What I Mean by 'Quality of Life'

There is a persistent lack of consensus on the meaning of QOL in the literature [27,34–37], so an upfront definition of what I mean by QOL is essential. Based on an extensive literature review, I define QOL as a subjective evaluation of "one's life perspective"[18, p.186] that occurs "within the context of the culture and value systems in which (people) live and in relation to their goals, expectations, standards and concerns" [25, p. 1]. Similar to several other dementia researchers [14,18,38–40], I have defined QOL as a wholly subjective construct. This implies that the person with dementia's evaluation of his or her own life is the gold standard for understanding QOL[41]. The definition also claims that multiple factors influence one's appraisal of their QOL (i.e. it occurs "within the context of the culture and value systems in which [people] live and in relation to their goals, expectations, standards and concerns"[25, p. 1]). According to this definition, the factors that influence QOL are distinct from the QOL construct. This dissertation is focused on identifying influencing factors of this subjective construct for people with dementia.

Existing Frameworks of Factors that Influence QOL in Dementia

I reviewed the quantitative dementia-specific literature seeking an existing conceptual framework of factors that influence this subjective conceptualization of QOL for people with dementia. The main reason that I did not use one of the existing conceptual frameworks[33,38–40,42–47] in the present study was because they appeared to be inconsistent with a subjective QOL definition. The primary criterion that I used to determine consistency with a subjective QOL definition was whether potential influencing factors were identified by people with dementia, or not. This is because previous research has shown that people without dementia lack insight into the factors that influence QOL for people living with cognitive impairment[46,48]. People without the disease frequently assume that QOL must worsen as dementia symptom severity increases, so frameworks that exclude people with dementia from the factor identification process tend to overemphasize the impact of dementia symptoms on QOL[26,28,40,42,44,47,49].

The conceptual frameworks that were inconsistent with a subjective definition of QOL included those that were developed using a process that explicitly excluded the perspectives of people with dementia during factor identification[42–44], did not describe if people with dementia were included or excluded[38,40], or that included people with dementia but also many other sources, making it unclear whose perspectives were represented [33,39,45,47,50]. There was one conceptual framework that was consistent with a subjective definition of QOL because it was developed by drawing solely on the perspectives of people with dementia[48]. However, the developers of this conceptual framework fail to describe their methods, such as study site or sample, limiting the extent to which their framework can be applied to other people with dementia beyond the original sample. I provide a more detailed description of each of these conceptual frameworks, and an in-depth analysis as to the extent to which they were derived from the perspectives of people with dementia in Paper 1.

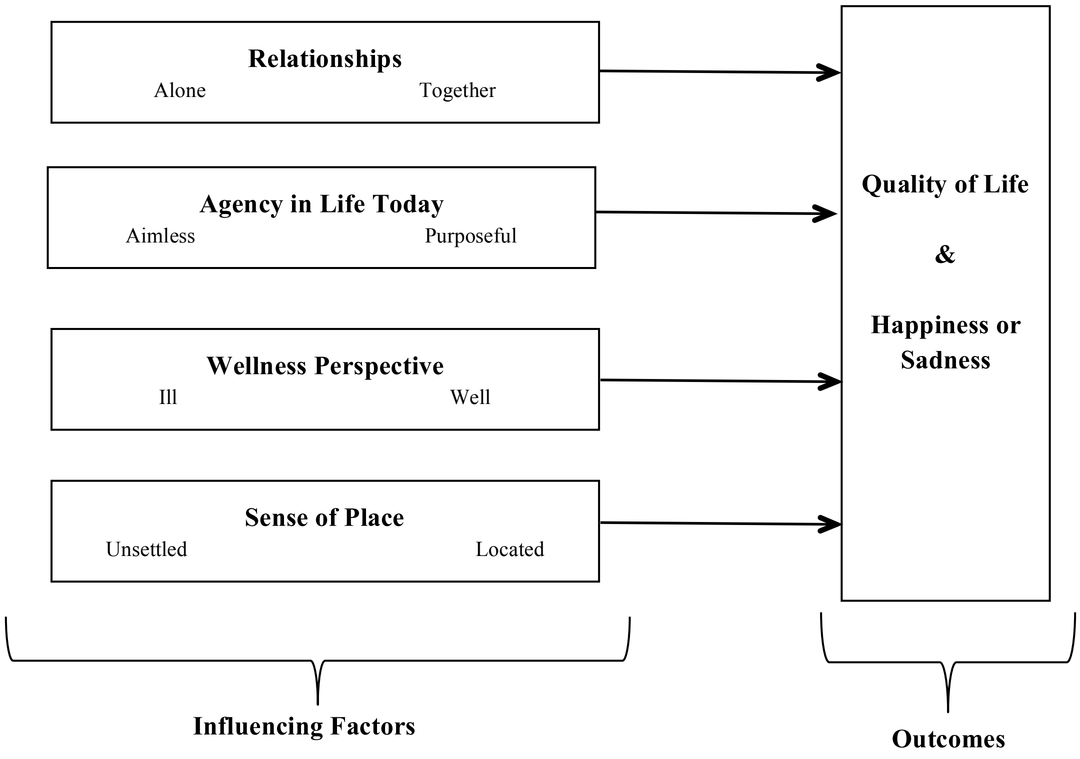
I found that few researchers who use quantitative methods had identified factors based on the perspectives of people with dementia, an observation also made by Ettema et al. (2005) in their review of the dementia-specific QOL literature [51]. To address this issue, there have been calls to assess which factors are important to QOL from the particular perspective of people with dementia[14,39,46,52]. Qualitative study findings with samples of people with mild, moderate and even severe dementia have been conducted which respond directly to this call by asking people with dementia about what factors affect QOL [41,53–63]. For consistency with the subjective definition of QOL that I use in this dissertation, I synthesized this existing qualitative evidence to develop a new conceptual framework of factors that influence QOL that represented the perspectives of people with dementia (described fully in Paper 2).

My Conceptual Framework

To remain consistent with the subjective definition of QOL, I derived a conceptual framework that described factors that influence QOL according to people with dementia. Research has identified that people with mild and moderate dementia can: a) talk about their perceptions, b) know what is important to them, and c) should be included in research to understand what matters to QOL[14,39,46,52]. I identified factors that could influence QOL based on a systematic review and metasynthesis of qualitative studies that asked people with dementia to describe which factors influenced their QOL[64] (Paper 2). Eleven studies (12 reports) met the inclusion criteria [41,53–63].

Four factors were described by people with dementia in the primary studies as having a direct influence on QOL[64] (Figure 1-1; also Paper 2). Experiences that had a positive impact on QOL were characterized by connectedness: "*the perception of a positive or harmonious linkage between one's sense of self and one's experiences of relationships, agency, wellness, and place"* [64, p. 11]. The following terms describe what connectedness looked like for each factor: together, purposeful, well, and located. The findings demonstrated that happiness or sadness were important outcomes of QOL and of each factor, according to people with dementia (Figure 1-1).

Figure 1-1. Conceptual framework of factors that affect QOL for people with dementia



1. Relationships (alone/together): interactions with others, with positive experiences characterized by respect, reciprocity, closeness, kindness, or love.

2. Agency in life today (aimless/purposeful): the person's current ability to express their sense of self, to enact control over the direction of daily life, to produce, to achieve, or to have a meaningful impact on others or society.

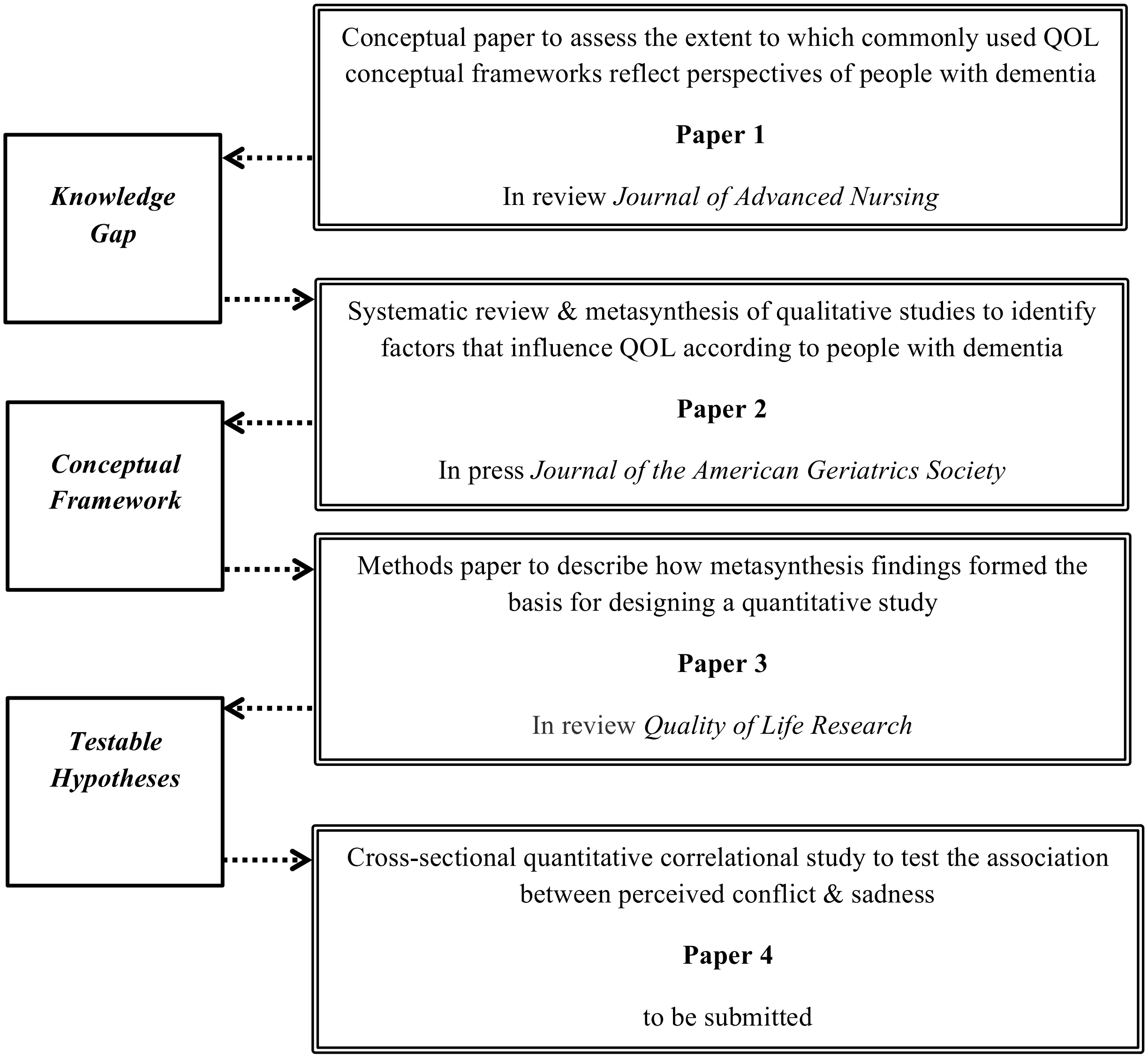
3. Wellness perspective (ill/well): the person's perspective on the meaning of their symptoms, with positive perspectives characterized by an optimistic outlook on life, and incorporation of the illness experience into the context of one's life as a whole.

4. Sense of place (unsettled/located): the person's perceived attachment or emotional bond to their immediate and surrounding environment.

Dissertation Overview

My dissertation includes four related and sequential papers. Briefly, the first is a conceptual paper where I assess the extent to which perspectives of people with dementia have been included to assess and conceptualize QOL in the quantitative dementia-specific literature. In the second paper, I use methods of systematic literature review and metasynthesis of qualitative evidence to identify factors that influence QOL according to people with dementia. The third is a methods paper where I describe how I used the metasynthesis findings (Paper 2) to design a quantitative study (Paper 4). In the fourth, I report on a cross-sectional, quantitative, correlational study that I designed to test the association between perceived conflict (a proposed influencing factor) and sadness (a proposed outcome of poor QOL). I derived the hypotheses tested in this study from the metasynthesis findings. The relationship between the four papers is also shown in Figure 1-2.

Figure 1-2. Four papers on factors that influence QOL for people with dementia



Conceptual paper to assess the extent to which commonly used QOL conceptual frameworks reflect perspectives of people with dementia

Paper 1

In review *Journal of Advanced Nursing*

Systematic review & metasynthesis of qualitative studies to identify factors that influence QOL according to people with dementia

Paper 2

In press *Journal of the American Geriatrics Society*

Methods paper to describe how metasynthesis findings formed the basis for designing a quantitative study

Paper 3

In review *Quality of Life Research*

Cross-sectional quantitative correlational study to test the association between perceived conflict & sadness

Paper 4

to be submitted

Paper 1: Quality of Life for Older Adults with Dementia: Where is the Person?

Objective: The purpose of this paper is to argue that, despite growing consensus that perspectives of people with dementia are essential to understanding what QOL is and how it can be achieved in this population, the *extent* to which people with dementia's perspectives were used by researchers who use quantitative methods to understand QOL continues to vary.

Description: There is growing consensus that capturing the perspective of older adults with dementia will improve understanding of their QOL. The purpose of this paper is to assess the extent to which perspectives of people with dementia have been used to assess and conceptualize QOL in the quantitative literature. A selection of tools developed with the intention of capturing QOL according to the perspectives of people with dementia were examined. The extent to which tool developers included perspectives of people with dementia during assessment, domain identification, and within an overall QOL conceptual framework was rated.

This paper extends the proxy versus self-assessment debates by demonstrating that the areas important to construct conceptualization, namely how domains are identified and where subjective QOL fits within a framework for overall QOL, have received far less dedicated attention by quantitative researchers in the field. There is a current lack of consensus on how the perspectives of older adults with dementia should be used in domain identification and QOL frameworks. This issue has remained largely unacknowledged, with little significant debate in the quantitative dementia-specific literature to date. I argue for transparency regarding whose perspectives are included to conceptualize QOL and debate about whose perspectives should be included.

Linkage: Paper 1 demonstrates that a gap exists in our understanding of what influences subjective QOL because previous research has not sufficiently demonstrated that influencing factors studied are actually important to QOL from the perspective of people with dementia. This research gap supports the rationale for Paper 2.

Paper 2 Factors that Affect Quality of Life from the Perspective of People with Dementia: A Metasynthesis

Objectives: To comprehensively and systematically identify, appraise and synthesize qualitative evidence on factors that affect QOL from the perspective of people with dementia.

Description: This empirical study applied the method of metasynthesis[65] to systematically review and synthesize primary qualitative studies that aimed to identify factors that influence QOL from the perspective of people with dementia. Research that was published or located in the grey literature was included. Expert-developed search strategies were applied in nine electronic databases. Reference lists of included articles and literature reviews identified during the search were reviewed. Structured inclusion criteria were applied to screen 5625 titles/abstracts in order to identify 11 qualitative studies published from 1975 to April 2012. Two independent reviewers appraised study quality using the Critical Appraisal Skills Programme checklist. All studies were included, regardless of their quality scores.

The 11 included studies recruited participants from long-term care and community based settings in the United Kingdom, United States, Canada, The Netherlands, Ireland, Australia and Japan. The primary studies' authors used interview and focus group methods and the total combined sample from all 11 studies included 345 people with mild, moderate and severe dementia. The findings from the primary studies were synthesized using analytic techniques of taxonomic analysis, constant comparison and importing concepts.

Results of this synthesis demonstrated that people with dementia commonly described four factors, and the experience of either connectedness or disconnectedness within each factor, as influencing their QOL. The four factors identified are all potentially modifiable areas to improve QOL for people with dementia, even in the context of worsening cognitive function. These factors, and the terms that represent connectedness/disconnectedness, were: relationships (together / alone), agency in life today (purposeful / aimless), wellness perspective (well / ill), and sense of place (located / unsettled). Although the purpose of the review was to identify influencing factors and not outcomes of QOL, happiness and sadness were highlighted as key outcomes of good and poor QOL, respectively, because they were discussed frequently as an outcome of, and at times synonymously with, good and poor QOL. This indicated that it is important to also consider happiness and sadness when trying to understand which factors influence QOL for people with dementia.

Linkage. Paper 2 begins to address the knowledge gap identified in Paper 1 by determining which factors influence QOL from the perspective of people with dementia. Further research is needed to determine whether the factors are associated with QOL (or with other related outcomes highlighted by people with dementia like happiness and sadness) in representative samples of people with dementia. Paper 3 provides rationale for and describes how I moved from metasynthesis themes on factors that influence QOL from the perspective of people with dementia to a quantitative study to test hypotheses derived from metasynthesis findings.

Paper 3: Embedding the Perceptions of People with Dementia into Quantitative Research Design

Objectives: The purpose of this paper is to describe how findings from a body of qualitative research on patient perspectives about QOL were linked to a clinical administrative dataset and then used to design a subsequent quantitative study.

Description: Patient perspectives about QOL are often found in the findings of qualitative research, and could be applied to steer the direction of future research. In this methods paper, it is described how themes from metasyntheses on what affects QOL according to people with dementia (O'Rourke et al[64]) and people who live in long-term care (Bradshaw et al[66]) were used to design a quantitative study of people with dementia in long-term care.

Selected themes and their supporting sub-concepts were mapped to an administrative dataset and used to determine the study focus, formulate nine hypotheses from themes and their sub-components, and select a patient-reported outcome. A literature review followed this process to confirm existence of a knowledge-gap, identify adjustment variables, and support design decisions. Several challenges were encountered in this process including (i) mapping broad themes to the administrative dataset; (ii) decisions associated with inclusion of variables *not* identified by people with dementia from the qualitative research; and (iii) selecting a patient-reported outcome, when the dataset lacked a valid measure of subjective QOL. From this process, a quantitative study to test the association between conflict in relationships and sadness for people with dementia in long-term care was designed. This approach can generate quantitative findings that will be meaningful with respect to the QOL of the target population.

Linkage: Increasingly, there are calls to enhance QOL in ways meaningful to the growing population of people with dementia in long-term care settings. There is a body of qualitative research that asks people with dementia to identify which factors matter to their QOL. However, there is a tension between describing the perspectives of select groups of people with dementia, and developing generalizable knowledge on how to improve QOL within large populations. This paper considers how to bridge metasynthesis evidence (Paper 2) with quantitative research (Paper 4).

Paper 4: The Association between Conflict and Sadness for People with Moderate and Severe Dementia in Long-Term Care

Objectives: In qualitative studies, people with dementia have described how conflict with others contributes to their sadness and worsens QOL. The purpose of this study was to test if conflict with family/friends, staff, or other long-term care residents was associated with sadness among older adults with moderate and severe dementia in long-term care.

Description: The design was cross-sectional, retrospective, and correlational. The data source was Resident Assessment Instrument 2.0 data collected between 2012-2013 from a random sample of 5001 residents with moderate and severe dementia in 613 Ontario long-term care facilities. Hypotheses were tested using multiple logistic regression with cluster correction. Potential confounders were assessed and included age, sex, education, length of stay, hearing and vision impairment, family/friend contact, use of psychopharmacological drugs, and pain. Effect modification by cognitive impairment and functional status was tested.

The mean age of the sample was 86.3 years (SD=7.03). Seventy-two percent were female and 45% had severe cognitive impairment. Fifty-nine percent displayed sadness and 12% reported conflict with others. Sadness (after adjusting for age, sex, family/friend contact, pain, cognitive impairment, and functional dependence) was positively associated with conflict with family/friends (OR 1.91; 95% CI 1.26-2.88; p=0.002) and staff (OR 1.51; 95% CI 1.07-2.13;

p=0.020). These associations did not differ depending on the level of cognitive impairment or functional dependence. The association between co-resident conflict and sadness differed for people with moderate (OR 2.02; 95% CI 1.45-2.82; p<0.001) as compared to those with severe dementia (OR 1.18; 95% CI 0.72 to 1.91; p=0.511).

The results demonstrated that Ontario long-term care residents with moderate and severe dementia who reported conflict with others had higher odds of sadness, except if the person had severe dementia and the conflict was with co-residents. Future research should determine if perceived conflict is modifiable in moderate and severe dementia, and whether reducing it decreases sadness and improves QOL.

Linkage: Paper 2 showed that people with dementia perceived that conflict in their relationships with others had a negative influence on their QOL and lead to sadness, both directly (i.e. perceived conflict→sadness) and indirectly (i.e. perceived conflict→ poor QOL→sadness). Paper 4 reports on a study that tests 9 hypotheses derived from these findings, in order to establish whether a sub-set of the associations proposed in the metasynthesis are generalizable to a population of people with moderate and severe dementia in Ontario long-term care facilities.

Summary of the Dissertation

To respond to the concern that QOL for people with dementia is sub-optimal, this dissertation identifies factors that affect QOL from the perspective of people with dementia that have the potential to be used as targets for interventions in future research. To remain consistent with a subjective definition of QOL, the four distinct but related papers that comprise this dissertation each focus on the importance of including the perspective of people with dementia in order to understand their QOL, and the factors that affect it (chapters 2-5). In chapter 6, I will describe general conclusions that are supported by the findings of my dissertation as a whole, and implications of my findings for future research, practice and policy.

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Chapter 2. Paper 1- Quality of Life for Older Adults with Dementia: Where is the Person?

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Introduction

There is a large and growing population of people with dementia worldwide [1,2]. In Canada, dementia is the greatest cause of disability among adults over 65 years of age [3]. Symptoms progress over time, and eventually become very severe [3]. People with mild dementia experience symptoms of minor forgetfulness like losing track of time or getting lost in familiar places, some communication impairment like difficulty finding the right word, and problems with complex decision-making[2]. People with moderate dementia forget recent events and people's names, have impaired speech and verbal comprehension, and depend on others to meet personal care needs like toileting and hygiene[2]. At the far end of the mild-moderate-severe continuum of dementia, people with severe dementia may no longer even recognize friends and family, they often use non-verbal communication because their verbal abilities are highly impaired, and they depend extensively on others to meet their needs, including requiring assistance to eat[2].

Because symptoms are chronic, progressive and incurable, maintaining and improving quality of life (QOL) is a key goal underpinning care for older adults with dementia [4]. QOL in the dementia literature is usually represented as a broad and holistic construct, as opposed to the narrower concept of 'health-related QOL', which focuses on the disease-related changes that the person experiences [5,6]. By definition, health-related QOL worsens with increased symptom severity[7,8]. As a result, while health-related QOL is less modifiable in dementia at the current time due to a dearth of knowledge on effective symptom treatment, maintaining the broader notion of QOL remains possible, important and desirable [4]. Health care providers thus strive to support QOL for older adults with dementia[4,9]. However, it is difficult to understand what improves QOL in the context of cognitive impairment [10], so QOL for people with dementia is also a research priority [3,11,12].

While there is no current consensus on the meaning of QOL for people with dementia[5,13–16], researchers have reached a relatively high level of consensus that QOL in dementia is, at least in part, a subjective construct [17–26]. It is therefore important, and perhaps even essential for construct validity [27], to capture the perspectives of people with dementia to understand their QOL. For over a decade, research has explored how to obtain valid reports of QOL from people with cognitive impairment [5,11,12]. Early studies on the topic highlighted some researchers' concern that people with dementia could not assess their QOL because of reduced cognitive function and lack of insight into their own disease and limitations [8,11,28]. Proxy-only evaluations to assess QOL were often used in response to this perceived problem [11]. Because proxy evaluations ask someone else to evaluate the person with dementia's QOL, a key limitation of this approach is that it excludes the perspectives of older adults with dementia.

More recent work has challenged the claim that cognitive impairment reduces people with dementia's ability to assess their own QOL. Research highlights that people with dementia retain awareness of their subjective state even if they lack insight into their cognitive function [21,29]. Furthermore, cognitive functioning may have no association with QOL, after adjusting for other factors [30]. Researchers also caution that proxy assessments do not accurately capture how people with dementia actually feel about their QOL [20,22] because, when compared to QOL ratings made by people with dementia, proxies' ratings are consistently lower [20,29,31,32]. Furthermore, evidence suggests that depressed caregivers rate people with dementia's QOL even lower, demonstrating how caregivers' mental health, which is potentially affected by stress in response to the responsibilities of caregiving, might further distort proxies' QOL appraisals [31].

In addition to the growing body of evidence against the validity of proxy reports, critiques have also been made of the QOL construct (and not just the assessment of that construct). The QOL construct has been criticized as ideological and bound to the norms and values of the 'well' population [33]. A normative view of QOL occurs when the construct is conceptualized by people without disease, and can contribute to stigmatization of older adults with dementia when increased dependence or cognitive impairment is assumed to worsen QOL [21,22,33]. One response to this critique is to conduct research on what QOL could mean in situations of worsening cognitive impairment and increasing dependence [10]. Ensuring that the QOL construct captures subjectivity — *the perspectives of people with dementia*—may be an important first step to determine how to achieve QOL in this population, and to avoid superimposing one's own views about QOL onto older adults with dementia [21,31,34]. This highlights that it is very important to consider whose views of QOL are reflected by the various conceptualizations of the QOL construct in the dementia-specific literature, yet this issue has received far less attention than has the question of who should assess QOL.

To extend the conversation beyond the issue of proxy versus self-assessment, this paper will critically appraise the extent to which subjectivity was captured during both QOL assessment *and* QOL conceptualization in the quantitative dementia-specific literature. The purpose of this paper is to critique the assessment approaches and underpinning QOL conceptualizations for a selection of well-known QOL tools that were designed to capture perspectives of people with dementia. In critiquing this literature, the main question was: *to what extent have the perspectives of people with dementia been included to understand QOL?* In the dementia-specific literature, the process of QOL conceptualization frequently includes both defining an overall QOL conceptual framework as well as delineating the essential components of QOL, called 'domains'[5,21,35]. As a result, the extent to which the perspectives of people with dementia have been used during QOL assessment and at two different points in QOL conceptualization, domain selection and to define an overall QOL conceptual framework, were examined. The findings will be of interest to researchers who define QOL subjectively, and aim to understand QOL from the perspective of people with dementia.

Extent of Subjectivity in Dementia-Specific QOL

To critically assess the extent that subjectivity (or the perspective of the person with dementia) has been used during QOL assessment and conceptualization, influential or frequently used/cited QOL assessment tools were identified from reading the dementia-specific QOL literature and from existing reviews [15,16,31,36]. Ten tools that were developed to measure QOL according to the perspectives of people with dementia were selected for further evaluation, and the published articles that described development of these ten tools were located and reviewed in detail. None of the selected tools were developed to measure health-related QOL, because this is a different concept [8,37].

The measurement tools were assessed according to the extent that the perspectives of people with dementia were included to understand QOL (Table 2-1). Three different points that are key to understand QOL were considered: the assessment of QOL, the selection of the domains that comprise QOL, and the definition of an overall QOL conceptual framework (Table 2-2) . For each of these points, there were categories that reflected the extent of reliance upon the perspectives of people with dementia, numbered from less to more reliance. The categories for the assessment of QOL were: 1=proxy and self-report were combined to assess QOL; 2= self-report or observation of experiences of people with dementia used to assess QOL. The categories for the extent to which perspectives of people with dementia were included to identify QOL domains were: 1=only others (i.e. people without dementia) identified domains; 2=views of others and people with dementia were combined to identify domains; and 3=only views of people with dementia were used to identify domains. For defining an overall QOL conceptual framework, there were two categories reflecting the extent to which perspectives of people with dementia were used to understand overall QOL: 1=subjective QOL is part of QOL; and 2=QOL is entirely subjective.

Insert Table 2-1 about here

Insert Table 2-2 about here

Assessment

Given the importance of capturing subjectivity in order to understand the construct, the question of who should assess QOL (e.g. people dementia or others on their behalf) drove the proxy versus self-assessment debate[21,29]. Just three of the ten tools described in tables 2-1 and 2-2 combined self-report and proxy measures to assess QOL [19,23,32]. Two of these tools were developed for people with mild and moderate dementia[23,32] , while one was developed for people with mild, moderate or severe dementia[19]. However, the specifics of the combined approaches vary. In the Quality of Life-Alzheimer's Disease (QOL-AD), separate proxy and self-assessments are taken [32]. How these authors envision the proxy assessment as contributing to the QOL evaluation is unclear, but it seems as though the authors favour the self-report measure, and conduct proxy assessments to advance the proxy versus self-assessment debate [20]. In contrast, in the Cornell-Brown Scale (CBS) for QOL in dementia, there is no separation between people with dementia's perspectives and others [23]. The clinician interviews the person with dementia and their caregiver and then rates QOL based on the knowledge gleaned from that interview process [23]. The Quality of Life Assessment Schedule (QOLAS) is yet another combined approach, and uses self-report for people with mild and moderate dementia, and proxy report for people with severe dementia [19].

Seven of the ten tools used an assessment approach intended to capture solely perspectives of people with dementia, via either self-report or observation of people with dementia. The four tools that relied exclusively on self-report were validated for use with people with mild and moderate dementia, but not for people with severe dementia [21,22,25,38]. The three other tools were designed to capture subjective experience through observation. Dementia Care Mapping (DCM), developed for people with dementia who receive long-term care, captures the person with dementia's experiences and perspectives through observation of twelve indicators of relative well-being, a term used by these tool developers as a QOL synonym [18,39]. Whether this tool is most appropriate for people with mild, moderate or severe dementia was not specified, but it has been used to measure QOL across all levels of dementia severity[40,41]. The QUALIDEM is a more recently developed dementia-specific QOL tool that uses observation of over 40 behaviors to assess QOL for people with dementia. Similar to the DCM, it is used for people with mild, moderate and severe dementia who receive care in long-term care settings [42]. The Apparent Affect Rating Scale (AARS) was also developed to capture inner states by observing positive and negative responses, but is only used for people with moderate or severe dementia [17].

Overall this analysis demonstrates that many QOL tools already rely upon the perspectives of people with dementia to assess QOL, and only a few tools combine self-report with proxy report to assess QOL in dementia[19,23,32]. In addition, there appears to be growing consensus that self-report is most appropriate to capture perspectives of people with mild and moderate dementia during QOL assessment, while observation is better for people with severe dementia. However, there are some exceptions to this because the observational approaches are also used for people with mild [18,43] and moderate dementia [5,18,42].

Domain Selection

While it is essential to consider who assesses QOL, it is equally important to consider whose view of QOL is represented by the domains that people with dementia are asked to appraise, or a subjective assessment of a set of normative criteria can result [16]. In other words, it is important to evaluate whether domains, conceptualized as the component parts of the QOL construct, reflect people with dementia's views about QOL or not [27]. Of the ten tools described in tables 2-1 and 2-2, developers of four tools excluded perspectives of people with dementia during domain identification[17,20,23,26]. Domains were selected based on the assumption that the domains of QOL for people with dementia were the same as for other populations. Based on this assumption, domains were derived from the QOL literature from people *without* dementia or from an initial theory of what comprised QOL, also constructed by someone without dementia [5,32]. This is problematic because people without dementia tend to propose domains that represent areas of life directly changed by the disease, while research shows that the relationship between QOL and symptoms like cognitive decline and physical dysfunction is inconclusive [16,22,31]; including these as domains may erroneously assume that QOL worsens with increasing dementia severity.

In response to this concern, developers of another four tools included people with dementia to identify domains[18,19,21,42]. However, in these cases, the perspectives of people with dementia were mixed with those of other individuals or bodies of literature. This approach has also been criticized because, as a result of mixed sources, the extent to which people with dementia's views are actually represented cannot be discerned [44]. During development of these tools, people with dementia's perspectives were combined in unspecified ways with findings from 'the literature' (few details were provided), and input from health care providers, families, and experts [35,42]. In another a mixed approach, QOL domains were identified based on discussions with people with dementia, observations of the factors that enhance and detract from QOL, and expert opinion [18]. Older adults with dementia have also been asked to select the two areas most important to their QOL from a pre-determined list [19]. This approach is also mixed because the list of domains to choose from was based on epilepsy research and modified after consultation with both people with dementia and their caregivers [19].

The development process for just two tools relied solely upon perspectives of people with dementia to select domains [22,25]. In contrast to the above tools which all mix perspectives to identify domains, one study asked just people with dementia to select the QOL domains during the development phase of the tool [22]. Another tool avoided pre-determined domains altogether, using open-ended questions to ask each person with dementia to nominate which areas were important to his or her QOL [25]. This approach produced an individualized set of domains, according to the perspective of each individual who was actually assessed.

The above shows that, among these ten tools which all aim to capture perspectives of people with dementia, domains have been selected based on perspectives from the older adult with dementia, researchers, health care professionals, caregivers, extant literature and theory, and all of these in a variety of combinations. Perspectives of people *without* dementia were used to identify domains for eight of the ten tools: development of four of these tools actually excluded perspectives of people with dementia; the other four included people with dementia, but their views were mixed with others' so whether the resulting domain lists represents views of people with dementia is unclear. Given this, perhaps the diversity in QOL domains by instrument is unsurprising. Domains were derived from the combination of many perspectives, and it is unclear whose views were prioritized and how differences in perspectives were resolved in order to select the final set of domains[44].

Defining an Overall Conceptual Framework

The positioning of subjective QOL within a conceptual framework that defines overall QOL is a fundamental but rarely discussed area of discord in the dementia-specific QOL literature. The crux of the issue relates to two opposing views: some research teams consider subjective QOL to be indicative of QOL as a whole, while others claim that subjective QOL is only one part of a larger QOL construct. Developers of four of the ten tools described in tables 2-1 and 2-2 applied a conceptual framework that considers subjective QOL to contribute only partially to our understanding of QOL as a whole [16,17,22,28]. Developers of the other six tools applied a conceptual framework that considers subjective QOL as equivalent to overall QOL[18,19,21,23,25,26]. The difference between these two views is further illustrated below by describing how an overall conceptual framework to define QOL was applied by developers of the Apparent Affect Rating Scale (AARS) [17], Dementia Care Mapping (DCM) [18], and the Dementia Quality of Life (DQOL) tool[21].

The conceptual framework applied by the developer of the AARS, although not new, is both an illustrative and important example because it has greatly influenced QOL conceptualization in dementia [13], and has been used as the conceptual underpinning for several other recently developed QOL tools [22,28,42]. Lawton, developer of the AARS, believed that observing emotional states was the major to way to learn about the preferences of people with moderate or severe with dementia (he does not propose how to assess QOL in people with mild dementia) [17]. To this end, he developed the Apparent Affect Rating Scale (AARS) to assess which environmental situations were associated with positive or negative affect for people with dementia [5]. But while such subjective accounts were important, he specified in his conceptual framework that subjectivity was only a piece of the larger QOL construct. For him, *overall* QOL must consider both subjective and objective evaluations [17].

Lawton proposed that the QOL construct consisted of four sectors: behavioural competence and objective environment were the objective sectors of QOL, while psychological well-being and perceived QOL were the subjective sectors [45]. Behavioural competence was how the person performed in their context and could include their activities of daily living (ADL), cognitive function and social behavior [45]. Objective environment was an assessment of environmental quality [45]. Psychological well-being was a global assessment of one's inner state, an "overall evaluation of self in environment" [17, p. 139]. Finally, perceived QOL was an evaluation the older adult with dementia made about each major domain of life. Because the four QOL sectors are structurally distinct, QOL may be positively rated according to objective assessments, even if the person's subjective 'perceived QOL' evaluation was negative [46]. Ways to resolve discrepancies between the four QOL sectors were not described, or were considered unimportant due to the "relative autonomy among sectors" [45, p. 355]. Subjective QOL was just one part of QOL as a whole.

Kitwood and Bredin's DCM is also influential and frequently used in practice to measure and improve QOL for people with dementia [39–41]. The DCM is similar to Lawton's AARS tool in that it also uses observation to assess how people with dementia experience and respond to their environment [18]. But despite using a similar assessment approach, the conceptual framework applied by developers of the DCM differs fundamentally from that underpinning the AARS because QOL was conceptualized as entirely subjective [18]. For Kitwood and Bredin, subjective

QOL is equivalent to QOL as a whole. This conceptualization of QOL gives primacy to the older adult with dementia's subjectivity and experience of QOL. In contrast to Lawton's conceptual framework, Kitwood and Bredin's approach means that QOL for the older adult with dementia cannot be rated positively unless their subjective experience of QOL is positive.

Overall, these two examples illustrate the two conceptual frameworks to define QOL applied by the developers of the ten selected QOL tools: that subjective QOL is either part of QOL, or that QOL is entirely subjective. These positions represent fundamentally different conceptualizations of overall QOL, shaped by the researcher's stance on the contribution that subjective accounts make to QOL as a whole. Rather than engaging in debate, these opposing conceptual frameworks tend to co-exist in relative isolation from one another. The conceptual frameworks developed by Lawton and Kitwood are both seminal and influential in the field, yet neither referred to the other's work. Kitwood and Bredin did not discuss how their work fit with or disputed other QOL frameworks in the area of dementia care [40]. This isolated their work from other influential writers like Lawton who, contrary to Kitwood and Bredin, included objective and subjective components to understand QOL [17,45]. Similarly, Lawton did not refer to Kitwood and Bredin's conceptual framework.

The implication of how one's chosen conceptual framework modifies the contribution that perceptions of people with dementia make towards understanding QOL is further illustrated here with a final example: the development of the Dementia Quality of Life (DQOL) tool[21]. The development of this tool is an interesting example because its developers' QOL conceptual framework shifted over time. The tool's developers, lead by Brod, initially state that QOL has subjective and objective components, but they do not describe how these fit together [21] . However, in their revised conceptual framework, they clearly indicate that, while QOL is *influenced by* objective factors (like context and functioning), the definition and domains of QOL refer entirely to the subjective assessment made by the older adult with dementia[35], demonstrating an important shift in their conceptual framework of QOL as a whole.

Consistency Within and Across Tools

Table 2-3, Table 2-4 and Figure 2-1 show that QOL tool developers are rarely consistent in terms of the extent to which they rely on the perspectives of people with dementia during assessment, domain identification, and to define an overall QOL conceptual framework. Only one tool relied exclusively upon perspectives of people with dementia for all of assessment, domain identification and to understand QOL as a whole [25]. These findings also demonstrate that there were only two tools that were similar to each other in terms of the extent to which the perspectives of people with dementia were used for all of assessment, domain identification and to define an overall QOL conceptual framework [18,35]. Both of these tools used self-report or observation of experience in QOL assessment (assessment=3), mixed perspectives of people with dementia with others to select domains (domain selection=2), and consider subjective QOL as equivalent to QOL as a whole (framework=2).

Insert Table 2-3 about here

Insert Table 2-4 about here

Insert Figure 2-1 about here

Conclusion

This paper considers the extent to which perspectives of people with dementia have been included to assess and conceptualize QOL in the quantitative dementia-specific literature. The findings demonstrate a relatively high level of consensus that perspectives of people with dementia should be captured during QOL assessment, either through self-report or observation.

However, when both QOL assessment and conceptualization are considered, approaches to including people with dementia are inconsistent, both within and across tools. There lacks consensus on the extent to which people with dementia should be included during domain selection and of the contribution that their perspectives make to understanding QOL as a whole. This calls into question how well the body of literature that relies upon these tools aims at a QOL target that reflects perspectives of people with dementia. This uncertainty will be troubling for researchers, policy-makers and practitioners who aim to understand how to enhance QOL according to the criteria and standards set by older adults with dementia. Meaningful debate is needed to consider, and perhaps reconsider, whether the field has done enough to consistently capture perspectives of people with dementia to understand their QOL.

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Table 2-1. Characteristics of QOL tools that intend to capture perspectives of people with dementia

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
Apparent Affect Rating Scale[5,17]	People with moderate to severe dementia	Observation of people with moderate to severe dementia	*Perceived QOL Domains:* family life, friends, standard of living, leisure activities, and residential environment *Areas to evaluate in people with dementia:* cognitive function, competence in activities of daily living, socially appropriate behavior, engagement in positive activities, and presence of positive and absence of negative affects *Areas measured by the AARS to capture 'inner states':* Three negative emotional responses (anger, anxiety/fear, depression/sadness) and	Sectors and Domains selected based on what is 'important to most people', according to literature from other populations and to Lawton's own assertions/ assumptions.	QOL is "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual" [5, p. 91] Four QOL Sectors include: behavioral competence, objective environment, psychological well-being, perceived QOL

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
			two positive responses (pleasure and interest).		
Dementia Care Mapping [18,39]	People with dementia who require care; stage of dementia is not specified	Trained evaluator observes five individuals in a communal area over a representative slice of time (e.g. 6 hours).	Twelve markers of relative well-being: the assertion of desire or will; the ability to express a range of both positive and negative emotion; initiation of social contact; affectional warmth; social sensitivity; self-respect; acceptance of other dementia sufferers; humor; creativity and self-expression; showing evidence of pleasure; helpfulness; and relaxation These 12 markers were distilled into the four senses of: personal worth, sense of agency, social confidence, and	Observations from clinical practice of people with advanced dementia, but who appeared to be ‘faring well as persons’, validated through expert consultation. This observational work is not in the public domain.	Overall QOL is the person’s experience of relative well-being

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
			hope		
Quality of Life Assessment Schedule (QOLAS) [19]	People with mild, moderate or severe dementia	Person with dementia with MMSE >10 If the person with dementia cannot respond, a proxy assesses QOL	Physical, psychological, social/family, daily activities, and cognitive functioning (or well-being).	Comprehensive review of epilepsy literature. Changed 'work/economic function' to 'daily activities' after pilot work with persons with dementia and their caregivers Person with dementia selects two priority domains from the pre-determined areas	Not clear, but appears to take the subjective QOL measure as capturing QOL as a whole: "The results suggest that patients with mild to moderate dementia can rate their own QOL and that the QOLAS is a promising method for assessing QOL in this patient group." [19, p. 240]
Quality of Life-Alzheimer's Disease (QOL-	People with mild and moderate dementia (MMSE > 10)	The person with dementia and a proxy provide separate	Physical health, energy, mood, living situation, self, and life as a whole	Measures selected to match Lawton's 4 sectors of quality of life for older adults	Refers to Lawton who "…provided a broad conceptual framework for QOL in older adults that includes four domains of importance:

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
AD)[20,28]		ratings of the person's quality of life			behavioral competence, the objective environment, psychological well-being, and perceived QOL." [15, p.510]
Dementia-Quality of Life (DQOL) [21,35]	People with mild and moderate dementia (i.e. MMSE >12)	Person with dementia	Self esteem, positive affect, negative affect, feelings of belonging, sense of aesthetics	Literature search and focus groups with persons with dementia, caregivers, and health care providers	QOL is subjective, but is influenced by objective factors QOL is "a multidimensional construct uniquely defined by the nature and experience of living with dementia" [21, p. 6] also "a multidimensional concept encompassing social, psychological, and physical domains" [35, p.25]
Bath Assessment of Subjective	People with mild and moderate dementia (MMSE ≥	Person with dementia	Health, Social interaction, Function, Mobility, Being occupied, Energy, Sleep, Psychological	In-depth interviews with people with mild to moderate-stage dementia	Subjective QOL is "the individual's own subjective perception of his or her position in life " [22, p. 789]

Tool	**Target Population**	**Assessment**	**Domains**	**Domain Selection**	**Conceptual Framework**
Quality of Life in Dementia (BAS-QUID) [22]	12)		well-being, Environment	(domains listed but primary study not published)	Refer to Lawton: Overall QOL is "a multidimensional construct that should include not only objective (observable) indices of well-being judged against socionormative criteria, but also the individual's own subjective perception of his or her position in life " [22, p. 789]
Cornell-Brown Scale for QOL in Dementia (CBS) [23]	People with mild and moderate dementia (i.e. MMSE ≥ 9)	Clinician rates the areas, after interview with person with dementia and caregiver. Can give separate ratings for	Mood, ideational/ behavioral disturbances, physical signs, cyclic functions (based on the idea that QOL is indicated by Positive affect, satisfactions, self esteem, and lack of negative affect)	Not described	"the QOL construct is multidimensional, subjective, and distinct from other disease factors, and that assessment should include measurement of positive and negative dimensions" [23, p. 109]

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
		patient and caregiver.			
QUALI-DEM [13,42,43]	People with mild to severe dementia	Observation of 40 behaviors for people with mild to very severe dementia by a trained observer	Care relationship, positive and negative affect, restless, tense behavior, positive self image, social relations, social isolation, feeling at home, having something to do	Literature study, an adaptation-coping model, focus group discussion with people with dementia, and expert opinion.	"Dementia-specific QOL is the multidimensional evaluation of the person–environment system of the individual, in terms of adaptation to the perceived consequences of the dementia" [13, p. 366] Refer to and emphasize Lawton's conceptualization of QOL: "Although Lawton's definition of QOL applies to all people, the operationalization has to be differentiated to the population under study (Lawton, 1997), for example for people with dementia. When QOL is measured within one population, the

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
					instrument has to be sensitive to the particular properties of that population. Lawton again stressed the multidimensionality of the concept and the need to assess QOL subjectively as well as objectively." [13, p. 358]
Schedule for the evaluation of individual QOL (SEI-QOL) [25]	People with mild dementia, but only 6 of 20 could complete procedure; suggest proxy responses may be used as dementia worsens, but the authors express	Person with dementia; not recommended for advanced dementia	No pre-determined areas of life, but prompting (reading a list of possible life areas) was sometimes necessary	Open-ended question to ask the person with dementia to nominate 5 areas of importance to their QOL	"QOL is considered to be what the individual says it is" [25, p. 155].

Tool	Target Population	Assessment	Domains	Domain Selection	Conceptual Framework
	concern with this approach and it is not examined empirically here				
Minnesota Resident QOL and Satisfaction Survey [26,38]	People with mild and moderate dementia	Self-report by the person with dementia; not recommended for people with advanced dementia	Meaningful activities, autonomy, privacy, relationships, and individuality	Literature review, a tool on QOL for people in long-term care facilities, expert opinion, focus groups, and discussions with stakeholders. Specifically who was included in these discussions or focus groups is not clear.	"QOL is a multidimensional and subjective construct, influenced by both individual and environmental factors" [26, p. 633]

Table 2-2. Extent of inclusion of perspectives of people with dementia by tool developer

First Author, Year	**Tool**	**Assessment**	**Domain**	**Framework**
Lawton 1994, 1997	Apparent Affect Rating Scale (AARS)	2	1	1
Kitwood 1992, 1995	Dementia Care Mapping (DCM)	2	2	2
Selai 2000	Quality of Life Assessment Schedule (QOLAS)	1	2	2
Logsdon 2000, 2002	Quality of Life-Alzheimer's Disease (QOL-AD)	1	1	1
Brod 1999, 2000	Dementia-Quality of Life (DQOL)	2	2	2
Trigg 2007	Bath Assessment of Subjective Quality of Life in Dementia (BASQUID)	2	3	1
Ready 2002	Cornell-Brown Scale for QOL in Dementia (CBS)	1	1	2
Ettema 2005, 2007 Bouman 2011	QUALIDEM	2	2	1
Coen 1993	Schedule for the evaluation of individual QOL (SEIQOL)	2	3	2
Abrahamson 2012, 2013	Minnesota Resident QOL and Satisfaction Survey	2	1	2

Note: For assessment, the categories were: 1=combine proxy and self-report; 2= self-report or observation of experiences of people with dementia. For domain identification, the categories were: others only=1; combine others and people with dementia=2; and people with dementia only=3. For conceptual framework, the categories were: subjective QOL is part of QOL=1; and QOL is entirely subjective =2.

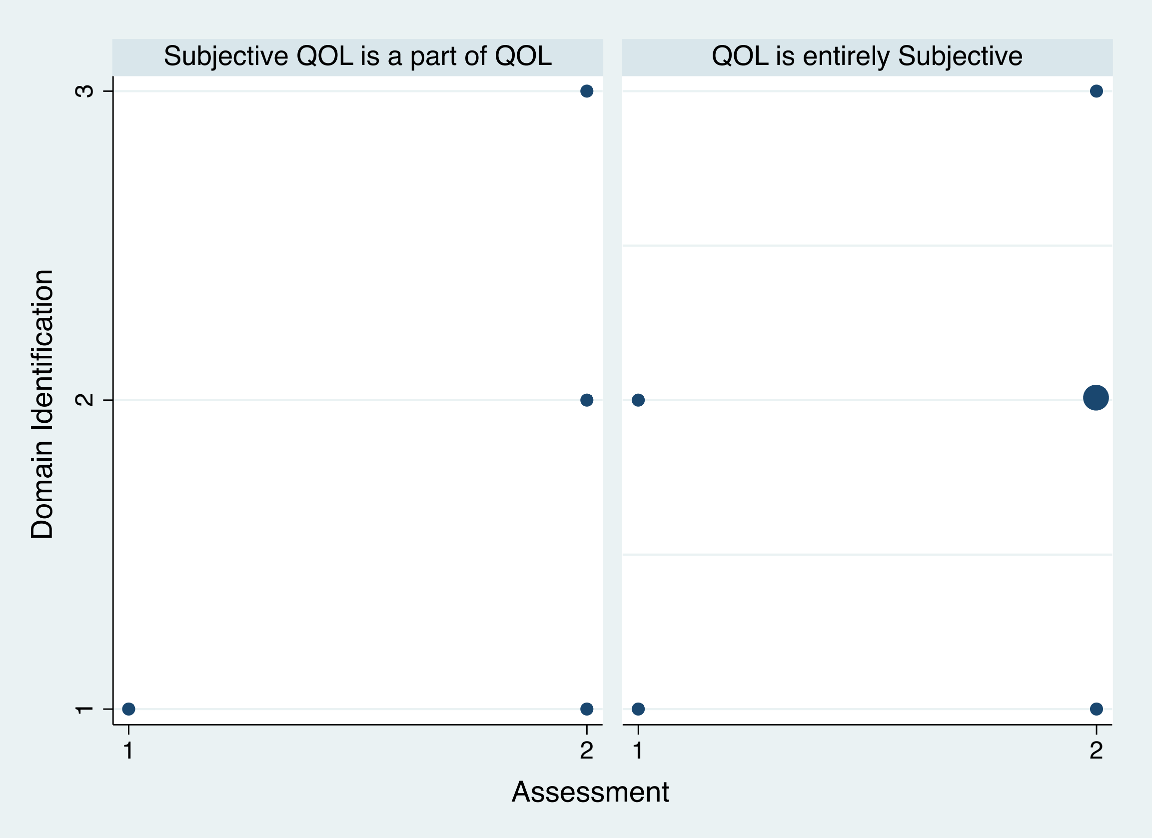
Table 2-3. Number of tools in each category for tools developed with an underpinning conceptual framework that subjective QOL is part of QOL (n=4)

	Domain Identification		
Assessment	*Others only*	*Mixed*	*People with dementia*
Mixed	1	0	0
People with dementia	1	1	1
Total	**2**	**1**	**1**

Table 2-4. Number of tools in each category for tools developed with an underpinning conceptual framework that QOL is entirely subjective (n=6)

	Domain Identification		
Assessment	*Others*	*Mixed*	*People with dementia*
Mixed	1	1	0
People with dementia	1	2	1
Total	**2**	**3**	**1**

Figure 2-1. Number of tools in each category according to extent of inclusion of the perspectives of people with dementia to both assess and conceptualize QOL



Note: All circles represent a single study, except for the larger circle that represents the two studies that rated the same on all variables of assessment, domain identification, and conceptual framework. For assessment, the categories were: 1=combine proxy and self-report; 2= self-report or observation of experiences of people with dementia. For domain identification, the categories were: others only=1; combine others and people with dementia=2; and people with dementia only=3.

Chapter 3. Paper 2-Factors that Affect Quality of Life from the Perspective of People with Dementia: A Metasynthesis

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Introduction

The growing population of people with dementia (PWD) require support to achieve good quality of life (QOL)[1–4]. Good QOL is a positive "evaluation of one's life perspective"[5, p. 186], influenced by context, value systems, and one's "goals, expectations, standards and concerns" [6, p.1]. Factors, entities that influence QOL[7], could be used as targets for improvement interventions[3]. However, there is little agreement on which factors affect QOL for PWD[8–10].

Research that targets outcomes that matter to patients is an international priority[11,12]. The United States, for example, has created the Patient-Centered Outcomes Research Institute that, by law, must capture patient perspectives to ensure relevance of research questions and outcome measures to address patients' needs[12]. In terms of QOL research for PWD, capturing patient perspectives to determine which factors affect QOL would identify patient-oriented targets for future research[13].

PWD can discuss their QOL[13–17], yet researchers rarely considered the perspective of PWD when developing instruments, selecting QOL factors based on literature from other populations, and expert or caregiver opinion[18]. Individuals without dementia have found it difficult to imagine a good QOL for people with dementia, and may have overemphasized disability[7] by focusing on direct consequences of dementia like cognitive impairment, dependence, and communication problems[15,19–24]. PWD have been included to identify QOL factors in some instrument-development studies, but these studies also contained expert or family data[13,16,25] or methods were not described[17] so it is unclear if PWD's views were accurately captured.

There are several exploratory qualitative studies where PWD were asked to describe what factors affect their QOL (see Table 1), but these have not been examined collectively.

Metasynthesis is a method to synthesize and examine qualitative studies' findings collectively[27] to derive more abstract generalizable conclusions[28,29]. The purpose of this study was to synthesize qualitative research findings in order to identify a set of factors that affect QOL from the perspective of PWD.

Methods

A metasynthesis approach involving a systematic review of qualitative studies, study appraisal and classification, and synthesis of findings [27] was used. Sandelowski and Barroso's metasynthesis method was selected because this method was designed to produce integrated conclusions (as opposed to a critique or other product) of the state of knowledge in a topic area [27]. A study was included if: a) it was qualitative research; b) a primary purpose was to identify factors that affect QOL from the perspective of PWD; and c) full-text was written in English after 1970.

Studies that did not differentiate perspectives of PWD from caregivers or family members were excluded because it was unclear whose viewpoint was reflected. 'No-finding reports', where raw data were presented without interpretation, were not defined as qualitative research and were excluded[27]. The date limitation was applied (during full text screening) because perceptions of factors may have differed prior to growth of the long-term care facility industry in the late 1960s[30] and framing of dementia as a disease in the 1970s[31].

Search Strategy

To ensure a comprehensive search, databases and search terms were identified in consultation with a health sciences research librarian. The following databases were searched from date of inception to April 2012: PsycINFO, Medline, Embase, CINAHL, Abstracts in Social Gerontology, Web of Science, Proquest Dissertations and Theses, Scopus, and OCLC

PapersFirst. Medical subject headings and keywords captured synonyms for ‘QOL’ and ‘dementia’. Expert-developed qualitative and mixed methods filters were applied to results in all but the two grey literature databases where filters were unavailable (i.e. Proquest Dissertations and Thesis and OCLC PapersFirst). Reference lists of included articles and literature reviews located during the search were reviewed.

Inclusion/exclusion criteria were finalized after two independent reviewers (HMO and LJ) screened a sample of 282 titles/abstracts and 10 full text articles. One reviewer (HMO) applied the finalized inclusion/exclusion criteria to all titles/abstracts and then to full text. A second reviewer (LJ) also screened seven full-text articles that did not clearly fit the criteria, to reach consensus on their exclusion.

Data Extraction and Quality Appraisal

One reviewer (HMO) extracted information into a Microsoft Office Word table for all included studies on: purpose, guiding orientations or conceptual frameworks, methodology, sampling, sample characteristics, data collection, analytic approach, findings (themes and supporting quotes), overall quality impressions, and applicable references. Two reviewers (HMO and LJ) followed a detailed guide to read and classify each study [27] . Using the Critical Appraisal Skills Program (CASP) tool [32], each reviewer then independently assessed whether the aims of each study were clear and could be addressed using qualitative methodology, and if appropriate and/or rigorous research design, recruitment, data collection, consideration of researcher influence, ethical procedures, and analysis had occurred. Whether the findings were clear and valuable was also assessed. CASP scores for each criterion were dichotomous (yes or no). Disagreements on CASP scores were resolved through discussion to determine the final CASP scores, establishing “negotiated consensual validity”[27, p.229]. Studies were included regardless of CASP scores because even procedurally problematic studies contained clear findings supported by evidence[27,33].

Analysis

HMO completed all analysis, and met periodically with WD and KDF to discuss and debate the emerging findings. Analysis was inductive and techniques included taxonomic analysis, constant targeted comparison, and importing concepts[27]. Taxonomic analysis was used to synthesize the concepts represented in the studies' findings and the steps were: list concepts represented in each study, group concepts based on their semantic relationships (e.g. x is a negative outcome of y), and define overarching key concepts.

Next, constant targeted comparison was used to specify conceptual boundaries and define key concepts by comparing in-study to extra-study phenomena[27]. In metasynthesis, constant comparison follows synthesis to compare "sets of findings as a whole" instead of individual quotes[27, p.201]. Synthesized findings were compared to concepts identified by WD and HMO from the following bodies of literature: QOL in healthy older adults, wellbeing for PWD, and factors related to QOL from the perspective of people without dementia.

Last, the concept of 'connectedness' was imported from extant literature to further synthesize the findings[27]. The importing concepts technique is used when a concept from other literature accurately represents and further integrates sets of metasynthesis findings (e.g. by describing an observed tension).

Results

Context and Quality

Twelve articles (reporting on 11 studies or n=11) met the inclusion criteria (Figure 3-1, Table 3-1). The majority of PWD were females over 65. Studies included some people with dementia that was mild (n=10), moderate (n=7), and severe (n=4). CASP scores ranged from three to nine out of ten (Table 3-1, Table 3-2). Most studies reported explicit findings supported by data and related to the original research question (n=9). Thus, the studies' findings were credible, despite the 'noise' of poor methodology or reporting. This is a priority quality consideration in metasynthesis[27].

Insert Figure 3-1 about here

Insert Table 3-1 about here

Key Concepts

Six key concepts, described in detail below, were identified. Connectedness (concept 1), was a state represented in each of the four influencing factors. The influencing factors were Relationships (concept 2), Agency in Life Today (concept 3), Wellness Perspective (concept 4), and Sense of Place (concept 5). Concept 6 was Happiness/Sadness, outcomes of good/poor QoL.

Concept 1: Connectedness

Each study supported connectedness as a key concept (Table 3-3). The importance of being connected to family, other residents, or PWD[34–36] and to one's immediate living environment[37] and external surroundings[35] was stated. Other terminology, such as interaction[7,35,38,39], participation[26,37,38], involvement[34], attachment[37,38], contact[26], and cooperating[40], further supported the concept of 'connectedness'. Descriptions of incorporating or making sense of challenges showed that the person, while ill, could remain connected to broader aspects of life[35,36,39,41]. Terms like ability, control, and autonomy implied connection between goals or desires and the ability to enact them[34–36,39,42,43].

Positive and negative experiences were possible within each factor, which respectively had a positive or negative influence upon QOL (Figure 3-2). Connectedness integrated the findings because positive experiences were characterized by connectedness in each factor. The terms for connectedness as opposed to disconnectedness for each factor are shown in brackets below. Overall, ‘connectedness’ was *the perception of a positive or harmonious linkage between one’s sense of self and one’s experiences of relationships, agency, wellness, and place.*

Concept 2: Relationships (Together / Alone)

Relationships affected QOL for PWD in all studies. Relationships included interactions with family, friends, and long-term care staff and co-residents[7,26,35–38,41,43]. Contact with others was important, and lack of opportunity to talk[26,34,37,38,42] or interact with others[26,34,37,41] detracted from QOL.

In all studies, relationships characterized by kindness, love, or respect enhanced QOL. These relationships lead to feeling accepted, listened to, or understood[26,36,37]. Receiving help[26,34,36,37], and helping others[7,26,34,36,41] were important for QOL, highlighting a desire for reciprocity.

While all studies emphasized close relationships with family and friends, kind and respectful interactions with acquaintances and long-term care staff were also important[7,26,35,37,38,40–42]. Experiencing distrust[26,37], conflict, or indifference from others[26,34] caused loneliness and worsened QOL[26,34,35,41,43].

Overall, ‘relationships’ were *interactions with others, with positive experiences characterized by respect, reciprocity, closeness, kindness, or love*. When PWD felt linked to others, they were *together* and experienced improved QOL. When PWD perceived disconnection in relationships because of absent or negative interactions, they were *alone*.

Concept 3: Agency in Life Today (Purposeful / Aimless)

Ability to express one’s sense of self, and to enact autonomy and independence in day-today living enhanced QOL[7,26,34–36,40,41,43]. Being able to determine the structure of daily activities[41], have a direction in life[43], or achieve one's goals[7,26,43] improved QOL for PWD. PWD frequently set achievable goals, such as living in peace and quiet[7,37,41] or enjoying life's simple pleasures[7,26,34,38,41,43], like listening to music. QOL worsened when disability[7,26] or rules in care settings[34,41] limited participation in desired activities. Financial stability was important to QOL[7,26,35,40] because it supported enactment of agency[7,26].

Contributing to others or society, a component of agency, mattered to QOL[7,26,34–36,41–43]. When contributions to others were less tangible, belief in a higher power could build confidence that, even if it was not understood, there remained a purpose to one's existence[7,26,35,40].

Overall, 'agency in life today' was *the person's current ability to express their sense of self, to enact control over the direction of daily life, to produce, to achieve, or to have a meaningful impact on others or society*. When perceived needs and desires for daily life linked to the ability to enact those needs and desires, PWD felt *purposeful* which positively influenced QOL. When daily life was disconnected from needs and desires, PWD were left feeling *aimless* which worsened QOL.

Concept 4: Wellness Perspective (Well /Ill)

Across all studies, PWD held different perspectives on the meaning of their chronic disease symptoms and emphasized that, for people living with chronic disease or other age-related changes, one's outlook on life affected QOL. It was not simply impairment, but how one experienced health, aging, or chronic conditions that affected QOL.

For example, people with multiple chronic diseases reported that when they perceived they were in good health[7,36,37,41], or able to do what they wanted[7,26,35], that this enhanced QOL. Some stated that things could be a lot worse[7,36], or that dementia-related changes were smaller than anticipated[36,41], thus maintaining optimism and a focus on wellness, while at the same time acknowledging their illness. Conversely, sensing that one's disease negatively affected others could lead to a focus on illness and reduce QOL[26,36]. While effects of forgetfulness on QOL were highlighted in several studies, others did not identify memory concerns as a prominent theme[34,37,38,40,42]. This variation supported that the meaning that PWD attached to their own symptom experience, not simple impairment, mattered to QOL.

Overall, 'wellness perspective' was *the person's perspective on the meaning of their symptoms, with positive perspectives characterized by an optimistic outlook on life, and incorporation of the illness experience into the context of one's life as a whole.* In a *well* perspective, illness experiences were incorporated into life and did not dominate. In an *ill* perspective, focus on illness disconnected PWD from broader life experiences, detracting from QOL.

Concept 5: Sense of Place (Located / Unsettled)

Across studies, meaningful attachment between PWD and their immediate and surrounding environment supported QOL. Feeling at home in one's immediate environment was important to QOL[7,26,37,40], but meaningful attachment to the long-term care environment occurred even in disorientation when PWD believed they were at work or visiting a relative[37]. Others developed attachment to the long-term care facility as a place that met their needs[42]. Interest or involvement in the world beyond one's immediate context maintained emotional bonds with the surrounding environment[26,34,38,42], and enjoyable outings assisted PWD in some studies to engage with broader contexts[26,35,41,42].

A profound sense of displacement could result when meaningful attachments were only to places other than the immediate environment[37]. When PWD lacked attachment to their immediate context, QOL decreased[37]. QOL worsened for PWD because of boredom and disengagement from their surroundings[34,35,43], or perceived absence of a role in their environment[40,43]. Further, devaluation of older adults and PWD caused isolation from broader society[7,34].

Overall, 'sense of place' was *the person's perceived attachment or emotional bond to their immediate and surrounding environment*. When PWD formed positive meaningful attachments to their current environment, they felt *located*. PWD felt *unsettled* when they perceived there was a misfit, negative emotions associated with, or no emotional attachment to their current environment.

Associations Among QOL Factors

There was evidence of associations among the factors that affect QOL. Being together in relationships contributed to being located in sense of place. For example, positive relationships with long-term care staff helped PWD feel at home[37] and meaningful family interactions linked PWD in long-term care to their community[34]. Being together as the result of receiving assistance also supported a well perspective[26,35,37,38,42]. An ill perspective could result when PWD felt alone as others withdrew in their time of need[37,42]. Further, PWD who felt aimless because they could not achieve what they wanted often held an ill perspective[7,26,35,37,42], which could be mitigated by receiving support from others[38]. Relationships supported PWD to become purposeful through goal-achievement[38] or participation in desired activities[37].

Insert Figure 3-2 about here

Concept 6: Happiness and Sadness

PWD in most studies described happiness and sadness as important *outcomes* of good or poor QOL, and all factors that influenced QOL also impacted happiness or sadness[7,26,34–37,40–42]

(Table 3-3). Being together led to happiness or enjoyment[7,26,34,37,40–42], whereas being alone led to grief, devastation, sadness, or depression[7,26,34,37,41,42]. A well perspective resulted in happiness or contentment[36,37,40,41], and being ill was linked to sadness and sometimes depression[34,37,39]. Being located resulted in happiness, enjoyment, or satisfaction[7,37,42], whereas feeling unsettled led to sadness[37]. A purposeful experience led to happiness, enjoyment, or pleasure[7,34,37,38,40,42], whereas feeling aimless could result in sadness[26,37]. Overall, 'happiness' was the experience *of feelings of pleasure, contentment, satisfaction or joy.* 'Sadness' was *an experience of being affected by unhappiness, grief, sorrow or mourning.*

Discussion

Factors Affecting QOL

A feeling of connectedness positively influenced QOL within each factor. Similarly, connectedness was also emphasized in QOL research among older adults without dementia[44]. Register's QoL framework included connectedness in each of six factors (metaphysical, spiritual, biological, relational, environmental, and societal)[44] and the factors in this metasynthesis differ in several ways. In this metasynthesis, being located explained linkage to society and environment, forming a single factor. Spirituality was not a stand-alone factor as in Register's theory, but was one way that PWD achieved feeling purposeful. Biological connectedness in Register's theory emphasized preventing illness, fixing health problems, and avoiding dependence, and optimistic perspectives in the face of permanent changes to one's health were not addressed[44]. In contrast, this metasynthesis emphasized a well perspective, and connectedness manifested in a context of substantial disability, similar to the wellness perspective described in a meta-study of research conducted with people with chronic disease[45].

These findings have similarities and differences to factors proposed as important to QOL for PWD in research that drew on the opinions of people without dementia. Clinicians, researchers, or family of PWD also emphasized social interactions and family relationships[15–17,21,23,25]. Unlike PWD, they proposed that cognitive function[15,16,24], behavioral dementia symptoms[22,23,25], ability to care for oneself[16,24], or functioning as though without disease[15,17,22,23,46,47] were factors that directly influenced QOL, or were even essential components of QOL, for PWD. This metasynthesis challenges these claims, suggesting that interaction of the experience of impairment, fit between perceived need and support received, and ability to enact agency affect QOL, not simply impairment or dependence. This helps explain why research on the association between cognitive impairment and QOL remains inconclusive[5,48].

These findings support the importance of daily activities to influence QOL for PWD[15,16,21,23], but such activities are captured within the more encompassing factor of agency in life today. Being occupied[17] or having something to do[25] better reflects the purposeful experience identified in this metasynthesis. Finally, researchers have proposed that environment influences QOL[17,21,47], but only a few have suggested factors that implied meaningful connection to environment, such as belonging[13] or feeling at home[25].

QOL and Happiness or Sadness

The relationship between happiness, sadness and QOL was not the focus of this study, but the high prevalence with which PWD connected happiness/sadness outcomes to QOL suggests that these concepts are highly related. In several studies, it appeared that some PWD used happiness as a synonym for good QOL[7,35,41] (but this was not a theme or explored fully in any study). To advance conceptual clarity, further qualitative research should assess whether happiness is a QOL synonym from the perspective of PWD, and quantitative work should test structural associations between QOL, its influencing factors, happiness, and sadness. Such research would also provide evidence on the validity of using feeling states as proxy measures for QOL, an approach frequently used for PWD with severe communication impairment[49].

This also has implications for research on psychological well-being because happiness has been included as a subcomponent of the multidimensional psychological well-being construct[50]. Psychological well-being is "a subjective sense of overall satisfaction and positive mental health"[19, p.66]. Lawton claimed that psychological well-being was separate from QOL[19]. The metasynthesis suggests that a component part of psychological well-being, happiness, is not separate from QOL. When PWD thought about their QOL they also thought, ultimately, about the impact on their happiness or sadness. Making sense of QOL factors for PWD may require in tandem consideration of their happiness and sadness.

Factors and Domains

Whether factors that influence QOL should be considered component parts of QOL (i.e. domains) is unresolved in the literature[18]. This metasynthesis does not propose a domain-based definition of the QOL construct from the perspective of PWD because the guiding questions in all primary studies asked participants to identify factors that influenced their QOL (e.g. what made QOL better, what contributed to or was important to QOL). In contrast, an instrument review showed that most dementia researchers include factors that 'contribute' to QOL as domains of a multidimensional QOL construct[10]. This risks conflating factors that influence QOL with domains essential to the concept of QOL[15]. Further research is required to establish what are the component parts of QOL from the perspective of PWD.

Strengths and Limitations

Excluding non-English articles may have missed relevant studies, and could partially explain why this review reflected the perspective of PWD living in countries with Western cultural systems (only one study was from Japan). Future work should explore whether PWD in lower income countries or other cultures identify different factors. Only four studies in this metasynthesis included individuals with severe dementia. Longitudinal work could investigate whether influencing factors change as dementia severity increases, or if there are changes to levels of unmet need within a static set of factors. The importance of happiness/sadness as outcomes of QOL may be overstated since a number of studies included interview questions about happiness, sadness, or well-being[26,37,38,40]. However, all studies found that PWD considered happiness/sadness as outcomes of good/poor QOL, regardless of the interview questions. The authors of the primary studies rarely discussed how they managed their influence upon the research process and results. Furthermore, PWD commonly experience communication difficulties. To ensure the data represents the views of PWD regarding QOL, future qualitative research should clearly report how researcher influence was managed when developing interview guides and during data collection (e.g. how leading questions were avoided). Strengths of this review include the comprehensive search, inclusion of grey literature, clear audit trail, and two independent reviewers for quality appraisal.

Conclusion

This study synthesized primary research on perspectives of PWD to identify four factors that influenced QOL: relationships, agency in life today, wellness perspective, and sense of place. The findings reveal that when PWD experienced connectedness within a factor (that is when PWD felt that they were together, purposeful, well, or located), this positively influenced

QOL and was associated with happiness. When PWD experienced disconnectedness within a factor (or felt alone, aimless, ill, or unsettled), this negatively impacted QOL and was associated with sadness. The factors that affect QOL according to PWD are promising targets for future clinical intervention studies that aim to improve QOL from the perspective of PWD. Research that utilizes a conceptual foundation derived from the perspectives of PWD may uncover innovative ways to support PWD to experience the best possible QOL and, importantly, happiness.

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Table 3-1. Description of articles included in the metasynthesis

Caption: Description and quality score of included studies

Country	Data Collection Approach & Questions	Setting & Sample Characteristics	Classification & CASP Score
[7]United Kingdom	Focus groups (n=25) How would you describe the quality of your life? – Why do you say that? What things give your life quality? What things take the quality away from your life? What would make the quality of your life better? What would make the quality of your life worse?	Site: community-living from 1 day hospital and 1 short-stay medical ward Cognitive Impairment: mild (n=13), moderate (n=9), severe (n=3) No severe expressive or receptive dysphasia Age: <65 (n=6), 65–80 (n=9), >80 (n=10) Male: 28 %	Thematic description 8
[37]Ireland	Interviews (n=15) Can you tell me briefly, what is it like for you living here? What is important to your life now? What makes you happy? What helps you enjoy your days here? What makes you sad? Do you see this Nursing Home as 'home'? What helps you to see this Nursing House as home? What prevents you from seeing this as your home? Do you have your own private room? Is privacy important to you? Do you like the way staff treat you?	Site: 3 nursing homes Cognitive Impairment: mild (n=5), moderate (n=5), severe (n=5) Age: from ages listed with the quotes, likely late 60s to early 90s Male: NR	Thematic survey 8

Country	Data Collection Approach & Questions	Setting & Sample Characteristics	Classification & CASP Score
	Do you like the way other residents treat you? Do you like the activities organized for you? What do you like most about living here? What do you like the least about living here? Is there anything that could be done to improve your life here?		
[26]The Netherlands	Interviews (n=65) Group discussions (n=78) Which aspects of daily life do you feel have an influence on your quality of life? What makes you feel happy? What is important to you in your life? Which aspects of daily life have a negative influence on your quality of life? What would bother you or upset you in your life?	Site: interviews in 3 nursing homes (n=37) and 3 community meeting centres (n=28); group discussion in 7 community meeting centres Cognitive Impairment: mild to moderately severe Age: nursing homes (69-98); meeting centres (mostly 70-80) Male: nursing home 30%; meeting centres NR	Thematic survey 6
[40]Japan	Interviews (n=18) What is important in your life? What do you consider important for life and happiness in general? What thing, circumstance, person, place, time and memory are most important in your life? What do you consider important in human life? What conditions	Site: 1 day care facility Cognitive Impairment: Moderate to severe Age: Men (66–93); Women (70–99) Male: 33%	Topical survey 8

Country	Data Collection Approach & Questions	Setting & Sample Characteristics	Classification & CASP Score
	make you happy?		
[41]Canada	Interviews (n=17) Please talk to me about what life is like for you. How would that look on paper? Or, how would that sound on the drum or chime? What is most important to you? What enhances the quality of your life? What makes it better? What diminishes your quality of life? What makes life more difficult? Who is most important to you? What do you like to do day-to-day? What are your hopes and dreams? What are your concerns?	Site: 1 locked unit (n=16) and 1 physical support unit (n=1) in 1 long-term care facility Cognitive Impairment: mild (n=2), moderate (n=6), moderate/severe (n=3), severe (n=6) Age: NR Male: 88%	Thematic survey 7
[34]Australia	Interviews (n=32) In what way does the organisation/environment (including caregiving) allow you to feel valued, able to express yourself and to nurture a meaningful quality of life? What things are you able to do that make your life good? Describe the factors that make life meaningful for you. Describe the factors that influence the way you feel valued in the care home. What do you contribute/like to contribute? Describe	Site: 4 care facilities provided assisted living, nursing home, dementia specific, and respite care across small units Cognitive Impairment: NR Age: 70–79 (n=3), 80–89 (n=25), >90 (n=4) Male: 31%	Thematic survey 8

Country	Data Collection Approach & Questions	Setting & Sample Characteristics	Classification & CASP Score
	any factors that influence your ability to feel free.		
[38]United Kingdom	Interviews (n=26) Spoke to people with dementia about their sense of well-being, and the kinds of things they felt were important to their quality of life. The interviews explored the every-day activities people were doing, why they enjoyed or did not enjoy them, and the factors that facilitated or constrained them.	Site: private homes (n=16) and unreported number of care home(s) (n=10) Cognitive Impairment: Mild to moderate Age: NR Male: NR	Topical survey 3
[42]United States	Interviews (n=25) What is life like for you? What contributes to your quality of life? What may diminish your quality of life? What are your priorities right now? Who is most important to you? What changes in your routine or relationships might change your quality of life? How would you like to change your quality of life? What can you do to make this happen? What are your concerns? What are your hopes and dreams?	Site: 1 multi-level care facility (n=23) and private homes (n=2) Cognitive Impairment: Mild to moderate Age: NR Male: 20%	Thematic description 9
[35,39]Canada	Interviews (n=20) What is life like for you? What contributes to your quality of life? What may diminish	Site: 1 centre for acute and chronic care (n=11), 1 acute care hospital (n=5), and 3	Thematic survey 9

Country	Data Collection Approach & Questions	Setting & Sample Characteristics	Classification & CASP Score
	your quality of life? What are your priorities right now? What changes in your routine or relationships might change your quality of life? How would you like to change your quality of life? What are your concerns? What are your hopes? Some people say that spirituality is important, is that a part of your life?	retirement-nursing homes (n=4) Cognitive Impairment: Mild Age: from 62 to 89 Male: 40 %	
[36]United States	Interviews (n=4) Think about your day-to-day experiences in living with Alzheimer's disease. Can you tell me about a specific incident that stands out in your mind as reflective of your perspective of quality of life?	Site: NR Cognitive Impairment: Mild Age: NR Male: NR	Thematic description 9
[43]United Kingdom	Focus groups (n=20) What does QOL in dementia entail? What elements of QOL in dementia are important? Are all the 13 items of the QOL-AD important for QOL in dementia? Are the items of equal importance? Does this scale cover all the important aspects of QOL for people with dementia?	Site: residential homes, nursing homes, day centers, and hospitals Cognitive Impairment: Not reported Age: over 69 Male: 27%	Topical survey 7

Note: NR=not reported

Figure 3-1. Metasynthesis search results

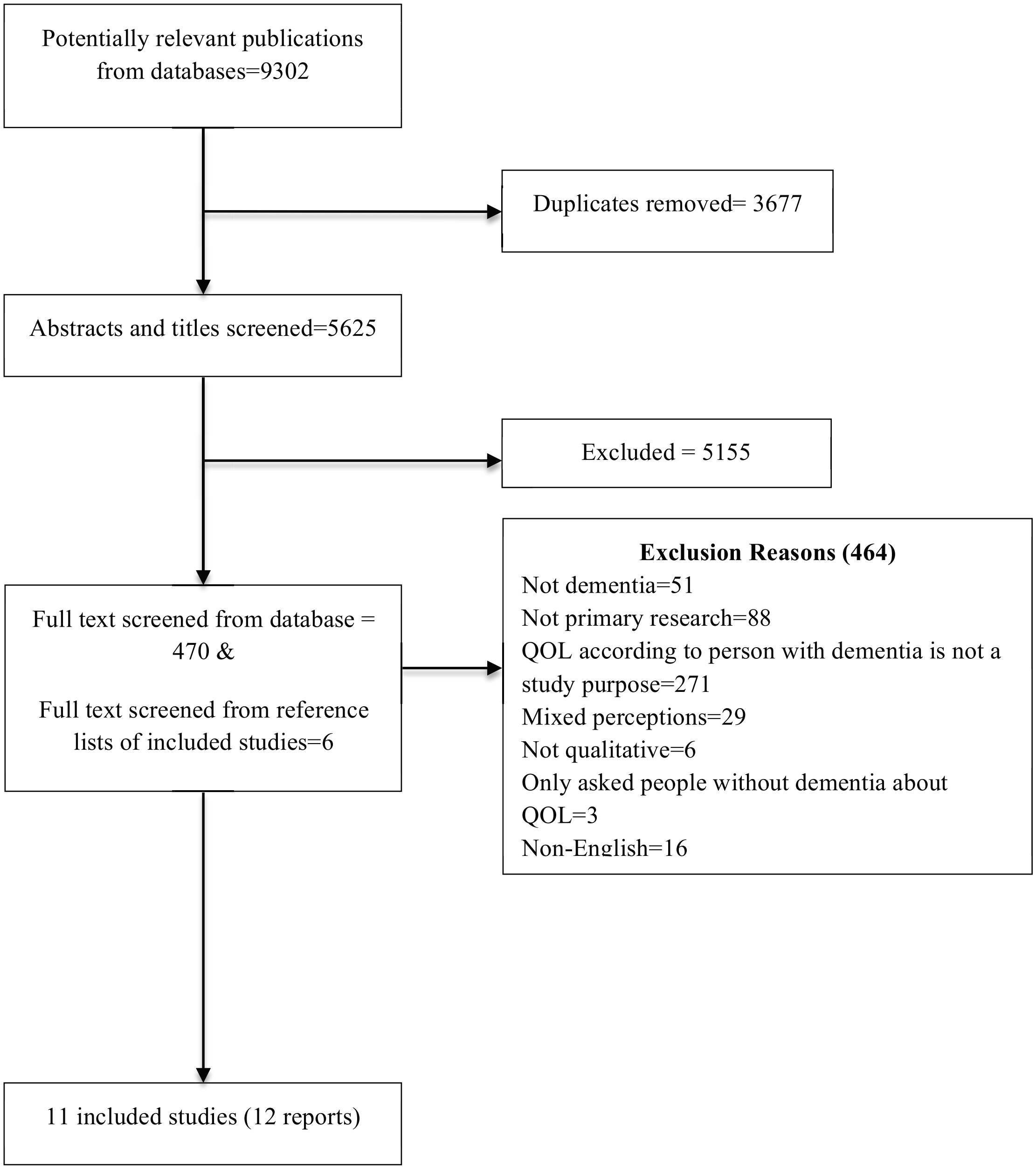

Figure 3-2. Factors that affect quality of life according to people with dementia

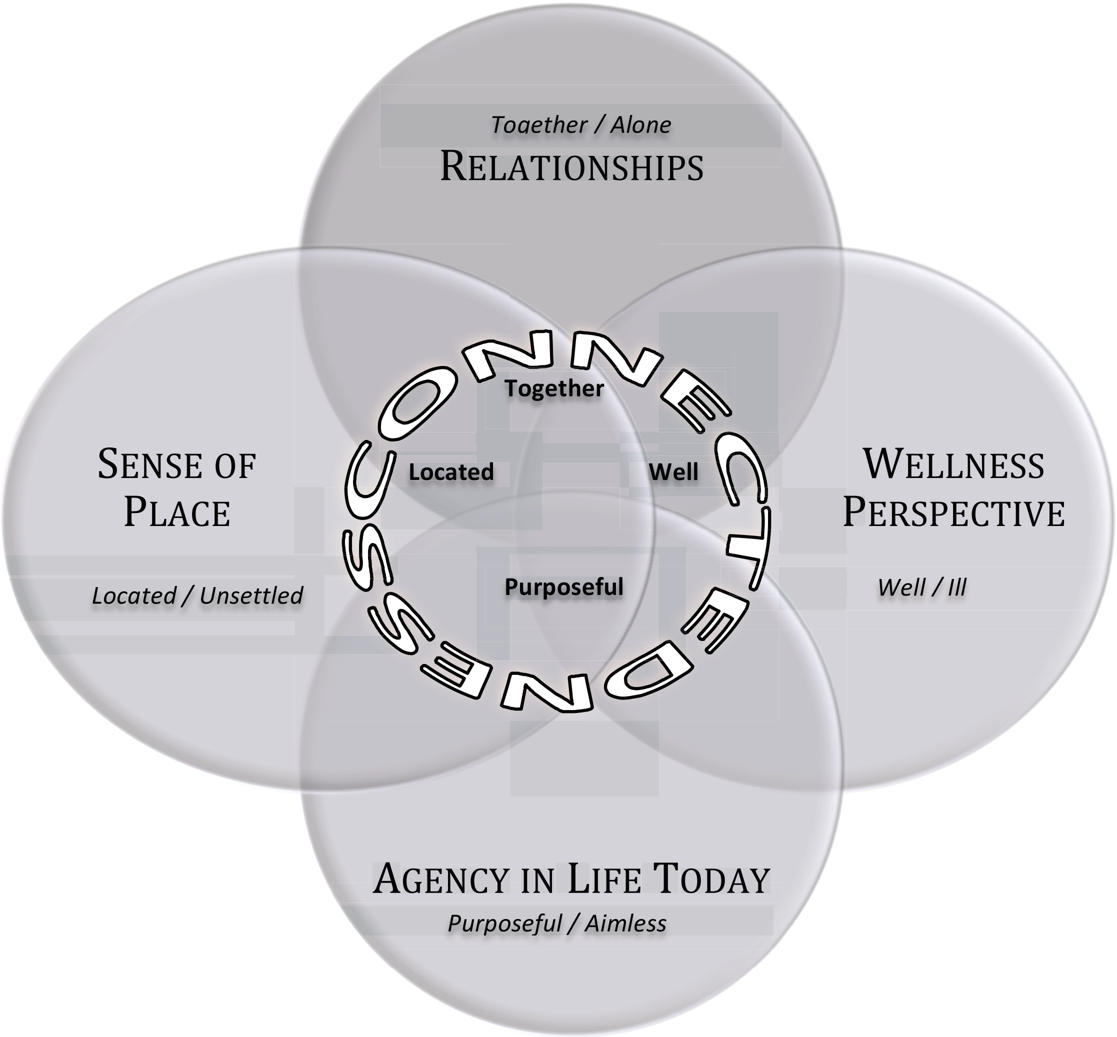

Figure Legends.

Figure 3-1 illustrates the search process and screening results at each stage.

Figure 3-2 illustrates the four factors, and the experiences of connectedness / disconnectedness for each factor. The overlapping circles show that relationships exist between the four factors. Connectedness in all four factors is illustrated in the centre of the figure where all circles overlap.

Table 3-2. Details of CASP quality assessment and findings classification

Study Classification	Score	Clear Aims	Qualitative Appropriate	Design Appropriate	Recruitment Appropriate	Data Collection Appropriate	Researcher Influence Considered	Ethical	Analysis Rigorous	Findings Clear	Valuable
[7] Thematic Description	8	Y	Y	Y	N	Y	N	Y	Y	Y	Y
[37] Thematic survey	8	Y	Y	Y	N	Y	N	Y	Y	Y	Y
[26] Thematic survey	6	Y	Y	Y	N	Y	N	N	N	Y	Y
[40] Topical Survey	8	Y	Y	Y	Y	N	N	Y	Y	Y	Y
[41]Thematic Survey	7	Y	Y	Y	Y	Y	N	Y	Y	N	N
[34]Thematic Survey	8	Y	Y	Y	Y	Y	N	Y	N	Y	Y
[38]Topical Survey	3	Y	Y	Y	N	N	N	N	N	N	N
[42]Thematic Description	9	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
[35,39]Thematic Survey	9	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
[36]Thematic Description	9	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
[43]Topical Survey	7	Y	Y	Y	Y	Y	N	Y	N	Y	N
Total "No"		0	0	0	5	2	10	2	4	2	3

Note: Y=Yes; N=No

Definitions

CASP quality appraisal tool: A tool developed by the Critical Appraisal Skills Programme (CASP) collaboration for qualitative methodologies. The tool is for quality appraisal of studies that use qualitative methods[32]. Other CASP tools have also been developed for quality appraisal of studies that employ other methods and designs.

Findings classification[27]: Qualitative studies can be classified based on the amount of transformation or interpretation that is used in generating the findings from the data. Qualitative findings (e.g. themes) are different from the raw data (e.g. quotes) that are collected in interviews or focus groups. Findings are the product of integrating the data, and may remain very similar to the original data, or may be more removed conceptually from the original data as a result of interpretation. This classification system, developed by Sandelowksi and Barroso, includes four possible categories of findings, listed from findings that are closest to those furthest from the qualitative data: Topical Survey (e.g. frequency of stating a topic); Thematic Survey (e.g. description of themes or patterns in the data that were recognized by the researcher); Conceptual/Thematic description (e.g. derivation of themes that are further from the original data, but which reframe or more fully integrate the data); and Interpretive Explanation (e.g. a single thesis or model used to provide a coherent, causal explanation of the data). ‘No Finding’ reports present only data with no integrated findings, and are not considered qualitative research.

Table 3-3. Link of findings from individual studies to metasynthesis key concepts derived using taxonomic analysis, constant targeted comparison, and importing concepts

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ---------------------- Disconnectedness
7	Social **interaction** **Loneliness** when friendships are absent *Devastation* at losing children	Independence Financial security Spending time as you like *Enjoyment* through leisure activities	Coping/ adapting to challenges with health led to *feelings of well-being* Health and memory/ thinking	*Happiness* when are in own home Living at home Negative perspectives/ stigmas of aging by self and others Comparison of self to others	Happiness Contentment Enjoyment of life Feelings of well-being ------------- Devastation	Interaction ---------------------- Loneliness
37	Social **contact** with family, long-term care staff and other residents of long-term care *Sadness and depression* at loss of family **Loneliness**, **feeling lost or abandoned and a quest for human**	*Pleasurable* activities (e.g. reading, listening to music, watching t.v., playing cards) outings, and *momentary pleasures* **Boredom** from a lack of activities	Health benefits from exercise *Sadness* at how physical and cognitive impairments **prevent participation in preferred activities** *Happy* when are in good form	**Attachment and feeling connected to one's environment** Other attempts to **make sense of one's relationship to environment** *Happy* when feel at home *Sadness* at recollecting former homes or losing home *Happy* about	Happiness Pleasure -------------- Sadness Depression	Contact Participation Attachment Feeling connected Sense-making ---------------------- Restrictions Loneliness Feeling lost Feeling abandoned Boredom

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
	contact *Feeling happy* about meeting new people *Happy* about receiving care *Happy* about being treated with respect and dignity Seeing family Outings with family result in *pleasure*	*Sadness* at **restriction on activities** because of physical/cognitive status and facility rules		having a private room *Sadness* about age or reaching the end of life		
37	Social **contact** with family, friends, and caregivers Knowing that family is doing well and **having good contact** with them Positive **interaction** with others **Loneliness**	Being **able/allowed** to express yourself *Enjoyment* of activities (e.g. reading, watching t.v. or movies, taking walks, going on vacation, listening to	Physical and mental health (mobility, deafness, forgetfulness) **Being able to do less and less** **Decreasing ability** to act autonomously due to physical impairments Not knowing the way anymore	**Attachment, involvement and interest in the things/world around you** Having security and privacy Nature **Not knowing the way** anymore	Happiness Enjoyment Cheerfulness -------------- Upset Sadness	Contact Interactions To be ‘in the midst’ Attachment Involvement ----------------------- Restriction on what you want to do Loneliness Not knowing the way

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
	Being accepted, acknowledged, and treated with respect by others Living **in the midst** of family Being understood Feeling supported Helping your partner or others *Feeling happy versus* **lonely** *upset*	music) Being **able and allowed** to do things Financial security to do what you want Self-determination and freedom Religion and a sense of responsibility to feel grateful, to have faith Being useful and giving meaning to life	Physical comfort Eating well			
40	Family Health of the family **Meeting a person** Peace, **cooperation**, kindness important in	Money Savings Autonomy Living quietly *as a condition for happiness*	My body My health Living gratefully as *a condition for happiness*	My role (important condition) Important places include **my house**, the day care facility, **birthplace, workplace,** rice field	Happiness	Meeting a person Cooperating Living together Birthplace, Workplace, My house, My role (interpreted as self connected to place)

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
	human life **Cooperating and living together** are *conditions for happiness*	Living ordinarily *as a condition for happiness*				
41	Relationships that are characterized by love, caring, listening, giving, **sharing**, and/or understanding led to *enjoyment, happiness, great/wonderful feelings,* confidence Having attention from others Giving to others Laughing Good talks **Meeting new people** Singing **together**	Living with loss of abilities Living with loss of occupations, or meaningful work Wish for freedom and **fewer restrictions** **Continue with certain life patterns** like walking every day, singing, playing piano, going to church	*Feel content* because did not experience as many changes in life as expected due to health issues Choosing an **attitude for living on, despite challenges** (e.g. making the best of things, looking on the positive side of life) Living with loss of energy Trouble with memory and expressing self to others	**Feeling worthy and wanted** **Contributing to others** and to the world Living with loss of home	Happiness Enjoyment Great/ wonderful feelings Contentment **---------------** Grief	Contributing to others Feeling worthy/wanted (interpreted as self connected to broader context) Sharing Meeting new people Community Continuity in life patterns Incorporating challenges to develop positive attitude Being together with others **-----------------------** Restrictions and strict routines

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
	Community Loss of siblings, parents, spouses, friends led to *grief*					
[34]	Family visits led to *happiness* **Lack of involvement** with family led to *hurt and sadness* Meaningful **conversation** Visitors to relieve **boredom and loneliness** **Companionship** **Friendship**	Control over the environment **Ability and freedom to do things** Engage in activities **when desired** Need to accomplish something meaningful To feel useful **Interference by residents and staff (restriction and control)** in life can reduce	Surrounded by ill/frail people led to feeling *depressed* Making the best of the life one has **Acceptance of current reality,** given age and health problems	**Link** to community and the outside world Recall previous memories **Existence beyond** care setting To feel **valued by** society Others perceptions of persons with dementia Feeling that one's concerns are insignificant led to *negative feelings* *Enjoyment* as a result of **partaking in** outside activities **Engage with** external environment	Happiness Enjoyment **---------------** Emotional hurt Sadness Depression Negative feelings	Involvement Conversation Companionship Friendship Ability and freedom to do things, when desired Linked to and engaged with community and to an existence beyond facility Valued by society (interpreted as self connected to broader context) Partaking in outside activities (interpreted as self connected to broader context) **-----------------------** Interference by others

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
		enjoyment Opportunities for decision-making and control *Enjoy* lack of responsibility for housework and meal preparation				Restriction
[38]	Social **interaction and participation** **Conversation** with others Time between person with dementia and their informal caregivers, that is not spent in physical care-giving tasks and receipt of support for physical care from others	*Enjoyment* of music Pottering in the home Creative activities Receiving support to complete activities that require a series of steps	Exercise and physical activity	Oral/personal histories and **reminders of past events** **Participation with local community** **Access to nature**	Enjoyment	Interaction Participation Conversation Reminders of past (interpreted as self connected to past) Access to nature (interpret as self connected to broader context)

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
[42]	Family Old and new friends, *enjoy* **meeting new people** **Talking, relating to or laughing with others** *Enjoy* **being with** family Helping others *Crying* when think about changing relationships with family *Acceptance* when think about changing family relationships *Satisfied* to live where people taking care of you, which takes away worry *Happy* that family is doing well	Living day-to-day **Participating** in ordinary daily activities Having things to do *Enjoying* music Wishing for simple immediate **accomplishments**	Illness brings challenges to other areas of life (doing things you enjoy, relationships and talking to others, moods) Hope to continue functioning properly	Earning one’s keep or maintaining one’s home *Enjoying* going outside *Enjoy* **keeping up to date on the news** *Satisfied* to **live where people taking care of you**	Happiness Enjoyment Satisfaction **--------------** Crying	Meeting new people Talking/laughing with others Being with others Feeling a sense of accomplishment (interpreted as desires connected to actions) Keeping up with world events (interpreted as self connected to broader context) Living where can receive care (interpreted as self connected to immediate environment)

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
[35,39]	Family and family support led to *happiness* and *enjoyment* Social **interactions** to avoid feeling **withdrawn, lonely, or bored** Social relationships as a means to access good medical care Helping others Loss of family members, missing family	Financial security Appreciation of art Religion **Sense of control** **Autonomy** Stability Relief from job-related stress/ responsibilities (contributes to good QOL) Recreational activities/hobbies/leisure Driving **Ability to complete** instrumental activities of daily living	General health Physical illnesses/ ailments/ frailty and symptom experiences with sleep, hearing, fatigue, vision, disturbances of consciousness **Ability to complete** instrumental activities of daily living Experiencing *depression* Falls Loss of competence Burden of memory loss and adjustment to diagnosis Hopes for longevity, cure, or arrest of the progressive cognitive decline Concerns with taking medications/	Living arrangements **Feeling useful or valuable** **Appreciate nature** Opportunity to travel	Happiness Enjoyment **-------------** Depression	Interactions Sense of control and autonomy (interpreted as desires connected to action) Ability to complete activities Make sense of illness Feeling useful or valuable (interpreted as self connected to broader context) Appreciate nature (interpreted as self connected to broader context) **----------------------** Withdrawn Lonely Bored

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
			medication side-effects Exercise Mobility Forgetting things Spirituality to help **make sense** of illness and to have hope for the future			
36	**Connected lives** Relationships with support groups Spousal support and love Ability to help others	**Ability to do things about my situation**	It could be worse Letting go of worry and anxiety Feeling *happy* with life Patience assists in **dealing with cognitive changes**	**Feeling left out, without a role** **Supporting others** with Alzheimer's disease	Happiness	Connected lives Ability to do things (interpreted as desires connected to action) Dealing with cognitive change Supporting others (interpreted as self connected to broader context) ----------------------- Feeling left out, without a role (interpreted as self not connected to broader context)
43	**Contact** with family, especially children	Having interests and hobbies	Physical health Memory difficulties	**Loss of a role in life** **Being able to**	Satisfaction	Contact Friendships

Study	Relationships	Agency in Life Today	Wellness Perspective	Sense of Place	Happiness --------------- Sadness	Connectedness ----------------------- Disconnectedness
	Good **friendships** **Loneliness**	**Achieving what you want** Having a direction in life **Boredom**	Make the best of it’ Take one day at the time’	**give to society** **Reminiscence**		Achieving what you want (interpreted as desires connected to action) Role in life (interpreted as self connected to broader context) Reminiscence (interpreted as self connected to broader context) Able to give to society (interpreted as self connected to broader context) **-----------------------** Loneliness Boredom

Note: The contribution of each primary study to the key study concepts is shown in each column. The links between each of the factors and happiness/sadness (*in italics*) and connectedness **(bold)** are shown within each cell.

Definitions

Metasynthesis: Systematic review and synthesis of qualitative research evidence

Taxonomic Analysis: Extraction and organization of all of the main concepts identified in the primary qualitative studies included in the metasynthesis. Higher order concepts are identified that can explain, capture, or organize many of the lower order concepts. In this way, the higher order concepts synthesize findings from multiple qualitative studies; these form the basis for deriving synthesized thematic findings.

Constant Targeted Comparison: Comparison of selected (usually higher order) concepts identified by the studies included within the metasynthesis to similar or equivalent concepts identified in other bodies of literature. By comparing the definitions of concepts from other bodies of literature to those identified in the metasynthesis, the definitions of the main concepts are refined by considering how they are similar to and different from other known concepts.

Importing Concepts: Known concepts from other bodies of literature are sometimes used in the findings (i.e. imported) if they improve the ability of the findings to represent the body of qualitative literature. For example, an imported concept may be used to integrate divergent findings, in order to provide a more coherent and integrated final synthesis product. In our study, the concept of connectedness was imported.

Chapter 4. Paper 3- Embedding the Perceptions of People with Dementia into Quantitative Research Design

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Background

Against the backdrop of a rapidly aging population, a growing body of literature emphasizes the need to determine whether health care interventions impact quality of life (QOL) of older adults with chronic illness [1,2]. The QOL construct is certainly not new, but its meaning has shifted over time [3,4]. Growth in popularity of QOL in the mid-1900s spurred philosophers, academics, and policy-makers to debate its meaning and utility [3]. In the 1970s, such debate shifted the earlier focus on objective social indicators to more subjective accounts of QOL [3].

Among dementia researchers specifically, there is growing consensus that the QOL construct contains subjective elements, and that capturing perspectives of people with dementia (PWD) is essential for valid QOL assessment [5,6]. Dementia researchers differ with respect to the weight they give to subjective QOL, from including it as one part of QOL as a whole [6–11] to defining QOL as a purely subjective construct [12–18]. In line with the latter approach, we define QOL as a subjective evaluation of "one's life perspective" [5] that occurs "within the context of the culture and value systems in which (people) live and in relation to their goals, expectations, standards and concerns" [19] .

Researchers examining diverse populations—including people with mental health concerns [20], cancer [21], or dementia [22–24], to name a few—have sought ways to engage patients in research to understand their QOL. In QOL research with PWD, there is increased attention on patient perspectives [25] and recognition that, while PWD experience cognitive decline which can limit insight into impairments [26], many can still discuss their QOL [14,27].

Researchers have noted potential advantages of including patient perspectives in QOL research for PWD. Patients may determine domains that are relevant to them [22,28,29], identify research questions and interventions responsive to their needs [22,30–32], inform more humane, dignified care [23,30,31,33], and change attitudes about what it means for PWD to achieve a good QOL [23,33]. Some tool developers have argued that if QOL is defined as subjective, then capturing the perspective of PWD is necessary for the content and construct validity of QOL measures [28,34–36]. The tool must reflect what is important to PWD in regards to their QOL. Thus, if a tool requires the person to assess aspects deemed nonessential for QOL by PWD, then it is not valid in that population [28].

Given the emphasis placed on patient perspectives, qualitative approaches hold great potential in QOL research as one of their main intents is to capture an insider's account of a phenomenon [37,38]. Furthermore, the inductive nature of qualitative research may stimulate innovative thinking in the area [37]. A growing body of qualitative research is examining QOL according to the perspectives of people with mild, moderate, and severe dementia from both community and long-term care (LTC) settings [22,23,28–36].

The rich findings from qualitative work could directly influence future QOL research and inform how QOL is understood and measured in this population [39]. However, while some instrument developers include patient perspectives to identify what areas matter to QOL [11,14,40,41], none to date have applied the body of pre-existing qualitative work in a transparent or replicable way. Instead, non-systematic reviews of QOL literature have been conducted; these may identify some but not all qualitative studies on the topic. Literature reviews are often followed by focus groups or interviews with PWD and others to determine those areas relevant to QOL for PWD [11,14,40,41]. From these descriptions, it is difficult to discern how the pre-existing body of qualitative literature was used during QOL tool development for PWD. To effectively build on what is known about QOL from the perspective of PWD, replicable approaches that clearly apply the body of existing qualitative findings are needed [42].

This article describes how findings from two systematic reviews of qualitative evidence on patient perspectives were linked to a clinical administrative dataset and then used to design a quantitative study. This resulting study is large, cross-sectional, and retrospective, focusing on the association between conflict and sadness for LTC residents with dementia. Hypotheses of associations among influencing factors and an outcome of QOL will be tested using clinical data from 4840 LTC residents with mild, moderate, and severe dementia in Ontario, Canada. Analysis is currently underway, and findings will be reported separately. Here, the steps are described to design a quantitative study grounded in the perspectives of what matters to QOL according to PWD.

Methods

Although similar to other research studies where a literature review was the foundation for a quantitative study conceptual framework, this approach differs in significant ways. Specifically, the main framework and focus were derived from the findings of studies reflecting PWD's perspectives on QOL. Moreover, an existing database was used to operationalize the variables chosen from this framework. The design of a study that combined these unique features was achieved in three steps.

Step 1: Review Themes from Systematic Reviews of Qualitative Evidence

Themes from two metasyntheses that report findings on QOL from studies conducted with overlapping patient populations were compared. Metasynthesis is a systematic review and qualitative evidence synthesis method that is gaining momentum within the current evidence-based practice climate because it aims to derive abstract findings appropriate for widespread application [42,43].

The first metasynthesis included 31 studies conducted with people in LTC facilities (many of whom had dementia) [44]. Our research team completed the second metasynthesis of 11 studies conducted with PWD (many of whom lived in LTC facilities) [45]. The first metasynthesis indicated Connectedness with Others, Caring Practice, Acceptance and Adaptation to their Living Situation, and A Homelike Environment as themes of importance to QOL for people living in LTC [44]. The second metasynthesis identified Relationships, Agency in Life Today, Wellness Perspective, and Sense of Place as themes that influenced QOL from the perspective of PWD [45]. Each theme was supported by many sub-concepts, with relationships among these sub-concepts.

Some of the themes from the two metasyntheses had significant overlap. For example, 'A Homelike Environment' was a theme in one [44], whereas the theme 'Sense of Place' in the other was supported by the sub-concept 'Sense of Home' [45]. A decision was made to focus on sub-concepts of the themes 'Relationships' and 'Connectedness with Others' because these themes, while from two different metasyntheses, were conceptually equivalent. Taken together, the findings from the two metasyntheses indicated that relationships characterized by "respect, reciprocity, closeness, kindness, or love" [45, p. 11] led to connectedness, or being together, in relationships with others, and this positively influenced QOL [44,45].

Step 2: Map Sub-Concepts to Database and Derive Hypotheses

The thematic findings from the two metasyntheses established which concepts were key to understanding what mattered to QOL from the perspective of PWD in LTC. However, the themes were not in a form characteristic of testable quantitative hypotheses. The main challenge in this stage was deriving hypotheses that were clearly grounded in the broad thematic metasyntheses findings but also variable-oriented and testable. During this stage, the overarching themes of ‘Relationships’ and ‘Connectedness with Others’, as well as the sub-concepts that supported them, were extracted. This resulted in a list of concepts that were compared to item descriptions from a clinical dataset: the Resident Assessment Instrument (RAI) 2.0. The main intent of this stage was to determine whether any RAI 2.0 measures matched the extracted concepts (see Table 4-1).

RAI 2.0 data are collected by health care providers using a standardized tool to assess and document a wide variety of LTC resident characteristics [46]. In the early days of RAI implementation in the United States, developers identified potential advantages of using the standardized clinical dataset for research [47]. We chose to map the metasyntheses findings to the RAI 2.0 for several reasons: the published studies demonstrated item and scale reliability and validity; the use of existing data reduces the burden of data collection imposed on patients and staff; population-level data are available in some Canadian jurisdictions; the use of clinical data to test hypotheses would mean that results refer directly to assessment items used by clinicians in everyday care planning and quality improvement; and RAI 2.0 data are collected internationally, which facilitates inexpensive replication studies in other contexts.

The many underlying sub-concepts proved to be a rich source of potential hypotheses, but the RAI 2.0 measures available limited what could actually be tested. The RAI 2.0 does not collect data to cover all aspects of the ‘Relationships’ and ‘Connectedness with Others’ themes. However, items are available to measure some of the sub-concepts that support these themes, specifically conflict with others [44,45]. These were selected as independent variables.

Selecting a dependent variable was more problematic. The metasyntheses themes described areas that influenced QOL, so most of the potential hypotheses were about the association between the sub-concepts and QOL. Such hypotheses were not testable because the RAI 2.0 does not contain a measure of subjective QOL. However, it was possible to derive testable hypotheses using sadness, which is an important and related outcome.

Sadness is not necessarily synonymous with poor QOL, but is a reasonable outcome variable for this study because it was identified in one metasynthesis as an outcome of poor QOL according to PWD and a direct outcome of negative relational experiences [45]. Furthermore, sadness is measureable across mild, moderate, and severe dementia and is reported in the RAI 2.0 data. The RAI 2.0 sadness items measures the person with dementia's perception of whether or not they are sad, based on verbal (i.e., negative statements) and non-verbal (i.e., tears or sad facial expression) reports. Mood or behavior measures have been used to glean information about perceived QOL in this population, as demonstrated by the tools located and described in a previous literature review [6].

To derive the specific hypotheses, sub-concepts that mapped to the RAI 2.0 data were evaluated and specific claims of associations among variables extracted. The following hypotheses were identified (Figure 4-1; Table 4-1) and focus on the associations between perceived conflict with others and sadness for PWD in LTC. Hypotheses regarding the influence of cognitive impairment (i.e. mild, moderate or severe dementia) and functional dependence (i.e. depending on others to eat or mobilize, for example) upon associations of conflict and sadness were also identified.

Hypothesis 1: Perceived conflict with staff is positively associated with sadness.

Hypothesis 2: Perceived conflict with family or friends is positively associated with sadness.

Hypothesis 3: Perceived conflict with other LTC residents is positively associated with sadness.

Hypotheses 4 & 5: As functional dependence or cognitive impairment increase, the strength of the association between conflict with staff and sadness also increases.

Hypotheses 6 & 7: As functional dependence or cognitive impairment increase, the strength of the association between conflict with family or friends and sadness also increases.

Hypotheses 8 & 9: As functional dependence or cognitive impairment increase, the strength of the association between conflict with LTC residents and sadness does not increase.

Step 3: Re-situate in the Broader Literature

Finally, a literature review using a systematic, comprehensive, and replicable approach was conducted to determine whether the association between conflict in relationships with others and sadness was already well understood for PWD. This ensured the hypotheses were not only important to QOL from the perspective of PWD but had not been tested previously.

The search strategy was developed in consultation with a research librarian to capture the concepts of “Long-term Care”, “Dementia”, “Conflict or Relationships”, and “Happiness or Sadness” (see Table 4-3). Studies on depression were not reviewed, because sadness was conceptualized as a more transient emotional state [45], different from the clinical diagnosis of depression that incorporates other elements [26]. A total of 607 unique titles and abstracts from Medline, PsycInfo, EMBASE, CINAHL, and Abstracts in Social Gerontology were screened for relevance. Thirty-six were retrieved in full text, including studies with general mood or affect outcomes, to determine whether sadness was included as an outcome of interest. No empirical research was located that tested the association between conflict in relationships and happiness or sadness for PWD in LTC settings.

Besides establishing a knowledge gap, the literature review contributed to the quantitative study rationale and design in other ways. First, the observational qualitative [48] and quantitative [49,50] studies identified demonstrated that PWD in LTC experience conflict with others, which supports the need to study this problem. Second, the review informed the study design. Because previous research had not tested the association between these variables, a cross-sectional study was designed to establish simple associations. Establishing associations was deemed a judicious first step, prior to conducting more resource-intensive research to rigorously test whether conflict *causes* sadness.

A third result of searching the extant literature was identification of adjustment variables for use in the analysis. Potential confounding variables were identified from studies that tested the effect of relationship-based interventions on mood, as this was the available body of literature that was conceptually similar to the proposed study. A variable was included as a potential confounder if it was tested in previous research, regardless of its statistical significance in the previous work. Such variables included age, sex, ethnicity, education, length of stay, physical disability, frequency of family/friend visits, and use of psychopharmacological drugs.

Two additional adjustment variables were included based on clinical knowledge. The first was pain, because the dependent variable (sadness) is partly measured by facial expressions that might be displayed if a person is in pain. The second variable was a facility identifier used for cluster correction. All adjustment variables were available in the RAI 2.0 data (see Table 4-2).

Discussion

A quantitative study was designed based on broad themes from two metasyntheses, which proved to be a rich source of information for hypotheses generation. This approach has advantages and disadvantages, as discussed below.

Hypotheses Fit with Extant Literature

By deriving hypotheses directly from the metasyntheses, research questions important to QOL from the perspective of PWD were identified; the conceptualizations of variables important to QOL found in other bodies of literature were not drawn upon. One disadvantage to the approach is that the fit between the study findings and related literature in the field may be more difficult to establish. The conceptualization process led the research in a different direction than most research on QOL of people with dementia: the proposed quantitative study is focused on perceived conflict in relationships. The challenge was to design a study to test the hypotheses generated from perspectives of the target population without isolating the work from the broader field.

Following hypothesis generation, additional variables were identified through a separate literature search of the broader field; these were included as adjustment variables (e.g., age), not as focal independent variables (e.g., conflict with staff). For example, PWD in the studies in the metasyntheses did not indicate that age directly influenced QOL or sadness. As a result, the proposed quantitative study did not focus on the direct relationship between age and sadness, but included age as potential confounding variable. Excluding variables such as age from the analysis risks producing findings that are easily dismissed on the grounds that a third variable actually explains an observed association; however, including age as a focal independent variable would undermine the impetus to ground the research questions in the perspectives of the target population. Instead, variables such as age were included as adjustment variables to acknowledge the broader literature without compromising the focus on patient perspectives.

Patient Perspectives, Several Times Removed

The primary qualitative research studies included in the metasyntheses focused on what influenced or was important to QOL from the perspective of PWD and LTC residents, and many people in both reviews were PWD who were also LTC residents. Thus, the hypotheses generated from the metasynthesis should be considered to reflect the priorities of PWD in LTC. However, the conceptual framework for the quantitative study was derived from the combined findings of two metasyntheses, and the individual perspectives of the target population may have been lost in the synthesis process. Metasynthesis themes and their sub-concepts are interpretive products [42]. They are supported by data from each of the individual studies but do not mirror them, and are broad enough to take findings of all included studies into account [42]. Such results are removed from the actual perspectives of PWD because they are interpretations of primary studies that, in turn, are interpretations of the original data [42]. Arguably, shaping these findings into quantitative hypotheses imposes yet another layer of interpretation, further removing the hypotheses from the original accounts of the PWD.

Thus, the synthesized findings are derived from the perspectives of PWD but are removed from the original experiential accounts. To counter this issue, the quantitative study serves an important role in bringing these hypotheses back to the actual experiences of PWD in LTC by testing all concepts proposed to influence QOL against a patient-reported outcome. This reflects the commitment to using patient perspectives as the measure by which to identify those areas that matter to QOL, a commitment carried through all stages of the study from conceptualization to hypothesis testing. In the quantitative study proposed in this article, sadness was used as the outcome variable. As previously discussed, the ideal outcome variable would be patient-reported QOL.

Starting from Synthesis

Some argue that metasynthesis findings are less likely to be idiosyncratic and more appropriately applied in practice (or generalized beyond the original sample) than findings from individual qualitative studies because they integrate findings from a variety of samples and settings [42,43]. Yet, findings of individual qualitative studies may be transferred to other situations [51,52]; indeed, case-to-case generalizability [53] is the application of the highly contextualized findings typical of primary qualitative research to other similar cases [51,52]. The person who intends to use the findings is responsible for judging case similarity, and the researcher must provide sufficient description of the context and cases to support this judgment. This differs from the analytic generalizability that occurs when conceptualizations or theories generated from in-depth qualitative study are applied to other similar contexts, or even to different populations or phenomena [51,52]. Analytic generalizability was the process used in this study.

Due to the small non-random samples characteristic of the qualitative research studies included in metasynthesis, synthesized findings cannot be generalized back to a population *in the statistical sample-to-population sense* [51,52]. Statistical generalizability refers to the application of results from a sample back to a defined target population [51,52]. This requires the use of sampling theory, which ideally consists of taking a large and random sample from a population with defined boundaries. Case-to-case generalization of metasynthesis findings may be appropriate, but the process of moving from individual cases to primary study findings and then to more abstract metasynthesis themes strips away some of the thick case description required for case-to-case transfer. Case-to-case transfer will depend on how much contextual detail is retained in this process. Analytic generalization fits well with metasynthesis, the intent of which is to seek more abstract and overarching explanations that the original primary studies [42,43] to generate research questions, create conceptual models, and inform future research design [54].

The approach described in this paper combines the strength of metasynthesis to generate new conceptualizations that have analytic generalizability with the potential of quantitative research to generate findings that are generalizable from sample-to-population. While valid uses of metasynthesis findings, case-to-case and analytic generalizability have limitations that may reduce the utilization of metasynthesis results that capture patient perspectives on QOL. Relying upon each reader to assess the fit between their client and the findings of a study (as in case-to-case generalization) or determine how to use an abstract theory in the care of PWD (as in analytic generalization) may limit research use in practice because neither produces specific system-level recommendations to reliably improve QOL at a population level. For example, the metasyntheses showed that connectedness in relationships with others was important to QOL according to PWD across several samples and settings. However, how to affect change in connectedness and whether its measureable sub-concepts are associated with outcomes relevant to PWD in LTC on a population level remains unknown.

There is a pragmatic argument [55] for creating studies that produce findings with sample-to-population generalizability because they allow for prediction of the effects of health service interventions in large samples in ways that cannot be achieved with either case-to-case or analytic generalization [51]. Statistical generalizability is a useful product if one wishes to propose system-level change within a population, such as improving the QOL for PWD who live in LTC settings.

Effective Use of Existing Resources

Using metasyntheses to develop a conceptual framework and employing an administrative clinical dataset makes effective use of existing resources. Here, syntheses of previously conducted studies were applied instead of conducting a new qualitative study to capture perspectives of PWD. Metasynthesis findings presume that truth ‘holds still’ for a period of time, but these findings are always situated within and relevant for a particular time and context [42]. Prior to designing a follow-up study, the research team should assess the appropriateness of any existing metasynthesis for their chosen context, questioning whether substantial contextual differences render themes irrelevant.

Alternatively, existing metasyntheses may be poorly reported. If reporting is poor, then extracting enough detail on the themes and their sub-concepts to generate testable hypotheses may be challenging or impossible. In this situation, the metasynthesis authors could be contacted to obtain additional detail. Or, an existing metasynthesis may not be available; in this case, the first step would be to synthesize the existing qualitative literature. In the case of no available body of qualitative research on QOL from the perspective of the target population, then conducting primary qualitative work to capture perspectives of the target population would be a justified expenditure of time and other resources.

Instead of collecting quantitative data, this study mapped the findings to an existing clinical dataset. This increases the relevance of research results for practice, because the findings were mapped to measures that health care providers use to assess LTC residents’ needs and develop care plans. In addition, utilization of this clinical dataset greatly strengthens statistical generalizability of the findings because the study sample will comprise a random sample of all people with mild, moderate, and severe dementia who lived in Ontario LTC settings during the study period. The findings will be generalizable to Ontario LTC residents with dementia and replication or longitudinal studies could be conducted with relative ease in other jurisdictions (in Canada and internationally) where RAI 2.0 datasets are also available.

Conclusions

Perspectives of a target patient population can be used as the basis to generate novel hypotheses meaningful to QOL for that target group. The three steps described herein link metasyntheses findings with a clinical database to design a quantitative research study. The approach is conceptually and methodologically defensible, and makes effective use of existing resources. Using metasynthesis findings instead of conducting a new qualitative study built effectively upon existing knowledge, and guarded against designing a large study based on idiosyncratic findings that lack analytical generalizability beyond the sample initially studied. By following the analytic generalizations from metasyntheses with statistical generalizations from a quantitative study, findings of the proposed study will be both grounded in the perspectives of the target population and in a form that can support health service recommendations at the population level. Research in other populations may similarly use synthesized qualitative research findings as a springboard to develop meaningful QOL research grounded in patient perspectives.

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Ethical Considerations

The manuscript does not contain clinical studies or patient data.

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Table 4-1. Mapping sub-concepts of the 'Relationships' and 'Connectedness with Others' themes to items in the RAI 2.0 database

Sub-concept	Considerations for selecting RAI 2.0 item	Selected Items
Relationships with family, friends, other residents, and care staff influenced QOL for people with dementia in LTC. [44,45]	Relationships with family, friends, other residents, and care staff are all important	
In addition to contact with others, the nature of one's relational interactions influenced QOL. Overall, relationships characterized by connectedness improved quality of life; disconnectedness worsened quality of life. [44,45]	Independent variable(s) should contain some measure of relationship quality, not simply contact with others. However, should adjust for contact with others.	
Conflict is one way to become disconnected in relationships. [44,45]	Conflict may be a focal independent variable.	
Conflict in relationships is an antagonistic state that results when PWD encountered individuals who did not respect their ideas or interests. [44,45] Evidence supporting importance of conflict: Residents entering private rooms uninvited. [44] Caregivers rushing off without meeting needs leave the person feeling vulnerable, helpless. [44] It is a basic relational need for people to be nice and show respect in casual interactions: a. In contrast to avoidance, angry reactions, rough care, accusations, lying, offending, or displaying indifference. [45] Negative experiences in relationships can include [45]: a. Distrust b. Arguing c. Dealing with differentness: Strangers and Odd people d. Finding oneself alone: Don't talk to others; don't receive visits.	There are many different ways in which perceived conflict in relationships with others can occur but, overall, it is characterized by the perception that others do not respect one's ideas/interests.	**Conflict items (Main Independent Variables):** Conflict with family/friends Conflicts with staff Unhappy with roommate or residents other than roommate **Contact items (included in adjustment variables):** Daily visits prior to

Sub-concept	Considerations for selecting RAI 2.0 item	Selected Items
		admission Current absence of personal contact with family/friends
When connected to others, subjective QOL (i.e. person's perception of their life as a whole) improved. When disconnected from others, subjective QOL worsened. [44,45]	Review the RAI 2.0 for a subjective QOL outcome measure. There is no RAI 2.0 measure for subjective QOL.	**None available**
Being connected to others was associated with happiness. Being disconnected from others was associated with sadness. [45]	Review the RAI 2.0 for measures of happiness or sadness as these are potential outcome measures. There is no RAI 2.0 measure for happiness; several items are available to measure sadness.	**Expression of sadness in the last 30 days, including any of:** Negative statements Sad/pained/worried facial expressions Crying/tearfulness
As cognitive impairment worsened and dependence on others increased, conflict with friends, family, and staff that one depends on had a stronger influence on QOL (and sadness). [45]	Cognitive impairment and dependence on others may moderate the effect of family/friend and staff conflict on QOL & sadness.	**Cognitive Impairment:** Cognitive Performance Scale (CPS). [56] **Functional Dependence:** Activities of Daily Living-Hierarchy Scale (ADL-HS). [57]

Table 4-2. Mapping adjustment variables from the extant literature to RAI 2.0 items

Adjustment Variable	RAI 2.0 Item
Age [58–63]	Age
Sex [58–60,62,63]	Sex
Ethnicity [62,63]	Ethnicity
Education [63]	Education
Length of stay in the facility [58,59,61,63]	Length of stay
Physical disability [59,62]	Hearing impairment
	Vision impairment
Frequency of family or friend visits [59]	Daily visits prior to LTC admission
	No current visits
Psychopharmacological drugs [58,59]	Use of psychopharmacological drugs
Pain [64]	Pain frequency
	Pain intensity

Figure 4-1. Study hypotheses

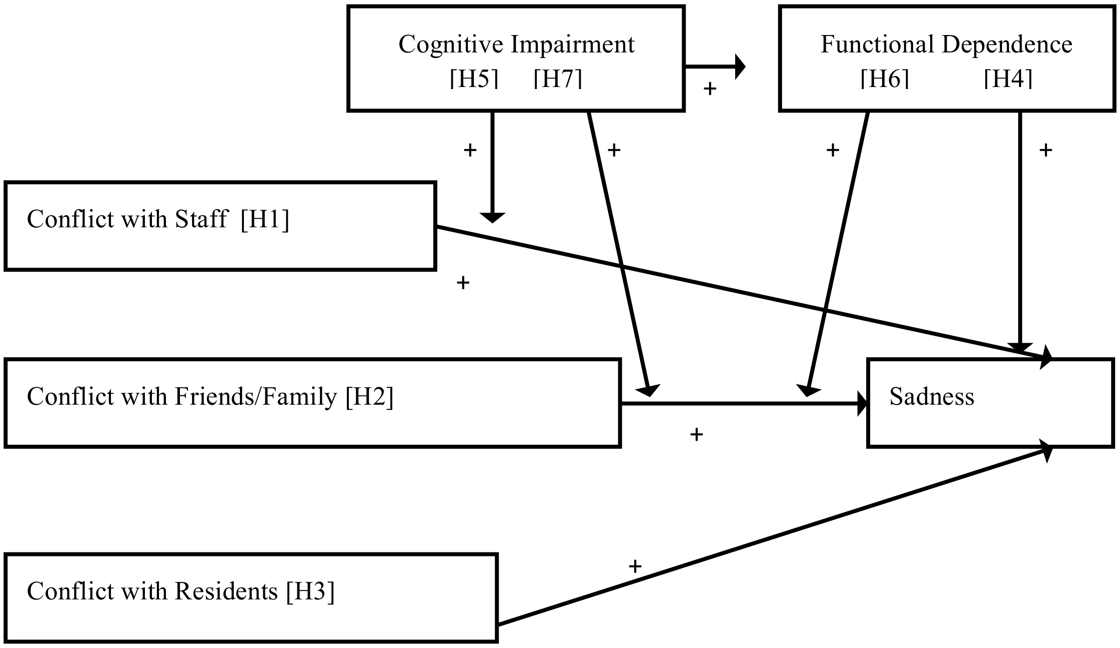

Figure notes: A plus sign over a single headed arrow denotes a positive relationship between each conflict variable and sadness. Cognitive impairment and functional dependence have an arrow pointing to the associations between sadness and conflict with staff and family/friends, as they are hypothesized to modify the strength of these associations. The framework does not explain the correlations among the independent variables (i.e., conflict with staff, friends/family, or residents) because the metasyntheses did not provide adequate direction for the nature of these hypotheses. The known causal relationship between cognitive impairment and functional dependence is shown by a single headed arrow, but will not be tested in the subsequent study

Table 4-3. Search strategy to re-situate new hypotheses in the extant literature

Purpose	Inclusion Criteria	Exclusion Criteria	Definitions
Identify studies of the effect of perceived conflict in relationships on happiness/sadness for people with dementia (PWD) in long-term care (LTC)	--Published in English ---Outcome is the happiness or sadness of PWD ---PWD must be living in a LTC setting ---The effect that the experience of perceived conflict in relationships has on either happiness or sadness for PWD is a primary study objective (i.e. not only included as a covariate in a study with other objectives)	---Studies focused on aspects of relationships other than conflict (e.g. pleasurable exchanges, social stimuli, social support) ---Studies about predictors of moods other than happiness or sadness (e.g. passive behaviors like withdrawal, less socialization, reduced interest in activities, anxiety)	Happiness: a state characterized by feelings of pleasure, contentment, satisfaction or joy Sadness: affected by unhappiness or grief; sorrowful or mournful

Table notes: Search strategy terms included MESH headings and keywords to capture long-term care, dementia, (Conflict OR Relationships), AND (happiness OR Sadness). Database-specific terms for Medline, PsycInfo, EMBASE, CINAHL, Abstracts in Social Gerontology were:

MEDLINE (187 results); PsycINFO (95 results); EMBASE (386 results)

Long-term Care: exp Nursing Homes/ or (Nursing home* or long term care or long term care facility or FTC or home for the aged or continuing care or extended care or residential care or personal care homes or lodges or care based facility or care homes or personal care home or skilled nursing facilities).mp.

Dementia: exp Dementia/ or (alzheimer* or dementia*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

Conflict OR Relationships: exp "Conflict (Psychology)"/ or conflict*.mp. or exp Family Conflict/ or exp Friends/ or exp Family Relations/ or exp Nurse-Patient Relations/ or exp Interpersonal Relations/ or relationship.mp.

Happiness or Sadness: exp Happiness/ or exp Affect/ or happy.mp. or mood.mp. or affect*.mp. or happiness.mp. or joy.mp. or enjoy*.mp. or 'affect rating scale'.mp. or AARS.mp. or pleasur*.mp. or content*.mp. or satisfy.mp. or satisfaction.mp. or (unhappy or unhappiness or sad or sadness or grief or grieve or sorrow* or mourn*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]

CINAHL (141 results)

Long-term Care: (SU Homes for the Elderly) OR (SU Old age homes) OR (SU Nursing home patients) or "nursing home" or "residential care" or "LTC" or "long term care"

Dementia: (SU dementia) or dementia or alzheimer*

Conflict OR Relationships: ((SU Interpersonal relations) or (SU Family Relations) or (SU Intergenerational Relations)) OR (relationship* or relations*) OR (SU conflict) or conflict*)

Happiness or Sadness: happiness or happy or joy or enjoy* or pleasur* or content* or satisfy or satisfaction or sad or sadness or grieve or grief or sorrow* or mourn* or affect* or mood or "affect rating scale" or AARS or (SU happiness) or (SU Affect)

Abstracts in Social Gerontology (65 results)

Long-term Care: (SU Homes for the Elderly) OR (SU Old age homes) OR (SU Nursing home patients) or "nursing home" or "residential care" or "LTC" or "long term care"

Dementia: (SU dementia) or dementia or alzheimer*

Happiness or Sadness: happiness or happy or joy or enjoy* or pleasur* or content* or satisfy or satisfaction or sad or sadness or grieve or grief or sorrow* or mourn* or affect* or mood or "affect rating scale" or AARS or (SU happiness) or (SU Affect)

Conflict OR Relationships:((SU Interpersonal relations) or (SU Family Relations) or (SU Intergenerational Relations)) or (relationship* or relations*) or (SU conflict) or conflict*

Chapter 5. Paper 4-The Association between Conflict and Sadness for People with Moderate and Severe Dementia in Long-Term Care

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Background

Dementia is a syndrome of progressive cognitive impairment and functional disability caused by several diseases, most commonly Alzheimer's disease and vascular dementia[1]. In 2010, there were 35.6 million people with dementia worldwide, most of whom were adults over the age of 65[2]. This number is projected to double every 20 years [2]. In high income countries, there is also a growing population of people over 85, which means that even more people are currently diagnosed with dementia, and live with its progressive symptoms[2].

The growing population of older adults with dementia greatly impacts long-term care (LTC) or nursing home services in Canada, where most (93%) LTC residents are adults over the age of 65 and nearly half (49%) are over the age of 85[3]. Furthermore, while the majority (55%) of Canadians with dementia are cared for at home[1], people with moderate or severe cognitive impairment comprise 60% of the residents cared for in LTC, versus 14% of clients that receive home care services [4]. Therefore, LTC remains an important site of care for people with moderate and severe dementia.

People usually live for seven to ten years with progressive symptoms following an initial dementia diagnosis[1]. Although people's trajectories are unique, following diagnosis, adults over 65 typically experience moderate symptoms during years two to five, and severe symptoms around the five year mark[2]. Because cures or disease modifying treatments for dementia remain elusive[5], this large and growing population of people with moderate and severe impairments require substantial support to maintain their quality of life (QOL). It is now a global priority to identify effective ways to improve QOL for older adults living with dementia [2,6], and supporting QOL is a priority for high quality LTC service delivery [2,3].

People evaluate their QOL by assessing the condition of their own life [7]. This is influenced by their culture, values, standards, concerns, goals, and expectations [8]. Older adults with dementia reported that QOL in LTC can be maintained even as disease symptoms worsen, if other factors that influence QOL are addressed [9,10]. It is therefore essential to identify and target factors that influence QOL in people with dementia in research to develop effective interventions, thereby making the best use of the 604 billion US dollars spent globally each year on dementia care and treatment[2]. Because we define QOL as subjective, as do several other dementia researchers[7,11,12], perspectives of older adults with dementia in LTC should be taken into account to identify the factors that influence their QOL [9].

Perceived Conflict: A Promising Factor Influencing QOL

There are two recent systematic reviews of qualitative research that synthesized factors that affect QOL of older adult residents in LTC with mild, moderate and severe dementia [13,14]. The first systematic review described factors that influence the QOL for LTC residents, many of whom also had dementia (31 studies) [14]. As such, this systematic review focused on QOL in a specific setting. Our research team conducted a second systematic review focused on QOL of people with a specific disease: dementia. The purpose of our systematic review was to understand which factors affect QOL according to people with dementia, many of whom also lived in LTC (11 studies) [13]. We extracted a sub-set of testable findings from both reviews to derive a conceptual framework and hypotheses that reflected people with dementia's perspectives of QOL and its influencing factors [15] (Figure 5-1).

These systematic reviews showed that relationships were an important factor that influenced QOL, according to people with dementia in LTC. However, relationships were not always beneficial to QOL; relationships characterized by perceived conflict (a break in relationships) had a negative influence on QOL. Perceived conflict was an antagonistic state, and occurred when friends, family, LTC staff, or co-residents did not respect the ideas or interests of the person with dementia [13,14]. Further to the effect of perceived conflict on QOL, our review showed that people with dementia frequently discussed sadness *as an outcome* (not an influencing factor) of perceived conflict and poor QOL[13]. This indicated that sadness was also a key outcome to consider when trying to understand the impact of influencing factors upon QOL for people with dementia in LTC [13]. We defined sadness as a state where people with dementia were affected by sorrow, mourning, unhappiness or grief [13].

These systematic reviews' findings described a variety of undesirable behaviors or reactions (both directed at and displayed by people with dementia) that reduced QOL, and which were classified as 'perceived conflict'. These included avoidance, anger, rough care, accusations, lying, offensive comments or actions, indifference, distrust, arguing, not talking to others, and feeling abandoned by family or friends [13]. Perceived conflict could also occur when co-residents entered another's private room uninvited [14], or when caregivers rushed away without fully meeting the resident's needs, causing the person to feel vulnerable and helpless [14].

The effect of perceived conflict with staff, family, or friends (but not co-residents) upon QOL and sadness was more pronounced as dementia severity increased [13]. Quantitatively-oriented hypotheses can be derived from this finding[15]. One potential mechanism for this relationship, derived from our systematic review, was that people with more severe cognitive impairment were more dependent upon staff and family or friends (but not on co-residents) to meet their needs[13]. As a result, we hypothesized that conflict with the people one relies upon—family, friends or staff—could more negatively influence QOL and sadness as cognitive impairment or dependence increased [13]. Alternatively, perceived conflict might be addressed less effectively at higher levels of impairment, making its effect on sadness and QOL appear more pronounced in the qualitative studies that included more impaired people, even though the strength of the effect upon sadness and QOL is the same.

In addition to the two reviews of qualitative studies, the nature of the LTC context supports the importance of perceived conflict to QOL for people with dementia. Experts posit that relationships are pivotal to QOL in LTC [4,16], in part because LTC residents live in group settings [14] where daily contact with others is unavoidable [17]. Residents must share dining space, activities, and sometimes even bedrooms with one another [14]. Furthermore, residents depend on staff to dress, eat, mobilize, and engage in social activities [17]. Thus, a high level of necessary interaction with others characterizes LTC contexts, so perceived conflict may be especially salient to QOL in this setting.

It is perhaps not surprising that conflicts could arise when relationships with staff or other residents become a necessity of daily life. It is noteworthy that previous research does suggest that perceived conflict is prevalent in LTC. In an ethnographic study of social interactions among people living in four LTC facilities in Sweden, people with dementia often felt offended by others which caused them to withdraw from interactions [18]. In one Canadian province, a high proportion of LTC residents perceived conflict with others, displaying this as physical (21%) or verbal (21%) aggression [19]. LTC residents with mild and more severe cognitive impairment in one LTC facility in the United States have reported conflict with family (11% and 8%, respectively), staff (13% and 6%), roommates (20% and 4%), and co-residents (13% and 5%) [20]. This shows that perceived conflict is an existing issue for LTC residents with dementia. However, while people with dementia in previous qualitative research have described the negative influence that perceived conflict has on QOL [13,14] and a related outcome—

sadness[13]—quantitative studies that employ large representative samples have not focused on this issue to date.

Quantitative Research on Perceived Conflict: Choosing an Outcome

Quality of Life: The association between perceived conflict and QOL has not been tested to date in this population, although there are measurement challenges that may prevent such studies specifically in LTC populations characterized by a high proportion of people with severe cognitive impairment [21]. Self-report QOL tools, the gold standard for evaluating subjective conceptualizations of QOL [22], have been developed for people with mild and moderate dementia, but reliability and validity of these tools for people with severe dementia has not been established [11,12,22–27]. This is largely due to the severe communication impairments that can prevent intelligible verbal responses to tool items.

To address this problem, researchers have developed observational tools to try to understand QOL for people with severe dementia based on their emotional and behavioral responses to situations [28–33]. These tools measure sadness, but also contain many other concepts like the extent of engagement, apathy, calm, or agitation[29]. While evaluating a range of emotional and behavioral outcomes has the advantage of providing a more comprehensive picture of the person's response to their environment, the systematic review findings did not support these other concepts as direct outcomes of either perceived conflict or of QOL according to people with dementia[13,14]. These other concepts likely have other causes[29,34], so testing for an association between perceived conflict and these other outcomes would be conceptually problematic and would not address the specific hypotheses grounded in perspectives of LTC residents with dementia derived from the previous qualitative research.

Sadness: While measurement challenges currently prevent testing the association between perceived conflict and QOL in severe dementia, the association between perceived conflict and sadness is testable for people with mild, moderate or severe dementia. Sadness was an outcome of both perceived conflict and poor QOL according to people with dementia in LTC [13], and is related to but different from depression. Sadness is one symptom of depression [35,36], along with apathy [35], short-term memory impairments [35], and insomnia [36] , among others. Sadness, unlike depression, is an inevitable part of the human condition and cannot be altogether avoided [37], but addressing preventable causes of sadness may improve QOL[13,30].

Perceived Conflict and Sadness

Recent research has begun to explore causes of sadness for people with dementia. Several previously described sadness stimuli for people with dementia include loss of people (e.g. due to death) [38,39], loss of places (e.g. relocation from home) [38], and pain [40]. Research has also documented that some people can experience sadness as an initial response to a dementia diagnosis [41,42]. The results from the previously described qualitative research syntheses proposed perceived conflict as another possible cause of sadness for people with dementia in LTC[13,14]. Demonstrating an association between perceived conflict and sadness would be a first step to support this causal relationship [43].

A small body of research has assessed the association between relationships (in general) and sadness, but perceived conflict has not been specifically targeted [44–53]. Instead, the effects of potentially therapeutic relational interventions have been examined, like providing residents with conversation or attention, and perceived conflict was not evaluated [44–53]. In addition, research has only rarely addressed residents' day-to-day interactions with co-residents, staff, and family/friends, relationships important from the perspective of people with dementia in LTC [13,14].

Instead, most studies evaluated the impact of therapeutic interactions delivered by research assistants [44,46,49,50] or volunteers [45]. In the few studies that have targeted resident's existing relationships with family [53,54] or staff [17,47,48] to improve mood, a single pre-determined relationship was targeted (e.g. interactions with staff, but not family or co-residents), regardless of the importance of enhancing this relationship from the perspective of that individual with dementia.

Although it is important to examine perceived conflict in people with dementia as previous studies have emphasized its potential to affect QOL and sadness [13,14], no reported research to date has examined this association. In LTC, where a large proportion of people have severe dementia and given current limitations with measuring subjective QOL, testing the association between perceived conflict and sadness is a reasonable first step. Presence and size of an association between conflict and sadness in a representative sample of people with mild, moderate and severe dementia should be established prior to designing studies to test whether it precedes sadness in populations of people with dementia in LTC, or developing interventions to test the modifiability of perceived conflict [55].

Study Purpose

The purpose of this study was to examine the association between perceived conflict and sadness among older adults with moderate and severe dementia in long-term care. We hypothesized that perceived conflicts with staff [H1], family/friends [H2], and co-residents [H3] would be positively associated with sadness. Findings from previous qualitative work described how people with dementia relied upon staff and family/friends (but not on co-residents) to meet their needs as their dementia progressed. As a result, if conflict was with staff or family/friends, then we anticipated stronger associations with sadness at higher levels of cognitive impairment and functional dependence (i.e. relying on others in order to complete activities of daily living like dressing, eating or toileting)[13]. That is to say, we hypothesized that cognitive impairment and functional dependence would modify effects for both staff and family/friend conflict.

Insert Figure 5-1 about here

Methods

Design

This is a cross-sectional, correlational retrospective analysis of clinical administrative data. We used Resident Assessment Instrument (RAI 2.0) data [56–58] that were collected by LTC facility staff between April 1 2012 and March 31 2013 and submitted to the Canadian Institute for Health Information (CIHI) [59]. We used RAI 2.0 data for this research because a complete sampling frame of the more than 18,400 individuals with dementia in Ontario LTC settings was available from a single source [59], greatly increasing study feasibility to obtain a representative and well-powered sample. Using RAI data for research also supports replication of study results because this assessment system is mandated for use in most Canadian jurisdictions and in the United States. Further, using clinical data may promote application of the findings to practice because the study variables map directly to clinicians' assessment data.

RAI 2.0 Assessment Procedures

Facility staff complete a full RAI 2.0 assessment for each resident annually, and an abbreviated quarterly assessment every three months until the next annual assessment is due. Staff complete additional assessments if there is a significant change in the resident's health status[60]. The RAI 2.0 assessments are based on discussions with the resident, care staff, and family members, observation of the resident, and review of the resident's medical record. The detailed RAI 2.0 data collection and entry instructions [58] and assessor training [61] reduce coding errors.

Previous research established the RAI 2.0 items' reliability (inter-rater and internal consistency) and validity (criterion, convergent, and predictive) [61–68]. However, more subjective measures, like perceived conflict and sadness, tend to be more difficult to measure validly than are objective outcomes, like physical status for example [69]. Cognitive impairment may further affect validity, as well as reliability [62,64,66]. To increase statistical power in case measurement error increased with dementia severity [43], we sampled people with mild, moderate and severe cognitive impairment (rather than limiting to severe impairment).

Sample and Setting

Staff in most Canadian LTC facilities collect RAI 2.0 assessment data, but not all facilities submit their data to CIHI. At the time of data request, all 683 Ontario facilities submitted data to CIHI; the only other Canadian jurisdiction with a complete sampling frame was Yukon territory (4 facilities) [61]. We requested Ontario data because the sampling frame was complete, the population was large (>18,400 residents with dementia), and the rate of missing annual assessments was very low (0.6%) [61].

We requested from CIHI a random sample of the most recent full assessment for 5324 residents with a dementia diagnosis assessed in the April 1 2012-March 31 2013 period [59]. We only requested full annual assessments to avoid missing data, as all items are mandatory for full assessments, but many, including perceived conflict items, are not required on quarterly assessments. The sample size we requested was 10% more than the calculated sample size (n=4840) required to identify a small (OR= 1.3), statistically significant association (alpha=0.05) with 80% power. Variance inflation factor estimates that account for all planned covariates were unavailable [70], so we calculated the sample size for a logistic regression model with two binary independent variables [70,71]. For this calculation, we assumed that 15% of the sample would report conflict and 20% would experience sadness.

CIHI uses software specifications and conducts internal checks to ensure that there are no missing data or invalid entries [59]. Data that does not meet CIHI specifications are rejected, and facilities must follow-up with CIHI within 45 days to submit corrections or missing data [59]. We requested data that were one year old so that CIHI could address any missing data issues.

Participants

Our inclusion criteria were adults over 65 years with a dementia diagnosis, who were residents of an Ontario LTC facility for at least three months, and who had a full RAI 2.0 assessment completed during the April 1 2012 to March 31 2013 assessment period. We excluded sub-populations of people with dementia who were not represented in the primary studies included in the two systematic reviews used to derive study hypotheses, and those whose mood presentation may differ substantially from those who were represented in the systematic reviews. These included people with psychiatric diagnoses including depression, anxiety disorder, manic depression, or schizophrenia (similar to studies on the effect of relationships on mood [48,52,72]) and comatose residents.

Our sample contained a small proportion of people with mild dementia, which resulted in empty cells when testing the interaction terms for the proposed effect modifiers. Small cell counts can bias estimates, decrease estimate precision, or result in an inestimable model [73]. To address this, we modified our inclusion criteria and dropped the 318 people with mild dementia from the analysis. This did not affect the integrity of the study to test hypotheses in people with moderate and severe dementia because the sample size still exceeded that required by the power calculation, but does mean that the findings are no longer generalizable to people with mild dementia. We also dropped people with sex coded as ‘other’ (i.e. not male or female) because there were only five people in this category, which lead to very small cell counts in the sex-adjusted model.

Variables

All variables (dependent, independent, effect modifiers, and confounding) were operationalized using RAI 2.0 data (see Table 5-1). These are described below.

Insert Table 5-1 about here

Sadness (dependent variable): We selected three categorical RAI 2.0 items that measure sadness (and not anxiety or other symptoms of depression) by comparing item content to the definition of sadness and to a validated depression screening tool that contains sadness items [74]. Selected items included one verbal indicator (resident made negative statements) and two non-verbal indicators (sad, pained, worried facial expression; crying/tearfulness). RAI 2.0 assessors score the usual 7-day frequency, considering the last 30 days (0 = indicator not exhibited in last 30 days; 1= indicator exhibited up to 5 days a week; 2= indicator exhibited 6 or 7 days a week) [58]. For consistency with the definition of sadness, we used these items to generate a single dichotomous measure (0 = no expression of sadness in the last 30 days; 1= usually one or more weekly expressions of sadness in the last 30 days). Previous research has shown that the inter-rater reliability for mood items (which include the sadness items used in this study) was high (0.89) and the Kappa value was acceptable (0.56) [20].

Independent variables (perceived conflict): Four dichotomous RAI 2.0 items assess if the resident perceived conflict with family or friends, staff, residents other than one’s roommate, and roommates in the past seven days. Not all residents have roommates, so we derived a single variable for conflict with co-residents (roommate or other). Assessment is based on the resident's comments during an interview, and on comments made in the presence of other staff, regular caregivers, or family [58]. For each item, RAI 2.0 assessors are directed to look for a wide a variety relationship issues, and these fit the conceptualization of conflict used in this study. The RAI 2.0 manual provides examples like: chronic complaints or criticism about staff; requests for roommate changes, grumbling about a roommate rummaging in one's belongings, or complaints about another resident's behavior, physical or mental status; and feeling abandoned by family [58]. Previous research shows that the correlation between raters for the perceived conflict items is high (0.94), the Kappa value is acceptable (0.74) [20], and that these items have good fit indices in confirmatory factor analysis among groups with high and low cognitive impairment [67].

Effect modifier variables (functional dependence and cognitive impairment): Effect modifiers change the strength of the association between two other variables [75]. We tested cognitive impairment and functional dependence as effect modifiers. The Cognitive Performance Scale (CPS) measures cognitive impairment based on comatose status, decision-making ability, short-term memory, making oneself understood, and eating [76]. CPS scores have shown agreement with the Mini-Mental State Examination (MMSE)[76–78], a widely used tool to assess cognitive impairment. In this study, we applied the MMSE definition of cognitive impairment as mild (MMSE=21-25), moderate (MMSE=11-20) and severe (MMSE=10 or less) [79] . Based on how CPS categories have been shown to correspond with average MMSE ratings in previous work[76,78], we re-coded the CPS scores to reflect the MMSE categories of mild (CPS = 0 to 1), moderate (CPS = 2 to 3), and severe (CPS = 4 to 6) impairment. Other research has used similar procedures to re-code the CPS into three categories of dementia severity[80–82].

The Activities of Daily Living Hierarchy Scale (ADL-HS) is a 7-point scale to measure overall functional dependence based on assessments of personal hygiene, toileting, locomotion, and eating (0 = independent, 1 = supervision, 2 = limited assistance, 3 = extensive1, 4 = extensive2, 5 = dependent, and 6 = total dependence) [83]. To address problems with small cell counts, we re-coded ADL-HS into four categories with clinical relevance proposed by Morris et al.[83]: relatively independent (0 or 1), limited impairment (2), extensive help (3 or 4), and severe or total dependence (5 or 6). All analyses were conducted on complete cases; there were no missing data.

Potential confounding variables: In this study, additional variables were included only to adjust the hypothesized associations between conflict and sadness, not to predict sadness or to explain variation in sadness[84,85]. Confounding variables must be associated with both the outcome and the focal independent variables [84,85], and as such were adjusted for using multiple logistic regression to obtain accurate estimates of association between perceived conflict and sadness[84,85]. We assessed additional variables to determine if they should be included in the analysis to adjust the estimates of association between perceived conflict and sadness [84,85]. We selected the following potential adjustment variables from intervention studies designed to test the association between relationships and mood: age [17,48,49,51–53], sex [17,49,51–53], education [17], length of stay in the facility [17,48,51,52], physical disability [48,52], frequency of family or friend visits [48], and use of psychopharmacological drugs [17,48]. Pain was also included because both pain and sadness are sometimes assessed based on similar facial expressions [86].

Analysis

We entered all data into STATA 13. We assessed each variable's distribution by displaying box plots for continuous variables and frequency tables for categorical variables, and checked outlier values to ensure that there were no data entry errors. We calculated means and standard deviations for continuous variables and proportions for categorical variables. We ran cross-tabs to check for small cell counts.

We conducted non-stepwise, purposeful logistic regression to select and adjust for confounding variables[84,85] and to test the hypotheses. Because resident observations were nested within facilities, we used the 'cluster' command in STATA to adjust for the within-facility correlation in sadness [73]. We tested the significance of each variable when entered as the sole independent variable in logistic regression. Then, we fit a multiple logistic regression model with all conflict variables, variables of theoretical (cognitive impairment, functional dependence, contact) and clinical (age, sex, pain) importance, and any other variables that were statistically significant at $p \leq 0.2$ level when we tested them alone. We used this conservative cut-point to prevent premature exclusion of potentially important confounding variables. We assessed effect modification in this model by testing for statistically significant ($p \leq 0.05$) interaction terms. We generated the interaction terms by multiplying each of the staff and family/friend conflict variables by cognitive impairment (e.g. FamilyConflictXCPS) and functional dependence (e.g. FamilyConflictXADL-HS). After keeping any interaction terms that were statistically significant, we then assessed for confounding. We removed potential confounding variables one at a time and assessed conflict variable coefficients for more than 15% change, which would indicate the need to adjust for the removed variable in the multivariable analysis. We also assessed whether removing a particular confounding variable affected estimate precision. For model diagnostics, we used the Hosmer-Lemeshow test for goodness of fit, and tested the linear assumption for continuous variables retained in the final model.

Ethics

We obtained ethics approval from the Human Research Ethics Board at the University of Alberta. We did not request direct resident identifiers (names, health care number, month and day of birth) from CIHI. We stored and analysed data securely in the local Health Research Data Repository [87].

Results

Sample Characteristics

The final sample included 5001 people with moderate and severe dementia from 613 LTC facilities. There were 1 to 41 residents from each facility (mean 13 residents per facility; SD 8.7). The sample had a high mean age (mean 86 years; SD 7.03), and the majority of people were female with non-Alzheimer's type dementia (see Table 5-2). Sadness was prevalent with over half of the sample (59%) displaying an indicator of sadness at least once per week. Conflict was less common, and 12% had conflict with family/friends, staff, or other residents in the last week.

Insert Table 5-2 about here

Unadjusted Estimates

All conflict variables were statistically significant when entered alone in cluster-corrected logistic regression models. All potential confounding variables, with the exception of age and hypnotic use, were significant at $p \leq 0.2$ when entered alone in cluster-corrected logistic regression models (see Table 5-3). Based on this, hypnotic use was a candidate for exclusion from subsequent analysis because it was not statistically significant at $p \leq 0.2$ or of clinical/theoretical importance (while age was of clinical importance, and therefore not a candidate for exclusion). However, to be conservative, we retained hypnotic use for further assessment as a potential confounder.

Insert Table 5-3 about here

Effect Modifiers and Confounders

All of the interaction terms for family/friend and staff conflict were non-significant at $p \leq 0.05$ in a model containing all possible confounders. This was an unexpected finding, as we anticipated that cognitive impairment and functional dependence would modify effects for both staff and family/friend conflict. The interaction term to test if the association between co-resident conflict and sadness differed as cognitive impairment increased was statistically significant, and so was included in the final model to calculate a separate odds ratio for people with moderate and severe dementia. As expected, the odds ratio for co-resident conflict and sadness did not change as functional dependence increased.

We then assessed confounding using the model with independent variables, all potential confounders and the significant interaction term. The odds ratios for the associations between conflict and sadness changed very little (<1% to 5%) when we removed potential confounding variables from the model one at a time, or when we removed all psychopharmacological use variables or both hearing and vision at the same time. There was also minimal change to the precision of the estimates. As a result, we included in the final multiple logistic regression model only those adjustment variables of clinical and theoretical importance. Variables excluded from the final model based on this confounder analysis included education, length of stay, psychopharmacological drugs, hearing and vision impairment, and daily contact with others upon admission. With all of these variables excluded, change to the estimates remained below 15% (0.15% to 10.42%). The largest % change in the estimate was for the association between co-resident conflict for people with severe dementia, where the point estimate for the odds ratio changed from 1.06 to 1.18 (but remained non-significant). Overall, while each of the excluded variables could still be associated with sadness, this stage of the analysis demonstrated that these variables did not have an important confounding effect upon the association between perceived conflict and sadness.

Multiple Logistic Regression

The final model included the focal independent variables (conflict with family/friends, staff, co-residents), clinically or theoretically important adjustment variables (age, sex, no visits, pain, cognitive impairment and functional dependence), and an interaction term to adjust for the difference in the association between co-resident conflict and sadness for people with severe as opposed to moderate dementia. Odds ratios for independent and adjustment variables are shown in Table 5-4. Age, the only continuous variable in the model, did not meet the linear assumption. As a result, we broke it into quartiles and added it to the model as a categorical variable.

People with moderate or severe dementia who had conflicts with staff had 1.51 times the odds of sadness (95% CI=1.07 to 2.13; p=0.020). Those with family and friend conflict had 1.91 times the odds of sadness (95% CI=1.26 to 2.88; p=0.002). People with moderate dementia who had conflicts with co-residents had 2.02 times the odds of sadness (95% CI=1.45 to 2.82; p<0.001). All of these associations were statistically significant. There was no association between co-resident conflict and sadness for people with severe dementia (OR= 1.18; 95% CI=0.72 to 1.91; p=0.511). Hosmer Lemeshow test results were non-significant, indicating that the model fit the data (Prob > chi2 = 0.4277). Thus when residents with moderate or severe dementia in LTC perceived conflict with staff or family/friends, the odds of sadness also increased. The odds of sadness also increased for residents with moderate dementia who perceived conflict with co-residents, but this association disappeared for people with severe dementia.

Insert Table 5-4 about here

Discussion

These findings supported an association between sadness and conflict with staff, family/friends, and co-residents. The odds ratios for the statistically significant conflict variables were reasonably narrow and of a magnitude comparable to the adjustment variables of mild or moderate pain and functional dependence, which were identified as high priority quality indicators from the perspective of clinicians and policy-makers [3,88]. The odds ratios for the statistically significant conflict variables were larger than for cognitive impairment, age, or sex.

Importance of Family and Friend Relationships

Although people with dementia in LTC facilities are in frequent contact with other residents and staff, the results showed that the quality of relationships with family and friends may be more important to people with dementia as their symptoms progress. The relatively small proportion of people who lacked contact with family and friends (4.52 %) had no statistically significant difference in the odds of sadness compared to those who maintained contact (OR= 1.17; 95% CI= 0.86 to 1.59; p= 0.324). Meanwhile, those with conflict with family or friends had 1.91 times the odds of sadness, an association that occurred in both moderate and severe dementia. This highlights that attention should be paid not only to supporting residents to maintain contact with family and friends, but to assessing and promoting the quality of that contact. Furthermore, conflict with family/friends was more highly associated with sadness than either staff or co-resident conflict among people with severe dementia. This supports previous literature on the sustained importance of family and friend relationships following admission to LTC facilities [13,14,53,89,90].

We did not expect any effect modification for co-resident conflict, but there was a statistically significant reduction in the strength of the association between co-resident conflict and sadness for people with severe compared to moderate dementia. Qualitative research has found that people with severe dementia become less aware of and concerned with their relationships with co-residents and staff, and more focused on friends and family [90]. Our results support this claim.

Conflict Prevalence

The prevalence of conflict in this study was comparable to the rates identified among more severely cognitively impaired residents in selected LTC facilities in the United States in 1998 [20]. These 1998 rates were 4 to 6% and this study's were 4 to 7%. Although the rates are from different populations, their comparability does suggest that the prevalence of perceived conflict has remained stable for over a decade. Interventions designed specifically to address conflict are likely needed to modify prevalence rates in the population. With the availability of longitudinal RAI 2.0 data, there is the opportunity to evaluate a population's rate of conflict over time, as is currently done with other measures like falls, pain and pressure ulcers [3].

Measurement of Conflict in the Cognitively Impaired

The prevalence of conflict with each of staff, family/friends, and residents was relatively low. However, perceived conflict may be underreported in populations of people with moderate and severe dementia. The conflict items are assessed by first asking the resident about whether they have any problems in their relationships with others. To ensure accurate results, the RAI 2.0 assessment procedure requires the assessor to also *observe* the resident with other staff, and to ask family and staff about whether they have seen signs of conflict [58]. However, Ontario LTC facilities have historically had some of the lowest regulated nursing staff hours in the country [91]. Given that regulated nursing staff often complete RAI 2.0 assessments, it is conceivable that the latter procedure may not be conducted as extensively, and conflict scored primarily by asking the resident about their relationships with others in the past seven days. This would lead to under reporting of conflict in people with moderate to severe impairment due to both communication difficulty and impaired recall of past events. Thus, conflict prevalence may actually be higher than reported. Because power to identify statistically significant findings is reduced when measurement error increases [43,92], this may have contributed to non-significant interaction terms. Future work should evaluate whether current practice in LTC facilities results in accurate assessment and documentation for RAI 2.0 conflict items among cognitively impaired people.

There are two other RAI 2.0 items that capture high intensity conflict situations and may have more robust measurement properties in samples of people with moderate and severe dementia because they do not rely upon self-report. These are verbally abusive behaviors (residents or staff threatened, screamed or cursed at) and physically abusive behaviors (residents or staff hit, shoved, scratched or sexually abused) [58]. We did not include these variables in the present analysis because they overlap conceptually with the measures of perceived conflict with staff and residents. Including overlapping or redundant covariates reduces power to identify significant effects and confuses interpretation of findings [92]. Further, the verbal and physical abuse items do not differentiate between abuse of staff and residents, thus mixing staff and resident conflict. Because this study's hypotheses differentiated between conflict with staff, family/friends, and co-residents, we will test different hypotheses for the verbal and physical abuse variables, and report findings in a separate publication.

Validity of Sadness Indicators

In this study, we defined sadness as a state where people with dementia were affected by sorrow, mourning, unhappiness or grief [13] ; we measured sadness using the variables negative statements (e.g. ‘nothing matters’ or ‘I would rather be dead’); sad, pained or worried facial expression; and crying or tearfulness[58]. Another validated tool that included items to measure sadness for people with dementia used similar items like sad expression, sad voice and tearfulness[74]. Similar to other sadness measures for people with dementia[34,93], the RAI 2.0 facial expression item contains both the terms ‘pained’ and ‘worried’ to describe to evaluators what a sad facial expression might look like. However, this does risk conflating a pained or worried expression with sadness. A similar issue exists for the flattened affect that is a side effect of psychotropic medication use, which could result in apathy being mistaken for sadness.

We adjusted for pain in the logistic regression model, but our literature review to identify confounding variables did not identify worried expression, nor was it measured separately in the RAI 2.0, so it was not included as an adjustment variable. Despite this limitation, we believe that a sad, and not worried, facial expression is most frequently measured because it is easier to observe than more subtle expressions like worry [29,30]. Our results also showed that psychotropic medication use was associated with sadness, but to a lesser extent than conflict (Table 5-3). Furthermore, adjusting for psychotropic medication use made little difference to the association between conflict and sadness, suggesting that this particular issue did not have a discernable impact on our findings. Given that sadness is a subjective state, some level of measurement error remains probable. Overall, we believe that the sadness indicators we used in this study identified primarily people who were sad. As this data is from 2011-2012 and both psychotropic medication administration and pain management practices will likely change and improve over time, this study should be replicated and these claims re-assessed at a later date.

Limitations

We faced several limitations when testing interaction terms and further study is warranted. Re-categorizing functional dependence and dropping people with mild dementia or other sex eliminated the empty cells and increased many cell counts, but there were still some categories produced by the functional dependence interaction terms that contained fewer than ten people. While the models remained estimable, the small numbers in each cell reduced the power of the statistical tests for functional dependence as an effect modifier [73]. In addition, because we dropped people with mild dementia from the analysis, we were unable to test if there were differences in odds ratios of conflict and sadness for mild compared to moderate or severe dementia. However, we believe that the associations between perceived conflict and sadness are robust and generalizable to people with moderate and severe dementia, and that the tests for effect modification by severe versus moderate cognitive impairment were not underpowered because they had fewer categories, resulting in larger cell counts. To establish more rigorous evidence that there is no difference in the association of sadness and conflict by functional status, or for people with mild compared to moderate dementia, future studies in LTC should use stratified random sampling to ensure adequate numbers of people with mild, moderate and severe dementia.

This study is also limited in its ability to contribute, conceptually, to the QOL literature. Testing the association between conflict and sadness contributes indirectly to our understanding of QOL for people with dementia in LTC because of the stated importance of both of these variables (one an influencing factor, the other an outcome) to QOL from the perspective of people with dementia [13,14]. However, due to lack of a subjective QOL measure in the RAI 2.0 dataset, we could not directly test the association between conflict and QOL. Other research has similarly used observational measures of mood to better understand QOL in severe dementia [23,30]. However, valid and reliable measures of subjective QOL are available for use in populations of people with mild and moderate dementia. Future research should directly test the association between conflict and QOL in mild and moderate dementia, and the potential mediating effect of QOL on sadness (i.e. perceived conflict→quality of life→ sadness).

The cross-sectional design prevents any claims to a causal association between conflict and sadness; it is conceivable that there could be situations where sadness could actually cause conflict. For example, if a sad resident caused a family member to feel guilt about LTC facility placement, and if this limited the amount that they visited, conflict might result if the resident felt abandoned. Although the cross-sectional design is limited in terms of establishing causality, this was an intentional and judicious first step to establish existence of an association using existing data prior to designing a potentially more resource-intensive study[55]. Future research using prospective longitudinal designs or interventions to reduce conflict should be conducted to generate evidence that conflict actually causes sadness.

A final limitation is that the results do not account for ethno-cultural diversity. Ethnicity may affect the association between sadness and conflict, and other research on the effects of relationships and mood have adjusted for ethnicity [52,53]. CIHI does not require facilities to submit the RAI 2.0 ethnicity variable and it therefore could not be obtained for this study. Making submission of this RAI 2.0 item mandatory would allow for adjustment of this variable in future research.

While this study had some clear limitations, it also had important strengths. These include a large well-powered sample to test the majority of the hypotheses, random sampling to obtain a representative sample of Ontario LTC residents with moderate and severe dementia, no missing data, multivariable analysis to adjust for potential covariates, cluster correction which calculates accurate standard errors as there were some residents living in the same LTC facility, and application of an explicit conceptual framework derived from the perspectives of people with dementia in LTC. Our use of an existing clinical dataset may facilitate application of the findings because the results apply directly to existing LTC resident assessment practice.

Generalizability

Study results are directly generalizable to Ontario LTC residents with moderate and severe dementia, but may not be generalizable to LTC residents whose characteristics or living environments differ significantly from the Ontario context. For example, Yukon LTC residents are younger and have fewer physical and cognitive impairments than Ontario residents [3]. Replication studies are warranted using samples from other countries and Canadian jurisdictions. Replication feasibility will be greatly enhanced by the growing number of facilities that mandate RAI 2.0 use, both in Canada and internationally.

Conclusion

Findings from previous qualitative syntheses have demonstrated that conflict affects sadness and QOL according to people with dementia in LTC [13,14]. We completed a cross-sectional study, the first to our knowledge to test the association between perceived conflict and sadness among LTC residents with moderate and severe dementia. These findings support the hypotheses that conflicts with family or friends, co-residents and staff are each associated with sadness in a large and representative sample of Ontario LTC residents with moderate and severe dementia. The compatibility of our findings with the perspectives of people with dementia from qualitative studies lends credence to the claim that people with dementia have insight into what affects their QOL [22]. Given the evidence of association generated by this study, next steps should include prospective studies to deepen understanding of conflict in LTC, and to determine if conflict precedes sadness. Such studies may also identify clues for how to modify perceived conflict in this population.

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Figure 5-1. Quantitative study conceptual framework

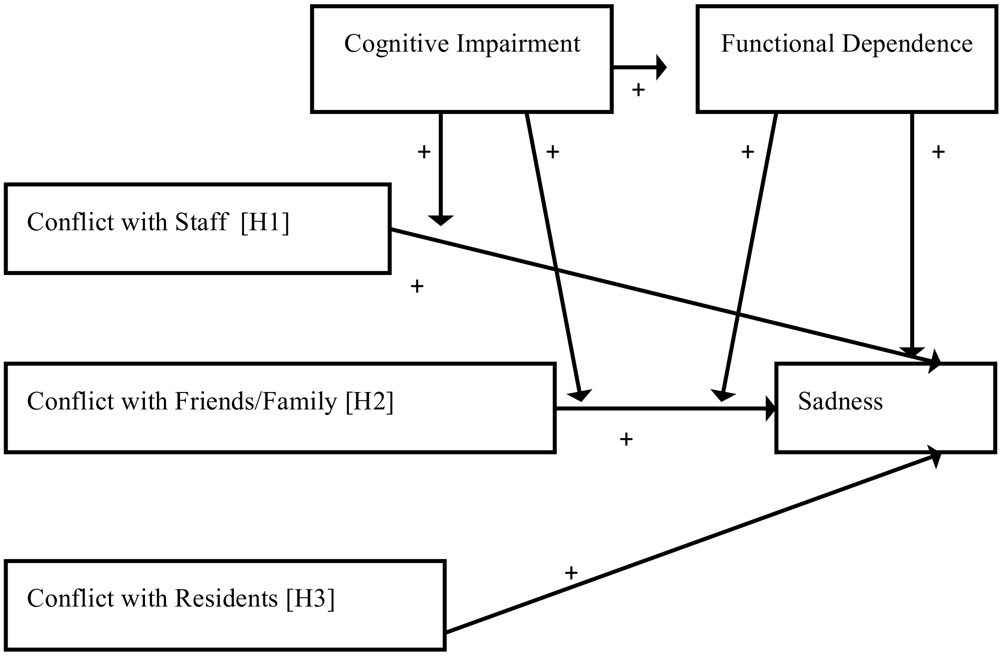

Figure 5-1 Notes: A plus (+) sign denotes a positive relationship. Cognitive impairment and functional dependence are proposed as effect moderators. For simplicity, only testable hypotheses are shown: the direct associations between perceived conflict and QOL (i.e. conflicts with each of staff, friends/family, or residents→ QOL) and the influence of QOL upon sadness (i.e. perceived conflict with staff→ QOL→sadness) are not shown.

Table 5-1. Summary of quantitative study variables

	Independent Variables	Moderators	Potential Confounding Variables	Dependent Variable
RAI 2.0 items	**Family/Friend Conflict** Conflict with family/friends (F2d) **Staff Conflict** Conflicts with staff (F2a) **Resident Conflict** Unhappy with other residents (F2c, F2b)	**Cognitive Impairment** Cognitive Performance Scale (CPS)[76] **Functional Dependence:** Activities of Daily Living-Hierarchy Scale (ADL-HS)[83]	**Age** (AA3) **Sex** (AA2) **Education** (AB7) **Length of Stay** (AB1 **Physical disability** ---Hearing impairment (C1) ---Vision impairment (D1) **Frequency of family/friend visits** ---Daily visits prior to long-term care facility admission (AC1s) ---No current visits (F2e) **Use of psychopharmacological drugs** ---Antipsychotics (O4a) ---Antianxiety (O4b) ---Antidepressant (O4c) ---Hypnotic (O4d) **Pain** Pain scale[94], derived from items on pain frequency (J2a) and pain intensity (J2b)	**Sadness in the last 30 days, indicated by any one of:** ---Negative statements (E1a) ---Sad/ pained/ worried facial expressions (E1l) ---Crying/ tearfulness (E1m)

Table 5-2. Sample characteristics (n=5001)

Variable	Descriptive Statistics
Age (years)	Mean 86.27 (SD 7.03) Range 65-109
Sex	Male 27.91 % (n=1396) Female 72.09% (n=3605)
No Contact with Family/Friends	4.52 % (n=226)
Alzheimer's Disease	33.93 % (n=1,697)
Pain	None 73.83% (n=3,692) Mild 17.74 % (n=887) Moderate 7.30 % (n=365) Severe 1.14 % (n= 57)
Conflict	Overall 11.59% (n=580) Staff 5.96% (n=298) Family/friend 3.56% (n=178) Co-resident 6.88% (n=344)
Sadness	Overall 58.53% (n= 2,927) Negative statements 13.58% (n=679) Sad/pained/worried facial expression 53.97% (n=2699) Crying 10.04% (n=502)
Antipsychotic use	36.37% (n=1,819)
Antidepressant use	43.97% (n=2199)

Antianxiety use	9.42% (n=471)
Hypnotic use	3.28% (n=164)
Cognitive Impairment	Moderate 55.07% (n=2754)
	Severe 44.93% (n=2247)
Functional Status	Relatively Independent 6.58% (n=329)
	Limited Impairment 8.96% (n=448)
	Extensive Help 45.07% (n= 2254)
	Severe, total dependence 39.39% (n=1970)
High School Education or Less	46.49% (n=2325)
Length of Stay in Years	Mean =2.94 (SD 2.71)
	Range =0.25 to 44.75

Table 5-3. Odds Ratio (OR), Robust standard error (SE), 95% Confidence Interval (CI) and p-value for all variables in unadjusted logistic regression models with cluster correction

Variable	**OR (SE)**	**95% CI**	**p-value**
Staff Conflict	2.12 (0.35)	1.54 to 2.91	<0.001
Family/Friend Conflict	2.60 (0.50)	1.78 to 3.80	<0.001
Resident Conflict	2.20 (0.29)	1.70 to 2.85	<0.001
Cognitive Impairment (reference=moderate)			
Severe	1.30 (0.09)	1.14 to 1.48	<0.001
Functional Dependence (reference=relatively independent)			
Limited impairment	1.37 (0.22)	1.00 to 1.87	0.047
Extensive help	2.03 (0.24)	1.61 to 2.56	<0.001
Severe/total dependence	1.77 (0.21)	1.40 to 2.24	<0.001
Age in years (reference=65-81)			
82-86	1.04 (0.09)	0.88 to 1.22	0.645
87-90	0.99 (0.09)	0.83 to 1.18	0.922
91-109	1.04 (0.09)	0.88 to 1.23	0.616
Sex (reference=Female)			
Male	0.91 (0.06)	0.81 to 1.03	0.127
Highest Level of Education (reference= no schooling)			
8th Grade	2.13 (0.50)	1.35 to 3.37	0.001
9th to 11th Grade	1.98 (0.50)	1.20 to 3.24	0.007
High School	2.19 (0.55)	1.34 to 3.59	0.002

Variable	OR (SE)	95% CI	p-value
Technical or Trade School	2.49 (0.69)	1.45 to 4.28	0.001
Some College	1.64 (0.43)	0.98 to 2.75	0.059
Bachelor's Degree	1.83 (0.52)	1.05 to 3.20	0.034
Graduate Degree	1.62 (0.49)	0.90 to 2.91	0.110
Unknown Education	1.87 (0.45)	1.17 to 2.99	0.009
Length of Stay in Years	0.97 (0.01)	0. 95 to 0.99	0.008
Hearing (reference=adequate)			
Minimal difficulty	1.35 (0.10)	1.17 to 1.57	<0.001
In special situations only	1.28 (0.13)	1.04 to 1.56	0.019
Highly impaired	1.42 (0.27)	0.97 to 2.07	0.069
Vision (reference=adequate)			
Impaired	1.17 (0.09)	1.01 to 1.35	0.034
Moderately impaired	1.07 (0.12)	0.86 to 1.33	0.541
Highly impaired	0.88 (0.10)	0.69 to 1.10	0.238
Severely impaired	0.88 (0.18)	0.59 to 1.31	0.523
Daily contact upon admission (reference=No)			
Yes	0.94 (0.07)	0.81 to 1.09	0.408
Unknown	0.74 (0.09)	0.58 to 0.95	0.020
No current contact with family	1.31 (0.21)	0.96 to 1.78	0.087
Hypnotic use	1.11 (0.19)	0.79 to 1.55	0.540

Variable	**OR (SE)**	**95% CI**	**p-value**
Antipsychotic use	1.32 (0.08)	1.16 to 1.49	<0.001
Antianxiety use	1.65 (0.17)	1.35 to 2.02	<0.001
Antidepressant use	1.40 (0.09)	1.23 to 1.59	<0.001
Pain (reference=No Pain)			
Mild	1.87 (.17)	1.56 to 2.24	<0.001
Moderate	2.27 (.31)	1.74 to 2.95	<0.001
Severe	3.96 (1.52)	1.87 to 8.40	<0.001

Table 5-4. Odds Ratio (OR), robust standard error (SE), 95% Confidence Interval (CI) and p-value for all variables in a multiple logistic regression model with cluster correction

Variable	**OR (SE)**	**95% CI**	**p-value**
Staff Conflict	1.51 (0.27)	1.07 to 2.13	0.020
Family/Friend Conflict	1.91 (0.40)	1.26 to 2.88	0.002
Resident Conflict-Moderate Dementia	2.02 (0.34)	1.45 to 2.82	0.000
Resident Conflict-Severe Dementia	1.18 (0.29)	0.72 to 1.91	0.511
Male	0.90 (0.06)	0.79 to 1.02	0.112
Age in years (Reference=65-81)			
82-86	1.03 (0.09)	0.88 to 1.22	0.697
87-90	0.99 (0.09)	0.82 to 1.19	0.945
91-109	1.03 (0.09)	0.87 to 1.23	0.714
Functional Dependence (Reference= relatively independent)			
Limited impairment	1.37 (0.22)	1.00 to 1.88	0.049
Extensive help	1.96 (0.25)	1.53 to 2.50	<0.001
Severe/total dependence	1.62 (0.22)	1.24 to 2.12	<0.001
Severe cognitive impairment	1.41 (0.11)	1.21 to 1.65	<0.001
No contact with family	1.17 (0.18)	0.86 to 1.59	0.324
Pain (Reference= no pain)			
Mild	1.88 (0.18)	1.56 to 2.26	<0.001
Moderate	2.20 (0.30)	1.69 to 2.88	<0.001
Severe	3.61 (1.42)	1.67 to 7.82	0.001

Chapter 6. Summary, Conclusions and Recommendations

By focusing on the perspective of people with dementia to understand QOL, I generated new knowledge about QOL for this target population. In this final chapter, I summarize my findings and highlight overall conclusions, strengths and limitations of my work to understand factors that influence QOL according to people with dementia. I close with implications of this work for future research, clinical practice and policy.

Summary of Findings

My dissertation was focused on the importance of including the perspective of people with dementia to understand QOL. Including the perspective of people with dementia was important whether conceptually defining QOL, or in the use of quantitative assessment tools, or in choosing influencing factors and outcomes of QOL. My work identified and addressed two key limitations of previous research to understand QOL from the perspective of people with dementia: *inconsistency* with a subjective definition of QOL and lack of consideration for the *collective knowledge* generated from multiple studies on the same topic. In responding to these limitations, I generated findings that highlight that the factors that influence QOL according to people with dementia extend beyond the areas traditionally considered under the purview of 'clinical care'.

Consistency with a Subjective Definition of QOL

Because my dissertation focused on a subjective definition of QOL, it was essential to critically assess whether the body of QOL literature that aimed to capture subjectivity (i.e. perspectives of people with dementia) to understand QOL had achieved its aims. In my first paper, I critically assessed the extent to which the quantitative dementia-specific QOL literature reflected the perspectives of people with dementia, and found that perspectives of people with dementia were included inconsistently to understand QOL. While much of this literature had captured perspectives of people with dementia during QOL assessment, there was little evidence that perspectives of people with dementia had in fact influenced identification of the domains, the essential components of QOL, that were included in quantitative tools to assess QOL. Furthermore, there was a lack of consensus between tool developers on the extent to which subjective QOL should contribute to the conceptualization of QOL as a whole. In other words, researchers who developed QOL assessment tools often included people with dementia's perspectives to assess, but not to conceptualize, QOL. This justified why further work was needed to ensure that quantitative methods to understand QOL were consistent with a subjective definition of QOL.

In contrast with the body of quantitative research, my second paper demonstrated that previous qualitative research studies about QOL from the perspective of people with dementia were consistent with a subjective definition of QOL. However, it was unclear what this body of qualitative work contributed, overall, to understanding QOL because findings from the multiple individual studies had not been considered collectively. Furthermore, the body of qualitative literature had not informed the quantitative literature, despite the fact that both aimed to better understand QOL from the perspective of people with dementia.

Consideration for the Development of Collective Knowledge

My methods advanced the development of collective knowledge on QOL from the perspective of people with dementia by synthesizing findings from existing qualitative studies, and by linking qualitative and quantitative studies. Metasynthesis is a method to synthesize the findings from multiple primary qualitative studies [1–3], and is used to build knowledge in a complex area[4]. For my second paper, I conducted a metasynthesis of the findings from multiple qualitative studies that had been conducted to understand QOL from the perspective of people with dementia. This work thereby advanced the field by developing collective knowledge on QOL from the perspective of people with dementia, with potential for future application in clinical work and policy-making [2,5–9].

I linked the qualitative literature with a quantitative study, described in my third and fourth dissertation papers, while maintaining a commitment to understanding QOL from the perspective of people with dementia. In my third paper, I clearly outlined a replicable approach to reduce the boundary between qualitative and quantitative research on the topic, and demonstrated that a synthesized body of qualitative research could reasonably and appropriately be used as the basis for designing a quantitative research study on QOL. I carefully detailed the three steps that I followed to design my quantitative study which included: a review of metasyntheses themes and their sub-components, identification of testable hypotheses that mapped to available data, and situating the topic in the extant body of literature.

Although I found it challenging, I was able to derive testable hypotheses from broad thematic metasynthesis findings. This resulted in a final study and fourth paper that was innovative and which tested hypotheses that were meaningful to people with dementia. My fourth paper was a quantitative study to test hypotheses derived from the body of existing qualitative literature, and provided an example of how the body of qualitative literature could be linked to quantitative research. Furthermore, my quantitative study related directly to an issue that mattered to QOL according to the perspective of people with dementia, and was consistent with a subjective definition of QOL.

Extending Beyond Clinical Issues

My dissertation supports that the factors that impact QOL for people with dementia extend well beyond more traditional clinical areas. The factors that influence QOL from the perspective of people with dementia include four potentially modifiable areas: Relationships, Sense of Place, Wellness Perspective, and Agency in Life Today. Connectedness was a concept that drew all of the findings together, because the experience of connectedness within each factor characterized a positive experience that enhanced QOL. If connectedness was achieved across all factors, then people with dementia felt together, well, located, and purposeful. These factors extend beyond more traditional clinical concerns like safety, symptom management, and support for activities of daily living, reinforcing the position that care to support QOL must consider non-clinical issues[10–12] .

I further emphasized the importance of Relationships, and the quality of relationships with family and friends, to QOL for people with moderate and severe dementia. Results from my quantitative study suggest that perceived conflict, a sub-component of the Relationships factor, is associated with sadness, a proposed outcome of poor QOL. Findings demonstrated that there was a significant increase in the odds of sadness for people with moderate or severe dementia who reported conflict with family, friends or staff. There was also an increase in the odds of sadness for people with moderate dementia who reported conflict with co-residents. Furthermore, the size and statistical significance of the odds ratios demonstrated that perceived conflict with family and friends had a stronger association with sadness for people with severe dementia than did conflict with either staff or co-residents. Overall, the findings from my quantitative study supported the association between perceived conflict and sadness for people with moderate and severe dementia, and highlighted the sustained importance of high quality family and friend relationships for people with moderate and severe dementia who live in long-term care.

Strengths and Limitations

Perspective of People with Dementia

My dissertation aims to identify factors that influence QOL from the perspective of people with dementia, and my dissertation has both strengths and limitations that affect the extent to which perspectives of people with dementia were reflected in the findings. There are several key strengths of my dissertation in this regard. First is the consistency between the subjective definition of QOL and the framework of factors that influence QOL. In my dissertation, I achieved this consistency by conducting a metasynthesis in order to derive a conceptual framework of factors that influence QOL from the perspective of people with dementia, and not their family members, health-care providers, or others. Because existing evidence suggests that others' perspectives about QOL differ from the perspectives of people with dementia [13–15], it was necessary to exclude others' perspectives in order to identify factors that reflected the perspectives of people with dementia.

It is important to note the additional strengths of my metasynthesis that were the comprehensive and systematic search I did on the published and grey literature, the use of two reviewers to appraise study quality, and the documented explicit audit trail of the search, screening, and extraction processes. These methods resulted in a comprehensive review and rigorous appraisal of the literature on the topic. Another important strength was my use of an integrative analytic approach to derive findings on factors that influence QOL. More aggregative analytic approaches, like metasummary, produce lists of themes and the frequency which those appeared in the primary qualitative studies, but are less likely to identify themes supported by all studies[2]. By using an integrative analytic approach, the themes I identified represent factors that influence QOL according to people with dementia in all of the qualitative studies included in this review. Moreover, the fully integrated findings from metasynthesis make a rich conceptual contribution[2].

My quantitative study also remained consistent with a subjective definition of QOL. A key strength of my quantitative study that should be highlighted is that it is based on a conceptual framework I derived from the specific body of literature that identified factors that influence QOL according to people with dementia. As a result, the findings are more likely to be relevant to people with dementia because the research questions reflect the priorities of this target population. Furthermore, the outcome variable used in this study, sadness, captures how people with dementia feel. Observation of feelings states in an approach that has been used to capture perspectives of people with severe dementia in other QOL research [16–21], and use of this outcome further demonstrates consistent inclusion of the perspectives of people with dementia.

My dissertation does have a limitation as result of the methods used to derive the conceptual framework. Because the hypotheses were derived from two syntheses of previous primary qualitative studies, the actual data collected from people with dementia were less current than if I had conducted a new qualitative study. The publication dates (1992 to 2012) suggest that the primary studies' data were collected between approximately 1990 and 2011. This could potentially limit my claim that the derived hypotheses represent the *current* perspectives of people with dementia. However, I do not believe it does because the majority of the studies included in both metasyntheses were published relatively recently (with only eight of the 41 studies included in the two reviews published before the year 2000), and there have been no major changes to either care or treatment of people with dementia over this time period.

Perspectives Across Dementia Severity

My dissertation papers do not all contribute equally to understanding QOL according to the perspectives of people with dementia at all stages of the disease. In my second paper, the metasynthesis, the perspectives of people with severe dementia were not represented to the same extent as those with mild and moderate dementia because interview and focus group methods have been less successful when used with people with severe dementia. In my fourth paper, the quantitative study in long-term care, people with mild dementia were not represented, as long-term care settings are characterized by a small proportion of people with mild dementia.

Despite being a limitation, this issue also produced an interesting finding that can support future research. While the metasynthesis findings better reflected perspectives of people with mild and moderate dementia, the hypotheses that I generated from the metasynthesis were still supported in the quantitative study that only included people with moderate and severe dementia. This is beginning evidence to support that people with mild and moderate dementia can identify factors that influence QOL across the spectrum of dementia severity, and these can be subsequently tested in populations of people with severe dementia. So, while my dissertation would have been strengthened by equal representation of people with mild, moderate and severe dementia in all studies, this is an interesting finding, and supports inclusion of people with mild and moderate dementia in early developmental work to inform future studies with people with severe dementia.

Use of Existing Resources

My dissertation made appropriate use of existing resources by synthesizing prior qualitative research and by testing hypotheses with data from an available clinical administrative data source. This was an ethical choice because making use of existing qualitative research findings and clinical administrative data reduced the burden of data collection imposed upon people with dementia [2,22]. Importantly, this ethical choice actually improved the quality of my dissertation findings by both guarding against idiosyncratic findings and improving statistical power and generalizability.

By synthesizing qualitative studies in my second paper, I used metasynthesis methods to guard against idiosyncratic findings which do not apply beyond the original study[2]. This was very important because I used the analytic generalizations from my metasynthesis to derive a conceptual framework for my quantitative study. In my third paper, I provide a detailed justification for why it is reasonable to build upon the analytic generalizations from metasynthesis by designing a quantitative study to derive statistical generalizations.

My decision to use a random sample of long-term care residents from an existing source of population-level data was also a key strength of my dissertation because, as a result, the findings from my fourth paper have external validity and apply directly to the population of people with moderate and severe dementia in Ontario. In addition, because I obtained a large sample (n=5001), the majority of the hypotheses were tested with at least 80% power to detect a statistically significant association. I was able to obtain this large random sample from a population with a complete sampling frame because of my decision to design a study that used an existing data source, the Resident Assessment Instrument (RAI) 2.0 data; this would not have been feasible had I collected primary data [23,24]. My use of readily available clinical data also facilitates replication, because many other jurisdictions collect RAI 2.0 data.

However, my use of existing data also had some limitations. The limitation of using existing qualitative studies to identify factors that influence QOL was that the authors of these studies did not always ask the study participants questions that would have advanced conceptual clarity of the findings (e.g. questions specifically asking people with dementia to differentiate between QOL and happiness/sadness, or to identify if there are other outcomes of QOL). The main limitation to using an existing data source for my quantitative study was that not all variables of interest were available in the RAI 2.0 (e.g. a subjective QOL measure).

An additional issue was that the RAI 2.0 Cognitive Performance Scale (CPS) does not align exactly with the MMSE definition of impairment. For example, the CPS category of 3 corresponds to a mean MMSE score of 15.4[25], which reflects moderate impairment (MMSE 11 to 20)[26]. However, the standard deviation of 8.0 shows that people with other levels of impairment may be captured within this category too, although to a lesser extent. This makes it more difficult to identify whether there are any differences in the association between sadness and conflict by impairment level, because the CPS categories mix MMSE impairment levels to some degree, decreasing power of the statistical test[27]. The issue is greatest for those with CPS=2 because, although this category will contain a majority of people with moderate dementia, the mean MMSE score of 19.2 is very near the border between mild and moderate dementia, so a substantial minority will have mild instead of moderate dementia.

Despite this issue, it was important to test the hypotheses about effect modification according to CPS categories that mapped as closely as possible to the MMSE, and re-coding this variable strengthened my dissertation in this regard. The effect modification hypotheses were derived from the metasynthesis (paper 2), and seven of the eleven studies included in the metasynthesis reported how dementia severity was rated. Of these, all but one[28] used the MMSE[29–34]. As a result, I recoded CPS scores to reflect the MMSE definition of mild (0,1), moderate (2,3) and severe (4,5,6) dementia. There are other studies that have re-coded the CPS using similar categories. For example, in one study the CPS was re-coded to reflect mild/no impairment (0,1), moderate (2,3), and severe/very severe (4, 5 or 6)[35]. In another study, the CPS was recoded to reflect mild (0,1,2), moderate (3) and severe dementia (4,5,6)[36].

Re-coding the CPS variable also helped to make sense of the meaning of CPS scores in the study sample. All individuals in the sample had a dementia diagnosis, yet 318 participants had a CPS score of 0 or 1. Taken at face value, this is confusing because the CPS terminology suggests that individuals who receive a score of 0 or 1 were cognitively 'intact' or 'borderline intact', respectively[25, p. M178]. Given that CPS values of 0 and 1 correspond to MMSE mean values of 24.9 and 21.0[25, p. M178], and because all people in the sample had a diagnosis of dementia, it is far more likely that CPS scores of 0 or 1 reflect mild dementia (i.e. MMSE rating of 21-25) than no dementia symptoms. Future research should carefully assess the likely meaning of CPS scores given sample characteristics to avoid erroneous labeling of people with mild dementia as 'cognitively intact'.

Ethno-Cultural Diversity

My dissertation is limited by a lack of ethno-cultural diversity. My metasynthesis only included studies written in English, and all of the included studies were conducted in high-income countries. Because I used findings from my metasynthesis to derive a conceptual framework for my quantitative study, the starting point for my quantitative study also reflected the views of people from primarily English-speaking, high-income countries. The sample used to test the hypotheses in my quantitative study only included residents of long-term care facilities in Ontario, Canada, and I could not adjust for ethnicity in the analysis because a measure of ethnicity was not available from the Canadian Institute for Health Information. Thus, the influence of ethnicity on these estimates is unknown and, while the findings may apply to populations of people with dementia who are similar to the Ontario residents [27], care should be taken if findings are generalized beyond the Ontario context because resident populations may differ elsewhere[37] .

Implications for Research

Taken as a whole, my dissertation findings have several implications for research. First, perspectives of people with dementia can contribute meaningfully to the dialogue on QOL by serving as a rich source for research questions. I applied the perspectives of people with dementia captured in previous research to generate both a conceptual framework of factors that influence QOL and testable hypotheses. My study to test the association between perceived conflict and sadness serves as an example of how the conceptual framework can serve as a source for research questions.

Second, my findings provide indirect support that perceived conflict may have a negative influence on QOL for long-term care residents with moderate and severe dementia, as my metasynthesis demonstrated that sadness was an outcome closely related to poor QOL according to people with dementia, and my final (quantitative) study supported an association between perceived conflict and sadness. Research to derive direct support for the association between perceived conflict and QOL should include future studies to test the association between perceived conflict and QOL (i.e. conflict with family/friends, staff, or co-residents→QOL).

Third, I produced a conceptual framework that can be used as the basis for future studies on factors that influence QOL. The hypotheses that I derived from the conceptual framework and tested in my quantitative study were focused on the direct associations between perceived conflict (with staff, family/friends, or co-residents) and sadness. These hypotheses did not contain any mediator variables, so I used multiple logistic regression, the appropriate technique to test direct (i.e. unmediated) associations and to adjust for confounding variables when the dependent variable is binary. However, there are many other hypotheses that can be derived from the metasynthesis findings that should be tested in future research, and some of these do contain mediator variables. For example, the potential mediating effect of QOL (i.e. perceived conflict→ QOL → sadness) could be tested using structural equation modeling, an analytic technique specifically for hypotheses that include mediator variables [38]. I did not test this hypothesis in my dissertation because a valid self-report QOL measure was not available in the RAI 2.0 dataset. Future studies that employ primary data collection can be conducted to test this hypothesis in populations of people with mild and moderate dementia, where valid self-report QOL measures are available.

There are other opportunities for future research that builds upon the conceptual framework that I produced. Many other hypotheses can be generated: each of the four factors that I describe in the conceptual framework can serve as a starting point for researchers who define QOL as a subjective construct and aim to explore what influences QOL for people with dementia. Future studies should also be specifically designed to explore the differences between QOL, happiness and sadness, and whether there are other important outcomes of QOL, according to people with dementia. Furthermore, my findings demonstrated that current research does not specifically identify what domains might comprise QOL, or how these may differ from influencing factors, according to people with dementia. Qualitative exploratory studies are needed to further clarify whether there are essential components of QOL from the perspective of people with dementia, and if so, what these components are.

Fourth, my findings provide empirical evidence that relationships, and especially those with family and friends, are of great importance to QOL for people with dementia. Given this, considering how QOL is maintained and enhanced within the context of relationships may be a promising area for future study. New insight may be gleaned from examining the perspective of people with dementia in the context of their relationships with family and friends. In such work, it is essential to differentiate between perspectives of people with dementia and their family members or friends. However, contemporaneous study of perspectives of both people with dementia and their family or friends may provide useful information. For example, effective interventions to reduce perceived conflict may need to influence the relational behaviors of both the person with dementia and the individual that they experience conflict with.

Implications for Practice and Policy

My work is timely because it directly responds to the current emphasis on patient perspectives to better understand priorities for care of people with dementia [39,40]. For clinicians or decision-makers who aim to improve QOL from the perspective of people with dementia, my dissertation highlights that there are a number of important conceptual issues to consider. Because of the lack of consensus on what QOL means, it is very important for clinicians and decision-makers to first clarify what they and their organization mean by QOL. If a subjective definition of QOL is adopted, then clinicians and policy-makers should also identify a framework of influencing factors and a QOL tool that is consistent with that subjective definition. Monitoring systems should then be put in place to assess QOL in long-term care facilities over time, and these should reflect the resident's perspective on QOL.

There are also practice and policy implications because my findings posit that relationships are a priority to support QOL for people with dementia. I highlighted that the clinical assessment system that clinicians currently use in long-term care (the RAI 2.0) contains measures of perceived conflict, a subcomponent of relationships. But despite current clinical assessment of perceived conflict, and the association that conflict has with resident sadness, these assessment items are not currently used to prompt clinicians to complete resident care plans to address this problem [41]. In addition, the perceived conflict items are only assessed and documented once per year [42]. Long-term care policy-makers should consider whether clinicians should assess resident perceived conflict at least quarterly, similar to many other RAI 2.0 measures [42]. Furthermore, to address issues like perceived conflict, long-term care facility decision-makers and clinicians should consider the extent to which care for people with dementia currently supports their need to maintain not only contact but *high quality relationships* with their family members and friends.

My findings support the need to make available to long-term care service providers adequate resources to address non-clinical issues in order to support QOL for people with dementia. Factors that influence QOL from the perspective of people with dementia are potentially modifiable, but focusing on the resident's agency in life today, sense of purpose, relationships, and wellness perspective requires careful consideration of the role of health care providers who care for people with dementia. In order to support QOL, providers' responsibilities must extend into areas of non-clinical care. As a result, resources will be needed to make it possible for clinicians to attend to more than residents' needs for hygiene, safety, and support to complete activities of daily living. In conclusion this dissertation highlights that, if long-term care practice aims to support QOL for residents with dementia, then a broad consideration of what that care entails is necessary.

Building on this Work

My career goal is to develop a program of research to design and test translatable, sustainable interventions to improve QOL for people with dementia. To build on my conceptual and observational dissertation work, I will complete post-doctoral training in intervention design, implementation, and evaluation. During my post-doctoral fellowship, I will develop a QOL intervention that aims to improve connectedness in relationships for people with dementia. Specifically, the purpose of my planned post-doctoral study is to design and pilot test an intervention[43] to promote connectedness in relationships and improve QOL for people with dementia in long-term care.

Methods will include: (1) a literature review to identify promising interventions used to enhance connectedness in relationships in other populations, and to examine how and why these interventions work or don't work in different siutations; (2) development of an intervention protocol based on the findings from separate focus groups with people with dementia, their family members, and caregivers; and (3) a pilot study to assess whether the intervention and study procedures are feasible and acceptable for use with people with dementia in long-term care, and to assess initial trends. Following my post-doctoral work, I will test both the interventions' efficacy to improve QOL, and the mediating effects of QOL on other outcomes important to people with dementia (e.g. Connectedness in relationships→QOL→ Sadness).

Conclusion

My dissertation promotes an understanding of QOL from the perspective of people with dementia. I analyzed the extent to which perspectives of people with dementia have been included in current conceptualizations of QOL in the quantitative literature, and conducted a metasynthesis of existing qualitative evidence to identify factors that influence QOL from the perspective of people with dementia. I designed a quantitative correlational study based on the findings of the metasynthesis, and demonstrated support for the association between perceived conflict and sadness for long-term care residents with moderate and severe dementia.

The conceptual framework of factors that influence QOL according to people with dementia is a rich source for future research questions. Furthermore, the four broad factors that I identified using metasynthesis methods—Relationships, Sense of Place, Wellness Perspective, and Agency in Life Today—can stimulate clinicians and decision-makers to discuss and carefully consider how long-term care providers can support QOL for residents with dementia. To contribute to this dialogue, my future research program will aim to identify effective approaches to inform best practice to improve QOL for people with dementia.

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Appendix 1. Ethics Approval

Notification of Approval - Amendment

Date:	June 25, 2013	
Amendment ID:	Pro00011753_AME3	
Principal Investigator:	Kimberly Fraser	
Study ID:	MS5_Pro00011753	
Study Title:	The association between sadness and relational conflict for people with dementia in long-term care	
Sponsor/Funding Agency:	AHFMR - Alberta Heritage Foundation for Medical Research CIHR - Canadian Institutes for Health Research	AHFMR CIHR
Sponsor/Funding Agency:	Knowledge Translation Canada	

RSO-Managed Funding:

	Project ID	Project Title	Speed Code	Other Information
View	RES0001962	CIHR CGM-98191 Jerke/Sales Stipend	N1425	
View	RES0010469	Vanier stipend: Investigating relationships among quality indicators for residents in long term care		
View	RES006976	KT Canada Stipend: Identifying high priority care areas to enhance quality of life for persons with dementia in long term care		
View	RES0000293	AHFMR HRFTS 200801552 Jerke	N1424	

Approval Expiry Date: April 28, 2014

Thank you for submitting an amendment request to the Health Research Ethics Board - Health Panel. The following has been reviewed and approved on behalf of the committee:

- Relationships among RAI 2.0 data elements will be tested, as previously proposed, but have now specified the relationships to test (i.e. associations between relational conflict and sadness) based on the findings of the metasynthesis conducted in phase 1 of the study. The title of the study has been modified to reflect this.
- Revised inclusion/exclusion criteria to capture a more specific population that is most appropriate for testing the specified relationships. The old criteria included all people in LTC settings in the CIHI database. The new inclusion criteria are: (i) resident of an Ontario LTC facility for at least 3 months when the assessment was completed; (ii) full RAI 2.0 assessment completed during the April 2012 to March 31 2013 assessment period; (iii) 65 years or older; (iv) male or female; (v) dementia diagnosis; (vi) mild, moderate, or severe dementia; and (vii) not comatose. The

exclusion criterion is: presence of any psychiatric diagnoses including depression, anxiety disorder, manic depressive, or schizophrenia.
- Revised sample size from 23000 to a random sample of 5324, to balance risks of Type1 and Type2 error
- Limited to Ontario residents, because this is the most complete sampling frame available of residents with dementia in long-term care
- Revised Protocol (18/06/2013)
- Health Research Data Repository Policies (18/06/2013)

Note: Approval for an amendment does not change the original approval date.

Sincerely,

Dr. Glen J. Pearson, BSc, BScPhm, PharmD, FCSHP
Associate Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

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