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PATIENT ENGAGEMENT SPECIAL SECTION

Embedding the perceptions of people with dementia into quantitative research design

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Abstract

Purpose Patient perspectives about quality of life are often found in the results of qualitative research and could be applied to steer the direction of future research. The purpose of this paper was to describe how findings from a body of qualitative research on patient perspectives about quality of life were linked to a clinical administrative dataset and then used to design a subsequent quantitative study.

Methods Themes from two systematic reviews of qualitative evidence (i.e., metasyntheses) identified what affects quality of life according to people with dementia. Selected themes and their sub-concepts were then mapped to an administrative dataset (the Resident Assessment Instrument 2.0) to determine the study focus, formulate nine hypotheses, and select a patient-reported outcome. A literature review followed to confirm existence of a knowledge gap, identify adjustment variables, and support design decisions.

Results A quantitative study to test the association between conflict and sadness for people with dementia in long-term care was derived from metasynthesis themes. Challenges included (1) mapping broad themes to the administrative dataset; (2) decisions associated with inclusion of variables *not* identified by people with dementia from the qualitative research; and (3) selecting a patient-reported outcome, when the dataset lacked a valid subjective quality-of-life measure.

Conclusions Themes derived from a body of qualitative research capturing a target populations' perspective can be linked to administrative data and used to design a quantitative study. Using this approach, the quantitative findings will be meaningful with respect to the quality of life of the target population.

Keywords Dementia · Quality of life · Alzheimer disease · Patient perspectives · Mixed methods

Background

Against the backdrop of an aging population, a growing body of literature emphasizes the need to determine whether healthcare interventions impact quality of life (QoL) of older adults with chronic illness [1, 2]. The QoL construct is 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, p. 186] that occurs "within the

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context of the culture and value systems in which (people) live and in relation to their goals, expectations, standards and concerns" [19, p. 1].

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. Specific to QoL research with PWD 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 QoL [23, 33]. Some tool developers have argued that if QoL is subjective, then capturing the perspective of PWD is necessary for the content and construct validity of QoL measures [28, 34–36]. 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 direct future QoL research to 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], these researchers did not appear to apply the body of preexisting qualitative work in a transparent or replicable way. Instead, non-systematic reviews of QoL literature (which will locate some but likely not all qualitative studies on the topic) were used in conjunction with focus groups or interviews with PWD and others to identify areas relevant to QoL for PWD [11, 14, 40, 41]. From these descriptions, it is difficult to discern how the qualitative literature informed QoL tools developed for PWD. To effectively build on what is known about QoL from the perspective of PWD, clear replicable approaches that apply existing qualitative findings are needed [42].

To respond to this need for methodological development, the aim of this paper is to describe an approach to link findings from two systematic reviews of qualitative evidence on patient perspectives to a clinical administrative dataset (the Resident Assessment Instrument 2.0 or RAI 2.0) in order to design a quantitative study. The results of the quantitative study, which uses RAI 2.0 data to test the association between an influencing factor (perceived conflict) and an outcome of QoL (sadness) among LTC residents with dementia in Ontario, Canada, will be reported separately. The purpose of this paper is to describe an approach to use findings from a body of qualitative literature 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 findings from these two metasyntheses are reported elsewhere [44, 45], so while all of the themes are introduced here, we describe just one in more detail. 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]. The themes referred to areas important to or factors that influence QoL, not aspects, domains or component parts of QoL. Each theme was supported by many sub-concepts, with relationships among these sub-concepts. As a result, there were many potential hypotheses about what influences QoL that could be derived from the themes and their sub-concepts.

Our team determined that it was not feasible to design a study to explore the impact of all themes upon QoL because such measures were not available in the RAI 2.0 data, and primary data collection would not be possible given the large sample size required (e.g., for power, the study we designed required nearly 5000 participants). A reasonable first step was to test those hypotheses that mapped to the RAI 2.0, the data source currently available in Canadian LTC settings.

For the present study, we focused upon sub-concepts of one theme to derive hypotheses that could be tested using available data. Some of the themes from the two metasyntheses had significant overlap. We decided to focus on sub-concepts of the themes “Relationships” and “Connectedness with Others” because these themes, while from two different metasyntheses, were conceptually equivalent. In other words, relationships were important to QoL from both the perspective of people in LTC facilities [44] and the PWD [45]. The findings from the two metasyntheses indicated that relationships characterized by “respect, reciprocity, closeness, kindness, or love” [45, p. 11] led to connectedness, or togetherness, in relationships, and this positively influenced QoL for PWD and LTC residents [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, but were not in the form 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. During this stage, the overarching themes of “Relationships” and “Connectedness with Others,” and the sub-concepts that supported them were extracted. This resulted in a list of concepts that were compared to item descriptions from the RAI 2.0 to determine whether any RAI 2.0 measures matched the extracted concepts (see Table 1).

RAI 2.0 data are collected by healthcare providers using a standardized tool to assess and document a wide variety of LTC resident characteristics [46]. Healthcare providers base their assessments on discussions with the resident, care staff, family members, observation of the resident, and review of the resident’s medical record. RAI developers have identified potential advantages of using this dataset for research [47]. We chose to map the metasyntheses findings to the RAI 2.0 for several reasons: Item and scale reliability and validity was previously demonstrated; to reduce the burden of data collection imposed on patients and staff; population-level data are available in some jurisdictions; the results would refer directly to assessment items used by clinicians in their practice; use of existing data made it feasible to obtain a sample large enough to test the hypotheses; 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 the range of testable options. The RAI 2.0 does not include 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 challenging. 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, a related outcome.

Sadness is not synonymous with poor QoL, but is a reasonable study outcome variable 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. Mood or behavior variables have been used to glean information about perceived QoL in other research studies that include people with severe dementia, as demonstrated by the QOL tools described in a previous literature review [6].

Then, the 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 (Fig. 1; Table 1) and focus on the associations between perceived conflict 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.

Hypotheses 1, 2, and 3 Perceived conflict with staff [H1], family/friends [H2], or LTC residents [H3] is positively associated with sadness.

Hypotheses 4 and 5 As functional dependence [H4] or cognitive impairment [H5] increase, the association between conflict with staff and sadness strengthens.

Table 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	Conflict items (main independent variables): Conflict with family/friends Conflicts with staff Unhappy with roommate or residents other than roommate
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	Contact items (included in adjustment variables): Current absence of personal contact with family/friends Daily visits prior to admission
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] Basic relational need in casual interactions for people to be nice and show respect: 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	
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
Being connected to others was associated with happiness. Being disconnected from others was associated with sadness [45]	Review 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]

Hypotheses 6 and 7 As functional dependence [H6] or cognitive impairment [H7] increase, the association between conflict with family/friends and sadness strengthens.

Hypotheses 8 and 9 As functional dependence [H8] or cognitive impairment increase [H9], the association between conflict with LTC residents and sadness stays the same.

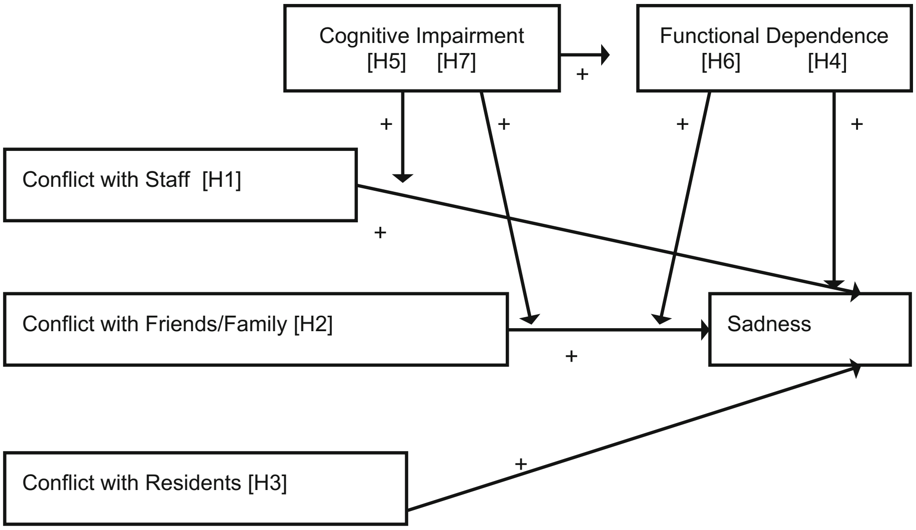

Fig. 1 Study hypotheses. A *plus sign* over a single *headed arrow* denotes a positive relationship between each conflict variable and sadness. Cognitive impairment and functional dependence have an *arrow* pointing to the associations between sadness and conflict with staff and family/friends, as they 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 support 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

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 and sadness was already well understood for PWD. This ensured the hypotheses that were identified as important to QoL from the perspective of PWD 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 "Appendix"). Studies on depression were not reviewed, because sadness was conceptualized as a more transient emotional state [45], different from the 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. Review of the 36 full-text studies demonstrated that no empirical research had been conducted to test the association between conflict 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 search located qualitative [48] and quantitative [49, 50] studies demonstrated that PWD in LTC experience conflict with others, supporting 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 associations. Resource-intensive research to rigorously test whether conflict *causes* sadness would be warranted in the future, if association was established.

Third, the literature review identified adjustment variables. Potential confounding variables were identified from six studies located from the full-text review that tested the effect of relationship-based interventions on mood (sadness was often one of the mood outcomes), as this was the available body of literature that was closest conceptually 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 2).

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

Adjustment variable	RAI 2.0 item
Age [58–63][a]	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
	Functional dependence: Activities of Daily Living-Hierarchy Scale (ADL-HS) which includes personal hygiene, toileting, locomotion, and eating [57]
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

[a] These six studies all assessed the impact of a relationship-based intervention upon several mood outcomes. One study included mood outcomes but not sadness [61]; three studies included multiple mood outcomes as well as sadness as part of a larger sub-scale [59, 60, 63]; and two studies included sadness as one of the mood outcomes [58, 62]

Discussion

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

Hypotheses fit with extant literature

By deriving hypotheses from the metasyntheses, research questions important to QoL from the perspective of PWD were identified, but the conceptualizations of variables important to QoL found in other bodies of literature were not drawn upon. The conceptualization process led the research in a new direction: The proposed quantitative study is focused on perceived conflict, an issue that research on QoL of PWD has not examined to date. While generation of a novel hypothesis important to QoL from the perspective of PWD was a clear strength, it is unusual not to also draw on the broader literature to identify factors. The challenge was to design a study to test the hypotheses about perceived conflict 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 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 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 made 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 healthcare 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 easily replicable in longitudinal studies and 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 standard The manuscript does not contain clinical studies or patient data.

Appendix: Literature review search strategy

Purpose: to identify studies of the effect of perceived conflict in relationships on happiness/sadness for persons with dementia in long-term care (LTC)

Inclusion criteria:

1. Published in English
2. Outcome is the happiness or sadness of people with dementia (PWD)
3. PWD must be living in a LTC setting
4. The effect of people with dementia experiencing perceived conflict in their relationships on happiness/sadness is a primary study objective (i.e., not only included as a covariate in a study with other objectives)

Exclusion:

1. Studies focused on aspects of relationships other than conflict (e.g., pleasurable exchanges, social stimuli, and social support)
2. Studies about predictors of moods other than happiness/sadness (e.g., passive behaviors like withdrawal, less socialization, and reduced interested in activities, anxiety)

Definitions:

Happiness: a state characterized by feelings of pleasure, contentment, satisfaction, or joy
Sadness: affected by unhappiness or grief; sorrowful, or mournful

General Search Strategy Structure:

1. Long-term care
   AND
2. Dementia
   AND
3. Conflict OR Relationships
   AND
4. Happiness OR Sadness

Database-Specific Terms (for Medline, PsycInfo, EMBASE, CINAHL, Abstracts in Social Gerontology)

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*

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