CARING AHEAD: PREPARING FOR END-OF-LIFE WITH DEMENTIA

CARING AHEAD: DEVELOPMENT AND EVALUTION OF A QUESTIONNAIRE TO MEASURE PREPAREDNESS FOR END-OF-LIFE IN CAREGIVERS OF PERSONS WITH DEMENTIA

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TITLE: Caring Ahead: Development and Evaluation of a Questionnaire to Measure Preparedness for End-of-Life in Caregivers of Persons with Dementia

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Lay Abstract

Providing care to a family member or friend with dementia can be very challenging and different than caring for persons with other disorders. Healthcare providers should provide a palliative approach to care which focuses on quality-of-life and helping family caregivers prepare for end-of-life. However, many family caregivers do not feel prepared for death and this can lead to serious mental health problems in bereavement. This thesis explores what feeling prepared for death means and describes the development and testing of a questionnaire to assess how prepared family caregivers feel for the end-of-life of someone with dementia. Through interviews and surveys with caregivers and professional experts, we developed and tested the Caring Ahead: Preparing for End-of-Life with Dementia questionnaire. Use of the new Caring Ahead questionnaire aims to help us understand how prepared family caregivers are feeling for end-of-life and what supports are needed.

Abstract

Family/friend caregivers of persons with dementia often do not feel prepared for end-of-life, which contributes to high rates of complicated grief, depression and anxiety in bereavement. This mixed methods study used an exploratory sequential design to explore the core concepts and indicators of preparedness, develop and evaluate a multidimensional questionnaire aimed at measuring caregiver preparedness for end-of-life for persons with dementia. In Phase 1, a qualitative study with an interpretive descriptive design was used to explore the core concepts and indicators of preparedness with 16 bereaved family caregivers recruited from six long-term care homes located in Ontario, Canada. In Phase 2, a quantitative, cross-sectional Delphi-survey was conducted with 5 caregivers and 12 diverse professional experts to select preparedness indicators/items and develop the Caring Ahead questionnaire. Lastly in Phase 3, the self-report, paper format questionnaire was evaluated for evidence of validity and reliability using a quantitative cross-sectional design. In this final phase, the questionnaire was completed through the postal mail by 134 caregivers from over 50 long-term care homes/residential care facilities, primarily in Ontario, Canada. Evidence for internal structure and concurrent validity was generated along with reliability coefficients suggesting internal consistency and stability in a test-retest. Findings from this study contributed to the conceptualization and operationalization of preparedness and produced the new, multidimensional questionnaire titled Caring Ahead: Preparing for End-of-Life with Dementia with preliminary evidence for

validity and reliability. This questionnaire aims to fill an existing gap expressed by researchers who aim to design and evaluate interventions promoting preparedness through a palliative approach. In addition, policy-makers should benefit from introduction of the Caring Ahead questionnaire as an outcome measure to monitor and evaluate the effectiveness of policies surrounding a palliative approach.

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List of Abbreviations

ACP	Advance Care Planning
CG	Caregiver
EOL	End-of-Life
HCP	Healthcare provider
IDCV	Instrument Development and Construct Validation Framework
LTC	Long-term care

Declaration of Academic Achievement

Ms. Pamela Durepos is the lead researcher of this mixed methods study reported in this sandwich thesis. As the lead researcher, Ms. Durepos' responsibilities have included: study design, data collection, analysis and interpretation. Ms. Durepos is the primary author of five manuscripts (i.e., chapters) included in this thesis. Responsibilities as the primary author have included: writing manuscript drafts, revising based on feedback from committee members, and gaining final approval for publication.

Drs Sharon Kaasalainen, Jenny Ploeg, Noori Akhtar-Danesh and Tamara Sussman are co-authors of the manuscripts included in this sandwich thesis. All authors contributed to the study design, interpretation of findings, revising of manuscripts and approval of final manuscript versions for publication.

Chapter 1

Introduction

The prevalence of dementia is rising around the world and the majority of physical, emotional and financial care for persons with dementia is provided by family/friend caregivers (World Health Organization [WHO], 2019). Caregivers [CG] experience unique challenges related to caring for a person with a neurological, often progressive, life-limiting disorder and often have difficulty obtaining high quality care and services for their family member (Mitchell, 2018). As a result, CGs take on many roles to meet their family member's needs such as: advocate, lawyer, medical expert, chaplain, nutritionist, physical therapist, entertainer, accountant, nurse (Orzeck, 2016). The all-encompassing CG identity and associated roles continue even when persons with dementia transition to residential care facilities such as long-term care [LTC](Schulz, Boerner, Klinger & Rosen, 2015). It is therefore not surprising that physical and mental health concerns are more prevalent amongst CG of persons with dementia than other types of CGs and continue even after the person with dementia has died (Corey & McCurry, 2018; Dassel & Carr, 2016; Tang et al., 2019).

A palliative approach is increasingly being recommended in dementia with the aim of improving the quality of care and outcomes for persons with dementia and their CGs (van der steen et al., 2014). Strategies supporting a palliative approach aim to help CGs prepare for the many losses associated with dementia, dying and bereavement (Canadian Hospice Palliative Care Association [CHPCA], 2015). Research indicates that feelings of preparedness predict CG outcomes in bereavement and can likely be modified to protect CGs against complicated grief, depression and anxiety (Hebert, Prigerson, Schulz & Arnold, 2006; Nielsen, Neergaard, Jensen, Bro

& Guldin, 2016; Supiano et al., 2020). As a result, healthcare utilization and societal costs of caregiving (e.g., reduced ability to work) would likely be decreased if care and support for CGs was optimized (Bremer et al., 2015). Therefore, optimizing CG well-being through strategies supporting a palliative approach and modifying feelings of preparedness should be a priority for nurses and healthcare providers in residential care facilities (where the majority of persons with advanced dementia reside)(Mitchell, 2019).

The newly introduced Framework for Palliative Care in Canada specifically calls for measures to evaluate and monitor the effectiveness of policies for a palliative approach (Canadian Institutes of Health Information [CIHI], 2018). Similarly, researchers have reported that the lack of a multidimensional questionnaire to measure preparedness is constraining research around caregiver well-being (Moore et al., 2020; Schulz et al., 2015). Lastly, family caregivers of persons with dementia themselves are advocating for holistic care and are consistently reporting that they are not supported or prepared for the end-of-life of their family member (Durepos, Kaasalainen, Carroll & Papaioannou, 2017; Terzakis, 2019). Hence, a multidimensional, holistic questionnaire measuring preparedness for end-of-life in dementia is needed to: 1) assess and identify family CGs with limited feelings of preparedness at risk for negative outcomes in bereavement; and 2) act as an outcome measure for strategies/policies supporting a palliative approach.

Problem Statement and Research Questions

The purpose of this study was to: 1) explore the core concepts and indicators of preparedness for end-of-life with dementia, and 2) develop and evaluate a holistic, multi-dimensional questionnaire to measure preparedness with evidence for validity and reliability. This study aimed to address current gaps in measurement tools and improve care and outcomes for CGs of persons with dementia. Research questions included:

Qualitative question:

1) What are the dimensions, core concepts and underlying traits of preparedness for end-of-life perceived by CGs of persons with dementia?

Quantitative questions:

2) What characteristics and behaviours indicate preparedness and should be included on a questionnaire to measure preparedness?
3) What is the validity and reliability of a questionnaire developed to measure preparedness for end-of-life of persons with dementia?

Mixed Methods question:

4) How can preparedness for end-of-life be measured in family CGs of persons with dementia?

Research Approach

This study used an exploratory, sequential quantitative dominant status instrument variant design guided by the Instrument Development and Construct Validation framework [IDCV](Onwuegbuzie, Bustamante & Nelson, 2010; Creswell

& Plano-Clark, 2017). If done well, instrument development and validation is a challenging and continuous process (Streiner, Cairney & Norman, 2015). Fortunately, the IDCV framework provides a comprehensive 10-step guide for the development of questionnaires with evidence for validity and reliability (Onwuegbuzie et al., 2010). This thesis study addressed the five initial steps of the IDCV framework necessary to produce a questionnaire with preliminary evidence for validity and reliability. Steps addressed included: conceptualization of the construct; identification of behavioural indicators; development of the initial questionnaire; pilot-test; design and field-testing of the revised questionnaire (Onwuegbuzie et al., 2010). Further research (beyond this study) will explore construct validity of the questionnaire will address the remaining steps of the IDCV framework (Onwuegbuzie et al., 2010).

Thesis Content

In preparation for this thesis, a concept analysis of preparedness titled: *What does death preparedness mean for family caregivers in dementia?* (Durepos et al., 2018) was published along with a review of existing questionnaires titled: *Caregiver preparedness for death in dementia: An evaluation of existing tools* (Durepos et al., 2019). These manuscripts are included to provide a background and rationale for this study in Chapter 2 and Chapter 3. The body of the thesis is comprised of Chapters 4, 5 and 6, with discussion of implications and conclusions reported in Chapter 7. A summary table of the papers is provided in Appendix A, a map of the research design is provided in Appendix B, and my personal relationship to this research topic is provided in Appendix C.

Chapter 4 is a manuscript published in Sage Open Nursing titled: *"A Crazy Roller Coaster at the End": A qualitative study of death preparedness with caregivers of persons with dementia* (Durepos et al., 2020a). This qualitative study represented Phase 1 and used an interpretive descriptive approach. The purpose was to explore bereaved CGs' end-of-life experiences with dementia and identify core concepts, domains/traits, barriers, and facilitators to preparing for death.

Chapter 5 is a manuscript submitted for publication to Palliative Medicine titled: *Caring Ahead: Mixed methods development of a questionnaire to measure preparedness for end-of-life in caregivers of persons with dementia* (Durepos et al., 2020b). This quantitative study represented Phase 2 and used a cross-sectional, Delphi-survey design. The purpose was to translate preparedness indicators described in Phase 1 into a pool of potential questionnaire items, generate consensus for items amongst caregivers and professional experts to develop a questionnaire, and pilot-test the questionnaire for acceptability and face validity.

Chapter 6 is a manuscript prepared for submission to The Journal of Pain and Symptom Management titled, *Evaluation of the Caring Ahead: preparing for end-of-life with dementia questionnaire.* This quantitative study represented Phase 3 and used a cross-sectional design with the evaluation of psychometric properties. The purpose of this study was to explore evidence for validity (internal structure and concurrent) and reliability (internal consistency and stability) of the questionnaire with current CGs of persons with dementia living in residential care facilities.

Lastly, Chapter 7 is a discussion of the novel findings, contributions, and implications of this thesis for research, policy, education, and practice. Strengths and limitations of this thesis are summarized as well as conclusions.

The sequential nature of this study and shared purpose of each manuscript (i.e., to inform development and evaluation of a questionnaire) resulted in overlapping content between the manuscripts/chapters. Similar background literature is reported throughout this thesis outlining the prevalence of dementia, challenges in end-of-life care, CG health and well-being, current knowledge of preparedness, links to outcomes in bereavement and limitations in existing preparedness measures. However, each manuscript/chapter fulfilled distinct objectives, incorporated a unique design and employed different research methods to produce findings that were essential to informing the next phase of study.

Chapter 2

What does death preparedness mean for family caregivers in dementia?[1]

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[1] Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2018). What does death preparedness mean for family caregivers in dementia? *American Journal of Hospice and Palliative Medicine*, *X*(X), 1-11. https://doi.org/10.1177/1049909118814240

Abstract

Purpose: The purpose of this study was to clarify the concept of death preparedness for family caregivers in dementia. Conceptualization was required to support the assessment, promotion and operationalization (i.e., measurement) of death preparedness through palliative care interventions such as advance care planning.

Methods: Rodgers' evolutionary method of concept analysis was selected to guide this study because of the dynamic nature of death preparedness influenced by context, setting and time. A comprehensive literature search was conducted. Authors performed constant comparative analysis to identify and interpret surrogate/related concepts, attributes, antecedents and consequences of death preparedness.

Results: Most importantly attributes included: (1) knowing and recognizing the symptoms of decline in dementia and what dying looks like; (2) understanding emotions and grief responses; (3) accessing and appraising supports needed to manage and care for dying; (4) organizing affairs and completing tasks in advance; (5) accepting that losses are inevitable and imminent; (6) reflecting on caregiving and finding meaning, 'a silver-lining'; and (7) closing, reconciling and renewing relationship bonds and completing the family member's life.

Discussion: This study contributed a full definition of death preparedness in dementia. Findings aligned with/expanded upon Hebert et al's (2006) Theoretical

Framework of Preparedness for End-of-Life. The use of problem and emotion-based coping strategies by caregivers with support from healthcare providers to promote feelings of death preparedness (including self-efficacy and control) and minimize uncertainty were implications of this study. Development of a holistic preparedness instrument is underway.

Background

Worldwide an estimated 50 million people are living with dementia, a life-limiting or terminal and often unpredictable neurological disorder[1] Each diagnosis of dementia is unique and influences approximately three family members or friends, with the majority of caregiving burden (i.e., physical, emotional and financial care) falling on spouses or adult children of the person diagnosed. [1,2] Persons with dementia and their family/friend caregivers [CG] can benefit from a palliative approach, which focuses on holistically promoting quality-of-life and supporting persons through care transitions.[3] However, access to palliative care and satisfaction with end-of-life [EOL] care remains limited, particularly in long-term care homes [LTC] where up to 70% of residents are living with dementia.[3-7]

Palliative and dementia care practice guidelines recommend that healthcare professionals [HCP] assist family/friend CGs to prepare for death through interventions like advanced care planning [ACP], education and psychosocial support.[8-10] Feeling prepared for death consistently predicts CG well-being in bereavement,[11-13] and is particularly significant for CGs in dementia who suffer more often from complicated grief, depression and anxiety after-death than other CGs. [11,14,15] Specifically, ACP interventions (i.e., ongoing discussions between HCPs, persons with life-limiting conditions and CGs about values and preferences for end-of-life [EOL]), are being promoted by researchers and policy-makers across industrialized countries as a way to discuss a palliative approach, improve EOL care and plan/provide a 'good death'.[16-20] However, feeling prepared or ready for death, particularly for CGs in dementia, is a complex, multidimensional and abstract concept not fully defined or understood.

Death preparedness is most commonly defined as, ‘feelings of readiness and awareness for impending death’[14] and is consistently reported as a priority for CGs of persons with dementia.[12.21,22] This definition is linked to Hebert and colleagues’, Theoretical Framework of Preparedness for EOL,[14, 23] which suggests domains of preparedness and related factors. However, concept attributes and underlying traits of death preparedness remain unclear making it difficult for researchers/policy-makers and HCPs to assess, discuss and promote death preparedness.[22] An in-depth conceptualization of death preparedness in dementia is also needed to guide the development of a death preparedness questionnaire, which can be used to evaluate the effectiveness of ACP interventions for CGs in dementia whom experience unique challenges at EOL.[4,12,22,24] Hence in this study, we conducted a concept analysis of preparedness for death in CGs of persons with dementia to: (1) contribute an in-depth definition of preparedness core concepts, attributes, antecedents and consequences, and (2) provide the basis for our development of an instrument (i.e., questionnaire) to measure death preparedness for family CGs in dementia.

Methods

Rodgers’ method of evolutionary concept analysis was selected to guide this study because it acknowledged the dynamic nature of the concept.[25] We perceived death preparedness as a fluctuating concept (rather than fixed or static) influenced by context, time and the perspectives of multiple disciplines. Iterative phases of analysis outlined by Rodgers[25] provided a methodological framework for this study in which we identified the concept and surrogate terms used within literature; identified a sample of articles describing the concept; collected and analyzed data using content analysis to determine concept antecedents, attributes and consequences; and formed hypotheses and implications regarding the concept. The literature search flow is summarized in Figure 1.

Step 1. Identify the concept of interest, definitions and surrogate terms/concepts

Surrogate or related terms to be used in the search were identified from key articles on death preparedness[14,23] such as: 'end-of-life', 'death', 'palliative', 'preparedness', OR 'death attitude', AND 'caregiver', AND 'dementia'. An in-depth analysis of surrogate concepts and extraction of definitions was performed later during content analysis.

Step 2. Identify a realm (setting and sample) for data collection

A search strategy was developed with a university librarian. Journal databases (Embase, Cinahl, Medline, PsychInfo and AgeLine) were searched to collect English articles describing preparedness and EOL experiences of CGs (including pre/post-death) of persons with dementia, between 1990-2017, from a variety of disciplines. Articles were screened for the following inclusion criteria: (1) current/bereaved, family/friend CGs were study participants or were the focus; (2) care recipients were persons who had dementia living in LTC (suggesting they had moderate to advanced symptoms of dementia) or were deceased with dementia listed as the primary diagnosis; and (3) authors described at least one preparedness attribute as well as one antecedent or consequence of preparedness (determined through constant comparative analysis of full-text articles).

Step 3 and 4: Collect relevant data to identify the antecedents, attributes, and consequences from multiple disciplines; Analyze data according to the above characteristics of the concept

The initial literature search resulted in 1817 articles (after duplicates were removed). These articles were screened by the first author (P.D.) who identified 180 articles for full-text screening. Using constant comparative analysis, authors coded key articles (i.e., those with CG death preparedness as the subject) according to an analytic framework of predetermined codes representing the elements of concept analysis (i.e., antecedents, attributes, consequences, surrogate terms and definition).[25,26] Multiple meetings occurred with authors until consensus was reached regarding the elements of preparedness. P.D. then screened and excluded articles from the 180 full-text sample, which did not describe at least one attribute, as well as one antecedent or consequence of preparedness and therefore did not provide in-depth insight into the concept. An additional author (H.P.) double-screened a sample of the full-text articles (n=10) and found adequate reliability of screening (Cohen's kappa=0.8) and then independently analyzed a sample of articles (n=6) apart from the other authors, comparing and triangulating the findings for credibility.[27]

A total of 63 articles were retained for inclusion in this review which met inclusion criteria and provided in-depth insight into the concept as a whole. Main reasons for article exclusion were: sample care recipients did not have dementia (n=51); articles were commentaries / opinion papers (n=13); caregiving did not occur at EOL (n=5); and authors did not describe at least one preparedness attribute, as well as one antecedent or consequence (n=39). Following identification of the included sample, the first author P.D. completed further in-depth analysis and data extraction for proof of preparedness elements.

Step 5. Identify hypotheses and implications for further development of the concept

Through analysis and researcher triangulation, hypotheses surrounding the aim and nature of preparedness characteristics, underlying traits and related concepts were formed. Further development of the concept is currently underway with a qualitative study to validate study findings, and generate items for a death preparedness questionnaire in dementia.

Findings

Sixty-three articles were retained for analysis including research studies (n=51), reviews (n=9) and theoretical papers (n=3). Disciplines varied between first authors representing: nursing (n=23), medicine (n=19), psychology (n=11), social work (n=7), gerontology (n=1) and sociology (n=2)(see supplementary Table). Articles from a wide variety of disciplines captured multiple perspectives and enhanced the validity of the findings.[25]

Evolving definition and use of the concept

The term ‘prepare’ or ‘preparing’ is defined as a transitive verb meaning: (1)

to make ready, or plan beforehand for some purpose, use, activity or event; and (b) to put in a proper state of mind. Relatedly, the term ‘preparedness’ is defined as the quality or state of readiness in case of an event.[28] The experience of death and the subsequent stage of bereavement comprise major stressors and transitions in a person and family’s life course that benefit from advance preparations.[29,30]

Death preparedness is considered a key element of a ‘good death’ along with pain and symptom management, life completion, contributing to others, and affirmation of the whole person.[31] Barry et al.[32] defined death preparedness as a person’s feeling of forewarning or readiness for death, and were the first to suggest that preparedness is a personal perception not solely dictated by the circumstance of death (i.e., sudden versus expected) as was previously believed.[12,29,30,33] Researchers working in palliative care and with family CGs of persons with dementia expanded upon Barry et al.’s[32] definition, developing the Theoretical Framework of Preparedness for EOL, which described relationships between communication, preparedness and CG outcomes after-death.[14,23]

Schulz et al.[34] further describes death preparedness as a preparatory psychological and practical adjustment, in which CGs engage when acknowledging imminent death. In our concept analysis, death preparedness was defined by authors in only nine (14%) of 63 articles, although all articles discussed preparing, being ready, grieving or anticipating death and bereavement. Authors referred to Hebert and colleagues’ definition[14,23] most often, or did not define preparedness at all, which supported the need for this study. Within multiple articles researchers acknowledged limitations (e.g., lack of clarity) in the preparedness definition, instruments measuring preparedness, and called for increased conceptualization to advance work in this area.[12,14,23,34]

Surrogate terms and related concepts

Common surrogate terms for death preparedness which emerged during content analysis included: 'readiness for death', 'ready to let go'[14,35-39] and prepared for death. [41-44] Preparedness was also termed a psychological 'forewarning' of death.[11,12,30,45,] Emotional preparedness (also referred to as psychological preparedness) was described in multiple articles as distinct from practical preparedness (also termed instrumental, mental or cognitive) preparedness, which illustrated consensus that preparedness was a multidimensional concept.[30,45-48]

The concept of CG self-efficacy and its relationship to preparedness were strong themes emerging from analysis of the literature. Self-efficacy referred to CG beliefs about their ability to perform required tasks or skills, and maintain control over the situation and personal emotions.[49] CGs described a need or preference to influence or exercise control over their lives and the life of their family member.[46] Particularly CGs' self-efficacy and 'readiness for decision-making' regarding treatments and care preferences as EOL approached was frequently discussed.[31,36,50-52] However, readiness for decision-making was often restricted to medical or practical choices that needed to be made, and therefore was not synonymous with multi-dimensional preparedness.[44] CGs also questioned their ability to control or regulate personal emotions that might arise during the death of their family member.[53,54] Death preparedness was therefore related to concepts of self-efficacy and control. Some authors also used the term 'preparedness for caregiving' (i.e., CG readiness to manage the physical, emotional and practical needs of the patient, and personal stress) synonymously with death preparedness. However, this concept has not been analyzed in the context of specifically caregiving for death.[12,54]

Characteristics of death preparedness

Attributes

Attributes are characteristics of the concept, which allow persons to discern if the concept is present in a situation.[25] Death preparedness was evidenced by seven attributes (see Table 1), which suggested cognitive, emotional and behavioural preparedness for death including: (1) knowing and recognizing the symptoms of decline in dementia and what dying looks like; (2) understanding emotions and possible grief responses; (3) accessing and appraising supports needed to plan, manage and provide care for dying; (4) organizing affairs and completing tasks in advance; (5) accepting that losses are inevitable and imminent; (6) reflecting on caregiving and finding meaning, 'a silver-lining'; and (7) closing, reconciling and renewing relationship bonds and completing the family member's life (see Figure 2). Strategies to meet these needs were planned, which typically reflected a pattern of coping the CG had employed previously.[35]

Antecedents

Antecedents are events/phenomena that commonly precede an instance of the concept.[25] Preparedness for death in CGs of persons with dementia was preceded by: (1) an illness-related event, which triggered clinical and intuitive awareness of dying; communication with HCPs regarding decline; (2) uncertainty regarding the future (e.g., dementia trajectory, death); and (3) grief regarding past, current and future losses (see Table 2).

Consequences of death preparedness

Consequences are the phenomena and events that occur after an instance of the concept[25] CG outcomes following death preparedness related to: (1) mental health; (2) adaptation/adjustment; (3) satisfaction with care and a good death for the person with dementia. (see Table 2).

Final definition of death preparedness

Based on this analysis, we fully define CG preparedness for death in dementia as: **a cognitive, emotional and behavioural quality (or state of readiness) to minimize uncertainty, maintain self-efficacy and control over current and future losses and death in persons with dementia.**

Implications

Expanding upon the Theoretical Framework of Preparedness for End-of-Life

Integrating findings from this concept analysis with elements of the Theoretical Framework of Preparedness[14] will serve as the conceptual basis for the development of a questionnaire on preparedness to be titled, 'Caring Ahead'.[55] The Preparedness Framework developed by Hebert, Prigerson and colleagues[14] describes relationships between uncertainty, EOL communication, CG preparedness and CG outcomes. The Framework is based upon findings from the REACH study [Resources for Enhancing Alzheimer Caregiver's Health). a randomized control trial evaluating the effects of complex interventions for CGs in dementia pre/post death.[56]

Authors suggested that dynamic conversations and ongoing communication (including ACP) with HCPs decreased CG uncertainty during EOL, predicted CG preparedness for death, and improved CG outcomes like mental health and adjustment.[14,22,56] Preparedness was described as having four content areas: (1) medical, (2) psychosocial, (3) spiritual and (4) practical. In turn, preparedness was conceptualized as having three dimensions relative to these content areas: (1) cognitive (information and knowledge), (2) affective (emotionally preparing), and (3) behavioural (tasks).

Study findings from our concept analysis align with and clarify understanding of preparedness dimensions, content areas and conceptual relationships outlined in the Preparedness Framework.[14] Namely, attributes identified in our analysis can be grouped according to content areas of the loss/death experience (i.e., medical, psychosocial, practical and spiritual), and also exhibit cognitive, affective and behavioural dimensions. Attributes can be linked to more than one content area. Examples of categorization by content area include: 'knowing the symptoms of decline in dementia' (medical); 'completing the family member's life' (spiritual);

‘accessing supports’ (psychosocial); and ‘organizing affairs’ (practical). Dimensions likely constitute the underlying traits of preparedness, and suggest CGs’ use of problem (cognitive and behavioural) and emotion-based (affective) coping strategies to minimize uncertainty, maintain control, self-efficacy.

Promoting problem and emotion-based coping skills

Attributes characterizing preparedness for death of persons with dementia are developed through strategies of problem-based and emotion-based coping. Problem-based coping refers to strategies used to directly work through or control a problem by: confronting the problem, appraising the anticipated event, seeking information and support, and completing tasks.[35,46,53,57] In contrast, emotion-based coping is defined as strategies used to indirectly regulate emotions in response to stressful/uncertain events, and hypothetically is linked to emotional preparedness.[57] Potentially, attributes of practical preparedness such as knowledge of dementia, understanding of grief and accessing support are facilitated through use of direct, problem-based coping strategies like information and support-seeking, which represent underlying cognitive and behavioural traits. Similarly, attributes such as acceptance and finding meaning may be developed through indirect coping strategies such as positive reframing in the face of inevitable loss, which represent an underlying affective trait.

The conceptual basis for ACP interventions and a preparedness instrument

Defining attributes of preparedness is key to developing multi-dimensional, holistic ACP interventions and an instrument by which to measure CG preparedness for death. The long, diverse and unpredictable trajectory of dementia makes designing and implementing acceptable, appropriately-timed ACP interventions for CGs challenging.[4] However, our insight into antecedents of preparedness reinforces that ACP interventions (like EOL conversations) addressing medical, psychosocial, spiritual and practical concerns, are particularly important at times of transition (i.e., illness-related events) and should stimulate CG preparations for death. Program models such as the 'Strengthening a Palliative Approach to Care in Long-term Care [SPA-LTC][58] program, exemplify a practical application of the Theoretical Framework and preparedness concept. The SPA-LTC program describes a systematic approach to identifying residents in LTC experiencing illness-related events and transitions to EOL through regular assessment of residents' Palliative Performance Scale[59]. In turn, identification triggers holistic EOL conversations between LTC staff and family CGs, termed 'Family Care Conferences'. Conferences aim to address CG's questions and prepare them for EOL.

Identification of preparedness attributes is also essential to operationalizing and measuring the concept. Currently, three different global-rating scores (i.e. single-item scales) currently aim to measure CG death preparedness,[11.32,56,60] and one dual-item scale.[13] However, these instruments do not address the holistic attributes identified in our concept analysis, and are therefore limited in their conceptual adequacy.[61] Global rating scales are mainly retrospective, and have been administered to CGs or family members between four months and five years after bereavement.

Only one global-rating scale[11] was administered prospectively to CGs whose family members with dementia were living in LTC.

Importantly, Hebert and colleagues[14,22] suggest that EOL conversations and ACP facilitate death preparedness by decreasing uncertainty, and are associated with improved CG mental health, adjustment and satisfaction with EOL care during bereavement. Thus, an instrument developed to measure death preparedness should theoretically act as a measure of the effectiveness of palliative care interventions such as ACP and predict outcomes in bereavement. In-line with the framework, we hypothesize that a questionnaire developed to measure preparedness for EOL may include subscales with items relevant to medical, psychosocial, spiritual and practical content areas. Within subscales may be a mix of attribute items representing underlying cognitive, affective and behavioural traits, indicating preparedness. Observable preparedness attributes may be linked to CGs' use of problem (cognitive and behavioural) and emotion-based (affective) coping strategies. Potential questionnaire items with a Likert-scale may include: 'I am confident I know what to expect as my family member's dementia progresses, for example, problems with swallowing, frequent infections, increased behaviours'; 'I feel confident I will have enough support from family and friends when my family member is dying'; or 'I have said the things I needed to say to my family member'.

Knowledge of the existing framework, integrated with findings from the concept analysis will be used to guide and direct a qualitative study exploring/validating the preparedness construct and generating questionnaire items with bereaved CGs of persons with dementia.[60] As such, we will utilize both a deductive approach (stemming from existing knowledge and conceptualization of death preparedness) along with an inductive approach (building and expanding upon the existing theory) to operationalize preparedness in a measurement instrument.

Conclusion

This study increases understanding of the core concepts or preparedness for death in dementia and supports operationalization of preparedness for death in dementia. Findings will be used to support the important development of a questionnaire to assess preparedness, measure and promote effective ACP interventions.

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References

1. World Health Organization. Dementia: A public health priority. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf Published 2012. Accessed September 5, 2018
2. Cahill S, O'Shea E, Pierce M. Creating excellence in dementia care: A research review for Ireland's national dementia strategy. http://hdl.handle.net/10147/215312 Published March 2003. Accessed September 5, 2018.
3. Coleman, AM. End-of-life issues in caring for patients with dementia: the case for palliative care in management of terminal dementia. *AM J HOSP PALLIAT ME.*
   2012; 29(1), 9-12.
4. Mitchell, SL. UpToDate: Palliative care of patients with advanced dementia. https://www.uptodate.com/contents/palliative-care-of-patients-with-advanced-dementia Updated July 16, 2018. Accessed September 5, 2018
5. Ontario Long-term Care Association. This is long-term care 2016. https://www.oltca.com/OLTCA/Documents/Reports/TILTC2016.pdf Published November 2016. Accessed September 5, 2018.
6. van der Steen JT. Dying with dementia: what we know after more than a decade of research. *J ALZHEIMERS DIS*. 2010.*22*(1), 37-55.
7. Lester PE, Stefanacci RG, Feuerman M. Prevalence and description of palliative care in US nursing homes: A descriptive study. *AM J HOSP PALLIAT ME.*

2016;*33*(2), 171-177.

8. Durepos P, Wickson-Griffiths A, Hazzan AA et al. Assessing palliative care content in dementia care guidelines: A systematic review. *J PAIN SYMPTOM MANAG*. 2017;53(4), 804-813.
9. van der Steen JT, Radbruch L, Hertogh CM et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *PALL MED*. 2014;28(3), 197-209.
10. Hudson P, Remedios C, Zordan R et al. Guidelines for the psychosocial and bereavement support of family CGs of palliative care patients. *J PALLIAT MED*. 2012;15(6), 696-702.
11. Schulz R, Boerner K, Klinger J, Rosen J. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *J PALLIAT MED*. 2015;18(2), 127-133.
12. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *CLIN PSYCH REV*. 2016;44, 75-93.
13. Caserta M, Utz R, Lund D, Supiano K, Donaldson G. Cancer caregivers' preparedness for loss and bereavement outcomes: Do preloss caregiver attributes matter? *OMEGA-J DEATH DYING*, 2017;0030222817729610.

14. Hebert R, Prigerson H, Schulz R, Arnold R. Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *J PALLIAT MED.* 2006;9(5), 1164-1171.
15. Kersting A, Brähler E, Glaesmer H, & Wagner B. Prevalence of complicated grief in a representative population-based sample. *J AFFECT DIS.* 2011;131(1), 339- 343.
16. Wickson-Griffiths A, Kaasalainen S, Ploeg J, McAiney C. A review of advance care planning programs in long-term care homes: are they dementia friendly? *NURS RES PRACT;* 2014,2014.
17. Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *PALLIAT MED.* 2014; 8(8):1000-1025.
18. Carr D, Luth E. Advance care planning: Contemporary issues and future directions, *INNOV AGING.* 2017;(1)1, igx012, https://doi.org/10.1093/geroni/igx012
19. Bill C-233: An Act respecting a national strategy for Alzheimer's disease and other dementia. http://www.parl.ca/DocumentViewer/en/42-1/bill/C-233/royal-assent Published June 22, 2017 Accessed September 5, 2018
20. Ministry of Health and Long-Term Care. Parliamentary Assistant John Fraser to the Minister of Health and Long-Term Care. Palliative and end-of-life care provincial roundtable report

http://www.health.gov.on.ca/en/public/programs/palliative/pdf/palliative_report.pdf Published 2017 Accessed September 5, 2018

21. Durepos P, Kaasalainen S, Carroll S, Papaioannou A. Perceptions of a psychoeducation program for caregivers of persons with dementia at end of life: A qualitative study. *AGING MENT HEALTH.* 2017; 0(0): 1-9.
22. Schulz R. Research priorities in geriatric palliative care: Informal caregiving. *J PALLIAT MED*. 2013;16(9), 1008-1012.
23. Hebert R, Schulz R, Copeland V, Arnold R. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J PAIN SYMPTOM MANAG.* 2009;*37*(1), 3-12.
24. Kaasalainen S, Brazil K, Ploeg J, Martin LS. Nurses' perceptions around providing palliative care for long-term care residents with dementia. *J PALLIAT CARE*. 2007;23(3), 173-183.
25. Rodgers BL Concept analysis: An evolutionary view. In: Rodgers BL, Knafl KA, eds. *Concept Development in Nursing.* Philadelphia: Saunders; 2000, 7-37.
26. Thorne, Sally. *Interpretive Description*. New York: Routledge, 2016.
27. Hallgren KA. Computing inter-rater reliability for observational data: an overview and tutorial. *TUTOR QUANT METHODS PSYCHOL.* 2012;8(1), 23-34.
28. “Preparedness”. (2018) Merriam-Webster Dictionary. Retrieved October 26, 2018 from https://www.merriam-webster.com/dictionary/preparedness
29. Hebert RS, Dang Q, Schulz R. Preparedness for the death of a loved one and

mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *J PALLIAT MED.* 2006;9(3), 683-693.

30. Hovland-Scafe CA, Kramer BJ. Preparedness for death: How caregivers of elders with dementia define and perceive its value. *GERONTOLOGIST.* 2016;gnw092.
31. Bosek MSD, Lowry E, Lindeman DA, Burck JR, Gwyther LP. Promoting a good death for persons with dementia in nursing facilities: family caregivers' perspectives. *JONA'S HEALTHCARE LAW, ETHICS AND REGULATION*. 2003;5(2), 34-41.
32. Barry L, Kasl, V., Prigerson, H. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *AM J GERIAT PSYCHIAT.* 2002;10(4), 447-457.
33. Granda-Cameron C, Houldin A. Concept analysis of good death in terminally ill patients. *AM J HOSP PALLIAT* ME. 2012;29(8), 632-639.
34. Schulz R, Rosen J, Klinger J, Musa D, Castle NG, Kane AL, Lustig A. Effects of a psychosocial intervention on caregivers of recently placed nursing home residents: A randomized controlled trial. *CLIN GERONTOLOGIST.* 2014;37(4), 347-367.
35. Almberg B, Grafström M, Winblad B. Major strain and coping strategies as reported by family members who care for aged demented relatives. *J ADV NURS.* 1997;26(4), 683-691
36. Cable-Williams B, Wilson D. Awareness of impending death for residents of

long-term care facilities. *INT J OLDER PEOPLE NURS.* 2014;*9*(2), 169-179.

37. Caron CD, Griffith J, Arcand M. End-of-life decision making in dementia: The perspective of family caregivers. *DEMENTIA*. 2005;4(1), 113-136.
38. Dupuis SL. Understanding ambiguous loss in the context of dementia care: Adult children's perspectives. *J GERONTOL SOC WORK*. 2002;*37*(2), 93-115.
39. Jones PS, Martinson IM. The experience of bereavement in caregivers of family members with Alzheimer's disease. *J NURS SCHOLARSHIP*. 1992;24(3), 172-176.
40. Peacock S, Duggleby W, Koop P. The lived experience of family caregivers who provided end-of-life care to persons with advanced dementia. *PALLIAT SUPPORT CARE.* 2014;12(2), 117-126.
41. Hennings J, Froggatt K, Keady J. Approaching the end of life and dying with dementia in care homes: The accounts of family carers. *REV CLIN GERONTOL.* 2010; 20(02), 114-127.
42. Lewis LF. Caregiving for a loved one with dementia at the end of life: An emergent theory of rediscovering. *AM J ALZHEIMERS DIS*. 2015;30(5), 488-496.
43. Raymond M, Warner A, Davies N, Iliffe S. Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. *DEMENTIA.* 2015;13(1), 96-110.
44. Reinhardt JP, Chichin E, Posner L, Kassabian S. Vital conversations with family

in the nursing home: preparation for end-stage dementia care. *J SOC WORK END LIFE PALLIAT CARE*. 2014;10(2), 112-126.

45. Arruda EH, Paun O. Dementia caregiver grief and bereavement: an integrative review. *WESTERN J NURS RES*. 2017;39(6), 825-851.
46. Lopez RP, Guarino AJ. Uncertainty and decision making for residents with dementia. *CLIN NURS RES*. 2011;20(3), 228-240.
47. Silverberg E. Introducing the 3-A grief intervention model for dementia caregivers: acknowledge, assess and assist. *OMEGA-J DEATH DYING*. 2007;54(3), 215-235.
48. Waldrop DP, Kusmaul N. The Living–dying interval in nursing home-based end-of-life care: Family caregivers' experiences. *J GERONTOL NURS*. 2011;54(8), 768-787.
49. Bandura A. *Self-efficacy: The exercise of control*. New York, NY: MacMillan; 1997.
50. Ashton SE, Roe B, Jack B, McClelland B. End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia–A qualitative study. *DEMENTIA*. 2016;15(5), 958-975.
51. Peacock SC, Hammond-Collins K, Forbes DA. The journey with dementia from the perspective of bereaved family caregivers: a qualitative descriptive study. *BMC NURS*. 2014;13(1), 42.
52. Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. *PALLIAT SUPPORT CARE*. 2014;12(3), 223-231.

53. Aneshensel CS, Botticello AL, Yamamoto-Mitani N. When Caregiving Ends: The Course of Depressive Symptoms After Bereavement. *J HEALTH SOC BEHAV.* 2004; 45(4), 422-440.
54. Schumacher KL, Stewart BJ, Archbold PG. Conceptualization and measurement of doing family caregiving well. *J NURSING SCHOLARSHIP*.1998; 30(1), 63-70.
55. Durepos P, Sussman T, Ploeg J, Akhtar-Danesh N, Punia H, Kaasalainen S. Developing a questionnaire to measure death preparedness in dementia, *In Press, CAN GERIAT J.* 2018
56. Holland JM, Currier JM, Gallagher-Thompson D. Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *PSYCHOL AGING.* 2009;24(1), 190-202.
57. Lazarus RS, Folkman S. *Stress, coping and appraisal.* New York, NY: Springer Publishing Company; 1984.
58. Goy ER, Carter JH, Ganzini L. Needs and experiences of caregivers for family members dying with Parkinson disease. *J PALLIAT CARE.* 2008; 24(2), 69–75.
59. Kaasalainen S, Sussman T, Neves P & Papaioannou A. Strengthening a Palliative Approach in Long-Term Care (SPA-LTC): A New Program to Improve Quality of Living and Dying for Residents and their Family Members. *J AM MED DIR ASSOC*, 2016; *17*(3), B21.

60. Anderson, F., Downing, G. M., Hill, J., Casorso, L., & Lerch, N. (1995). Palliative performance scale (PPS): a new tool. *J PALLIAT CARE*, 1995;*12*(1), 5-11.
61. Durepos P, Ploeg, J, Akhtar-Danesh N et al. A review of instruments measuring preparedness for death in caregivers. *Under Review November 2018 to: SAGE OPEN NURS.*
62. Streiner DL, Norman GR, Cairney J. *Health measurement scales: a practical guide to their development and use.* Oxford, UK: Oxford University Press; 2015.
63. Albinsson L, Strang PA palliative approach to existential issues and death in end-stage dementia care. *J PALLIAT CARE*. 2002;*18*(3), 168-174.
64. Albinsson L Strang P. Existential concerns of families of late-stage dementia patients: questions of freedom, choices, isolation, death, and meaning. *J PALLIAT MED.* 2003;6(2), 225-235.
65. Almberg BE, Grafstrom M, Winblad B. Caregivers of relatives with dementia: experiences encompassing social support and bereavement. *AGING MENT HEALTH*. 2001; 4(1), 82-89.
66. Biola H, Sloane PD, Williams CS et al. Physician Communication with Family Caregivers of Long-Term Care Residents at the End of Life. *J AM GERIATR SOC.* 2007;55(6), 846-856.
67. Chan D, Livingston G, Jones L, Sampson EL. Grief reactions in dementia carers: a systematic review. *INT J GERIATR PSYCH.* 2013;28(1), 1-17.

68. Crespo M, Piccini AT, Bernaldo-de-Quirós M. When the care ends: Emotional state of Spanish bereaved caregivers of persons with dementia. *SPAN J PSYCHOL*. 2013;16.
69. Engel SE, Kiely DK, & Mitchell SL. Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *J AM GERIATR SOC*. 2006;54(10), 1567-1572.
70. Exline JJ, Prince-Paul M, Root BL, Peereboom KS, Worthington Jr EL. Forgiveness, depressive symptoms, and communication at the end of life: a study with family members of hospice patients. *J PALLIAT MED*. 2012;15(10), 1113-1119.
71. Forbes S, Bern-Klug M, Gessert C. End-of-Life Decision Making for Nursing Home Residents with Dementia. *J NURSING SCHOLARSHIP* 2000;32(3), 251-258.
72. Gessert CE, Forbes S, Bern-Klug M. Planning end-of-life care for patients with dementia: roles of families and health professionals. *OMEGA-J DEATH DYING*. 2001;42(4), 273-291.
73. Ghesquiere A, Martí Haidar YM, Shear MK. Risks for complicated grief in family caregivers. *J SOC WORK END LIFE PALLIAT CARE*. 2011;*7*(2-3), 216-240.
74. Givens JL, Prigerson HG, Kiely DK, Shaffer ML, Mitchell, SL. Grief among family members of nursing home residents with advanced dementia. *AM J*

GERIATR PSYCHIAT. 2011;19(6), 543-550.

75. Givens JL, Jones RN, Mazor KM, Prigerson, HG, Mitchell SL. Development and psychometric properties of the family distress in advanced dementia scale. *J AM MED DIR ASSOC.* 2015;16(9), 775-780.
76. Haley WE, Bergman EJ, Roth DL, McVie T, Gaugler JE, Mittelman MS. Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptoms. *GERONTOLOGIST.* 2008;48(6), 732-740.
77. Hampton M. *Self-efficacy in caregiving and caregiver stress in adult informal caregivers of individuals at the end-of-life.* [dissertation]. Arlington, TX: The University of Texas; 2014.
78. Holley CK, Mast BT. The impact of anticipatory grief on caregiver burden in dementia caregivers. *GERONTOLOGIST.* 2009;49(3), 388-396.
79. Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GK, Davies, A. Predictors of complicated grief: A systematic review of empirical studies. *DEATH STUD*. 2010;34(8), 673-698.
80. Meuser TM, Marwit SJ. A comprehensive, stage-sensitive model of grief in dementia caregiving. *GERONTOLOGIST.* 2001;41(5), 658-670.
81. Moore KJ, Davis S, Gola A, et al. Experiences of end of life amongst family carers of people with advanced dementia: longitudinal cohort study with mixed methods. *BMC GERIATR.* 2017;17(1), 135.
82. Muders P, Zahrt-Omar CA, Bussmann S, Haberstroh, J, Weber M. Support for families of patients dying with dementia: A qualitative analysis of bereaved

family members' experiences and suggestions. *PALLIAT SUPPORT CARE*. 2015;13(3), 435-442.

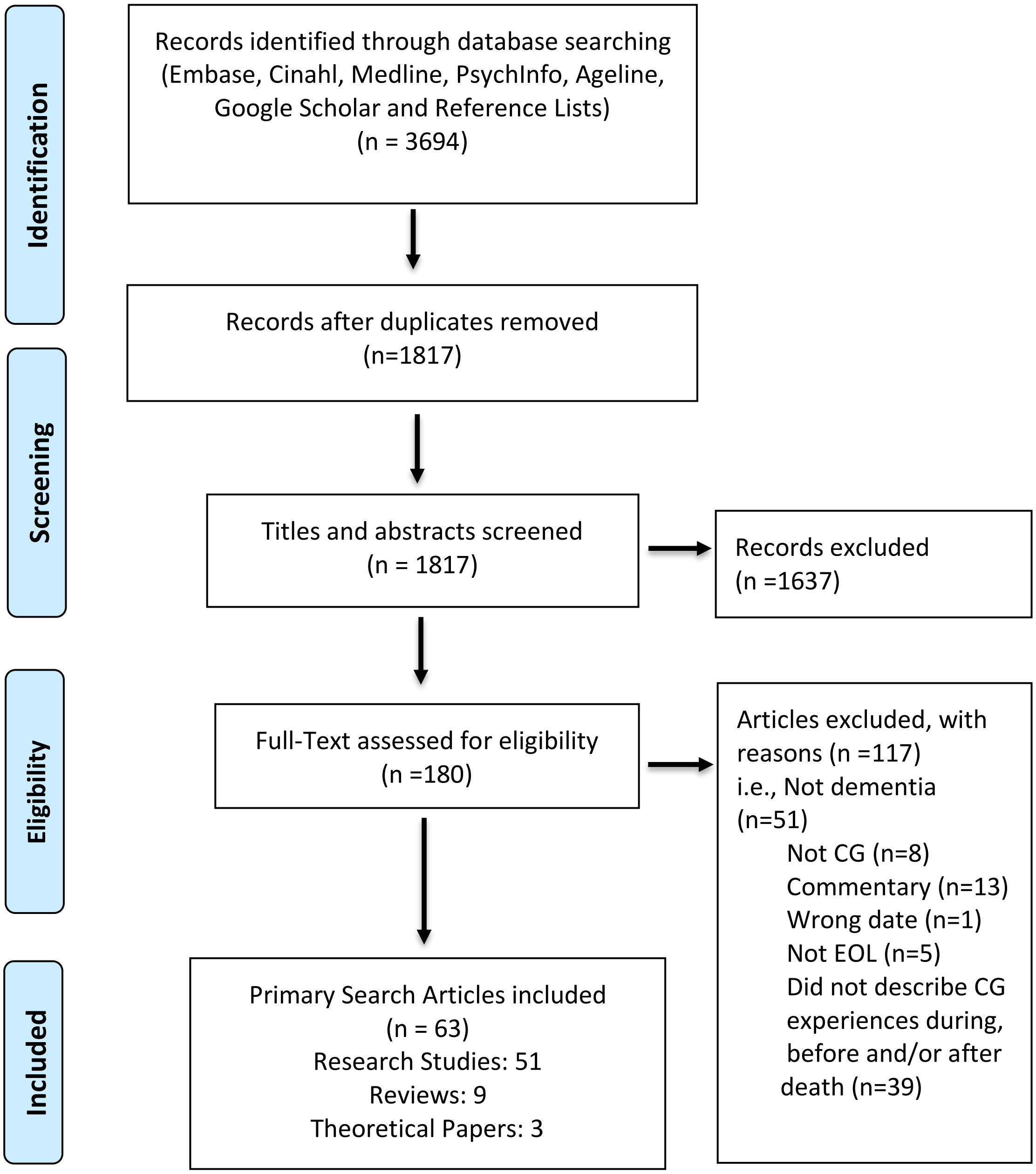
83. Orzeck P. Identities in transition: Women caregivers in bereavement. *J SOC WORK END LIFE PALLIAT CARE*. 2016;12(1-2), 145-161.
84. Orzeck P, Silverman M. Recognizing post-caregiving as part of the caregiving career: implications for practice. *J SOC WORK PRACT*. 2008;22(2), 211-220.
85. Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *GERONTOLOGIST.* 1999;39(2), 177-186.
86. Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: family caregiver burden. *J ADV NURS.* 2007;58(5), 446-457.
87. Peacock S. The experience of providing end-of-life care to a relative with advanced dementia: An integrative literature review. *PALLIAT SUPPORT CARE.* 2013;11(2), 155-168.
88. Romero MM, Ott CH, Kelber ST. Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. *DEATH STUD.* 2014;38(6), 395-403.
89. Russell C, Middleton H, Shanley C. Dying with dementia: the views of family caregivers about quality of life. *AUSTRALAS J AGEING*. 2008;27(2), 89-92.

90. Sampson, E. L., Jones, L., Thune-Boyle, I. C., et al. Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *PALLIAT MED.* 2011;*25*(3), 197-209.
91. Schulz R, Boerner K, Shear K, Zhang S, Gitlin LN. Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *AM J GERIAT PSYCHIAT*. 2006;14(8), 650-658.
92. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *NEW ENGL J MED*. 2003;349(20), 1936-1942.
93. Shanley C, Russell C, Middleton H, Simpson-Young V. Living through end-stage dementia: The experiences and expressed needs of family carers. *DEMENTIA*. 2011;10(3), 325-340.
94. Singer AE, Goebel JR, Kim YS, et al. Populations and interventions for palliative and end-of-life care: a systematic review. *J PALLIAT MED*. 2016;19(9), 995-1008.
95. Thompson GN, McClement SE, Menec VH, Chochinov HM. Understanding bereaved family members' dissatisfaction with end-of-life care in nursing homes. *J GERONTOL NURS*. 2012;38(10), 49-60.
96. Van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. *BMC MED*. 2013;11(1), 105.
97. Vandervoort A, Houttekier D, Vander Stichele R, van der Steen J T, Van den

Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter? A nationwide postmortem study. *PLOS ONE*. 2014;9(3), e91130. doi:10.1371/journal.pone.0091130

98. Hebert R, Copeland V, Schulz R, Amato C, Arnold R. Preparing family caregivers for the death of a loved one: Implications for hospital social workers. *J SOC WORK END LIFE PALLIAT CARE*. 2008;4(4): 269-285.
99. Hebert RS, Schulz R, Copeland V, Arnold, RM. What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *J PALLIAT MED*, 2008;*11*(3), 476-483.

Figure 1. Literature Search Flowchart



Note. From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed100

Figure 2. Characteristics of Caregiver Preparedness for Death of Persons with Dementia

Antecedents	Attributes	Consequences
1. Living with Grief and Burden; 2. Illness-Related Event; 3. Advance Care Planning, End-of-Life Communication with Care Providers 4. Uncertainty about the Situation and the Future	1. Knowing and recognizing symptoms of decline in dementia and what dying looks like; 2. Understanding emotions and grief responses; 3. Accessing and appraising supports needed to manage, plan and provide care around death; 4. Organizing affairs and completing tasks in advance; 5. Accepting that losses are inevitable and imminent; 6. Reflecting on caregiving and finding meaning, 'a silver-lining'; 7. Closing, reconciling and renewing relationships, completing the family member's life.	1. Mental Health and Well-being after Death; 2. Adaptation and Adjustment in Bereavement; 3. Satisfaction with End-of-Life Care and Quality of Dying for the Person with Dementia

Table 1. Attributes of Caregiver Preparedness for Death of Persons with Dementia

Attribute	Description
1. Knowing and recognizing symptoms of decline in dementia and what dying looks like	Having common information-needs met regarding dementia and the person with dementia's health status to support decision-making[21,23, 34, 35, 44, 93] • i.e., prognosis, dementia as a terminal disorder, trajectory, benefits/risks of treatments, signs and symptoms of decline and dying, common causes of natural death (e.g., pneumonia, urinary infections)[14] • CGs often unaware of knowledge gaps, have different preferences for information-sharing (e.g., quantity, format, person-delivering)[23, 35] • Continuous appraisal of the person with dementia's quality-of-life and alignment with values influences perception of death (e.g., 'wanted' or 'welcomed')[87]
2. Understanding emotions and grief responses	Expecting and recognizing emotional responses such as pre-death grief, guilt, anger and ambiguous loss[38, 67, 71] • Complexity related to the person with dementia's neurological decline, unpredictable trajectory, pre-death grief related 'psychological death' (e.g., when meaningful communication ceased), often 'surprising' intense grief with physical death[39, 87, 93] • Receiving information about types/stages of grief to validate and normalize emotions experienced or expected[80, 98] • Supports feelings of control, ability to cope with emotions and potential 'reactivated grief'[47, 53, 56, 65, 74, 84]
3. Accessing and appraising supports needed to manage, plan and provide care around death	Seeking, receiving, having access to experts, role models and friends for psychosocial (e.g., empathetic listening, validation, decision-making and socialization) and practical support (e.g., assistance with household chores, financial paperwork, providing physical care, maintaining a bedside vigil) in-line with preferences[41,85,96] • Appraising personal capacity and seeking training/help

Attribute	Description
	to feel confident around EOL care/affairs[30,86,93] • Receiving psychosocial support and communication with HCPs integrated into care of persons to feel less alone in role, competent, in control of care[21,40,82,83,87,88, 90,94] • Resolving conflicts and strengthening support networks[23, 51, 70, 84]
4. Organizing affairs and completing tasks in advance	Organizing legal and financial affairs, completing funeral, ritual and burial planning to avoid decision-making and decreasing tasks required at time of death when grief inhibits concentration/decision-making[23,30,51, 98] • Supports feeling emotionally 'present' during physical death dying person during death[30, 51] • 'Keeping busy' may promote avoidance but can be positive if not interfering with other aspects of preparedness[30, 88]
5. Accepting that losses are inevitable and imminent	Death acceptance, 'coming to terms' refers to peaceful awareness of physical death and losses approaching and unavoidable, with uncertain timing [30, 31, 35, 63] • Re-framing situations, making best of the time left and identifying positive aspects of death [35] • Acknowledging need for adaptation and assimilation of new reality/identity (which cannot be changed) without persons with dementia [35, 83] • Intentionally making the best of time left, focusing on enhancing the person with dementia's comfort [21,38] • Accepting that caregiving role/identity is fulfilled, and they are facilitating a good life and death for the person with dementia to the best of their abilities [38, 67, 83] • Self-blaming, guilt or avoidance of death interferes with acceptance and preparedness [38]
6. Reflecting on caregiving, finding meaning, a 'silver lining'	Reconstructing meaning of life and death through 'sense-making' of loss, uncertainty and death and existential beliefs around human life, purpose, a higher power, freedom and responsibility [64,79,83] • Benefit-finding (reframing) and progressive identity

Attribute	Description
	change (adaptating to a new role) to support self-organization, self-efficacy and control [79, 83] - Finding meaning/infusing structure into uncertain situations (i.e., death) through spiritual or religious rituals [40, 41, 51, 79] - Acknowledging spiritual questions such as 'why did this happen', 'where is God in this situation', 'what is the meaning of suffering', 'where will my loved one go when they die' and aiming to resolve concerns [47, 98]
7. Closing, reconciling and renewing relationships, completing the family member's life	Emotionally engaging (i.e., feeling connected to) and consciously 'letting go' or loosening the bond on the physical relationship to the person with dementia, while reinforcing relationships with others [30,31,39,47,65,67,68,79] - Fulfilling final perceived obligations (e.g., being present at time of death) saying goodbye and express sentiments (e.g., gratitude, forgiveness and love [45,67,30, 82] - Acting as a surrogate for the person with dementia (whom were unable to complete tasks themselves) to participate in rituals, activities and saying goodbye, celebrating life completion and closure in line with their values [79,89] - Planning and celebrating spiritual beliefs brought peace and structure in-line with personal and the person with dementia's values [31,40,67,89,99]

Table 2. Antecedents and Consequences of Caregiver Death Preparedness for Persons with Dementia

Antecedent	Description
1. Illness-related event and communication from HCPs	• Transition phases for residents occur in LTC triggered by illness-related events raising clinical awareness of decline and quality-of-life including: an acute phase (admission to LTC), living-dying interval (ACP, decision-making) terminal phase (last days or weeks)[37,48] • CGs develop emotional awareness of nearing death, time passing, advancing age[35,36] • Communication with HCPs regarding the illness-event provides opportunity to discuss future plans and begin preparations[14,50,66] • ACP interventions facilitating structured communication are positively correlated with death preparedness[11]
2. Uncertainty about what is happening and what to expect	• Illness-related situations (e.g. death) are complex, unpredictable, ambiguous and often have inconsistent, available information raising CGs' medical psychosocial, practical and spiritual questions[30,46,98] • Uncertainty increases around the person with dementia's quality-of-life, CG role and responsibility, potential decisions faced during death and future identity post-caregiving[21,37,80] • Feelings of ambiguous loss and pre-death grief develop because the person with dementia is physically present but psychologically absent[67,80]
3. Living with pre-death grief and burden	• CGs experience pre-death grief: an emotional response to past, present and future, acknowledged losses, characterized by longing, anger, guilt, regret and physical symptoms[12,65,67] • Burden (i.e., stress or load relative to physical, emotional, spiritual and financial CG strains) accumulates[34]

	• Unique grief because the person with dementia cannot provide comfort or participate in 'joint grieving'[51,87] • Inconsistent relationship between pre-death grief and preparedness, e.g., lengthened time of pre-death grieving triggered early awareness in CGs' for approaching death, and increased preparedness; • OR high levels of pre-death grief related to low levels of preparedness[12,65,67,85] CG burden linked to lower levels of perceived preparedness for EOL[74,79]

Consequence	Description
1. Mental health and well-being after death.	• Increasing preparedness negatively correlated with CG depressive symptoms, complicated grief (intrusive thoughts and longing affecting function), anxiety and immunologic compromise[11,29,45] • Relief after-death, well-being and mental health related to preparedness[21,30,39,48,53,67,92,98]
2. Adaptation and adjustment to death	• CG adaptation and adjustment to a new role, identity and reality linked to preparedness[11,30,39,42,47,83,84,98]
3. Satisfaction with EOL care and quality of dying for the person with dementia	• Higher satisfaction or 'peace of mind' with EOL care[44,69,71,82,100] • 'Good death' for the person with dementia characterized by: minimal distress, suffering, life completion (e.g., CG present to say goodbye), death occurring in the preferred location (e.g., LTC versus hospital)[30,31,36,70]

Chapter 3

Caregiver Preparedness for Death with Dementia: An Evaluation of Existing Tools[2]

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[2] Durepos, P., Ploeg, J., Akhtar-Danesh, N., Sussman, T., Orr, E. & Kaasalainen, S., (2019). Caregiver Preparedness for Death with Dementia: An Evaluation of Existing Tools. *Aging and Mental Health,* https://www.tandfonline.com/doi/full/10.1080/13607863.2019.1622074

Abstract

Objectives: Death preparedness amongst family caregivers [CG] is a valuable and measurable concept. Preparedness predicts CG outcomes in bereavement and is modifiable through a palliative approach which includes advance care planning [ACP] interventions. Improving death preparedness is important for CGs of persons with dementia whom are more likely to develop negative outcomes in bereavement, and experience less than adequate palliative care. However, the adequacy of existing tools to measure death preparedness in CGs of persons with dementia is unknown, which limits intervention design and prospective evaluation of ACP effectiveness.

Methods: We conducted a review and evaluation of existing tools measuring the attribute domains and traits of CG death preparedness. Literature was searched for articles describing caregiving at end of life [EOL]. Measurement tools were extracted, screened for inclusion criteria, and data extracted regarding: conceptual basis, population of development, and psychometrics. Tool content was compared to preparedness domains/traits to assess congruency and evaluate the adequacy of tools as measures of death preparedness for CGs of persons with dementia.

Results: Authors extracted 569 tools from articles, retaining seven tools for evaluation. The majority of tools, n=5 (70%) did not sample all preparedness domains/traits. Few tools had items specific to EOL; only one tool had a specific item questioning CG preparedness for death, and only one tool had items specific to dementia.

Conclusion: Limitations in existing tools suggest they are not adequate measures of death preparedness for CGs of persons with dementia. Consequently, the authors are currently developing a questionnaire to be titled, ‘Caring Ahead’ for this purpose.

Introduction

Preparing family and friend caregivers [CG] for the death of a person with a life-limiting illness is a key recommendation of guidelines for a palliative approach and end-of-life [EOL] care. Palliative care is a holistic approach to care that aims to improve persons' and families' quality of life when facing problems related to life-threatening illness (World Health Organization, 2019). Recommendations to promote 'death preparedness' are echoed consistently by both CGs and persons living with illness, who report that feeling ready and aware are priorities of a 'good death' (Barry, Kasl & Prigerson, 2002; Durepos, Kaasalainen, Carroll & Papaioannou, 2017; Hovland-Scafe & Kramer, 2017). Evidence for a correlative and predictive relationship between death preparedness and CG outcomes in bereavement (including complicated grief, depression and anxiety), also highlights the importance of preparing CGs for loss (Nielsen, Neergaard, Jensen, Bro & Guldin, 2016). Despite recommendations, some CGs continue to feel unprepared for death (Schulz, Boerner, Klinger & Rosen, 2015).

Feeling unprepared for death is particularly concerning for CGs of persons with dementia, who are already more likely to experience negative outcomes after death than other CGs (Hebert, Prigerson, Schulz, & Arnold, 2006; Kersting, Brähler, Glaesmer & Wagner, 2011; Schulz et al., 2015). Improving EOL care for this population is essential within care settings such as long-term care [LTC] where persons with dementia experience burdensome interventions, avoidable hospital transfers and poor experiences at EOL following an already challenging journey

(Kaasalainen, Sussman, Neves, & Papaioannou, 2016; Mitchell et al., 2009). Policy-makers, researchers and healthcare professionals report that implementing advance care planning [ACP] interventions, along with a palliative approach can overcome barriers and improve EOL care (Dixon, Karagiannidou & Knapp, 2018). As such, widespread efforts to implement holistic ACP interventions (ongoing discussions between persons living with illness, CGs and healthcare professionals about wishes, values and preference for care) are underway in Westernized countries (Downar et al., 2018).

The promotion of ACP to improve CG death preparedness is supported by theoretical and empirical evidence, (Hebert, Prigerson et al., 2006; Hebert, Schulz, Copeland & Arnold; Nielsen et al., 2016). However, the effectiveness of a palliative approach which includes ACP is most often evaluated retrospectively and indirectly by assessing: if the preferred place of death was achieved, if an advanced directive was completed, and if healthcare services delivered matched those preferred (McMahan, Knight, Fried & Sudore, 2013). While these outcomes are valuable measures, CGs, researchers and healthcare professionals in palliative care argue that they provide limited insight into effect of interventions on EOL experiences beyond the medical domain (McCabe, You & Tatangelo, 2016; Wickson-Griffiths, Kaasalainen, Ploeg & McAiney, 2014). One prospective study of CGs in LTC conducted by Schulz and colleagues in 2015 did demonstrate a positive relationship between participant levels of engagement in ACP and the more holistic concept of CG death preparedness, however the adequacy of tools used to measure the complex concept of death preparedness is currently not known.

In a recent a concept analysis conducted by the authors, death preparedness was described as a dynamic and fluid concept, formally defined as “a cognitive, emotional and behavioural quality (or state or readiness) to minimize uncertainty, maintain self-efficacy and control over current/future losses related to dementia and death” (Durepos et al., 2018, p.4). Multiple models/frameworks describing caregiving, stress, coping and grief were identified during the concept analysis and were examined to discern if they addressed death preparedness, including for example: the Marwit and Meuser Model of Grief in Dementia Caregiving (Meuser & Marwit, 2001); Pearlin’s Caregiving and Stress Process Model (Pearlin, 1999); Lazarus and Folkman’s Stress Appraisal and Coping Model (1984). Of the models identified, only the ‘Theoretical Framework of Preparedness for EOL’ (Hebert, Prigerson et al., 2006; Hebert et al., 2009) specifically aimed to describe the domains and traits of CG death preparedness.

Consequently, the authors expanded upon Hebert and colleagues (2006; 2009) framework and developed an integrated conceptual model specific to ‘CG preparedness for EOL for persons with dementia’ with preparedness attributes organized within four domains: medical, psychosocial, spiritual and practical (Durepos et al., 2018). Underlying traits were hypothesized as: cognitive, affective and behavioural, and characterized as problem-based (e.g., cognitive/behavioural) or emotion-based (affective) coping mechanisms (see Figure 1). Conceptualized antecedents (pre-cursors) to preparedness included ACP and healthcare professional communication, while consequences (outcomes) were characterized as CG mental health, quality of death and satisfaction with EOL care. The theoretical relationships between ACP, CG death preparedness and CG mental health are supported by empirical evidence and affirm the use of CG death preparedness as a prospective measure of ACP effectiveness, prior to death. Based on this conceptual understanding, multi-dimensional tools aiming to measure death preparedness in CGs of persons with dementia should contain items sampling each domain and trait of the 'CG preparedness for death in dementia' model, and should have been developed or tested in similar CG populations.

To our knowledge, no review or evaluation of the adequacy and congruence of multi-dimensional tools to measure death preparedness in CGs of persons with dementia has been undertaken prior to this study. Importantly, reviewing CG preparedness tools provided insight into holistic outcome measures available for ACP effectiveness. Hence the aims of this study were: (1) to evaluate the adequacy and congruence of multi-dimensional tools (addressing multiple domains/traits using multiple items) to measure the concept of death preparedness in CGs of persons with dementia; and (2) to generate evidence for the use, revision or creation of a new tool to measure death preparedness in CGs of persons with dementia.

Methods

Search

A search was conducted in order to locate existing, quantitative measurement instruments related to death preparedness domains or traits. On the advice of a university health science librarian, Embase, Medline, PsychInfo, Health-Assessment and Psychological Instruments [HAPI] and CINAHL databases, were searched for articles describing tools, from disciplines relevant to the concept (e.g., nursing, social work, medicine and psychology). Articles which met inclusion criteria were: (1) published in English between 1960 until December 2018, and (2) described the use, development or evaluation of instruments measuring preparedness domains or traits; (3) for CGs; (4) and/or during EOL. Research into caregiving gained popularity and interest in the 1970s (Zarit, 2006), and therefore we collected articles published in 1960 or later in an effort to capture all relative literature and instruments. Dementia was not included as a search term to avoid prematurely narrowing findings. GoogleScholar, article reference lists and key palliative care or dementia-related organizations (e.g., Alzheimer Society) were also searched for citations of additional tools.

Tools were extracted from articles and analyzed which met the following eligibility criteria: (1) targeted adult family member or friend CGs who self-identified, or were care recipient identified, as informal, unpaid persons providing care (e.g., physical, emotional, financial) to an adult care recipient over 19 years old with whom they had a relationship; (2) were administered prior to, during or after death; (3) included items specific to providing care/caregiving; (4) and/or included items specific to the death or EOL of a family member or friend; and (5) included items which addressed at least 70% of conceptual preparedness domains and traits (medical, psychosocial, spiritual, practical, cognitive, affective, behaviour)(see Figure 1).

Tools were excluded if they: (1) were not available in English (from the publishing authors), or were translations of already collected English tools; (2) did not target family/friend CGs providing care to adults; (3) did not contain specific items regarding caregiving, palliative care, EOL or death of a family member; (4) did not address 70% of conceptual preparedness domains and traits. Seventy percent was selected as the cut-off for tool inclusion because 0.7 is recommended as an acceptable level of correlation (e.g., agreement) between raters when evaluating content validity (Streiner, Norman & Cairney, 2015). Hence, the authors rationalized that tools sampling 70% of preparedness domains and traits demonstrated moderate content validity and warranted further analysis.

Data collection

Citation titles and abstracts were screened for eligibility by a single reviewer and irrelevant articles removed. The full-texts of remaining articles were then reviewed by three individual authors who consulted with an additional author regarding ambiguous articles until consensus was reached regarding eligibility. Authors extracted quantitative measurement tools from included articles and screened tools against eligibility criteria. Authors independently double-screened a sample of 50 tools for inclusion criteria and demonstrated adequate inter-rater reliability (kappa=0.902) using SPSS statistical software. Authors then continued to individually screen tools for inclusion. Discrepancies or questions surrounding the inclusion of individual tools were resolved through discussion between the authors.

Data analysis

The adequacy and congruence of each tool for our intended purpose was evaluated by extracting and exploring each tool's: (1) purpose/stated aim; (2) conceptual content; (3) target/tested population; (4) setting; (5) administration timing; and (7) psychometrics (Waltz, Strickland, Lenz, 2010). The conceptual content of each tool was evaluated for congruence against the 'CG preparedness for EOL of persons with dementia' model by creating content validation matrices and mapping tool items (i.e., content sampled) onto four attribute domains (i.e., medical, psychosocial, spiritual, practical) and three traits (i.e., cognitive, affective, behaviour)(Hebert, Prigerson et al., 2006; Durepos et al., 2018). A point was given for each domain or trait sampled and a total summative score out of seven was calculated for each tool. Tools obtaining scores of 5/7 (i.e., sampling 70% of domains/traits) were perceived as demonstrating moderate content validity (e.g. 0.7) and were included in this review (Streiner et al., 2015).

Results

The search resulted in 1073 citations after duplicates were removed. Following title/abstract screening, 450 articles were retained for full-text screening and tool extraction, including 18 systematic or scoping reviews of measurement tools. Subsequently, 558 tools were extracted from articles. See Figure 1 for search flow.

When multiple versions of a tool were identified, the long-version, or version targeted at family members/CGs/palliative care/EOL was included and others excluded as duplicates (n=11). The long and/or targeted population tool version provided a greater/focused selection of items to examine for concept adequacy (Waltz et al., 2010). One tool had prospective and bereaved versions with minor differences in language and was treated as a single instrument, the Bereavement Risk Inventory Screening Questionnaire-Prospective/Bereaved Version [BRISQ](Roberts et al., 2017).

Primary reasons for tool exclusion were: (1) contrasting tool purpose (e.g., to assess patient symptoms) or contrasting target population (e.g., healthcare professionals, CGs of children, patients with terminal illness)(n=106); and (2) inadequate coverage (i.e., sampling) of conceptual domains and traits (n=435). Tool content narrowly focused on: preparedness antecedents (e.g., CG mood, quality of life pre-death)(n=120) or preparedness consequences (e.g., CG satisfaction with EOL care, grief post-death)(n=50); or inadequately sampled (less than 70%) of domains or traits of the 'CG preparedness for EOL of persons with dementia' model (i.e., medical, psychosocial, spiritual, practical, cognitive/affective/ behaviour)(n=215). Three different global-rating scores (i.e. single-item scales) which aimed to measure CG death preparedness (Barry et al., 2002; Goy, Carter & Ganzini, 2008; Holland, Currier & Gallagher-Thompson, 2009; Schulz et al., 2015), and one dual-item scale (Caserta, Utz, Lund, Supiano & Donaldson, 2017) were identified and excluded. Global-rating scores required abstract thinking by respondents and did not define domains/traits of the measured concept (Streiner et al., 2015). Therefore they did not meet our inclusion criteria. After exclusions, a total of seven instruments were selected for evaluation as measures of preparedness for death in CGs of persons with dementia.

Analyzed tools

Characteristics and psychometrics of the selected tools are summarized in Table 1 and Table 2 including: the Preparedness for Caregiving Scale [PCS](Archbold, Stewart, Greenlink & Harvath, 1990); Anticipatory Grief Scale [AGS](Theut, Jordan, Ross, & Deutsch, 1991); Family Inventory of Needs [FIN](Kristjanson, Atwood, Degner, 1995); Caregiving at Life's End Questionnaire [CGLE](Salmon, Kwak, Acquaviva, Egan, & Brandt, 2005); Carer Support Needs Assessment Tool [CSNAT](Ewing, Brundle, Payne & Grande, 2013); Family Distress in Advanced Dementia Scale [FDAD](Givens, Jones, Mazor, Prigerson & Mitchell, 2015) and the Bereavement Risk Inventory Screening Questionnaire [BRISQ](Roberts et al., 2017).

Evaluation of tool adequacy and congruence

Purpose. According to Waltz et al. (2010), the purpose of a tool is the goal or stated aim for use and is linked to the format and scale content. Tools selected for evaluation in this review aimed to measure aspects of CG experiences at EOL and sampled conceptual domains/traits of preparedness, although for most tools, measuring death preparedness was not the primary aim. Tools were examined for congruence with our intended aim of measuring preparedness for death in a population of adult, informal CGs of persons with dementia at EOL. Specifically, the purpose of included tools was to assess or evaluate: (1) CG/family member needs and preferences (n=3); (2) emotional distress and preparedness for the future (n=2); (3) risk for developing mental-health challenges in bereavement (n=1) and (4) symptoms of grief (n=1). The PCS (Archbold et al., 1990) was the only tool with the primary aim of evaluating CG preparedness, but the aim was not synonymous with death preparedness. Consequently, the conceptual adequacy of PCS items was limited. PCS items focused on assessing preparedness for elements of caregiving, for example: "How well prepared do you think you are to take care of your family member's physical needs?" (Archbold et al., 1990, p. 378). Theoretically, tools assessing the extent to which CG needs were met at EOL may also indicate levels of preparedness.

Three tools, including the BRISQ (Roberts et al., 2017), FDAD (Givens et al., 2015), and the PCS (Archbold et al., 1990), included preparedness items, however only the BRISQ contained a specific item to assess preparedness for death. The overall aim of the BRISQ questionnaire was to identify CGs at risk for poor outcomes after death based on multiple factors. The item stated, "Sometimes individuals do not feel prepared to lose someone close to them. To what extent did/do you feel emotionally unprepared for the loss of _______?" (Roberts et al., 2017, p. 152). Overall, none of the included instruments were designed for the purpose of assessing CG preparedness for death, which limited their adequacy for this aim.

Conceptual basis. The conceptual basis of a tool refers to the theoretical model and empirical evidence for concept domains and relationships to other concepts (Waltz et al., 2010). Multiple models were described as the conceptual basis for included instruments such as: Pearlin's Stress Outcomes Model (Pearlin, 1999), the Hospice Experience Model of Care (Egan & Labyak, 2005) and Role Theory (Burr, Leigh, Day & Constantine, 1979). The Theoretical Framework for Preparedness of EOL (Hebert, Prigerson et al., 2006; Hebert et al., 2009) and the 'CG preparedness for death dementia' model (Durepos et al., 2018) on which this review is based were not used as the conceptual basis for any existing tools.

Content validation matrices were created to examine the adequacy of domains/traits of preparedness against the 'CG preparedness for EOL for persons with dementia' model. Evaluated tools consistently sampled: cognitive, problem-based coping strategies/traits: information or support-seeking (n=7), psychosocial feelings of support and relationships (n=7), and the use of behavioural, problem-based coping strategies: e.g., acquiring skills/competency as a CG (n=7). For example, six instruments included information-seeking items such as, "I need to have my questions answered honestly" ([FIN]; Kristjanson et al., 1995, p. 125) or "How well prepared do you think you are to get the information you need from the healthcare system?" ([PCS]; Archbold et al., 1990, p. 378). Overall, the CGLE (Salmon et al., 2005) and the CSNAT (Ewing et al., 2013) sampled all domains/traits (100%) of death preparedness in this analysis, suggesting they are the most adequate and best measures of conceptual content. However, the CGLE is also the most lengthly combining 73 items with multiple caregiving tools, and neither tool included a specific item about death preparedness, or caregiving of persons with dementia.

Fewer instruments sampled the medical domain (n=5) of death preparedness including knowledge of disease prognosis, disease symptoms or expectations for the future. Five instruments posed broad questions to assess CG knowledge/awareness of the future such as, “Do you need more support with knowing what to expect in the future when caring for your relative?” ([CSNAT]; Ewing et al. 2013, p. 397) or “I have felt that I don’t know what to expect in my loved one’s illness” ([FDAD]; Givens et al., 2015, p. 776). While these items allowed CGs to express uncertainty about the future, they were not specific to death or to dementia and could be narrowed to discern CGs level of knowledge about the trajectory of dementia. For example, items could include: ‘I know what changes to expect in my family member’s eating and drinking as my family member’s dementia progresses’ or ‘I know how my family member’s awareness and communication may change as dementia progresses’. Such items would provide a more adequate assessment of CG expectations and preparedness for death than the current broad questions.

The two content areas of death preparedness sampled least by tools were: affective coping strategies such as: acceptance, avoidance, reframing (n=5); and the practical domain which assesses legal concerns, finances, funeral and burial plans, and resources for caregiving (n=2). No tools assessed CGs’ funeral or burial planning, except for the bereaved (retrospective) CG version of the BRISQ. Importantly, only one instrument ([AGS]; Theut et al., 1991) had items specific to dementia, for example, “I feel it is unfair that my relative has dementia”, whereas all others referred only to illness.

Population, setting and administration timing. Assessing the adequacy of tools as measures of death preparedness in CGs of persons with dementia required evaluation of the *population* (target and sample population), *setting* (locations/sites/context of testing) and *timing of administration* (retrospective/prospective orientation/language) of tools for congruence with our aim (Waltz et al., 2010). Four tools were tested in LTC (n=4), the leading site of death for persons with dementia and participants in the majority of studies were: CGs, English-speaking, Caucasian, females, approximately 65 years of age, spouses/adult children of the care recipient, assisting with multiple activities of daily living and providing emotional/financial support; and possessed at least high-school education. Five tools were tested with persons with dementia or other degenerative neurologic diseases. More than half (n=5) of the tools used a prospective time orientation to evaluate CGs' current or future anticipated needs/emotions pre-bereavement. Current CGs were caring for persons at various time points prior to death (i.e., 2 weeks to one year).

The sample, target population and settings for tool development and evaluation suggests they are appropriate for studies of death preparedness with CGs of persons with dementia, who share similar characteristics and experience EOL in common settings. However, the suitability and interpretability of tools for CGs who are not Caucasian, speak different languages, are of differing cultures or have different education/reading levels would require evaluation through piloting. The timing of instrument administration (while variable) suggests that CGs may be open to the use of such tools.

Psychometric properties. Authors presented a range of evidence for instrument *validity* including: face and content (n=7), criterion (concurrent, n=5; predictive, n=3) and construct (factor analysis, n=3). Face and content validity were supported through author descriptions of item generation, selection and reduction along with piloting of instruments. A content validity index [CVI] was provided for one instrument, the CSNAT (Ewing et al., 2013), and was calculated to systematically identify and increase confidence in items selected as most relevant by a proportion of experts (Streiner et al., 2015). Sample sizes overall were appropriate (greater than 50 or 100 participants) for use of these statistical measures, however p values were often reported without confidence intervals to justify the statistical significance of concept relationships (Anthoine, Moret, Regnault, Sébille & Hardouin, 2014). Tool developers of the FIN (Kristjanson et al., 1995) and the PCS (Archbold et al., 1990) reported factor loadings (i.e., Eigenvalues) and latent traits underlying the instrument construct, which provided evidence for construct validity in specific CG populations and settings.

As a measure of *reliability*, the majority of tools included in this review cited Cronbach alpha's for internal subscales, and then also examined correlations between subscales to examine if domains were distinct, or were too homogenous for sampling. For some tools such as the FIN (Kristjanson et al., 1995), Cronbach's alpha was reported at 0.96, which suggests item redundancy or oversampling of the construct (falsely overestimating the participant's score). However, inter-item correlations reported for the FIN between 0.30-0.70 indicated items were unique and not redundant, thus internal consistency was estimated by taking into account multiple reliability coefficients (Nunnally, 1978).

Additional evidence for the reviewed tools' ability to discriminate between groups, sensitivity to change and stability over time (e.g., measures of association) were examined through use of Pearson, Spearman or bivariate correlations. For example, Salmon et al. (1995) used a test-retest reliability to examine the stability of participant scores on the CGLE, however the time period between tests was not described. Missing data were described in studies of five tools and procedures used to mitigate for missing data (e.g., replacing with a participant mean score or excluding participant data) were reported in two studies (Archbold et al., 1990; Schur et al., 2015).

Overall, the psychometric properties reported for existing tool support their use for specific populations and settings (e.g., Caucasian, spouse, female CGs) in-line with their stated purpose. Consistent reporting on instrument development procedures and statistical testing for multiple forms of validity (i.e., face, content, criterion and construct) and reliability (i.e., internal consistency) supported the use of the reviewed tools in populations of CGs of persons with a variety of terminal illnesses in a variety of settings. Additional testing for reliability, and description of missing data would increase confidence in the stability, internal consistency and sensitivity to change over time (Streiner et al., 2015). In summary, the tools included in this review demonstrated some congruence with the purpose, population, setting and administration timing for measuring death preparedness in CGs of persons with dementia.

Discussion

This review of tools provides an evaluation of the adequacy and congruence of existing tools to measure CG preparedness for death for persons with dementia. Implications for the development and measurement of ACP interventions conceptually based upon the model of CG preparedness for EOL of persons with dementia are also inherent. Factors which limited the adequacy of tools for our intended purpose were related to development and evaluation designs including: (1) sample *populations* where cancer was the predominant diagnosis, in contrast to dementia where EOL experiences vary (n=5)(Kim & Schulz, 2008; Mitchell et al., 2009), (2) *settings* such as home or hospital, in contrast to LTC where persons with dementia receive EOL care more often (Mitchell et al., 2009), (3) retrospective *timing* of administration, which limits researchers' ability to respond to low preparedness levels prior to bereavement, (4) *psychometrics* which provided little evidence for: discriminate abilities, stability and sensitivity to change (i.e., reliability), which are important to evaluate differences in preparedness between groups of CGs and pre-post interventions.

Most importantly, *the conceptual basis* and the content sampled (i.e., domains and traits of preparedness) in most (n=5) tools were inadequate to support their use as measures of death preparedness for CGs of persons with dementia. While the CGLE (Salmon et al., 2005) and the CSNAT (Ewing et al., 2013) tools sampled all conceptual domains and traits, items specific to dementia (e.g., knowledge of dementia, trajectory of dementia, pre-death grief) were lacking. In contrast, the AGS (Theut et al., 1990) and FDAD (Givens et al., 2015) sampled specific items related to dementia but did not address EOL. Particularly within all included instruments, affective coping strategies/traits and practical content related to CG preparedness were lacking. Even when preparedness domains and traits were addressed, items were often not specific to EOL, death or dementia, which limits the adequacy of existing instruments for our intended purpose.

The information needs of CGs' of persons with dementia have been well documented, which supports their inclusion in tools measuring CG preparedness for death in dementia. A systematic review of CG needs in dementia found that in 75% of high-quality studies sampled, CGs desired information on the diagnosis, progression and symptoms of dementia, and access to care services (Gabe, You & Tatangelo, 2016). Caregivers also perceived that the provision of information and communication could be improved in order to facilitate their caregiving role. Theoretically, a lack of information contributes to uncertainty, inhibits CG's self-efficacy for caregiving and impairs decision-making, control and planning for EOL, thus limiting CGs preparedness for death (Durepos et al., 2018; Hebert, Prigerson et al., 2006; Hovland-Scafe & Kramer, 2017). Based on this theory, information on dementia should be an integral part of ACP interventions to prepare CGs for death, and should be evaluated using specific items on death preparedness measures for this population.

This review and evaluation using a conceptual model of death preparedness for CGs for persons with dementia holds implications for researchers, healthcare professionals and policy-makers looking to design and measure the effectiveness of ACP interventions. Most ACP interventions are not currently based upon conceptual models and therefore may not address the multiple domains or traits characterizing CG preparedness, despite empirical and theoretical evidence for correlative and predictive relationships between ACP, CG death preparedness and CG outcomes (Durepos et al., 2018; Hebert, Prigerson, et al., 2006; Lin, Evans, Koffman, Armes, Murtagh & Harding, 2019). As such, basing ACP interventions on the 'CG preparedness for EOL of persons with dementia model' would likely strengthen interventions and improve effectiveness (Lin et al., 2019).

The lack of conceptual basis for most ACP interventions also influences the selection of ACP effectiveness outcomes. A meta-analysis of ACP studies found that ACP effectiveness outcomes focused on the completion of advance directives, occurrence of EOL conversations, concordance between care preferences and care received, and use of healthcare services and patient symptoms (Houben, Spruit, Groenen, Wouters & Janssen, 2014). It is unclear if these outcome measures sample CGs feelings of acceptance, peace and closure in their relationship with the dying person (i.e., spiritual preparedness), or if they have completed funeral, burial or final arrangements (i.e., practical preparedness) prior to death. These are essential aspects of a palliative approach and EOL care which should be addressed in ACP interventions.

Researchers have acknowledged the limitations of current measures and recently conducted a delphi-survey to identify outcomes which define successful ACP (Sudore et al., 2018). The top ranked outcomes were defined as: (1) achieving care consistent with goals; (2) surrogate decision-maker designation; (3) surrogate decision-maker documentation; (4) discussions with surrogates; and 5) accessible documents and recorded wishes. The domains of ACP (i.e., process (e.g., attitudes), actions, quality of care, and health care utilization) appear to be multi-dimensional, however it is unclear if they prospectively address the domains and traits of CG preparedness for death.

Limitations

This review is not without limitations. We acknowledge that although our search was comprehensive, tools and studies describing their use or development may have been missed that would have influenced the findings of this review, particularly regarding psychometrics. Non-English tools were also excluded which limits the validity of our results. Tools which focused on outcomes relative to preparedness (e.g., satisfaction with care/quality of EOL care) were excluded as they focused on the consequences of preparedness. However, such tools including the ‘Family Assessment of Treatment at EOL’ (Casarett et al., 2008), the Family Evaluation of Hospice Care scale (Connor, Teno, Spence & Smith, 2005) and the Bereaved Family Survey (Thorpe, Smith, Kuzla, Scott & Ersek, 2016) could provide additional insight into needs perceived by bereaved CGs that should be met prior to death. As such, current retrospective tools assessing satisfaction or services could be used to design and prospectively measure ACP intervention.

Most importantly the evaluation of tools was based on the authors' conceptual model and definition of death preparedness attribute domains and traits. While a systematic, transparent process was used to support the credibility and trustworthiness of the 'CG preparedness for EOL of persons with dementia' model, we acknowledge that this model represents an interpretation of the concept. Using an alternate model to evaluate tools within this review would likely change the results. In addition, to ensure inter-rater reliability, authors made critical judgements regarding the relevance and meaning of items in order to evaluate their congruence with a conceptual model. In light of these limitations, persons looking to utilize tools to measure preparedness should first consider if: (1) the theoretical foundation of the tool aligns with their target population's perception of preparedness, and (2) how their population would interpret the meaning and relevance of items.

Conclusion

Most existing multi-dimensional measures did not sample essential content indicative of CG death preparedness and were not specific to dementia. Qualitative research with CGs of persons with dementia is needed to deepen understanding, clarify definitions and potentially validate perceived preparedness attributes to inform development of a measurement questionnaire. As such, the manuscript's authors are now undertaking a mixed-methods study titled, 'Caring Ahead' to develop a multi-dimensional questionnaire measuring CG preparedness for death for persons with dementia.

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Disclosure Statement

The authors have no conflicts of interest to report.

References

Anthoine, E., Moret, L., Regnault, A., Sébille, V., & Hardouin, J. B. (2014). Sample size used to validate a scale: A review of publications on newly-developed patient reported outcomes measures. *Health and Quality of Life Outcomes, 12*(1),1.

Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, *13*(6), 375-384.

Barry, L., Kasl, S.., & Prigerson, H. (2002). Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American Journal of Geriatric Psychiatry*, *10*(4), 447-457.

Casarett, D., Pickard, A., Bailey, F. A., Ritchie, C. S., Furman, C. D., Rosenfeld, K., ... & Shea, J. (2008). A nationwide VA palliative care quality measure: the family assessment of treatment at the end of life. *Journal of Palliative Medicine*, *11*(1), 68-75.

Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2017). Cancer caregivers' preparedness for loss and bereavement outcomes: Do preloss caregiver attributes matter?. *OMEGA-Journal of Death and Dying*, 0(0), 1-21. doi.org/10.1177/0030222817729610

Connor, S. R., Teno, J., Spence, C., & Smith, N. (2005). Family evaluation of hospice care: results from voluntary submission of data via website. *Journal of Pain and Symptom Management*, *30*(1), 9-17.

Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their Carers: a systematic review and critical discussion. *Journal of Pain and Symptom Management*, *55*(1), 132-150.

Downar, J., Moorhouse, P., Goldman, R., Grossman, D., Sinha, S., Sussman, T., ... & Network, C. F. (2018). Improving end-of-life care and advance care planning for frail older adults in Canada. *The Journal of Frailty & Aging*, *7*(4), 240-246.

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2018). What does death preparedness mean for family caregivers in dementia? *American Journal of Hospice and Palliative Medicine, X*(X), 1-11. https://doi.org/10.1177/1049909118814240

Durepos, P., Kaasalainen, S., Carroll, S., & Papaioannou, A. (2017). Perceptions of a psychoeducation program for caregivers of persons with dementia at end of life: A qualitative study. *Aging and Mental Health, 0*(0): 1-9. DOI:10.1080/13607863.2017.1399347

Egan, K. & Labyak, M.J. (2001) Hospice care: A model for quality end-of-life care. In Ferrell, B.R., Coyle, N. (Eds.): *Textbook of palliative nursing*. New York, NY: Oxford University Press, 2001.

Ewing, G., Brundle, C., Payne, S., Grande, G., & National Association for Hospice at Home. (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *Journal of Pain and Symptom Management*, *46*(3), 395-405.

Givens, J. L., Jones, R. N., Mazor, K. M., Prigerson, H. G., & Mitchell, S. L. (2015). Development and psychometric properties of the family distress in advanced dementia scale. *Journal of the American Medical Directors Association*, *16*(9), 775-780.

Goy, E.R., Carter, J.H., & Ganzini, L. (2008). Needs and experiences of caregivers for family members dying with Parkinson disease. *Journal of Palliative Care*, *24*(2), 69–75.

Hebert, R., Dang Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *Journal of Palliative Medicine, 9*(3), 683-693.

Hebert, R., Prigerson, H., Schulz, R., & Arnold, R. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine*, *9*(5), 1164-1171.

Hebert, R., Schulz, R., Copeland, V., & Arnold, R. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management, 37*(1), 3-12.

Henriksson, A., Andershed, B., Benzein, E., & Årestedt, K. (2012). Adaptation and psychometric evaluation of the Preparedness for Caregiving Scale, Caregiver Competence Scale and Rewards of Caregiving Scale in a sample of Swedish family members of patients with life-threatening illness. *Palliative Medicine*, *26*(7), 930-938.

Holland, J. M., Currier, J. M., & Gallagher-Thompson, D. (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. *Psychology and Aging*, *24*(1), 190-202.

Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist, 49*(3), 388-396.

Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M.,..& Bauld, C. (2012). Guidelines for the psychosocial and bereavement support of family CGs of palliative care patients. *Journal of Palliative Medicine, 15*(6), 696-702.

Kersting, A., Brähler, E., Glaesmer, H., & Wagner, B. (2011). Prevalence of complicated grief in a representative population-based sample. *Journal of Affective Disorders*, *131*(1), 339-343.

Kim, Y., & Schulz, R. (2008). Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health. 20*(5), 483-503.

Kristjanson, L.J., Atwood, J.&Degner, L.F. (1995). Validity and reliability of the family inventory of needs (FIN): Measuring the care needs of families of advanced cancer patients. *Journal of Nursing Measurement, 3,* 109–126.

Lazarus, R. S., & Folkman, S. (1984). *Stress, coping and appraisal.* New York, NY: Springer Publishing Company.

Lin, C. P., Evans, C. J., Koffman, J., Armes, J., Murtagh, F. E., & Harding, R. (2019). The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: A systematic review of randomised controlled trials. *Palliative Medicine*, *33*(1), 5-23.

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. The Gerontologist, 56(5), e70-e88

McMahan, R. D., Knight, S. J., Fried, T. R., & Sudore, R. L. (2013). Advance care planning beyond advance directives: Perspectives from patients and surrogates. *Journal of Pain and Symptom Management, 46*(3), 355-365.

Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist, 41*(5), 658-670.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., . . .Hamel, M. B. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine, 361*(16), 1529-1538.

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, 44, 75-93.

Nunnally, J.C. (1978). *Psychometric theory.* New York, NY: McGraw Hill.

Pearlin, L. I. (1999). The stress process revisited. In *Handbook of the sociology of mental health* (pp. 395-415). Springer, Boston, MA.

Roberts, K., Holland, J., Prigerson, H. G., Sweeney, C., Corner, G., Breitbart, W., & Lichtenthal, W. G. (2017). Development of the bereavement risk inventory and screening questionnaire (BRISQ): Item generation and expert panel feedback. *Palliative and Supportive Care, 15*(1), 57-66.

Salmon, J. R., Kwak, J., Acquaviva, K. D., Egan, K. A., & Brandt, K. (2005). Validation of the Caregiving at Life's End questionnaire. *American Journal of Hospice and Palliative Medicine, 22(*3), 188-194.

Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine, 18*(2), 127-133.

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (1998). Conceptualization and measurement of doing family caregiving well. *Journal of Nursing Scholarship, 30*(1), 63-70.

Schur, S., Neubauer, M., Amering, M., Ebert-Vogel, A., Masel, E. K., Sibitz, I., ... & Schrank, B. (2015). Validation of the Family Inventory of Needs (FIN) for family caregivers in palliative care. *Palliative & Supportive care, 13*(3), 485-491.

Streiner, D., Norman, G., & Cairney, J. (2015). *Health measurement scales: A practical guide to their development and use.* (5th ed). Oxford, UK: Oxford University Press

Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A., Korfage, I. J., Ritchie, C. S., ... & Howard, M. (2018). Outcomes that define successful advance care planning: a Delphi panel consensus. Journal of pain and symptom management, 55(2), 245-255.

Theut, S. K., Jordan, L., Ross, L. A., & Deutsch, S. I. (1991). Caregiver's anticipatory grief in dementia: A pilot study. *The International Journal of Aging and Human Development,33* (2), 113-118.

Thorpe, J. M., Smith, D., Kuzla, N., Scott, L., & Ersek, M. (2016). Does mode of survey administration matter? Using measurement invariance to validate the mail and telephone versions of the bereaved family survey. *Journal of Pain and Symptom Management, 51*(3), 546-556.

Waltz, C., Strickland, O., Lenz, E. (2010). *Measurement in nursing and health research.* New York, NY: Spring Publishing Company.

Wickson-Griffiths, A., Kaasalainen, S., Ploeg, J., & McAiney, C. (2014). A review of advance care planning programs in long-term care homes: are they dementia friendly?. *Nursing Research and Practice*, 1-11.

World Health Organization (2012). Dementia: A public health priority. UK:WHO

Figure 1. 'Caregiver Preparedness for EOL of Persons with Dementia' conceptual model

Loss and Transition

Antecedents	Preparedness Attributes: Domains and Traits	Consequences
1. Living with grief and burden; 2. Illness-related event; 3. Advance Care Planning & End-of-Life communication with care providers; 4. Uncertainty about the situation and the future	1. Medical: Knowing and recognizing signs of decline and dementia, and what dying looks like; 2. Psychosocial: Understanding emotions and grief; Accessing and appraising supports and relationships to manage and plan for death 3. Practical: Organizing legal, financial and household affairs and completing tasks in advance; 4. Spiritual: Accepting that losses are inevitable and imminent; Reflecting on caregiving and finding meaning, 'a silver-lining'; Reconciling, renewing and closing a relationship; Completing the family member's life; 5. Cognitive: Information and support-seeking, problem-based coping 6. Affective: Emotional-regulation, reframing, avoidance/acceptance, emotion-based coping; 7. Behavioural: Active task completion and planning, problem-based coping	1. Mental health and well-being after Death; 2. Adaptation and adjustment in bereavement; 3. Satisfaction with End-of-Life care and Quality of dying for the person with dementia

Note. From: Durepos et al., (2018) What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Care,* X(X), 1-11. Adapted from: Hebert, R., et al. (2006). Preparing caregivers for the death of a loved one. *Journal of Palliative Medicine, 9*(5), 1164-1171.

Figure 2. Measurement Instrument Literature Search Flowchart

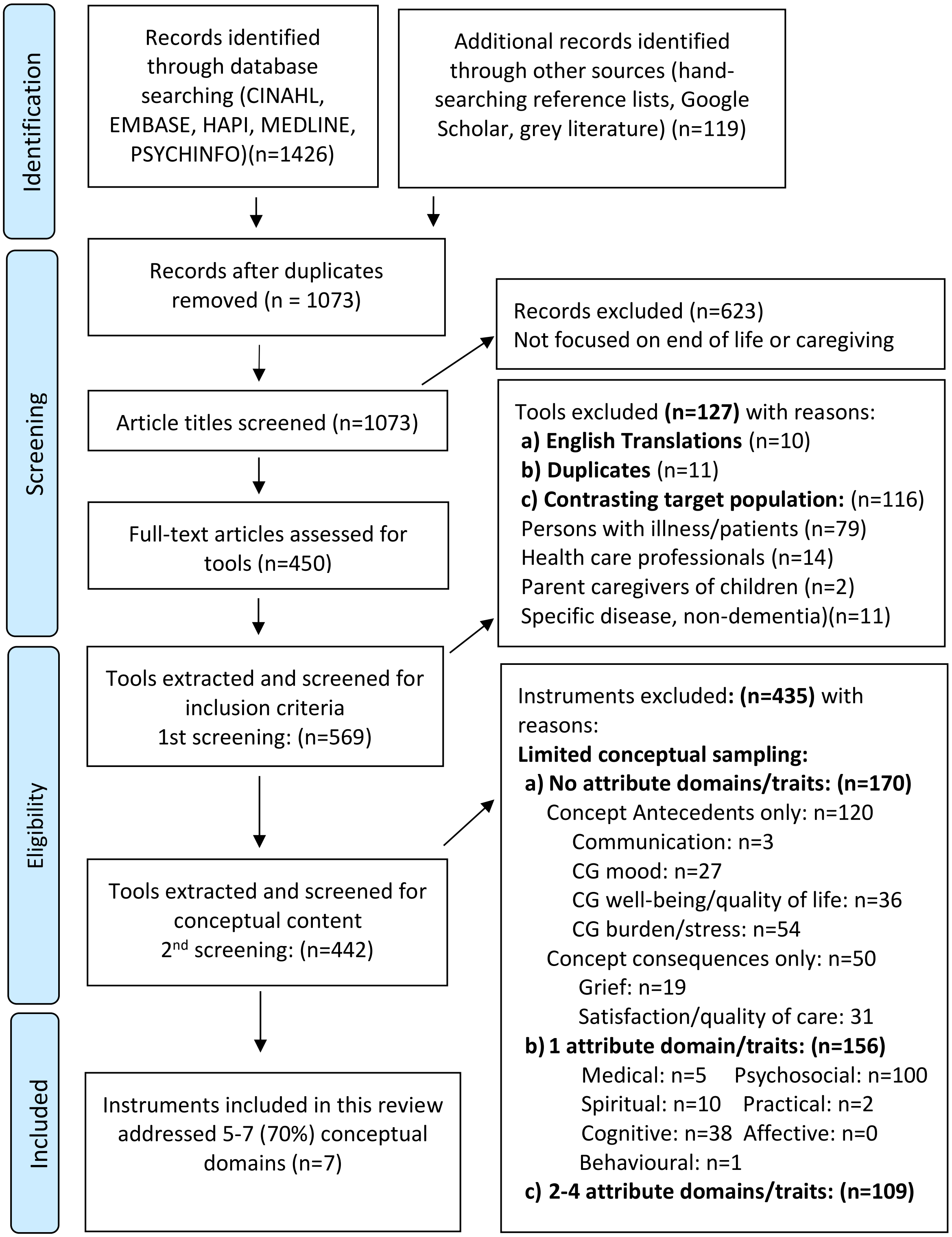

Table 1. Preparedness Tools; Characteristics and Development

Instrument, Development References	Country of Development	Purpose	Population; Setting	Conceptual Basis	Scale Items	Content Subscales and Item Example	Response Format
Anticipatory Grief Scale[1] [AGS] Theut et al., 1991	United States	Assess grief	Current CGs in dementia; home	Concept of Anticipatory Grief, Freud Psychoanalytic Model, Pearlin's Stress Outcomes Model	12	No subscales; Content: anger, hostility, irritability, loss of identity E.g., I have the personal resources to help me cope with my relative and his/her illness.	5-point Likert
Bereavement Risk Inventory Screening Questionnaire[2] [BRISQ] Roberts et al., 2017	United States	Identify bereavement risk for mental-health problems	Professional experts, current and bereaved CGs in cancer; Oncology in-patient center, hospital in-patient hospice	Dual-Model Process of Bereavement; Two-Track Bereavement Model	34-38	3 Subscales: 1) Background factors 2) Illness/ health related factors 3) Bereavement-related factors E.g., To what extent do you feel like your life lacks meaning and purpose since ___'s death?	4-point Likert

Instrument, Development References	Country of Development	Purpose	Population; Setting	Conceptual Basis	Scale Items	Content Subscales and Item Example	Response Format
Carer Support Needs Assessment Tool[3] [CSNAT] Ewing et al., 2013a	United Kingdom	Assess CG needs	Bereaved CGs of multiple diseases including Parkinson's, Motor Neuron Disease Multiple settings hospice, LTC, hospital	Not described	14	2 Subscales: 1) Enabling the carer to care, 2) Direct support for the carer E.g., Do you need more support with dealing with your worries?	4-point Likert
Caregiving at Life's End Questionnaire[4] [CGLE] Salmon et al., 2005	United States	Assess CG needs	Current/bereaved CGs persons with multiple diseases including dementia; Hospice	Hospice Experience Model of Care	73	7 Subscales: 1) Importance of tasks, 2) Comfort with tasks, 3) Meaning of Caregiving, 4) Self-acceptance, 5) Closure, 6) Burden 7) Gain E.g., I accept the finality of my family member or friend's approaching death.	5-point Likert
Family Distress in Advanced Dementia[5] [FDAD] Givens et al., 2015	United States	Assess CG needs and preparedness	LTC	Not described	21	3 Subscales: 1) Emotional Distress. 2) Preparedness, 3) Nursing Home Relations E.g., I have felt unsure about the course of my loved one's illness	5-point Likert

Instrument, Development References	Country of Development	Purpose	Population; Setting	Conceptual Basis	Scale Items	Content Subscales and Item Example	Response Format
Family Inventory of Needs [FIN] Kristjanson et al., 1995	United States, Canada	Assess CG needs	Bereaved CGs of persons with advanced cancer Hospital	Fulfillment Theory	34	2 Subscales: 1) Importance of needs, 2) Fulfillment of Needs E.g., I need to know the probable outcome of the patient's illness	Rate importance 0-10, Rate fulfillment yes = 1 no = 0
Preparedness for Caregiving Scale[7] [PCS] Archbold et al., 1990	United States	Assess CG preparedness	Multiple	Role Theory Lazarus and Folkman's Stress and Coping Framework	8	No subscales; Content: preparation for physical needs, stress, overall E.g., How well prepared do you think you are to take care of his or her emotional needs?	4-point Likert

Note. Criteria utilized from: Waltz, C., Strickland, O., Lenz, E. (2010). *Measurement in nursing and health research.* New York, NY: Springer Publishing Company. Abbreviations: [1]AGS: Anticipatory Grief Scale; [2] BRISQ: Bereavement Risk Inventory Questionnaire; [3] CSNAT: Carer Support Needs Assessment Tool; [4] CGLE: Caregiving at Life's End Questionnaire; [5]FDAD: Family Distress in Advanced Dementia; [6]FIN: Family Inventory of Needs; [7]PCS: Preparedness for Caregiving

Table 2. Content Validation Matrix Summary: Sampling of CG Preparedness for EOL of Persons with Dementia Concept

Concept	Examples of Items	Included Instruments							
		AGS[1]	BRISQ[2]	CSNAT[3]	CGLE[4]	FDAD[5]	FIN[6]	PCS[7]	Total Addressing the Domain/ Trait
Traits									
Cognitive	Information-seeking, support-seeking, problem-based coping	1	1	1	1	1	1	1	7
Affective	Emotional reframing, acceptance, avoidance, emotion-based coping	1	1	1	1	0	0	1	5
Behavioural	Task completion, skills and competency, planning and action, problem-based coping	1	1	1	1	1	1	1	7
Domains									
Medical	Knowledge of medical changes/needs to expect, prognosis	0	1	1	1	1	1	1	6
Psychosocial	Feelings of social / professional support, relationships	1	1	1	1	1	1	1	7
Spiritual	Feelings of acceptance, meaning, purpose, religious rituals, closure	1	1	1	1	1	1	0	6
Practical	Funeral planning and burial, financial and legal planning, household management	0	0	1	1	0	0	0	2
Total Attribute Domains or Traits Sampled (N=7)		5	5	7	7	5	5	5	
Additional Content									
Dementia						1			1
Prepared for Death			1						1

Note. Instruments which contained items sampling attribute domains/traits of preparedness were coded as ‘1’ if any attributes were addressed by items. Instruments included in this review sampled $\geq$ 70% of attribute domains or traits. Adapted from: Streiner, D., Norman, G., & Cairney, J. (2015). *Health measurement scales: A practical guide to their development and use.* (5th ed). Oxford, UK: Oxford University Press. Abbreviations: [1]AGS: Anticipatory Grief Scale; [2] BRISQ: Bereavement Risk Inventory Questionnaire; [3] CSNAT: Carer Support Needs Assessment Tool; [4] CGLE: Caregiving at Life’s End Questionnaire; [5]FDAD: Family Distress in Advanced Dementia; [6]FIN: Family Inventory of Needs; [7]PCS: Preparedness for Caregiving

Supplemental Table. Preparedness Tool Psychometrics

Instrument, Key Psychometric References	**Sample Size and Population**	**Setting of caregiving**	**Time Orientation and Delivery**	**Scale Items**	**Validity**			**Reliability**	**Non-Response, Missing Data**	**Limitations**
	Age in Years Mean (M), Population Characterstics: Gender, Ethnicity, Relationship to Care Recipient, Education reported in percent % of sample.		*Prospective: Pre-Death* *Retrospective: Bereaved or recall*		*Face & Content Validity*	*Criterion Validity: Concurrent Predictive* *Tests: Pearson/ Spearman's/ Bivariate Correlation; Regression Modeling*	*Construct Validity: Convergent Divergent Discriminant Factor Analysis* *Tests: Pearson/ Spearman's Correlation; Kruskal-Wallis; Rank sum; Exploratory, Principal Component, Confirmatory Factor Analysis; Cluster Analysis*	*Internal Consistency, Stability, Sensitivity to Change* *Tests: Cronbach's Alpha Inter-item correlation, Item-total correlation, Test Retest, T-Test*		
Anticipatory Grief Scale (AGS) Theut et al., 1991	n=27 Current CGs, Age M=68 yrs All Females, All Spouses, Education beyond high school 73% Care Recipient: Age M=72yrs Dementia symptoms M=4 yrs. MMSE M=17 (range 7-29)	Home Recruitment from 1 site (outpatient clinic)	Prospective: Caregiving M=3.5 yrs (range 1-13 years)	12	Authors clinical experience used for development	Concurrent: Pearson's Correlation Hopkins Symptoms Checklist subscales: anxiety, depression, hostility (p<0.001)		Internal consistency: Cronbach's alpha: 0.84	Not described	Small sample, limited details about sample (e.g., ethnicity of sample, or distribution of scores, no qualitative data to support content/face validity, limits validity of scale, missing data not described
Holley & Mast, 2009	n=80 Current CGs, M=60 years, Caucasian, 86% Female, 74% Adult Child, 61% Educated beyond high school 91%	Multiple: LTC, hospital, home, hospice	Prospective: Time Caregiving M=4 yrs M=43 hrs/wk	12		Concurrent: Bivariate Correlations: Marwit-Meuser CG Grief Inventory, r=0.67-0.80		Internal consistency: Cronbach's alpha: 0.89	Not described	Small sample inhibited sub-group analyses to assess levels of AGS for stages of dementia. Primarily

Instrument, Key Psychometric References	**Sample Size and Population**	**Setting of caregiving**	**Time Orientation and Delivery**	**Scale Items**	**Validity**			**Reliability**	**Non-Response, Missing Data**	**Limitations**
AGS continued.	Care Recipient: M=81 years, 70% Female, Mild, moderate, advanced dementia					Zarit CG Burden Index, r=0.68; Montgomery Burden Scale, r=0.72 Predictive, Multiple Regression: AGS increased predicted variance of CG Zarit Burden Index by 14% beyond other factors (e.g., depression)				Caucasian sample (not generalizable), Possible participation bias, (CGs or their family members may differ from others not participating, CGs reported information about their family member's behaviours, disease state, CG observations are subjective and not objective measures. Cronbach's alpha is high, may be due only to large number of items. All these factors may influence the validity of findings.
Bereavement Risk Inventory Screening Questionnaire (BRISQ) Roberts et al., 2017	n=7 Current CGs, n=8 Bereaved CGs, Age M, 57 yrs, Caucasian 86%, Female, 59%, Spouses, 59%, Care Recipients: Advanced cancer diagnosis	In-hospital oncology center, In-hospital hospice unit, Recruitment from 2 sites	Prospective: Providing care to a person with advanced cancer Retrospective: 2 months to 1 year after death	34, 38	Expert panel review with Content Validity Index Calculated; Cognitive interviewing with 15 CGs				Not applicable	Potential recall bias, Few details on care recipients hard to assess generalizability
Carer Support	n=225	Hospice, home,	Prospective:	14	Carer	Concurrent:		Sensitivity to	24%	Potential recall

Instrument, Key Psychometric References	**Sample Size and Population**	**Setting of caregiving**	**Time Orientation and Delivery**	**Scale Items**	**Validity**			**Reliability**	**Non-Response, Missing Data**	**Limitations**
Needs Assessment Tool (CSNAT) Ewing et al., 2013	Current CGs, Age M, 66 yrs, Caucasian, 86% Female, 66%, Spouses, 79% Care Recipients: Age M, 69 yrs Cancer 87%, Illness, M 2yrs, Alive after study conclusion, 52%	LTC, hospital Recruitment from 5 'Hospice at Home' service sites	Time Caregiving M=1.5 yrs		Advisory Group, Steering Committee of Hospice, Interviews and Pilot study with 10 Current CGs	Spearman's Correlations Preparedness for Caregiving Scale ($P<0.0001$), Global Health ($P<0.0001$), Caregiving Strain, ($P<0/0001$) Caregiver Distress, ($P<0.0001$) Positive Caregiving Appraisal, ($P=0.008$) Care Recipient's Activities of Daily Living, ($P<0.0001$)		Change, Paired Sample T-Test: CSNAT CG Strain Baseline vs. 4 Weeks $t= -2.49$, $p=0.014$	Response Rate, Non—respondents compared to respondent with Chi-square tests, Non-respondents more likely to have care recipients over 85 yrs old ($P<0.0001$) and less likely to be alive after the study finished ($P=0.026$), CGs perceived to be in high distress were excluded Missing data not described	bias, low response rate, statistically significant differences between non-respondents, tool may not be appropriate for people very close to death or in high distress
Caregiving at Life's End Questionnaire (CGLE) Salmon et al., 2005 CGLE	n=34 Current and n= 17 Bereaved CGs, Age M 65 yrs, Caucasian 98%, Female 76%, Spouse 63% Care Recipients: Age M 77 yrs, Male 59%, Neurological Diseases 29%	Multiple: Not described Recruitment from 1 state hospice service institute	Retrospective: 6 to 12 months after death, And Prospective: Care Recipient receiving hospice care x 2 weeks Time Caregiving: M 2 yrs, M 82 hrs/wk,	73	CGLE National Advisory Committee: experts in the fields of hospice, aging studies, caregiving, spirituality, EOL care, and current CG	Concurrent: Pearson's Correlation Internal Subscales: Self-acceptance and Meaning, ($P<0.001$) Closure and Comfort, ($P<0.001$) Gain and Meaning, ($P<0.001$)		Internal consistency: Cronbach's alpha: 0.67-0.94 Test-retest, Paired T-Test n=6 Re-test but timing not described, Subscale changes non-significant	44% Response rate, Missing responses: Ten percent of all pilot- study participants did not answer 9 questions, which researchers then reworded	Potential recall bias, low response rate, Setting not described
Family Distress in Advanced	n=130 Current CGs,	LTC	Prospective: Resident in	21	Interviews with 16	Concurrent: Pearson	Exploratory Factor Analysis: 3 Factor	Internal consistency:	69% Response	Missing data only described

Instrument, Key Psychometric References	**Sample Size and Population**	**Setting of caregiving**	**Time Orientation and Delivery**	**Scale Items**	**Validity**			**Reliability**	**Non-Response, Missing Data**	**Limitations**
Dementia (FDAD) Givens et al., 2015	Age M 61 yrs, Caucasian 95%, Adult Child 72%, Educated beyond high school 76% Care Recipients: residing in LTC M=4yrs (range 0.5-13yrs)	Recruitment from 31 LTC homes	LTC 4 yrs average		Current CGs, Additional cognitive interviewing with 8 CGs (Separate sample)	Correlations: Emotional and Personal Health Questionnaire (Depression), r =0.34), LTC Relations Subscale and Satisfaction with Care-End of Life Dementia, r =0.35, Zarit Burden Scale, r . 0.50 Internal Subscale Correlations:(p =0.005, p<0.01)	Model, Eigenvalues reported	Cronbach's alpha: 0.72-0.83	Rate, demographic data from non-respondents compared and reported as not different, 1 participant's data removed because more than 50% of questionnaire responses missing	for 1 participant, sample mainly Caucasian, all English speaking limits generalizability, items change from retrospective to prospective, negatively worded could bias responses
Family Inventory of Needs (FIN) Kristjanson et al., 1995	n=109 Current CGs Age 31-50 yrs 39%, Over 65 yrs 30% Female 69% Spouse 50% Educated beyond high school 41% Care Recipients: Age Over 65 yrs 76% Female 52% Advanced stage 3-4 cancer	Hospice Recruited from 3 hospice program	Prospective: Care recipient life expectancy < 6 months	34	6-member expert panel of bereaved CGs for up to 1 year surveyed, cognitive interviewing	Concurrent: Pearson correlation: McCusker care Satisfaction Scale 0.77-0.79 Predictive: Multiple regression: 31% Variance of FAMCARE total score	Principal Components Factor Analysis: Eigenvalues and Scree plot reported, Unidimensional construct Cluster Analysis: Unidimensional construct	Internal consistency: Cronbach's alpha: 0.83-0.96 Inter-item correlations: 50% of items met present criteria 0.50-0.70 Pearson Correlation Test-Retest: 0.91	Not described	
Schur et al., 2015	N=308 Current CGs Age M 53.6 yrs Female 60% Spouse 52% Child 30% Educated beyond	Hospital	Prospective: less than 6 months life expectancy			Concurrent correlations: Integrated Hope Scale, Impact of Event Scale, Hospital Anxiety and	Discriminative Validity: Item discrimination indices: 0.4-0.7	Internal Consistency: Cronbach's alpha: 0.94-0.96	Questionnaires with more than 2 missing responses per subscale and were	

Instrument, Key Psychometric References	**Sample Size and Population**	**Setting of caregiving**	**Time Orientation and Delivery**	**Scale Items**	**Validity**			**Reliability**	**Non-Response, Missing Data**	**Limitations**
	high school 20% Care Recipients: Advanced metatistic cancer					Depression Scale,		Pearson Correlation Test-Retest: R=0.97	classified as unusable	
Preparedness for Caregiving Scale (PCS) Archbold et al., 1991	n=78 Current CGs Age M 63 yrs Caucasian 97% Female 62% Spouse 35% Educated beyond high school 55% Care Recipients: Age M 78 yrs Female 70% Caucasian 99% Cognitively impaired 31%	Home, LTC Recruited from hospital	Prospective: 6 weeks and 9 months after hospital discharge Caregiving Time: M 1.5 years (range 1 month – 24 yrs)	5		Predictive: Multiple regression: 5-16% of CG Role Strain Measure at 6 wks, and 3-12% at 9 months		Internal Consistency: Cronbach's alpha: 0.72-0.96	Respondents and non-respondents compared and reported as similar. Missing data reported as 'small'. During multiple regression a listwise deletion procedure was used. For predictor variables the group mean was used for missing data.	Minimal information provided about care recipients or reason for hospitalization, test for differences between respondents/ non-respondents not described, correlations of variables not reported, stated 'available from author'
Henriksson et al., 2011	n=124 Current CG:s Age M 58 yrs Female 61% Spouses 78% English speaking Care Recipients: Cancer diagnosis 96% Other chronic diseases, including neurological 4%	Multiple: Home and hospital, all receiving 24-hr specialist palliative care	Prospective: Receiving specialist palliative care services x 10 wks	8			Convergent: Spearman's correlation: Caregiver Competence Scale r=0.76 (p<0.001) Reward for Caregiving Scale r=0.34 (p<0.001) Confirmatory Factor Analysis, one dimension	Cronbach's alpha: 0.94 (95% CI 0.92), Stability: Intraclass Correlation n=30 CGs Baseline and 6 wks 0.84 (95% CI 0.69-0.92)	Missing data only related to one individual.	

Note. Criteria adapted from: Streiner, D., Norman, G., & Cairney, J. (2015). *Health measurement scales: A practical guide to their development and use.* (5th ed). Oxford, UK: Oxford University Press.; Nunnally, J.C. (1978). *Psychometric theory.* New York, NY: McGraw Hill; Waltz, C., Strickland, O., Lenz, E. (2010). *Measurement in nursing and health research.* New York, NY: Spring Publishing Company. For two instruments, two sources of data regarding psychometrics are included as they provided additional insight into validity and reliability, and increased the sample size for testing beyond the earlier publication.

Chapter 4

"A Crazy Roller Coaster at the End": A Qualitative Study of Death Preparedness with Caregivers of Persons with Dementia[3]

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[3] Durepos, P., Ploeg, J., Sussman, T., Akhtar-Danesh, N., & Kaasalainen, S. "A crazy roller coaster at the end": A qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nursing, 6:* 1-11. Doi: 10.1177/2377960820949111

Abstract

Introduction: Caregivers of persons with dementia experience challenges that can make preparing for end-of-life particularly difficult. Feeling prepared for death is associated with caregiver well-being in bereavement and is promoted by strategies supporting a palliative approach. Further conceptualization of caregiver preparedness for death of persons with dementia is needed to guide the practice of healthcare providers and to inform development of a preparedness questionnaire.

Objectives: We aimed to: 1) explore the end-of-life experiences of caregivers of persons with dementia to understand factors perceived as influencing preparedness; and 2) identify the core concepts (i.e., components), barriers and facilitators of preparedness for death.

Methods: This study used an interpretive descriptive design. Semi-structured interviews were conducted with sixteen bereaved caregivers of persons with dementia, recruited from long-term care homes in Ontario. Data was analyzed through reflexive thematic analysis.

Findings: Four themes were interpreted including: 'A crazy rollercoaster at the end' which described the journey of caregivers at end-of-life. The journey provided context for the development of core concepts (i.e., components) of preparedness represented by three themes: ‘A sense of control, ‘Doing right’ and ‘Coming to terms’.

Conclusion: The study findings serve to expand the conceptualization of preparedness and can guide improvements to practice in long-term care. Core concepts, facilitators and influential factors of preparedness will provide the conceptual basis and content to develop the Caring Ahead: Preparing for End-of-Life with Dementia questionnaire.

Introduction

Family/friend caregivers of persons with dementia experience challenges in the caregiving journey that can make preparing for death particularly difficult. The early introduction of a palliative approach focused on optimizing quality-of-life while preparing for end-of-life [EOL] is recommended (van der Steen et al., 2014). A palliative approach aims to promote caregiver feelings of death preparedness, a complex multi-dimensional, dynamic concept associated with well-being in bereavement. In this study, we explored the EOL experiences of caregivers of persons with dementia living in long-term care settings to understand preparedness for death. The findings contributed to the conceptualization of death preparedness and will be used to inform development of the Caring Ahead: Preparing for EOL with Dementia questionnaire.

Literature Review

An estimated 50 million persons worldwide are living with dementia, a neurocognitive, unpredictable and often progressive disorder that can impair memory, thinking, mobility and personality (Mitchell et al., 2009; World Health Organization [WHO], 2019). The majority of care for persons with dementia is delivered by family/friends who provide an increasing amount of emotional, physical and financial support as dementia progresses (WHO, 2019). Positive experiences and benefits of caregiving include feeling needed and having purpose, reciprocating care, skill development and personal growth (Quinn & Toms, 2018). However, caregiving is also associated with negative physical and mental health symptoms pre and post-bereavement, burden and increased health-care utilization by caregivers (Bremer et al., 2015; Watson et al., 2018).

Burden, depression and anxiety are reported as significantly higher ($p<0.001$) amongst caregivers of persons with dementia than other caregivers (Harding et al., 2015; Karg et al., 2018; Romero et al., 2014). In addition, negative symptoms and burden accumulate as dementia advances and can influence bereavement (Costa-Requena et al., 2015). Up to 20% of caregivers experience complicated grief (i.e., intrusive thoughts inhibiting function) after the death of a person with dementia, compared to only 3.7% of the general population (Hebert et al., 2006a; Kersting et al., 2011). The high prevalence of mental health concerns amongst caregivers of persons with dementia demonstrates a major health disparity.

There is promising evidence that outcomes for caregivers and the quality-of-dying for persons with dementia is improved when caregivers feel more prepared for EOL (van der Steen et al., 2013). However, between 53 and 67% of caregivers of persons with neurodegenerative diseases feel unprepared for death (Terzakis, 2019). 'Death preparedness' (i.e., awareness and readiness for death) is modifiable through interventions and predicts caregiver outcomes in bereavement such as, complicated grief, depression and anxiety (Barry et al., 2002; Caserta et al., 2019; Hebert et al., 2006a). Relationships between communication with healthcare providers and complicated grief (adj Odds Ratio [OD] 0.8, 95%CI 0.4,1.5), as well as between advance care planning (i.e., conversations about goals and wishes for care) and death preparedness (B=0.27, 95% CI 0.1,0.45) have been demonstrated that should be leveraged to guide improvements in care (Nielsen et al., 2016; Schulz et al., 2015).

Altogether, there is strong evidence that promoting preparedness for death in caregivers of persons with dementia has positive impacts and should therefore be an aspect and quality indicator for EOL care. However, limitations exist in the conceptualization, definition and measurement of preparedness for death. Reviews of preparedness studies and instruments have found that the concept of caregiver preparedness for death for persons with dementia is often not defined and existing instruments have limited conceptual adequacy (Durepos et al., 2019; Nielsen et al., 2016; Terzakis, 2019). To address these gaps, we conducted a concept analysis of death preparedness for caregivers of persons with dementia using literature, developed a theoretical definition and the 'Caregiver Preparedness for End-of-Life of Persons with Dementia' model (see Figure 1)(Durepos et al., 2018). The new model built upon and integrated the 'Theoretical Framework of Preparedness' developed by Hebert, Prigerson, Schulz and Arnold (2006b).

Based on this new model, preparedness is defined as, "a self-perceived cognitive, affective and behavioural quality or state of readiness to maintain self-efficacy and control in the face of loss" (Durepos et al., 2018, p4). The concept is described as having seven attributes across medical, psychosocial, spiritual and practical domains (Durepos et al., 2018; Hebert et al., 2006b). Cognitive (knowledge, information), affective (emotional-regulation, attitude, support) and behaviours (skills, actions) are described as traits underlying the concept, promoted through problem and emotion-based coping strategies (Durepos et al., 2018; Hebert et al., 2006b). Strategies such as EOL discussions are theorized as reducing uncertainty, enhancing preparedness for changes, needs and losses within domains, and promoting caregiver well-being in bereavement (Durepos et al., 2018; Hebert et al., 2006a). Caregiver death preparedness is therefore a holistic quality indicator/outcome for strategies supporting a palliative approach and EOL care.

Aims

The aims of this qualitative study were to identify the core concepts of preparedness for death amongst caregivers of persons with dementia and to understand influential factors, facilitators and barriers. Study implications are particularly relevant for nurses and healthcare providers practicing a palliative approach in long-term care where the majority of persons with dementia experience EOL. This study represented phase one of a mixed methods study (qual->QUAN) to develop and evaluate the 'Caring Ahead: Preparing for EOL with Dementia" questionnaire (Creswell et al., 2011). Research questions included: 1) What are the experiences of caregivers of persons with dementia during EOL, and what factors influence preparedness for death? 2) What are the core concepts (i.e., components), facilitators and barriers to preparedness for death?

Methods

Design

This study used an interpretive descriptive design (Thorne, 2016) as it is appropriate for exploring a phenomenon relevant to clinical practice and aims to produce a coherent conceptual description of a phenomenon applicable to practice. The authors are members of health disciplines (nursing and social work) and this study emerged from clinical practice with persons with dementia and caregivers in long-term care. Interpretive description assumes the existence of multiple realities constructed through social interactions with the world and influenced by context (Thorne, 2016). The research approach was loosely based on constructive realism and the authors assumed they were interacting with participants to create a representation of preparedness by describing the underlying, common and shared patterns in their experiences (Cupchik, 2001; Thorne, 2016). Pre-existing theoretical knowledge informed sampling and data collection in this study, but the analysis was inductive with the end study-product grounded in the data (Thorne, 2016).

Sampling

Purposive sampling, including criterion, maximum variation and snowball sampling strategies, was used to recruit a sample of bereaved caregivers of persons with dementia to act as information-rich cases from long-term care settings (i.e., 24-hour residential care facilities) in Central Ontario (Patton, 2015; Thorne, 2016). Participants were recruited with the following criteria: 1) English-speaking adults over 18 years old; 2) bereaved between 3 to 24 months, who previously provided: 3) unpaid, emotional, physical or financial care; 4) to a family member/friend with dementia residing in long-term care. Participants with diverse characteristics (e.g., gender, relationship) known to influence caregiving and EOL experiences were recruited for maximum variation (Patton, 2015; Schulz et al., 2015; Thorne, 2016). All participants resided in Canada. However, the majority of Canadians report having beliefs and traditions influencing EOL experiences that stem from an additional ethnic origin (Ontario Palliative Care Network, 2019).

Recruitment

Staff members in two long-term care homes (i.e., Director of Care and administrative assistant) and an educator with the local Alzheimer Society assisted with recruitment by posting flyers in their settings and by contacting bereaved caregivers known to them by email or telephone to let them know about the study (Patton, 2015). Participants were offered a $25 gift card as an incentive. To minimize researcher intrusion, interested participants contacted us or gave permission to staff to share their contact information (Roberts & Gilloway, 2011). Recruited participants let other persons who met the inclusion criteria know about the study which facilitated snowball sampling (Patton, 2015). Sampling continued until the data became redundant (Thorne, 2016).

Data collection and analysis

Semi-structured interviews were conducted by the lead author (P.D.) in the participants' preferred location (i.e., home or by telephone) from June to September 2018. P.D. is a nurse (PhD student) with specialty training in a palliative approach, counselling and experience conducting research interviews about EOL. An iterative interview guide was used to explore experiences at EOL and perceptions of preparedness, with questions organized around domains of the existing Preparedness Model (see Supplement)(Durepos et al., 2018; Hebert et al., 2006a; Thorne, 2016). The interviews lasted 30 to 90 minutes. P.D. recorded field notes during interviews to capture data about participants' moods, emphasized concepts and recorded a reflective note in her reflexive journal to record personal reactions immediately following the interview (Braun & Clarke, 2014). Interviews were audio recorded, transcribed, identifying information was removed and transcripts were proofed for accuracy against the recording (Patton, 2015).

Data analysis began concurrent with data collection as P.D. was immersed in the data, listened repeatedly to interview recordings, and recorded emerging patterns in her field notes and journal. Meaningful participant quotations within transcripts were defined as the units of analysis (Elo et al., 2014).The authors used an inductive data-driven approach to analyze the data (Thorne, 2016) and followed the six-steps of reflexive thematic analysis: 1) becoming familiar with the data by reading and re-reading transcripts; 2) generating initial surface-level codes to organize and describe the data within transcripts; 3) searching for common, underlying patterns across the data-set and collating initial codes into themes that went beyond the surface-level; 4) reviewing the themes in relation to the data; 5) defining and labelling themes with details and the overarching narrative; and 6) reporting the findings (Braun & Clarke, 2014). The authors each analyzed three transcripts independently until they had generated and reviewed themes (i.e., step 4)(Braun & Clarke, 2014; Patton, 2015).

The authors then met together, discussed and compared their findings and defined preliminary themes based on consensus.

Using the themes as codes, P.D. proceeded to analyze all of the remaining transcripts using QSR's NVIVO 12.0 qualitative analysis software. P.D. developed new codes to reflect the data as needed and clarified/modified the themes to produce a coherent conceptual description of preparedness core concepts, facilitators, barriers and influential contextual factors. P.D. met frequently with the study authors during analysis over the next three months to ensure the findings were data-driven (Elo et al., 2014; Thorne, 2016).

Trustworthiness

To enhance conformability and ensure the findings were data-driven we critically reflected on our assumptions and potential influences on the research process. As the lead author P.D., also critically reflected on her role as the research instrument to ensure the interview questions were not leading, recorded her reactions to the data in a reflexive journal and debriefed with another author (Elo et al., 2014). The authors maintained an audit trail of decisions made regarding the study design, sampling, data collection and analysis for transparency and dependability (Elo et al., 2014). Credibility of the findings was promoted through the independent analysis of transcripts by all authors for researcher triangulation (Elo et al., 2014).

Ethical considerations

This study was approved by the Hamilton Integrated Research Ethics Board (#4503). Written informed consent was obtained prior to each interview. Sensitive interviewing techniques were employed including: frequent breaks and/or discontinuation of the interview if needed, a list of supportive resources provided at the end of the interview, validation of emotions availability of the interviewer for follow-up and connection to additional resources if needed)(Brayda & Boyce, 2014; Roberts & Gilloway, 2011). All of the participants demonstrated emotions during the interview (e.g., crying, sadness), however no participants wanted to end the interview. The majority of participants expressed that completing the interview was beneficial to their well-being and was a rewarding way to help caregivers.

Findings

A sample of 16 bereaved caregivers, primarily adult-children (70%) of persons with dementia (i.e., care recipients) who were deceased were interviewed (see Table 1). The overarching theme, 'A Crazy Roller Coaster at the End' described the challenging journey that caregivers experienced leading up to death and provided context for the development of core concepts (i.e., components) of preparedness for EOL. Three additional themes represented inter-connected core concepts comprising preparedness. 'A Sense of Control' managing the situation focused on the person with dementia and meeting their needs. 'Doing Right' fulfilling obligations focused on meeting societal needs and customs at EOL. 'Coming to Terms' adapting to loss focused on meeting the needs of the caregiver themselves. Figure 2 displays the three core concepts comprising preparedness that were developed (and influenced) by the context of the caregiving journey.

Theme 1. "A crazy rollercoaster at the end": The challenging journey of caregiving and preparing for EOL.

This theme described participants' experiences of caring for their family member as a dynamic, process of emotional upheaval, responses to decline and created context for the development of preparedness. Specifically, the rate (sudden or gradual), nature of decline (expected or unexpected) and quality-of-life of the person with dementia were contextual factors along the journey that influenced the core concepts of preparedness.

Participants described experiencing, "one crisis after another, after another…with so many ups and downs for years" (P01) and a "crazy rollercoaster at the end…we weren't prepared for" (P12). A pattern of medical events characterized the last year of the person with dementia's life, including the loss of "vocal capabilities…ability to focus… swallowing… recognizing family" (P15). Participants described persons with dementia as having "a long, slow deterioration in overall health and quality-of-life" (P04). However, the final months/days of life were often described as rapid or sudden. A participant explained, "We had lots of time…years even, but no time…when it mattered" (P16).

During the last year of life, persons with dementia were perceived as, "already gone" (P15) and "ready to die" (P07). Participants expressed that persons with dementia had poor quality-of-life and the participants were therefore "ready" (P06) or "waiting for it to be over" (P05). Thus, the quality-of-life for the person with dementia appeared to influence feelings of preparedness for death. A predictable trajectory and nature decline (expected by the participant) as well as a slower rate of decline were also viewed as motivating and promoting preparedness. A participant explained, "I had some time because there was some lead-up right? They said, 'she's got [pneumonia]' and she slowly slipped away…that's a great gift" (P06). In contrast, rapid and unexpected decline presented barriers to preparedness. A participant explained, "He went from completely functional to hell in 45 days…I wasn't prepared for that rate of decline" (P16). Overall, the journey of caregiving for someone with dementia during EOL was described as a roller coaster and preparedness was influenced by contextual factors such as the quality-of-life of the person with dementia, the rate and nature of decline.

Theme 2. "A sense of control": Managing the situation.

A core concept comprising preparedness was managing the situation which focused on meeting the needs of the person with dementia. Managing the situation meant feeling competent in the caregiver role and confident in goals for the person with dementia, and was facilitated by being proactive, knowledgeable about dementia and resourceful. Some participants described themselves as, "…checking all the boxes" (P16) and "…staying on top of things" (P15). Strategies such as organizing and planning, advocating and articulating goals, information and resource-seeking assisted participants to maintain a sense of control and meet the needs of the person with dementia. A participant explained, “I felt in control…I did exactly what I wanted to do every step of the way…If they say someone is dying, don’t just sit there! Make plans (P06). Another participant explained, “We worked hard to educate ourselves…Our intent was always to make sure that we were able to give him all the supports that he needed…” (P11).

Having transparent, collaborative relationships and confidence in healthcare providers and other family members to meet the person with dementia’s needs also enabled participants to manage the situation. A participant shared, “the charge nurse had her finger on everything…I knew they would keep him comfortable” (P14). Communication from healthcare providers assisted participants to understand the person with dementia’s health status, which promoted a sense of control. A participant explained, “I called a physician friend …he was the one who said, ‘it sounds like he’s palliative’…and it was just reassuring to hear that…” (P02). In contrast, inadequate care, a lack of continuity and limited communication with staff were perceived as barriers to preparedness. Information-seeking and communicating with staff were important for participants to understand the potential nature for decline and trajectory of changes associated with dementia described as influencing preparedness in the caregiving journey (Theme 1).

Theme 3. “Doing right”: Fulfilling obligations.

A core concept of preparedness was fulfilling perceived moral and legal obligations that are the result of societal needs and expectations for EOL. Obligations were perceived "duties" (P01) to fulfill before, during and after death. Meeting moral obligations to society meant supporting quality-of-life, dignity, comfort and companionship while dying and traditional/customary celebrations of life and legacy at EOL (e.g., cultural, spiritual, personal). Alternatively, legal obligations to society meant completing worldly, practical and financial affairs at EOL. Participants perceived that fulfilling obligations was necessary to avoid regrets and emotional distress. A participant explained, "I don't think you can ever fully prepare…But I would say no regrets is the most important thing…" (P06). The fulfillment of obligations was facilitated by understanding the person with dementia's wishes related to traditions/customs, legal affairs and making arrangements before death.

A participant summarized moral obligations to be fulfilled:

> You want to bring that person as many experiences, connections and enforcement or recognition of their contribution to the lives of family members and their friends. To give them self-esteem, to give them comfort they've made the most of their lives (P03).

Another participant explained how they had fulfilled the need for a traditional ceremony for EOL, "I arranged…a prayer service…You felt like you had done right by her you know" (P15). Participants explained that (similar to managing the situation) fulfilling moral obligations was facilitated by planning, making arrangements and information-seeking about societal traditions at EOL:

> In the Jewish tradition…There are laws that are supposed to be followed when it comes to any rite of passage… It almost becomes like an exercise that you've done before (P09).

For some participants fulfilling legal obligations, such as completing financial and government affairs was a relatively smooth process. A participant explained, "By the time [my husband] passed everything was in place…Everyone should have a will" (P02). For other participants fulfilling legal obligations and "all the different things that we had to tie up…was a steep learning curve" (P13) and "a nightmare" (P15). Participants perceived that consolidating and joining bank accounts, having a will, designating surrogate decision-making power, and learning about their family member's estate in advance of death facilitated the fulfillment of legal obligations. A sudden or rapid rate of decline (as described in Theme 1) for the person with dementia during the caregiving journey therefore made it more difficult to fulfill obligations.

In this study, obligations and the fulfillment of duties were influenced by the relationship of the participant (i.e., spouse vs. adult child), gender and culture. Spouse participants interviewed described having less difficulty fulfilling obligations than adult child participants, and therefore relationships may have created a barrier. Discussions about health and EOL for example were sometimes described as, "private…between your Dad and I" (P16), meaning that they were reserved for spousal relationships. Participants of minority ethnic origins (n=3) also emphasized that gender and culture influenced how their societal obligations were defined, and how they were fulfilled. A participant of Chinese origin stated for example, "Traditionally…My Dad didn't tell my Mom what was going on with the money…All of a sudden he's not there anymore and we had to dig up stuff" (P13). A participant of South Asian ethnic origin also explained, "In my country girls are sometimes lower class… My brother got Power of Attorney, and staff had to call him for permission for everything, even though I was there" (P10). In summary, fulfilling obligations focused on meeting societal obligations and duties during EOL that were influenced by culture, gender and relationships.

Theme 4. "Coming to terms": Adapting to loss.

This theme focused on the caregiver themselves, and their constant need to adapt to decline, loss and changing identity. Accepting what could not be changed (including personal limitations), finding meaning, reframing the situation to focus on positive aspects, and coping with emotions were perceived as facilitating 'coming to terms'. A participant described accepting change and loss stating, "I think you sort of got used to the idea over a period of time. I mean you knew he was going to die, you just didn't know quite when" (P07) and "There's no quality of life really, I didn't want him to live that way" (P15). A predictable trajectory/expected nature of decline, as well as perceptions of limited quality-of-life within the caregiving journey therefore promoted participants adaptation to loss. Feelings of existential distress contrasted those of acceptance and were often associated with perceptions that obligations were not fulfilled and the needs of the person with dementia were not met. A participant stated, “I have to forgive myself…I tell myself I did my best…But he didn’t deserve that…it was just not fair” (P16).

Strategies of reframing or “making the best of the situation” (P06), focusing on positive aspects and “being thankful” (P08) were perceived as facilitating acceptance, adaptation and reconciliation with change and loss. Participants described positive aspects of their experiences such as, “a new closeness…where we had been emotionally distant before” (P01), “intimacy” (P02), and “a new softness in his personality” (P16). Similarly, reflecting on personal growth and searching for meaning amidst challenges were described as important. A participant shared, “There was a greater purpose in this because we’ve been able to help out other people…it's part of the healing” (P11). Practicing self-care, setting priorities, seeking emotional support, and coping with emotions or, “going into the feeling” (P02) also facilitated ‘coming to terms’. A participant described prioritizing her family stating, “It was like we were standing in the middle of a hurricane. So, we really worked hard to focus on our own little family just to support and love on each other” (P11).

Participants perceived that during EOL and bereavement, caregivers were adapting to a new identity and were therefore, “…in transition” (P02). Adult children perceived they were an “orphan now” (P07), “the head of my family” (P16) and the “next generation to go” (P09). In contrast, spouse caregivers spoke more often about losing their purpose. A spouse participant explained, “You wake up in the morning and you don’t have a purpose…the little birds have left the nest, the wife is gone…That’s what you’re on earth for right?” (P02). Participants perceived that caregivers should, "…keep their friends" (P01) and "…sustain their hobbies, anything that gives them purpose" (P07) in order to adapt and prepare.

Adapting to loss was also facilitated by resolving conflicts, reconciling with the person with dementia, and finding peace within oneself. Participants perceived that, "saying what you need to say" (P05), "letting go" (P11) and "writing in a journal" (P07) were beneficial. A meaningful reconciliation between the person with dementia and another family member was described by a participant who shared, "Even though he was non-responsive they were able to reconcile…there's all kinds of stuff if you're brave enough to go after it" (P16). Similarly, other participants explained, "I learned that lesson with my mother, to make sure I said the things that were on my mind before she left me…to get it off my chest" (P09) and "I have peace" (P10). In particular, participants expressed a need to accept personal limitations related to unmet needs and unfulfilled obligations to the person with dementia. Coming to terms was therefore closely linked to the perceived development of core concepts in Theme 2 and Theme 3.

Discussion

Four themes emerged in this study. The first theme, 'A roller coaster at the end' described the journey of caregivers of persons with dementia and factors (rate, nature of decline and quality-of-life) perceived as influencing feelings of preparedness for death. The description of this journey provided context for the development of three core concepts of preparedness for death: managing the situation, which focused on the person with dementia; fulfilling obligations, which focused on society; and adapting to loss, which focused on the caregiver themselves. The study findings are particularly relevant to healthcare professionals (e.g., nurses and healthcare providers) supporting persons with dementia and caregivers in long-term care. The findings serve to: 1) further conceptualize preparedness for death; and 2) highlight facilitators and barriers that can guide practice. Altogether these findings will provide the conceptual basis for a preparedness questionnaire.

In general, the study findings support the validity of the pre-existing theoretical knowledge of preparedness (Durepos et al., 2018; Hebert et al., 2006a). Preparedness was previously defined as, "a self-perceived cognitive, affective and behavioural quality or state of readiness to maintain self-efficacy and control in the face of loss" (Durepos et al., 2018, p4). In addition to highlighting 'A sense of control' as a core concept of preparedness however, the findings from the study suggest that the core concepts 'Coming to terms' and 'Doing right' are equally important. Previously 'adaptation' was also previously perceived as a consequence whereas in this study adapting emerged as a core concept. Caregiving is theorized as a process of adaptation, referred to as 'seeking normal' and 'coming to terms' in a grounded theory exploring caregiver experiences at EOL (Duggleby et al., 2017; Penrod et al., 2012). Therefore, the theoretical definition of preparedness may need to be amended to include all three core concepts. A new definition could state, 'caregiver preparedness for death in dementia is a self-perceived cognitive, affective and behavioural quality or state of readiness to manage the situation, fulfill obligations and adapt to loss'.

The core concepts identified also provide new insight into the meaning of, and relationships between preparedness attributes. Perceived attributes of preparedness such as ‘knowing and recognizing signs of decline and dementia’ are currently organized into medical, psychosocial, practical and spiritual domains in the existing model (Durepos et al., 2018). However, the attributes could be re-grouped according to the core concepts which may be more meaningful that organizing attributes by domain. For example, participants described the attributes ‘Accepting that losses are inevitable and imminent’; ‘Reflecting on caregiving and finding meaning; Understanding emotions and grief; and ‘Reconciling, renewing and closing a relationship’ as facilitators for ‘Coming to terms’ in this study. Re-grouping and revising the attributes in light of the core concepts which are written in lay language, may make the concept of preparedness more accessible and concrete for healthcare providers to discuss and promote in practice (Lietzelman et al., 2017).

Perceived facilitators of preparedness in this study can be promoted in practice by healthcare providers and can be translated into questionnaire items aimed at measuring preparedness. Facilitators include for example: making arrangements in advance to fulfill obligations, articulating goals for EOL, maintaining a social network and sources of purpose other than caregiving, having transparent collaborative relationships with care providers, seeking out supportive resources and ‘back-up’, practicing self-care and coping with emotions. It is promising that strategies supporting a palliative approach (e.g., Goals of Care conversations) are increasingly being implemented in long-term care that incorporate preparedness facilitators identified in this study (Kaasalainen & Sussman, 2019). However, further research evaluating the impact of interventions on caregiver death preparedness as an outcome is needed to assess intervention effectiveness/quality.

Facilitators/barriers to preparedness identified here also correspond with unmet needs of caregivers reported in long-term, such as poor communication with healthcare providers, a lack of psychosocial support, and limited access to resources (De Cola et al., 2017; Whitlatch & Orsulic-Jeras, 2018). End-of-life discussions with healthcare providers in particular are lacking and occur with only 22% of caregivers in long-term care, which likely impedes preparedness (Morin et al., 2016). Having unresolved conflicts with the person who is dying (i.e., unfinished business) and a perceived inability to provide comfort, are also linked to poor caregiver outcomes and distress in bereavement (Holland et al., 2020); highlighting the need for strategies such as reconciling, promoting comfort and personhood described as facilitators of preparedness in this study.

Strengths and Limitations

Study strengths include strategies to enhance trustworthiness of the findings such as: 1) journaling and debriefing for reflexivity and conformability; 2) researcher triangulation; 3) maintenance of an audit trail for dependability and 3) maximum variation sampling for transferability. Thick-description of the methods and findings was provided to support and transferability, transparency and dependability (Elo et al., 2014; Thorne, 2016). Spousal caregivers, persons with lower socioeconomic status and education, and persons from minority cultures were recruited with a wide range of experiences. However, the high proportion of adult-child caregivers and few persons representing minorities limits the inferences that can be made about subgroups in the study. A population-based, representative sampling strategy was not used and therefore the findings may only be applicable to participants in the study (Patton, 2015). In addition, data regarding the participants' number of hours caregiving was not collected that may have influenced EOL experiences. Lastly, data were collected retrospectively and were of an extremely sensitive nature. Participants may have experienced recall bias and/or selectively shared data that influenced the study findings (Patton, 2015).

Implications for Practice

Healthcare providers (including nurses and allied health) are promoting a palliative approach to improve EOL experiences and outcomes for persons with dementia and their caregivers. However, strategies often remain focused on medical (e.g., pain and symptom management) or practical aspects of death (e.g., documentation of resuscitation status), and professionals often avoid discussing emotional aspects of death (e.g., grief, traditions, spiritual beliefs)(Brazil et al., 2012; McMahan et al., 2013). Based this study, it is clear that both practical and emotional support are needed by caregivers to promote feelings of preparedness. Spiritual and psychosocial care are requisite palliative care competencies for nurses and other healthcare providers in most countries (Ontario Palliative Care Network, 2019). Therefore, providers require additional training to support caregivers in existential distress, to practice active listening, psychotherapy, coaching persons in self-care and goal-setting (Kulasegaram et al., 2018). Providers should focus on being transparent, collaborative, sharing information about dementia and 'what to expect', keeping caregivers informed about health changes and helping caregivers understand the meaning of the changes to promote feelings of preparedness for death.

Conclusion

Overall, this study fulfilled the objectives to explore the EOL experiences of caregivers and produce a coherent conceptual description of preparedness that is relevant to clinical practice. Four themes were interpreted describing the caregiving journey and factors influencing preparedness, and three core concepts comprising preparedness: managing the situation, fulfilling obligations and adapting to loss. The situations and losses experienced by caregivers as they prepared for EOL (Theme 1) provided insight into the information-needs of caregivers that healthcare providers should anticipate and address (e.g., surrounding dementia trajectory). The core concepts of preparedness focused on meeting the needs of the person with dementia, society and the caregiver. Behaviours (e.g., organizing, arranging, communicating) described as facilitating core concepts of preparedness should also be promoted in healthcare providers' practice, and included on the Caring Ahead: Preparing for EOL with Dementia questionnaire.

Declaration of Conflicting Interests

The authors have no conflicting interests to declare.

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References

Barry, L. C., Kasl, S. V., & Prigerson, H. G. (2002). Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American Journal of Geriatric Psychiatry*, *10*(4), 447-457.

Brayda, W., & Boyce, T. (2014). So you really want to interview me?: Navigating "sensitive" qualitative research interviewing. *International Journal of Qualitative Methods, 13*(1), 318-334.

Braun, V., Clarke, V., & Rance, N. (2014). How to use thematic analysis with interview data (process research). In A. Vossler & N. Moller (Eds.), *The Counselling & Psychotherapy research handbook.* London, UK: Sage Publications Inc.

Brazil, K., Kaasalainen, S., McAiney, C., Brink, P., & Kelly, M. L. (2012). Knowledge and perceived competence among nurses caring for the dying in long-term care homes. *International Journal of Palliative Nursing*, *18*(2), 77-83.

Bremer, P., Cabrera, E., Leino-Kilpi, H., Lethin, C., Saks, K., Sutcliffe, C., ... & Right Time Place Care Consortium. (2015). Informal dementia care: Consequences for caregivers' health and health care use in 8 European countries. *Health Policy, 119*(11), 1459-1471.

Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2019). Cancer caregivers' preparedness for loss and bereavement outcomes: do preloss caregiver attributes matter?. *Omega-Journal of Death and Dying*, *80*(2), 224-244.

Costa-Requena, G., Val, M. E., & Cristòfol, R. (2015). Caregiver burden in end-of-life care: advanced cancer and final stage of dementia. *Palliative & Supportive Care*, *13*(3), 583-589.

Creswell, J., Klassen, A., Plano Clark, V., & Smith, K. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health*, 541-545.

Cupchik, G. (2001). Constructive realism: An ontology that encompasses positivist and constructivist approaches to the social sciences. Forum: Qualitative Social Research, 2, 1–9.

De Cola, M. C., Lo Buono, V., Mento, A., Foti, M., Marino, S., Bramanti, P., ... & Calabrò, R. S. (2017). Unmet needs for family caregivers of elderly people with dementia living in Italy: what do we know so far and what should we do next?. *Inquiry: The Journal of Health Care Organization, Provision, and Financing*, *54*, 0046958017713708.

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2018). What does death preparedness mean for family caregivers in dementia? *American Journal of Hospice and Palliative Medicine*, *X*(X), 1-11. https://doi.org/10.1177/1049909118814240

Durepos, P., Ploeg, J., Akhtar-Danesh, N., Sussman, T., Orr, E. & Kaasalainen, S., (2019). Caregiver Preparedness for Death with Dementia: An Evaluation of

Existing Tools. *Aging and Mental Health,* https://www.tandfonline.com/doi/full/10.1080/13607863.2019.1622074

Duggleby, W., Tycholiz, J., Holtslander, L., Hudson, P., Nekolaichuk, C., Mirhosseini, M., ... & Swindle, J. (2017). A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliative Medicine*, *31*(7), 602-616.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, *4*(1), 2158244014522633.

Harding, R., Gao, W., Jackson, D., Pearson, C., Murray, J., & Higginson, I. J. (2015). Comparative analysis of informal caregiver burden in advanced cancer, dementia, and acquired brain injury. *Journal of Pain and Symptom Management*, *50*(4), 445-452.

Hebert, R., Dang Q., & Schulz, R. (2006a). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *Journal of Palliative Medicine, 9*(3), 683-693.

Hebert, R., Prigerson, H., Schulz, R., & Arnold, R. (2006b). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine, 9*(5), 1164-1171.

Holland, J. M., Plant, C. P., Klingspon, K. L., & Neimeyer, R. A. (2020). Bereavement-related regrets and unfinished business with the deceased. *Death Studies*, *44*(1), 42-47.

Kaasalainen, S., & Sussman, T. (2019). Evaluating the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) Program in Canada. *Journal of the American Medical Directors Association*, *20*(3), B17.

Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics*, *18*, 189.

Kersting, A., Brähler, E., Glaesmer, H., & Wagner, B. (2011). Prevalence of complicated grief in a representative population-based sample. *Journal of Affective Disorders, 131*(1), 339- 343.

Kulasegaram, P., Thompson, G., Sussman, T., & Kaasalainen, S. (2018). End-of-Life Care Communication Training Programs for Long-Term Care Staff: A Scoping Review. *Journal of Pain and Symptom Management*, *56*(6), e80.

Litzelman, D. K., Inui, T. S., Schmitt-Wendholt, K. M., Perkins, A., Griffin, W. J., Cottingham, A. H., & Ivy, S. S. (2017). Clarifying values and preferences for care near the end of life: the role of a new lay workforce. *Journal of Community Health*, *42*(5), 926-934.

McMahan, R., Knight, S., Fried, T., & Sudore, R. (2013). Advance care planning beyond advance directives: perspectives from patients and surrogates. *Journal of Pain and Symptom Management*, *46*(3), 355-365.

Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., ... & Hamel, M. B. (2009). The clinical course of advanced dementia. *New England Journal of Medicine*, *361*(16), 1529-1538.

Morin, L., Johnell, K., Van den Block, L., & Aubry, R. (2016). Discussing end-of-life issues in nursing homes: a nationwide study in France. *Age and Ageing, 45*(3), 395-402.

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, *44*, 75-93.

Ontario Palliative Care Network (2019). Ontario Palliative Care Competency Framework. Available from: https://www.ontariopalliativecarenetwork.ca/en/competencyframework

Patton, M. (2015). *Qualitative research and evaluation methods* (4th ed.). Washington, DC: Sage Publications Inc.

Penrod, J., Hupcey, J., Shipley, P., Loeb, S., & Baney, B. (2012). A model of caregiving through the end of life: Seeking normal. *Western Journal of Nursing Research, 34*(2), 174-193.

Quinn, C., & Toms, G. (2018). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *The Gerontologist*. *59*(5), e584-e596.

Roberts, A., & McGilloway, S. (2011). Methodological and ethical aspects in evaluation research in bereavement. *Bereavement Care, 30*(1), 21-28.

Romero, M. M., Ott, C. H., & Kelber, S. T. (2014). Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. *Death Studies, 38*(6), 395-403.

Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine*, *18*(2), 127-133.

Terzakis, K. (2019). Preparing Family Members for the Death of a Loved One in Long- Term Care. *Annals of Long-term Care*, *27*(2), 25-31.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). New York, NY: Routledge

Van der Steen, J. T., Onwuteaka-Philipsen, B. D., Knol, D. L., Ribbe, M. W., & Deliens, L. (2013). Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. *BMC Medicine, 11*(105).

Van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., ... & Koopmans, R. T. (2014). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, *28*(3), 197-209.

Watson, B., Tatangelo, G., & McCabe, M. (2018). Depression and anxiety among partner and offspring carers of people with dementia: A systematic review. *The Gerontologist, 59*(5), e597-e610.

Whitlatch, C. J., & Orsulic-Jeras, S. (2018). Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *The Gerontologist, 58*(suppl_1), S58-S73.

World Health Organization [WHO] (2019). Dementia key facts. Retrieved from: https://www.who.int/news-room/fact-sheets/detail/dementia

Figure 1. 'Caregiver Preparedness for End-of-Life of Persons with Dementia' model

Loss and Transition

Antecedents	**Preparedness Attributes, Domains & Traits**	**Consequences**
1. Living with Grief and Burden; 2. Illness-related event; 3. Advance Care Planning & End-of-Life communication with Care Providers; 4. Uncertainty about the Situation and the Future	**1. Medical:** Knowing and recognizing signs of decline and dementia, and what dying looks like **2. Psychosocial:** Understanding emotions and grief responses; Accessing and appraising supports and relationships to manage, plan and provide care around death 3. **Practical:** Organizing legal, financial and household affairs and completing tasks in advance **4. Spiritual:** Accepting that losses are inevitable and imminent Reflecting on caregiving and finding meaning, 'a silver-lining' Reconciling, renewing and closing a relationship Completing the family member's life. **5. Cognitive:** Information/support-seeking, problem-based coping **6. Affective:** Emotional-regulation, reframing, avoidance/ acceptance, emotion-based coping **7. Behavioural:** Active task completion, planning, problem-based coping	1. Mental Health and Well-being after Death; 2. Adaptation and Adjustment in Bereavement; 3. Satisfaction with End-of-Life care and Quality of Dying for the person with dementia

Note from: Durepos et al., (2018) What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Care,* X(X), 1-11. DOI: 10.1177/1049909118814240; and Durepos et al. (2019) Caregiver preparedness for death in dementia: An evaluation of existing tools. *Aging and Mental Health,* DOI: 10.1080/13607863.2019.1622074

Figure 2. Findings: Core concepts of preparedness developed in the context of the caregiving journey.

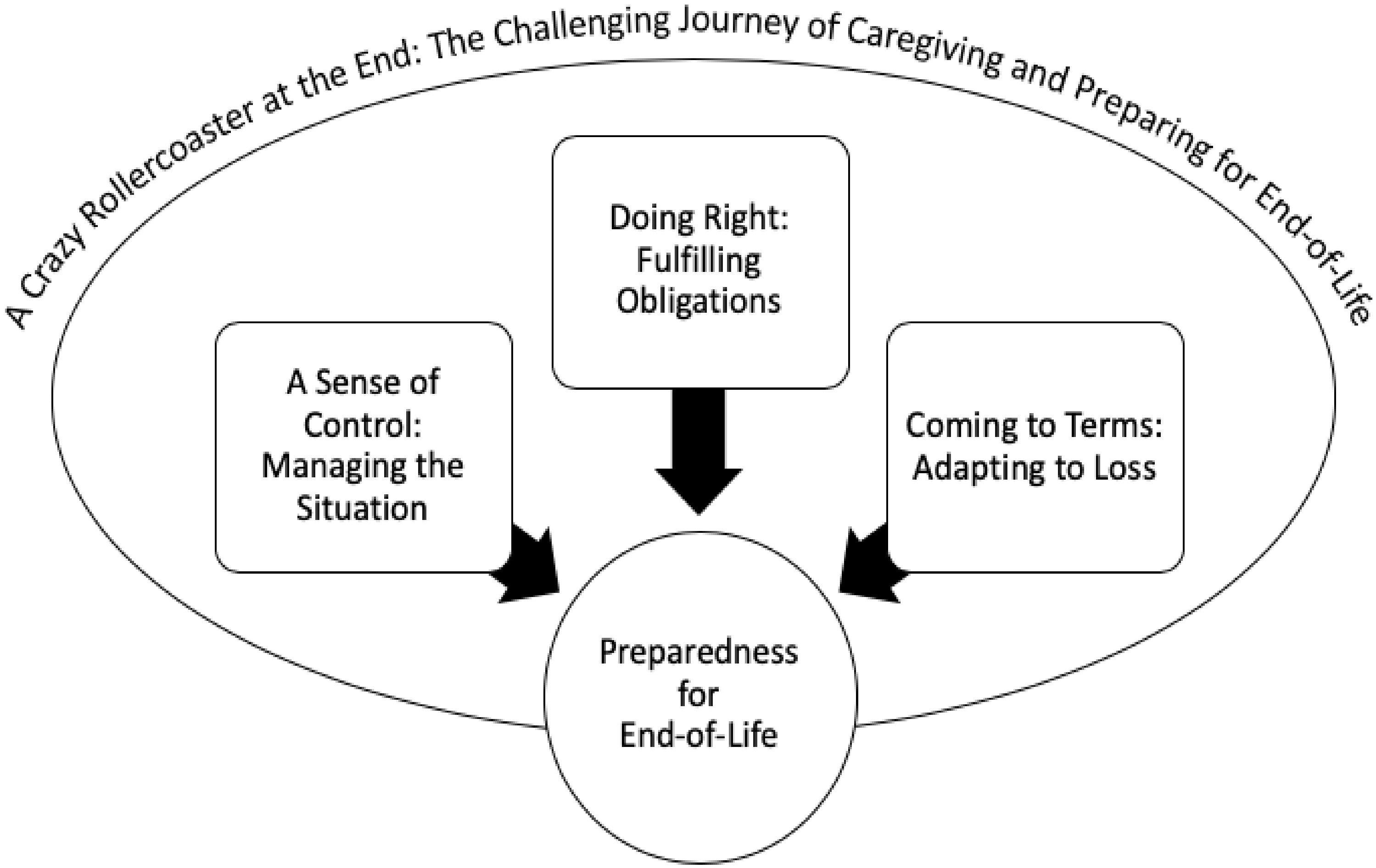

Table 1. Participant sample (n=16).

Characteristic		N (%)	Mean (SD)
CG Gender	Male	7 (43.8)	
	Female	9 (56.3)	
CG Age (years)			60 (11.5)
CG Relationship to deceased	Spouse	3 (18.8)	
	Adult Child	12 (75.0)	
	Other (Nephew)	1 (6.3)	
CG Time bereaved (months)			9.6 (6.9)
CG Present at time of death	Yes	7 (43.8)	
Location of death	LTC	11 (68.8)	
	Hospital	4 (25.0)	
	Home	1 (6.3)	
CG Ethnic Background	British	10 (62.5)	
	European	3 (18.8)	
	Asian	2 (12.5)	
	South Asian	1 (6.3)	
CG Religion	Agnostic	4 (25.0)	
	Christian (any denomination)	9 (56.3)	
	Jewish	2 (12.5)	
	Hindu	1 (6.3)	
CG Employment Status	Retired	5 (31.3)	
	Full-time	8 (50.0)	
	Part-time	2 (12.5)	
	Currently not working	1 (6.3)	
CG Education	Less than High School	1 (6.3)	
	High School	1 (6.3)	
	College / University	8 (50.0)	
	Graduate School	6 (37.5)	
CG Household Annual Income	51-100,000	6 (37.5)	
	$101-150,000	3 (18.8)	
	$151-200,000	3 (18.8)	
	Greater than $200,000	4 (25.0)	
CR Gender	Male	8 (50.0)	

Characteristic		**N (%)**	**Mean (SD)**
	Female	8 (50.0)	
CR Age (years)			85.9 (6.4)
CR Time in LTC (years)			2.9 (1.8)
CR Time with dementia (years)			9.4 (6.0)
Type of dementia	Alzheimer's	6 (37.5)	
	Vascular	3 (18.8)	
	Korsakoff	1 (6.3)	
	Unknown	6 (37.5)	
CR Ethnic background	British	10 (62.5)	
	European	2 (12.5)	
	South Asian	1 (6.25)	
	East Asian	2 (12.5)	
	Nordic	1 (6.25)	
CR Religion	Agnostic	2 (12.5)	
	Christian (any denomination)	11 (68.8)	
	Jewish	1 (6.3)	
	Hindu	1 (6.3)	
	Muslim	1 (6.3)	
CR Education	Less than high school	2 (12.5)	
	High school	5 (31.3)	
	University / college	5 (31.3)	
	Graduate school / professional certificate	3 (18.8)	
	Trade school	1 (6.6)	

Note: CG=Caregiver; CR=Care Recipient, i.e., Person with Dementia; LTC=Long-term Care. The sum of percentages may be greater than 100.0 due to rounding to a single decimal place.

Supplemental Table. Semi-structured interview questions.

Preparedness Domain	Questions
Medical	• What events stand out to you from the last year of your family member's life? • Were these events that you expected? • What do you think was helpful in preparing for these events?
Psychosocial	• What relationships were important to you in the last year of your family member's life? • What was your relationship with your family member like? • What relationships were helpful to you? • What were your emotions like during this time? • Were you surprised by your emotions? Why or why not?
Practical	• What tasks did you have to complete for your family member? • What kind of services did you use after-death? • Were the tasks that you had to complete things you expected, or had done before? • What was helpful in completing these tasks?
Spiritual	• What are your beliefs around death and dying? • What beliefs did your family member have? • What traditions or practices did you follow when your family member was dying or afterwards?

Chapter 5

Caring Ahead: Mixed Methods Development of a Questionnaire to Measure Preparedness for End-of-Life of Persons with Dementia[4]

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[4] Durepos, P., Akhtar-Danesh, N., Ploeg, J., Sussman, T., & Kaasalainen, S. Caring ahead: Mixed methods development of a questionnaire to measure preparedness for end-of-life of persons with dementia. Submitted to*: Palliative Medicine, April 2020.*

Abstract

Background and Aim: Preparedness for end-of-life in dementia is a direct, holistic outcome measure for strategies supporting a palliative approach, however current preparedness questionnaires have limitations. In this study we aimed to develop the Caring Ahead: Preparing for End-of-Life with Dementia questionnaire to be used as a holistic, outcome measure for strategies in a palliative approach.

Design: A mixed methods, sequential design was used to develop the Caring Ahead questionnaire in Ontario, Canada between January 2018 and June 2019. The process was informed by the Instrument Development and Construct Validation Framework. Phases included: 1) interviews with 16 bereaved caregivers of persons with dementia from long-term care to identify preparedness indicators/generate questionnaire items; 2) Delphi-survey with 17 caregivers and experts to select questionnaire items; and 3) pilot-testing and cognitive interviewing with three caregivers to evaluate face validity and response process for the questionnaire.

Results: Interviews generated 114 potential questionnaire items. Of these, 73 potential items were presented to caregivers and experts through a Delphi-survey, and 30-items were selected for the draft questionnaire. The draft questionnaire was revised and face validity improved through pilot-testing and cognitive interviewing. The final 30-item questionnaire is organized into medical, relationship/personal, spiritual and practical subscales.

Conclusions: The new Caring Ahead questionnaire will make a valuable contribution to researchers, healthcare providers and policy-makers seeking a holistic outcome measure for strategies supporting a palliative approach. Future psychometric testing is needed to evaluate construct validity and reliability in the questionnaire.

What is already known about this topic?

- Feeling prepared for death predicts family caregiver outcomes and is a quality indicator for strategies supporting a palliative approach.
- Death preparedness has not been fully operationalized, and current instruments used to measure this construct have limitations.

What this paper adds?

- This paper describes the development of the 'Caring Ahead: Preparing for End-of-Life with Dementia' questionnaire.

Implications for practice and policy

- Healthcare professionals, researchers and policy-makers should be able to evaluate the quality and impact of strategies supporting a palliative approach using the questionnaire.

Introduction

Family caregivers of persons with dementia can experience unique challenges that impact their health and well-being beyond death into bereavement (1). Persons with dementia and their caregivers experience barriers to accessing healthcare and often receive inadequate end-of-life care (2,3). New international and national, dementia and palliative care framework aim to address inequities by promoting the early introduction of a palliative approach in dementia (4-6). While evidence supports policies to integrate a palliative approach into care, new outcome measures are needed to assess the quality of strategies (4,7).

Approximately 49.5% of deaths of persons with dementia occur in long-term care [LTC], making this the most common location for end-of-life care (8). It is concerning that 50% of caregivers of persons with dementia report feeling unprepared for end-of-life (9) because death preparedness predicts complicated grief and caregiver outcomes in bereavement (10,11). Fortunately, death preparedness can be modified through strategies supporting a palliative approach (10-12). Hence, assessing death preparedness (i.e. readiness for death)(13) should provide a holistic outcome measure for strategies consistent with a palliative approach.

A palliative approach is a philosophy that focuses on providing holistic care to promote quality-of-life and smooth transitions for persons with life-limiting illnesses and their families (7). A palliative approach aims to address common concerns during illness such as: disease and end-of-life management, spiritual care and grief (15). Hence, guidelines for implementing a palliative approach and associated outcome measures should incorporate a holistic, multi-dimensional perspective. However, guidelines for dementia often negate end-of-life management, grief/loss and spiritual care (16,17). Outcomes measures for strategies associated with a palliative approach are also lacking, and are often indirect, retrospective and limited to documentation of resuscitation status (17-19). Preparedness for death, rather, could be assessed as a prospective, direct outcome measure for strategies within a palliative approach.

Death preparedness is a multi-dimensional, dynamic and complex construct that has been defined as a "self-perceived cognitive, affective and behavioural quality or state to maintain self-efficacy and control in the face of loss and death" pp4 (20). Preparedness is described as having medical, psychosocial, spiritual and practical domains with underlying cognitive, affective and behavioural traits (see Figure 1)(10,21,22). Preparedness has been linked to end-of-life conversations, which supports the measurement of preparedness as a standardized, holistic outcome for strategies supporting a palliative approach (19,23,24).

Despite the multi-dimensional nature of preparedness, the construct is often assessed with a single-item or the generic Preparedness for Caregiving Scale (12,25,26). Assessing a construct with a single-item is problematic because single-item measures are: unidimensional, require abstract-thinking, have been shown to underestimate change and are occasion-specific, meaning that responses can change significantly based on a single-situation (26-28). In contrast, multi-item measures investigate dimensionality, allow the sampling of common core and unique variance in items, have been shown to have stronger predictive ability, are less occasion-specific, and demonstrate carry-over effect between items (27,28). Although there is potential for item redundancy and increased burden with multi-item questionnaires (27), investigating dimensionality is essential to identify critical domains of preparedness and tailor interventions.

Use of the generic Preparedness for Caregiving Scale (25) is currently the most common means of assessing caregiver death preparedness (12). While evidence for the validity of this scale has been demonstrated in the context of end-of-life (13), preparing for caregiving and preparing for death are not synonymous constructs. Generic questionnaires do not assess pertinent concerns associated with a specific condition, and are less responsive to detecting change over time (27-30). Condition-specific questionnaires rather, are purposefully developed to adequately sample the concept by addressing content and issues relative to a specific condition. Therefore, face validity and content validity are typically higher in condition-specific questionnaires (29,30). Hence, a multi-dimensional, multi-item, condition-specific questionnaire is needed to assess caregiver preparedness for the end-of-life of persons with dementia.

Aims

In this study we aimed to contribute a standardized, holistic, direct-outcome measure for strategies supporting a palliative approach. Objectives were to: identify preparedness indicators, develop and pilot-test the 'Caring Ahead: Preparing for End-of-Life with Dementia' questionnaire. A sequential, mixed methods study design was selected because the findings from phase 1 were needed to inform subsequent phases (30,31). The Good Reporting Criteria for a Mixed Methods Study was followed (32).

Methods and Results

This mixed methods study was guided by the Instrument Development and Construct Validation framework [IDCV] which describes a process for developing a questionnaire (31). We conducted previous work to conceptualize the construct of interest, develop the 'Caregiver Preparedness for End-of-Life of Persons with Dementia model (20) and build upon the 'Theoretical Framework of Preparedness for End-of-Life' (22). The current study used three phases (qual ->QUAN) to identify indicators and generate questionnaire items (Phase 1), select questionnaire items (Phase 2), and evaluate validity and response process (Phase 3)(see Figure 2). The study protocol was approved by the Hamilton Integrated Research Ethics Board (#4503) in May 2018. Informed, written consent was obtained for Phases 1 and 3, and implied consent was obtained for Phase 2.

Phase 1: Interviews to identify indicators and generate questionnaire items

Methods. A qualitative, interpretive descriptive approach was used to identify behaviours underlying preparedness to be used as indicators (31,33,34). Semi-structured interviews were completed with 16 bereaved caregivers of persons with dementia recruited from six LTC homes in Ontario, Canada during summer 2018. Data was analyzed using reflexive thematic analysis (33). A detailed report of the study is published elsewhere (21).

Results. Through the interviews, 114 potential preparedness indicators were identified indicating three underlying traits, four domains and three core concepts: 1) managing the situation; 2) fulfilling obligations; and 3) adapting to loss (21). Through discussion with one caregiver and one expert (nurse researcher in dementia/caregiving), the potential indicators were reduced to 73. A Content Validation Matrix was completed to ensure the items addressed all concepts, traits and domains of preparedness (30,31). Potential indicators were translated into 73 potential questionnaire items based on participant quotes. To reduce jargon, the term ‘psychosocial’ was replaced with ‘relationships and personal’ and domains were re-labelled as preparation subscales (30). Items were organized according to the primary domain they addressed to reduce respondents’ cognitive workload (30), although domains were not discrete. Less sensitive items were situated at the beginning of each subscale with sensitive items introduced gradually to minimize distress (30).

Phase 2: Delphi-survey to select questionnaire items

Methods. The guidelines for Conducting and Reporting Delphi Studies were followed to present 73 potential questionnaire items to one panel of caregivers and one panel of professional experts (35). The survey was administered through LimeSurvey, an online-survey platform in winter 2019 (36). The aim was to select, reduce and revise items for the questionnaire with face and content validity. The Delphi-survey is useful for determining collective values, obtaining feedback, equally valuing opinions and facilitating group interaction without face-to-face meetings, thus reducing social desirability bias (30,37). The survey was piloted with one caregiver, one expert nurse researcher, and two graduate students (35,37).

Professional experts and caregivers were invited via email to participate in the Delphi-survey on an expert or caregiver panel. Expert panelists were: 1) reputable professionals/researchers; 2) with greater than five years of experience; 3) in the field of dementia, caregiving and dying. Caregiver panelists were: 1) currently providing emotional, physical or financial care to persons with dementia living in LTC or were bereaved within three to 24 months. Caregiver panelists were known to us through organizational partnerships (i.e., Alzheimer Society, Canadian Frailty Network).

In Round 1, panelists rated the importance of items using a 7-point Likert scale with anchors (1=Strongly Disagree, 7=Strongly Agree) where a selected item (rated 6/7) was defined as one which was important to select for the draft questionnaire. Panelists provided suggestions regarding item wording (30,35,37). Criteria for item selection consensus was defined as: Content Validation Index [CVI] $\geq$ 0.8 and a median score of $\geq$6 from both panels. Achieving consensus from both panels ensures perspectives are equally valued, while defining CVI $\geq$ 0.8 and using multiple selection criteria efficiently reduces items (35,37).

In Round 2, panelists were provided with the item CVI, each panel's median score and the original item (if the wording was revised). Panelists 'accepted or rejected' (rated 0/1) items selected based on consensus in Round 1, and re-rated items (from 1-7) that had met partial criteria for consensus (i.e., CVI =0.75; median score of 7 from one panel). The survey was stopped when the item pool was reduced (34). Content analysis of panelist comments guided item revision and exclusion (33). Final analysis of the selected items with a Content Validation Matrix aimed to identify conceptual gaps in the draft questionnaire (20,22,30).

Results. Thirty persons were invited and 17 agreed to participate in the Delphi-survey including five caregivers and 12 experts (response rate 57%). No panelist attrition occurred between rounds. Recommendations for Delphi-survey sample size vary, however a sample of 15-20 participants has been described as adequate (30,37). Caregivers were 59 years old on average, 60% were female, 80% were adult-children or children-in-law of the person with dementia, and 60% were bereaved. Experts were 50 years old on average, had an average of 20 (SD12.6) years of experience and represented a variety of settings and disciplines (see Table 2).

In total 24 questionnaire items were selected based on consensus in the Delphi-survey. Suggestions from all panelists focused on clarifying the meaning of items, simplifying/ reducing item length and selecting/suggesting the pertinent examples to include with the item. Expert panelists also recommended to soften language/avoid distress. For example, ‘I am confident’ was perceived as too strong and was revised to ‘I believe’; and listing examples of potential changes to prepare for after death (e.g., moving houses, swallowing changes) was viewed as too distressing (see supplement file B for item revisions). A Content Validation Matrix of the selected items demonstrated conceptual gaps, particularly related to affective traits, and relationship/personal and spiritual domains (20,30). Therefore, we maintained an additional six items (see Figure 3). The draft questionnaire was comprised of 30 items organized into four subscales.

Phase 3. Pilot-testing and cognitive interviewing to evaluate face validity and response process

Methods. Pilot-testing and cognitive interviewing with the 30-item draft questionnaire were conducted with caregivers to explore face validity of the draft questionnaire (30,31). Cognitive interviewing is a process whereby participants: complete a questionnaire with an interviewer; explain their interpretation of questions and response process by ‘thinking-aloud’; and make suggestions to refine items to increase the face validity of items (30). Cognitive interviewing has been commonly used to develop and refine instruments including those in palliative care (30,38).

Current caregivers of persons with dementia who had not participated in earlier study phases (31) were recruited from three LTC homes in summer 2019. A semi-structured interview guide with questions such as, ‘what does this statement mean to you?’ and ‘what other ways would you say this statement?’ were used to explore participants’ response process (i.e., interpretation of items) to assess face validity (30). Field notes were used to record participant interpretations, response processes and suggestions, and data were analyzed through content analysis (33). Suggested items and the original items were presented to each subsequent participant.

Results. Three participants responded to flyers in LTC advertising the study. Participants ranged in age from 35 to 68 years old, were all female, and included one spouse, one adult-child, and one adult child-in-law of a person with dementia. Overall, participants perceived that the questionnaire content was acceptable (not distressing), relevant and applicable, the length was appropriate (not burdensome), and questionnaire instructions were clear. Participants stated their interpretation of items, reflected and described their personal response, and suggested item revisions. Based on this feedback, seven items were revised to: 1) clarify ambiguous items

(Question [Q]2, Q8, Q14, Q22, Q28); 2) identify preferential language (Q5, Q9); and 3) increase applicability/inclusivity of the items for diverse persons (Q7, Q19).

To clarify items, all three participants recommended adding examples and using universal direct language. Specifically assessing the knowledge of ‘what the dying process may be like for my family member’ (Q8) was perceived as important, and listing ‘changes to expect as dementia advances, for example: swallowing, eating difficulties’ (Q2) was recommended. Although these recommendations contrasted experts’ suggestions in the Delphi-survey, items were revised to increase face validity for the target population (i.e., caregivers).

Preferences for the word ‘wishes’ over the word ‘goals’ and ‘has died’ over the words ‘is gone’ were expressed. Participants perceived that the word ‘wishes’ was more familiar, personal and sensitive than the term ‘goals’ (Q5). Participants perceived that the word ‘gone’ was a euphemism and preferred clear communication. In addition, participants explained that many persons with dementia were cognitively unaware and had been ‘gone’ for a period of time before death (Q9) and therefore recommended replacing ‘gone’ with the words ‘has died’. To make items more inclusive and applicable to diverse caregivers, participants recommended adding the word ‘personal’ as an example of traditions (Q19), and the reference to ‘my family’ was revised to ‘people important to my family member’ (Q7). See Table 3 for final questionnaire items with Phase 3 revisions bolded.

Discussion

Main findings

The purpose of this mixed methods study was to identify indicators of preparedness, generate questionnaire items and develop the ‘Caring Ahead’ questionnaire. Questionnaire items were translated directly from participant quotes to indicate underlying traits, domains and core concepts of preparedness (20,22). The final questionnaire is comprised of 30 items organized into medical, relationship/personal, spiritual and practical subscales.

Strengths and limitations

Study strengths include following the IDCV framework to promote face, content and eventual construct validity in the questionnaire (31). As is recommended by the IDCV framework, we expanded or recruited a new participant sample in each subsequent study phase to legitimize (i.e., enhance the validity and reliability) findings from the previous phase (31). The IDCV framework has been used to develop the Transformative Experience Questionnaire and other instruments demonstrating evidence for validity and reliability during psychometric testing demonstrated (31,39). Hence, following the IDCV framework is a study strength that will promote validity and reliability during future psychometric evaluations.

Study limitations include the small sample size in the Delphi-survey compared to other Delphi-studies which have reported sample sizes over 50 (40). Also, the Delphi-survey response rate (57%) was lower than the recommended 70% and could result in response bias and instability (37). However, response stability has been demonstrated in Delphi-surveys with approximately 20 respondents, and mental health studies often have smaller sample sizes with adequate stability reported (37).

Future evaluative phases of the Caring Ahead questionnaire will be conducted with a sample of 200 caregivers, which aligns with sample sizes used in the majority of instrument development studies (41).

Participants were primarily female in this study, which may influence the transferability of the questionnaire to male caregivers. Similar sample demographics have been reported in other instrument development studies, including the Caregiver Grief Scale (42) and the Carer Support Needs Assessment Tool (43), which suggests this is a common phenomenon. Targeted recruitment of participants from male/other genders in future study phases is needed to explore transferability and sex and gender-based analysis (44).

What this study adds

New insight into preparedness indicators was gleaned through this study that will help to standardize measurement and further understanding of this construct. Preparedness indicators reflected problem and emotion-focused coping behaviours (e.g., information seeking) and the outcomes of such behaviours (e.g., having knowledge), which have previously been theorized as attributes and/or facilitators of preparedness (20,22,45,46) Problem-focused coping strategies outwardly address a problem whereas emotion-based strategies focus inward (47). Positive mental health outcomes (e.g., reduced depression) associated with caregiver preparedness have also been associated with problem-focused coping, emotional-support and acceptance (48). These associations support the validity of the preparedness indicators identified, and their relationship to mental health. Researchers and healthcare providers should therefore assess caregiver coping skills as indicators of preparedness related to positive health outcomes.

Insight into the language preferences of caregivers and experts related to dying was also gained from this study. Euphemisms are defined as language substitutions, replacements or social safeguards to soften words that are considered taboo or harsh (49). While, multiple experts in the Delphi-survey suggested items needed to be ‘softened’ or less harsh, caregivers perceived that euphemisms (e.g., is gone) impeded item clarity. Similar to the perceptions of caregivers in this study, euphemisms have been reported as: obscuring the truth, contributing to miscommunications, paternalistic and used to avoid end-of-life discussions (50,51,52). Experts in this study may therefore have been trying to demonstrate sensitivity while risking miscommunication/paternalism.

Healthcare providers’ use of clear language such as ‘imminent death’, ‘dying’ and ‘end of life’ is associated more often with a malignant diagnosis and with the involvement of palliative care providers (55). Hence, caregivers of persons with dementia may be more at risk of experiencing miscommunications around death. Internationally palliative care organizations are recommending that healthcare providers’ normalize death and use clear, universally-understood language (53,54). As such, questionnaires should incorporate clear terms such as ‘dying’ and ‘end-of-life.’ Future research is needed to further evaluate psychometrics (i.e., content/construct validity and reliability) in a larger sample, and with different populations.

Conclusion

A 30-item 'Caring Ahead' questionnaire to measure caregiver preparedness for death in dementia was developed in this study. This questionnaire aims to reflect the multi-dimensional nature of preparedness with items sampling underlying traits, domains and core concepts. Evaluation of the questionnaire with current caregivers of persons with dementia living in LTC is currently underway. Once tested, this questionnaire can be used by healthcare professionals, researchers and policy- makers as a holistic outcome measure for strategies supporting a palliative approach.

Declarations

Authorship

Each author participated in the design, analysis and reporting of this study in all three phases.

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Declaration of conflicts of interest.

None declared.

References

1. Mitchell S. Care of patients with advanced dementia. In Morrison R, Yaffe K, Wilterdink J. (eds.) *Up to date.* Wolters Kluwer, Up to Date Inc; 2019.
2. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics*. 2018;18(1): 189.
3. Kim Y, Schulz R. Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health.* 2008;20(5): 483-503.
4. Health Canada. *Framework on palliative care in Canada.* Available from: https://www.canada.ca/content/dam/hc-sc/documents/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada/framework-palliative-care-canada.pdf [Accessed 9 April 2020].
5. Public Health Agency of Canada. *A dementia strategy for Canada: Together we aspire.* Available from: https://www.canada.ca/content/dam/phacaspc/images/services/publications/diseases-conditions/dementiastrategy/National%20Dementia%20Strategy_ENG.pdf [Accessed 9 April 2020]
6. World Health Organization. *Global action plan on the public health response to dementia.* Available from:

https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=8A33E0C7F683E7AB2723BCD0FFE4A44C?sequence=1 [Accessed 9 April 2020]

7. World Health Organization. *WHO definition of palliative care.* Available from: https://www.who.int/cancer/palliative/definition/en/ [Accessed 9 April 2020]
8. Van der Steen JT, Radbruch L, Hertogh CM. de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: a delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*. 2014;28(3): 197-209.
9. Dasch B, Bausewein C, Feddersen B. Place of death in patients with dementia and the association with comorbidities: a retrospective population-based observational study in Germany. *BMC Palliative Care*. 2018;17(1): 80. Available from: https://doi.org/10.1186/s12904-018-0334-0
10. Terzakis K. Preparing family members for the death of a loved one in long-term care. *Annals of Long-term Care*. 2019;27(2): 25-31.
11. Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GK, Davies A. Predictors of complicated grief: a systematic review of empirical studies. *Death Studies*. 2010;34(8): 673-698.
12. Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review.* 2016;44: 75-93.

13. Henriksson A, Hudson P, Öhlen J, Thomas K, Holm M., Carlander I et al. Use of the preparedness for caregiving scale in palliative care: a rasch evaluation study. *Journal of Pain and Symptom Management*. 2015;50(4): 533-541.
14. Barry L, Kasl S, Prigerson H. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American Journal of Geriatric Psychiatry.* 2002;10(4): 447-457.
15. Canadian Hospice Palliative Care Association. *The way forward national framework: A roadmap for an integrated approach to care.* Available from: http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf [Accessed 9 April 2020].
16. Durepos P, Wickson-Griffiths A, Hazzan AA, Kaasalainen S, Vastis V, Battistella L et al. Assessing the palliative care content of dementia care guidelines: A systematic review. *Journal of Pain and Symptom Management.* 2016;53(4): 804-813.
17. McMahan, RD, Knight SJ, Fried TR, Sudore RL Advance care planning beyond advance directives: Perspectives from patients and surrogates. *Journal of Pain and Symptom Management.* 2013;46(3): 355-365.
18. Blondo PD, Lee LD, Davison SN, Simon JE, Advance Care Planning Collaborative Research and Innovation Opportunities Program. How healthcare systems evaluate their advance care planning initiatives: results from a systematic review. *Palliative Medicine.* 2016;30(8): 720-729.

19. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *Journal of Pain and Symptom Management*. 2018;55(1): 132-150.
20. Durepos P, Sussman T, Ploeg J, Akhtar-Danesh, N, Punia, H, & Kaasalainen, S. What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice & Palliative Medicine,* 2018;1-11.
21. Hebert R, Prigerson H, Schulz R, Arnold R. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. *Journal of Palliative Medicine.* 2006;9(5): 1164-1171.
22. Gonella S, Basso I, Dimonte V, Martin B, Berchialla P, Campagna S, Di Giulio P. Association between end-of-life conversations in nursing homes and end-of-life care outcomes: A systematic review and meta-analysis. *Journal of the American Medical Directors Association.* 2018;20(3): 249-261.
23. Schulz R, Boerner K, Klinger J, Rosen J. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine.* 2015;18(2): 127-133.
24. Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*. 1990;13(6): 375-384.

25. Durepos, P, Sussman, T, Ploeg, J, Akhtar-Danesh, N, Kaasalainen, S. "A crazy roller coaster at the end:" A qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nursing, 11:* 1-6.

26. Diamantopoulos A, Sarstedt M, Fuchs C, et al. Guidelines for choosing between multi-item and single-item scales for construct measurement: a predictive validity perspective. *Journal of the Academy of Marketing Science.* 2012;40: 434–449.

27. Gnambs T, Buntins K. The measurement of variability and change in life satisfaction. *European Journal of Psychological Assessment*. 2017;33: 224-238.

28. Page TE, Farina N, Brown A, Daley S, Bowling A, Basset T, et al. Instruments measuring the disease-specific quality of life of family carers of people with neurodegenerative diseases: a systematic review. *BMJ Open*. 2017;7(3): e013611.

29. Streiner D, Norman G, Cairney J. *Health measurement scales: A practical guide to their development and use.* 5th ed. Oxford: Oxford University Press; 2015.

30. Onwuegbuzie AJ, Bustamante RM, Nelson JA. Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research,* 2010;4(1): 56-78.

31. O'Cathain A, Murphy E, Nicholl J. The quality of mixed methods studies in health services research. *Journal of Health Services Research & Policy*. 2008;13(2): 92-98.

32. Braun V, Clarke V, Rance N. How to use thematic analysis with interview data

(process research). In A Vossler, N Moller (eds.), *The Counselling & Psychotherapy Research Handbook.* London: Sage Publications Inc; 2014.

33. Thorne, S. *Interpretive description: Qualitative research for applied practice* 2nd ed. New York: Routledge; 2016.
34. Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliative Medicine*, 2017;31(8): 684-706.
35. Limesurvey GmbH. *LimeSurvey: an open source survey tool, computer software.* Hamburg: Limesurvey GmbH. Available from: http://www.limesurvey.org [Accessed 9 April 2020].
36. Jorm A. Using the delphi expert consensus method in mental health research. *Australian & New Zealand Journal of Psychiatry.* 2015;49(10): 887-897.
37. Roberts K, Holland J, Prigerson HG, Sweeney C, Corner G, Breitbart W, et al. Development of the bereavement risk inventory and screening questionnaire (BRISQ): Item generation and expert panel feedback. *Palliative and Supportive Care,* 2017;15(1): 57-66.
38. Koskey KL, Sondergeld TA, Stewart VC, Pugh KJ. Applying the mixed methods instrument development and construct validation process: the transformative experience questionnaire. *Journal of Mixed Methods Research*, 2018;*12*(1): 95-122.

39. Sudore RL, Heyland DK, Lum HD, Rietjens JA, Korfage IJ, Ritchie CS, et al. Outcomes that define successful advance care planning: a delphi panel consensus. *Journal of Pain and Symptom Management*, 2018;*55*(2): 245-255.
40. Michels CT, Boulton M, Adams A, Wee B, Peters M. Psychometric properties of carer-reported outcome measures in palliative care: a systematic review. *Palliative Medicine*. 2016;30(1): 23-44.
41. Meichsner F, Schinköthe D, Wilz G. The Caregiver Grief Scale: development, exploratory and confirmatory factor analysis and validation. *Clinical Gerontologist*. 2016; 39(4): 342-361.
42. Ewing G, Grande G on behalf of the National Association for Hospice at Home. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care at home: a qualitative study. *Palliative Medicine.* 2012;27(3):244-256.
43. Arbel I, Bingham KS, Dawson DR. A scoping review of literature on sex and gender differences among dementia spousal caregivers. *The Gerontologist*. 2019;*59*(6): e802-e815.
44. Hebert R, Schulz R, Copeland V, Arnold R. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management.* 2009;37(1): 3-12.
45. Hovland-Scafe CA, Kramer BJ. Preparedness for death: how caregivers of elders with dementia define and perceive its value. *Gerontologist.* 2016;gnw092.

46. Rodríguez-Pérez M, Abreu-Sánchez A, Rojas-Ocaña MJ, del-Pino-Casado R. Coping strategies and quality of life in caregivers of dependent elderly relatives. *Health and Quality of Life Outcomes*, 2017;15(71): 1-8.
47. Gilhooly KJ, Gilhooly, MLM, Sullivan MP, McIntyre A, Wilson L, Harding E, et al. A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatrics*. 2016;16(106): 1-8.
48. Rawlings D, Tieman JJ, Sanderson C, Parker D, Miller-Lewis L. Never say die: death euphemisms, misunderstandings and their implications for practice. *International Journal of Palliative Nursing*. 2017;23(7): 324-330.
49. Breaux BO. The language of death and dying. *Rehabilitation Professional*. 2016;24(2): 57-68.
50. Danilina EA, Kizyan EE, Maksimova DS. Euphemisms in advertising discourse: putting on a positive face and maintaining speech etiquette. *Training Language and Culture*. 2019;3(1): 8-22.
51. Devlin M, Maida, V. The demon in deeming: Medical paternalism and linguistic issues in the palliative care setting. *Canadian Family Physician*, 2017;63(3): 191.
52. Litzelman DK, Inui TS, Schmitt-Wendholt KM, Perkins A, Griffin WJ, Cottingham, A, et al. Clarifying values and preferences for care near the end of life: the role of a new lay workforce. *Journal of Community Health*, 2017;42(5): 926-934.
53. Pallium Canada. *The words we use.* Available

from:https://www.pallium.ca/videos/ [Accessed 9 April 2020]

54. Wentlandt K, Toupin P, Novosedlik N, Le LW, Zimmermann C, Kaya E. Language used by health care professionals to describe dying at an acute care hospital. *Journal of Pain and Symptom Management.* 2018;56(3): 337-343.
55. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA statement. *PLoS Med.* 2009;6(7): e1000097. doi:10.1371/journal.pmed1000097

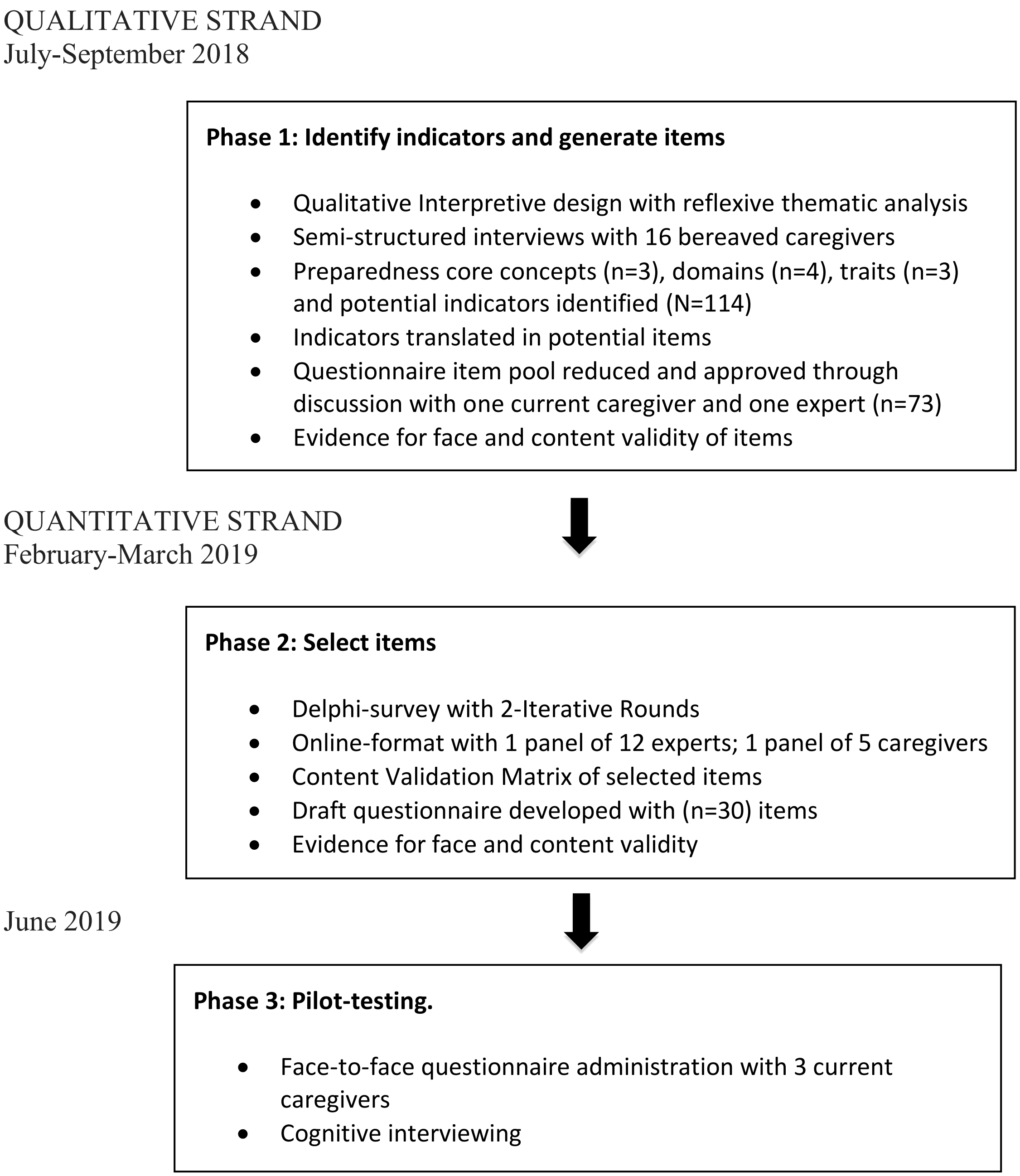
Figure 1. ‘Caregiver Preparedness for End-of-Life of Persons with Dementia’ model

Loss and Transition

Antecedents	Preparedness Attributes, Domains & Traits	Consequences
1. Living with Grief and Burden; 2. Illness-related event; 3. Advance Care Planning & End-of-Life communication with Care Providers; 4. Uncertainty about the Situation and the Future	**1. Medical:** Knowing and recognizing signs of decline and dementia, and what dying looks like; **2. Psychosocial:** Understanding emotions and grief responses; Accessing and appraising supports and relationships to manage, plan and provide care around death; 3. **Practical:** Organizing legal, financial and household affairs and completing tasks in advance; **4. Spiritual:** Accepting that losses are inevitable and imminent; Reflecting on caregiving and finding meaning, ‘a silver-lining’ Reconciling, renewing and closing a relationship; Completing the family member’s life; **5. Cognitive:** Information and support-seeking, problem-based coping; **6. Affective:** Emotional-regulation, reframing, avoidance/acceptance; emotion-based coping; **7. Behavioural:** Active task completion and planning, problem-based coping	1. Mental Health and Well-being after Death; 2. Adaptation and Adjustment in Bereavement; 3. Satisfaction with End-of-Life care and Quality of Dying for the person with dementia

Note reprint with permission from: Durepos et al. (2018) What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Care,* X(X), 1-11. DOI: 10.1177/1049909118814240

Figure 2. Mixed methods design: Exploratory, sequential quantitative dominant status, instrument-variant design (qual -> QUAN)



QUALITATIVE STRAND
July-September 2018

Phase 1: Identify indicators and generate items

- Qualitative Interpretive design with reflexive thematic analysis
- Semi-structured interviews with 16 bereaved caregivers
- Preparedness core concepts (n=3), domains (n=4), traits (n=3) and potential indicators identified (N=114)
- Indicators translated in potential items
- Questionnaire item pool reduced and approved through discussion with one current caregiver and one expert (n=73)
- Evidence for face and content validity of items

QUANTITATIVE STRAND
February-March 2019

Phase 2: Select items

- Delphi-survey with 2-Iterative Rounds
- Online-format with 1 panel of 12 experts; 1 panel of 5 caregivers
- Content Validation Matrix of selected items
- Draft questionnaire developed with (n=30) items
- Evidence for face and content validity

June 2019

Phase 3: Pilot-testing.

- Face-to-face questionnaire administration with 3 current caregivers
- Cognitive interviewing

Figure 3. Delphi-survey item flow.

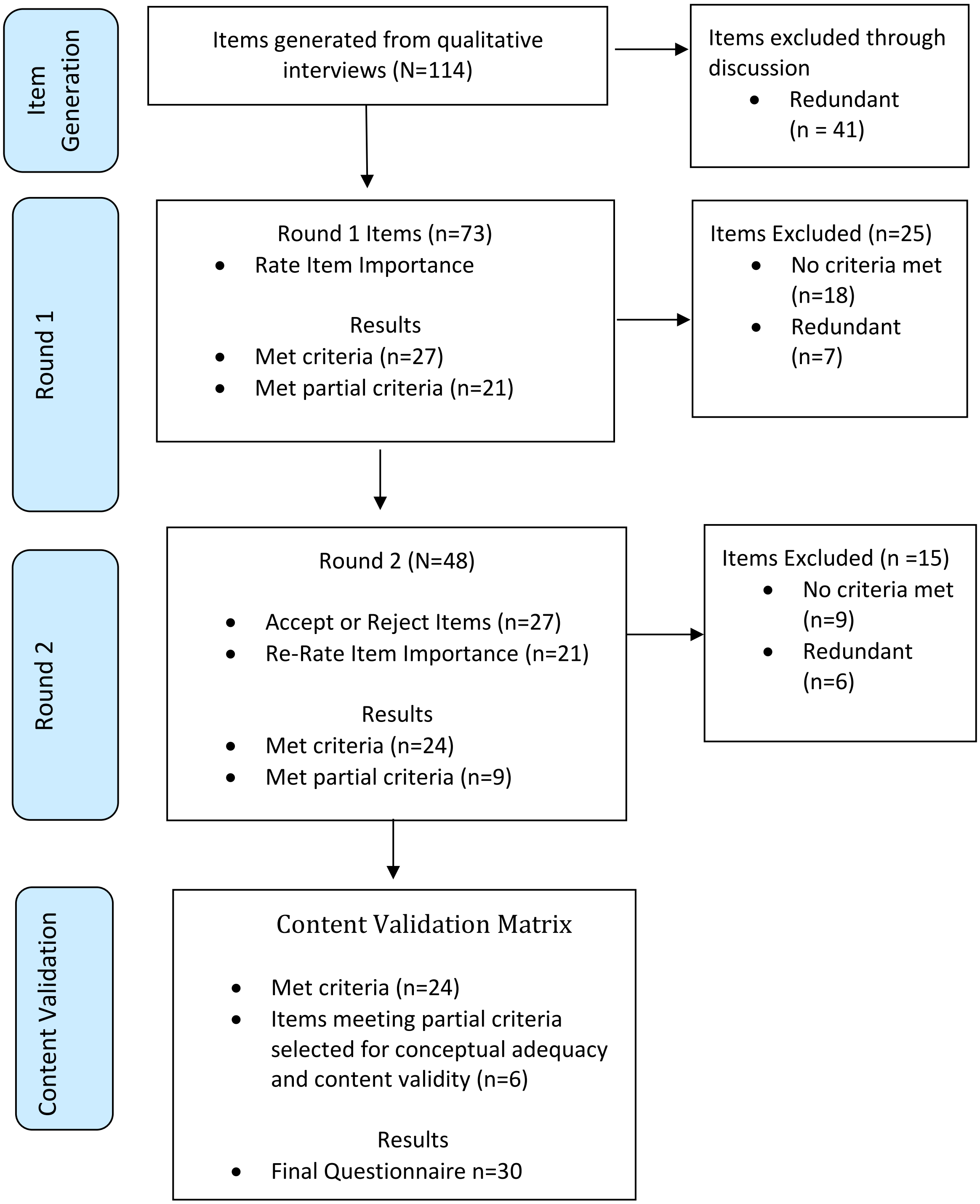


Table 1. Phase 1 Preparedness Indicators (n=73)

Domain/ Subscale	Indicators	Trait				Core Concept		
		Cognitive	Behaviour	Affective	Global	Control	Obligations	Adaptation
		Knowledge	Actions, skills, resources	Emotional-regulation, attitudes, beliefs, supports	All traits	Managing the situation	Fulfilling moral/legal obligations	Adapting to loss
Medical Preparations n=20	• knowing about dementia trajectory, potential treatment decisions, dying process, current health status, person with dementia's goals and preferences • communicating, organizing and planning to meet the person's needs and goals, seeking practical support/resources for care	5	3	1	1	7	1	1
Relationship/ Personal Preparations n=18	• knowing about grief, emotions and emotional-supports available • seeking emotional support, resolving/ having skills to cope with conflict, promoting quality-of-life, reconciling, closing and grieving the relationship with the person with dementia, arranging activities for life completion, practicing self-care	1	5	3	1	2	1	6

Domain/ Subscale	Indicators	Trait				Core Concept		
		Cognitive	Behaviour	Affective	Global	Control	Obligations	Adaptation
		Knowledge	Actions, skills, resources	Emotional-regulation, attitudes, beliefs, supports	All traits	Managing the situation	Fulfilling moral/legal obligations	Adapting to loss
Relationship preparations continued.	• feeling capable of fulfilling the caregiver role, emotionally supported, accepting personal limitations							
Spiritual Preparations n=20	• knowing the person with dementia's beliefs and preferred traditions, what spiritual support is available • arranging preferred traditions/practices, communicating traditions/practices to staff, planning to adapt to a new identity, reflecting on caregiving • feeling peace, there is meaning, purpose and positives in caregiving, moral obligations have been met, spiritually supported, accepting losses are imminent and inevitable	1	3	2	1	1	1	3

Domain/ Subscale	Indicators	Trait				Core Concept		
		Cognitive	Behaviour	Affective	Global	Control	Obligations	Adaptation
		Knowledge	Actions, skills, resources	Emotional-regulation, attitudes, beliefs, supports	All traits	Managing the situation	Fulfilling moral/legal obligations	Adapting to loss
Practical Preparations n=15	• knowing what after-death procedures/ policies must be followed, how to contact family, who to contact for legal support • seeking financial/legal support, organizing financial, legal affairs, arranging funeral/after-death services and memorials, communicating plans to staff, planning to manage household affairs after-death • feeling legal obligations have been met, affairs are in order	1	4	2	1	2	4	1

Table 2. Phase 2 Delphi-survey Panelists (n=17)

Caregiver Panel (n=5)		Mean (SD)	N (%)
Age (years)		58.8 (11.2)	
Gender Identity	Female		3 (60.0)
	Male		2 (40.0)
Relationship	Spouse		1 (20.0)
	Adult Child		2 (40.0)
	Adult Child in-law		2 (40.0)
Caregiver Status	Bereaved		3 (60.0)
	Current		2 (40.0)
Expert Panel (n=12)		**Mean (SD)**	**N (%)**
Age (years)		49.8 (13.7)	
Gender Identity	Female		10 (83.0)
	Male		2 (17.0)
Years Experience		20.2 (12.6)	
Discipline	Medicine		2 (17.0)
	Nursing		2 (17.0)
	Psychology		2 (17.0)
	Health Research		1 (7.0)
	Social Work		2 (17.0)
	Spiritual Care		2 (17.0)
	Law		1 (7.0)
Setting	Clinical/Community		6 (50.0)
	Academic/Research		6 (50.0)
Country	Canada		8 (67.0)
	Europe		1 (8.0)
	USA		3 (25.0)

Table 3. Phase 3 final questionnaire items (n=30)

		Core Concept	Trait	Source
Medical Preparations (n=9)				
1	I believe I understand my family member's current health status.	Control	Cog	C
2	I believe I know what changes to expect as dementia advances, for example: **swallowing, eating difficulties.**	Control	Cog	C
3	I understand I may be faced with decisions such as: transferring to hospital, treating infections.	Control	Cog	C
4	I believe I know what treatments my family member would choose.	Oblig	Cog	C
5	I have shared my family member's **wishes** with health care providers, for example: focusing on living longer, maximizing comfort.	Control	Beh	A
6	Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.	Control	Beh	A
7	I have discussed end-of-life care preferences with the **important people in my family member's life, for example: friends, family.**	Control	Beh	C
8	I have learned what the dying process may be like **for my family member.**	Control	Cog	A
9	I understand that dementia (and Alzheimer's) is a condition **that leads to death.**	Adapt	Aff	C
Relationships and Personal Preparations (n=8)				
10	I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.	Control	Beh	C
11	I would like to be more involved in planning care with health care providers.	Control	Beh	C
12	I accept that I am doing my best for my family member.	Adapt	Aff	C

13	I have someone to go to for emotional support about my family member's health.	Adapt	Aff	C
14	I understand what my grief process may be like after my family member **has died.**	Adapt	Cog	A
15	I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers.	Adapt	Aff	A
16	I am making the most of my time with my family member, for example: by saying what I need to say to them.	Adapt	Beh	C
17	I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.	Oblig	Beh	A
18	I am spending time reflecting on my family member's life, for example: by sharing stories.	Adapt	Beh	C
Spiritual Preparations (n=5)				
19	I have a plan to honour traditions or **practices** my family member would want, for example: **personal,** cultural, spiritual, religious.	Oblig	Cog	C
20	I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.	Control	Beh	C
21	I have someone I can talk to about the meaning of illness or dying.	Adapt	Aff	A
22	I worry about having purpose in my life after my family member **has died.**	Adapt	Aff	C
23	I am practicing activities which give me strength such as: spending time in nature.	Adapt	Beh	A
Practical Preparations (n=6)				
24	My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.	Oblig	Beh	C
25	I have someone I can contact if I need help managing my family member's affairs.	Adapt	Aff	C

Practical Preparations continued		Core Concept	Trait	Source
26	I know how to notify family and friends when my family member dies.	Control	Cog	C
27	After-death services are arranged for my family member such as: burial or cremation.	Oblig	Beh	C
28	I believe I can manage my personal affairs after my family member **has died,** for example: finances, housing.	Adapt	Beh	C
29	I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.	Oblig	Cog	C
30	I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.	Oblig	Beh	C

Note: Abbreviations: C=Consensus in delphi-survey; A=Authors maintained item from delphi-item pool to support conceptual adequacy and content validity as evidenced by Content Validation Matrix. Cog=Cognitive, Beh=Behavioural, Aff=Affective. Core Concepts: Control=managing the situation, Oblig=Fulfilling obligations, Adapt=Adapting to loss. **Bolded** words were revised based on pilot-testing and cognitive interviews.

Supplement Table A. Phase 1 indicators and items generated (n=73).

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q1	Med	Beh	Control	Information-seeking on dementia	"We worked really hard to educate ourselves about what was coming down the pipe"	I look for information to understand dementia in the later stages.
Q2	Med	Cog	Control	Knowing the trajectory of dementia	"I knew the progression of the disease…she stopped swallowing"	I feel confident I know what changes to expect in the future as my family member's dementia advances, for example: pneumonia, infections, increased behaviours or difficulty eating.
Q3	Med	Cog	Control	Knowing that dementia is incurable	"It is part of the acceptance. There is no going back, there's no cure."	I understand that dementia (including Alzheimers) is a life-threatening (fatal) condition with no cure.
Q4	Med	Cog	Control	Knowing what decisions may be needed	"We would not resuscitate her because that's not what she would want. But then we also didn't want…her in pain in a nursing home with a Urinary Tract infection that could be treated with IV. So, we need to be consulted each	I understand treatment decisions I may need to make for my family member, for example: using antibiotics, intravenous (IV) fluid, transferring to hospital, tubes for feeding or breathing.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
					time something comes up so we can make that decision”.	
Q5	Med	Cog	Control	Knowing about causes of dying with dementia	“I kind of knew…that Pneumonia is a common thing with the elderly.”	I understand that dying from an infection like pneumonia, is a natural way to die for a person with dementia.
Q6	Med	Cog	Control	Understanding medical information provided by staff	“The nurses and doctors were also very good at dumbing things down because they do it a lot.”	Care providers explain medical information in a way that I can understand, for example: printed pamphlets, face to face discussion.
Q7	Med	Cog	Control	Knowing about current health status	“[Staff] were very forthright about what was happening… and helped to prepare us every step of the way.”	I feel I understand my family member's current state of health, for example: their stage of dementia.
Q8	Med	Cog	Control	Recognizing decline	“I saw that the week or two before that she was eating less and less and having a harder time swallowing...I was sort of prepared and knew what was going to happen.”	I recognize decline in my family member's health, for example: eating less, less social, behaviour changes (more or less).
Q9	Med	Cog	Oblig	Knowing the person’s goals	“Know what your loved ones wishes are…”	I feel confident I know what my family member would choose for care if they could, for

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
						example: to focus on lengthening life, comfort / quality of life, or a combination of both.
Q10	Med	Beh	Control	Discussing goals with staff	“[Staff] were good at asking us what we wanted and guiding us to be realistic…right from the beginning”	Care providers and I have discussed my family member's wishes and goals for the end-of-life, for example: to focus on lengthening life, comfort / quality of life, or a combination of both.
Q11	Med	Beh	Control	Discussing goals with family	“It was a family decision…we decided we will treat him with whatever happens in the home”	My family and I have discussed possible treatments or goals for our family member with dementia, for example: prolonging life, transferring to hospital, focusing on quality of life, dying in the care facility.
Q12	Med	Beh	Control	Discussing care preferences with staff	“The head Nurse told me that unless I wanted him to go to hospital there was nothing they could do and that if he went to hospital, they would start all kinds of interventions, which she didn’t recommend”.	Care providers and I have discussed preferences around hospital transfer for treatments if issues arise.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q13	Med	Beh	Control	Planning care to meet needs with staff	"I knew we wouldn't let him be uncomfortable…"	Care providers and I have discussed a plan for keeping my family member comfortable in his/her last hours, for example: treating pain or restlessness.
Q14	Med	Cog	Control	Knowing the person's prognosis	"He said, 'it sounds like he is palliative' and it was just reassuring to hear that."	Care providers and I have discussed how long my family member may live.
Q15	Med	Beh	Control	Discussing communication preferences	"Whenever there was any change…we were notified of that…I liked that."	Care providers and I have discussed how I should be notified if my family member is dying, for example: call anytime, call only during the day.
Q16	Med	Beh	Control	Confident in skills to provide care	"I intuitively know what people with dementia need…I moved a bed into her room. I changed everything around. I got a lavender thing. I put classical music in there. I put pictures up that she knew. I just made it as cozy as I possibly could".	I feel confident that I can help care for my family member when they are dying, in the way that I would like.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q17	Med	Cog	Control	Knowing about the dying process	"People need to know what to expect. They're going to make raspy breathing sounds."	I understand the process of dying, for example: noisy 'rattling' breathing, pale / cool skin, stopping eating, restlessness or drowsiness.
Q18	Med	Beh	Control	Discussing death location with staff	"We…talked to the nursing home about resuscitation….If we had a preference it would have been to pass away in the nursing home versus a hospital setting."	Care providers and I have discussed the location where I would like my family member's death to occur.
Q19	Med	Beh	Control	Discussing preferences for dying (e.g., pain management) with staff	"I did suggest to [staff] they have a cot or something…if people want to stay..."	Care providers and I have discussed my preferences for when my family member is dying, for example: having a cot in the room, having music, having a private room, not wanting them to be alone, wanting to be present or not.
Q20	Med	Global	Control	Global Medical Preparedness		Overall, I feel prepared for medical changes which might occur when my family member is dying.
Q21	Rel	Aff	Adapt	*Limited support from	"Surround yourself with support…When you're alone you're just	I do not feel I will receive enough support from family and friends around my family

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
				family for care	anxious…You don't know what your loved one is going to need".	member's death, for example: making decisions, providing hands-on care. *reverse worded item
Q22	Rel	Aff	Adapt	*Concern for conflicts in care with family/ friends	"Everyone just kind of shied away from the conflict…Families need to have some guidance in how to have those difficult conversations".	I expect there will be conflicts (i.e., disagreements) in my family around my family member's death. *reverse worded item
Q23	Rel	Beh	Control	Confident to meet needs of the person with dementia	"This is my specialty…we were checking all the boxes…"	I feel confident in my responsibilities for my family member in their care facility, for example: decision-maker, companion, hands-on-care provider.
Q24	Rel	Beh	Control	Advocating for the person with dementia	"You have to take the leadership role and be the advocate".	I am confident that I can be a strong advocate for my family member's needs.
Q25	Rel	Beh	Control	Managing the situation	"You know that meant a lot having everything just the way you want it…it comes down to being able to be in control of what you need and want that really was important".	I feel I have some control over the care of my family member.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q26	Rel	Aff	Control	Trusting staff with care	“The charge nurse…had her finger on everything.”	I feel confident that care providers will provide quality end-of-life care for my family member.
Q27	Rel	Aff	Control	*Limited collaboration with staff	“You can’t rely on the staff.”	I do not feel satisfied with the relationship I have with my family member's care providers. *reverse worded item
Q28	Rel	Aff	Control	Feeling staff are accessible	“Communication is the key to everything right? I mean when you feel informed you feel a little more in control.”	I feel confident that I can speak to care providers when I would like to.
Q29	Rel	Aff	Adapt	Feeling emotionally supported by staff	“Everybody needs support of people around them…there were some staff there that were really good at listening to myself, my sister and my wife.”	I feel confident that I will receive enough emotional support from care providers when my family member is dying, for example: by listening to my concerns, providing words of comfort or being present.
Q30	Rel	Aff	Adapt	*Feeling concern over conflicts with staff	“They basically said, ‘we need you to come pick up your mom’s furniture’…it was really upsetting…not an hour after the funeral”.	I expect to have conflict (i.e., disagreements) with care providers around my family member's death. *reverse worded item

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q31	Rel	Global	Control	Having supportive resources to prepare for death	"[Staff] helped to prepare us every step of the way."	Overall, care providers are supportive in helping me prepare for my family member's death.
Q32	Rel	Cog	Adapt	Recognizing your emotions	"I think you know really we're in a quiet mourning even when they're still around at the end…I think that's something that's good for people to know."	I recognize that I may be grieving before my family member with dementia has died.
Q33	Rel	Cog	Adapt	Knowing what emotions to expect	"I was surprised that I was so grief stricken by it."	I understand that I may experience strong emotions that are normal when my family member dies, for example: intense grief, numbness, relief or shock.
Q34	Rel	Beh	Adapt	Feeling capable to cope with emotions	"Giving into the grief was important. Allowing myself to feel the grief and the sadness and 'go into the feeling'…not to avoid the feelings, to go in to them and to go through them…let myself be sad. Again, I turned down so many invitations".	I feel confident that I can cope with emotions (e.g., grief) I may experience.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q35	Rel	Aff	Adapt	Having access to emotional support	“Everybody should take advantage of counselling.”	I can access additional emotional support if I need to, for example: from a support group or counsellors.
Q36	Rel	Beh	Adapt	Reconciling and closing the relationship with the person with dementia	“Tell them what you want to tell them. Do what you have to do to be free of any guilt, remorse, regret. Tell them the truth. Even if you don’t think they can hear you, tell them the truth…say what you need to say.”	I have said the things I needed to say to my family member.
Q37	Rel	Aff	Adapt	Accepting changing relationship	“I was ready to let that go”	I feel prepared to let go of my family member.
Q38	Rel	Beh	Oblig	Valuing the family member’s life	“I have absolutely no regrets...I treated her like a queen”	I am satisfied with how much time I am able to spend with my family member.
Q39	Spirit	Aff	Adapt	Accepting death is imminent	“She was 93 so I really knew it could be any time.”	I have accepted that my family member's time may be short.
Q40	Spirit	Aff	Adapt	Accepting death is inevitable	“You knew he was going to die you just didn’t know when”	I have accepted that I cannot change my family member's future.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q41	Spirit	Aff	Adapt	*Avoiding thinking about death	"I went on thinking, he's just never going to die, I'm never going to have to deal with it…I just ignored it all the time so that when it actually occurred I was in shock".	I avoid thinking about my family member's death. *reverse worded item
Q42	Spirit	Beh	Adapt	Reflecting on caregiving and finding positives	"I think you have to find the purpose and the meaning in things because it's part of healing".	I recall positive moments that occurred during my time as a caregiver.
Q43	Spirit	Aff	Adapt	Accepting personal limitations	"I've spent a lot of time forgiving myself…my smart brain knows there's nothing more I could do…I did my best."	I have accepted that I have done my best as a caregiver for my family member.
Q44	Spirit	Aff	Adapt	Finding meaning in caregiving	"I have only gratitude and I think having the experience of being a caregiver has been good for me, really good for me".	I feel I have grown as a person through caregiving.
Q45	Spirit	Beh	Adapt	Coping with emotions	"It helped…having my faith…I would talk to God and the angels a lot…It was a spiritual experience. Just being there with him	I can practice activities which help me to feel at peace if I want, for example: spending time in nature, reflective time or prayer.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
					it was so peaceful….and it meant so much just to be outside.”	
Q46	Spirit	Aff	Adapt	Finding meaning in death	“I knew she was ready. She lived a good life and what she wanted to die.”	I can make sense of my family member's death.
Q47	Spirit	Cog	Oblig	Having a plan to follow traditions/ practices	“I never forgot anything...I brought Holy Ash everyday”	I have a plan to honour spiritual, cultural or religious traditions that my family member would want around dying, if any.
Q48	Spirit	Beh	Control	Discussing plans for traditions/ practices with staff	“There was pressure…but one person at [LTC] was really great at getting that in place...a priest that did come and gave my Mom her Last Rites”.	Care providers and I have discussed my wishes for cultural, religious or spiritual traditions around death, for example: prayers or blessings, opening a window for the spirit.
Q49	Spirit	Aff	Adapt	Feeling spiritual support is available	“The [staff] asked me…I had an idea of what I wanted. I brought the Minister in three times…the same Minister that I knew and there was some continuity there…I texted him all the time.”	I have someone to ask for help in planning spiritual, cultural or religious traditions around death if wanted.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q50	Spirit	Aff	Oblig	Feeling life is complete	"I knew she was ready. She lived a good life and what she wanted to die".	I feel that my family member's life is complete, for example: they have no unfinished business.
Q51	Spirit	Aff	Adapt	Feeling spiritually supported	"I went to Synagogue that next year…I said to our Rabbi the other day 'I felt different'… this overwhelming sense, like…I'm the head of my family…there's just this emptiness".	I have someone to talk to if I have concerns about the meaning of illness, death or dying.
Q52	Spirit	Aff	Adapt	Believing a spiritual relationship with the person can continue after death	"Their light kind of lives in everybody…There's probably not a week that goes by that something doesn't come up with my Mom as part of that conversation still".	I feel confident that I can maintain a bond (i.e., connection) with my family member after they are gone, if I want to.
Q53	Spirit	Aff	Adapt	Feeling comfortable with existential beliefs	"He was a believer…there's some comfort in sort of the thought that he felt he was going to probably a better world".	I do not worry about where my family member will go when they die, for example: afterlife.
Q54	Spirit	Beh	Oblig	Planning ways to	"I had thought about the memorial through the last	I have a plan to remember my family member, for example:

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
				complete and value the person's life	year…I gave the Eulogy and that gave me a lot of satisfaction…just writing it helped me focus my feelings".	obituary, donation, sharing their belongings.
Q55	Spirit	Aff	Adapt	Accepting uncertainty	"You can't plan 100%, but maybe just some conversations around what you may expect and…what's normal could help people."	I have accepted that I cannot plan everything for the future.
Q56	Spirit	Aff	Adapt	Believing you can adapt to a new identity	"In some ways it's a relief…I mean my purpose was the kids and I worked…maintain a hobby…make an obvious effort to find something."	I feel confident that I can adapt to a new life without my family member.
Q57	Spirit	Aff	Adapt	Feeling life will have purpose after death	"You wake up in the morning and you don't have a purpose. What do you do? Like the little birds have left the nest, the wife is gone…that's it. That's what you're on earth for right."	I feel that my life will have no meaning or purpose after my family member is gone. *Reverse worded item
Q58	Spirit	Global	Adapt	Feeling spiritually	"I was calling God to take her. So she was in no more	Overall, I feel at peace with my family member dying.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
				prepared for death	pain. She would not go hungry. She was not thirsty. She was in good hands and I was so happy. …when she died…I felt peace."	
Q59	Pract	Beh	Oblig	Arranging after-death services for the body	"We agreed that we would be cremated…have a plan in place that can be acted on".	I have planned my family member's burial or cremation with service providers, for example: funeral director, direct-deposition service, crematorium.
Q60	Pract	Beh	Oblig	Arranging practices to close the person's life	"I arranged a prayer service…you felt like you had done right by her…and by…yourself".	I have planned my family member's funeral, memorial or celebration service, if wanted.
Q61	Pract	Beh	Control	Discussing after-death services with staff	"[Staff] made it clear that they needed to have arrangements made so that could be dealt with when he passed. They gave us a couple of options for local service providers…I was so thankful to have those arrangements in place".	Care providers in the facility are aware of the services planned for my family member after death, for example: funeral home / direct-deposition.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q62	Pract	Cog	Control	Knowing how to contact family/friends after death	“Trying to get in touch with everybody….How do I get in touch with her friends who aren’t on email?...It would have been nice to have a list you know like you do when you have a baby coming? But… people don’t want to think about it.”	I know how to notify family and friends when my family member dies.
Q63	Pract	Aff	Adapt	Feeling concerned over family conflict after-death	“We had this fight…about giving up the Attorney of Property. And he did finally…I only had a narrow window to see what was going on with his accounts…”	Our family does not agree on how our family member's affairs should be settled, for example: financial, estate, legal. *Reverse worded item
Q64	Pract	Cog	Oblig	Knowing about after-death processes	“They told us right in the beginning…we give you two days to remove your contents, it wasn’t obnoxious or anything…”	I understand the policies in the care facility for after my family member's death, for example: removing belongings, final payments and timeline.
Q65	Pract	Beh	Oblig	Organizing legal affairs	“We had settled our wills some time ago. I mean all the practical things have been done”.	My family member's legal documents are organized, for example: will, insurance, birth certificate.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q66	Pract	Beh	Oblig	Organizing financial affairs	"As much as you…as they get older, get all those things in order. Get all the account numbers, get all the passwords. Join all the accounts…so then there's no problems or issues with getting access."	My family member's financial affairs are in order for after-death, for example: bank accounts, credit cards, pension payments, properties owned, investments, income.
Q67	Pract	Cog	Oblig	Knowing about legal affairs	"We went in and we had Powers of Attorney drawn up for property and for… care…that…turned out to be a good move".	I know who my family member's Power of Attorney is for Finances and Care.
Q68	Pract	Aff	Adapt	Knowing who to contact for support with affairs	"Luckily, they had also an accountant, so we were able to pull some stuff from the accountant. The accountant would flag some stuff, 'we need this, this and this too for taxes".	I know who to contact if I need help managing my family member's affairs, for example: legal, financial.
Q69	Pract	Cog	Oblig	Knowing how to settle an estate	"The State Departments and Trust companies… People aren't even aware of that stuff…this was the first time I'd gone through all that…it's a struggle".	I understand the process for settling my family member's estate after-death, for example: notifying government agencies, closing bank accounts.

Question	Subscale	Trait	Core Concept	Indicator	Quote	Initial Item
Q70	Pract	Beh	Adapt	Feeling confident you can manage your household affairs	"To have to worry about your finances on top of everything else that's just an added stress…I was fortunate enough not to worry about any of that."	I feel confident I can manage my personal affairs after my family member is gone, for example: enough money to pay bills, ability to move homes if needed.
Q71	Pract	Aff	Control	Feeling a sense of control	"Every decision I made, it just felt so good that everything worked out just the way I wanted."	I feel in control of my life.
Q72	Pract	Beh	Adapt	Planning for new identity	"I'd say I'm in transition in some ways…trying to downsize."	I am planning for my future after my family member is gone.
Q73	Pract	Global	Oblig	Feeling practically prepared for death	"We had settled everything years ago…everything was set."	Overall, I feel prepared to manage my family member's affairs after they are gone.

Note. Abbreviations: Subscales: Med=Medical, Rel=Relationship/Personal, Spirit=Spiritual, Pract=Practical. Traits: Cog=Cognitive, Beh=Behavioural, Aff=Affective. Core Concepts: Control=managing the situation, Oblig=Fulfilling obligations, Adapt=Adapting to loss.

Supplement Table B. Items selected for the draft questionnaire from Phase 2 (n=30).

Revised Item #	Previous Item #	Domain	Trait	Core Concept	Indicator	Revised Item
1	Q7	Med	Cog	Control	Knowing about current health status	I believe I understand my family member's current health status.
2	Q2	Med	Cog	Control	Knowing the trajectory of dementia	I believe I know what changes to expect as dementia advances.
3	Q4	Med	Cog	Control	Knowing what decisions may be needed	I understand I may be faced with decisions such as: transferring to hospital, treating infections.
4	Q9	Med	Cog	Oblig	Knowing the person's goals	I believe I know what treatments my family member would choose.
5	Q10	Med	Beh	Control	Discussing goals with staff	I have shared my family member's goals with health care providers, for example: focusing on living longer, maximizing comfort.
6	Q11	Med	Beh	Control	Discussing goals with family	I have discussed end-of-life care preferences with my family members.
7	Q12	Med	Beh	Control	Discussing care preferences with staff	Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.
8	Q17	Med	Cog	Control	Knowing about the dying process	I have learned what the dying process may be like.

Revised Item #	Previous Item #	Domain	Trait	Core Concept	Indicator	Revised Item
9	Q3	Med	Adapt	Aff	Knowing that dementia is incurable	I understand that dementia (including Alzheimers) is a terminal condition.
10	Q23, 24	Rel	Beh	Control	Organizing care	I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.
11	Q25	Rel	Beh	Control	Managing the situation	*I would like to be more in control over my family member's situation.
12	Q43	Rel	Aff	Adapt	Accepting personal limitations	I accept that I am doing my best for my family member.
13	Q29, 35	Rel	Aff	Adapt	Having emotional support from staff and family	I have someone to go to for emotional support when my family member is dying.
14	Q33	Rel	Cog	Adapt	Knowing what emotions to expect	I understand what my grief process may be like after my family member has died.
15	Q22, 30	Rel	Aff	Adapt	Concern over conflict with staff or family/friends	*I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers.
16	Q36	Rel	Beh	Adapt	Reconciling and closing the relationship with the person with dementia	I am making the most of my time with my family member, for example: by saying what I need to say to them.

Revised Item #	Previous Item #	Domain	Trait	Core Concept	Indicator	Revised Item
17	Q50	Spirit	Beh	Oblig	Helping to complete life	I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.
18	Q54	Spirit	Beh	Adapt	Reflecting on the person's life and legacy	I am spending time reflecting on my family member's life, for example: by sharing stories.
19	Q47	Spirit	Beh	Oblig	Planning to follow spiritual/ cultural/ personal traditions or beliefs	I have a plan to honour traditions or practices my family member would want, for example: cultural, spiritual, religious.
20	Q48	Spirit	Beh	Control	Discussing spiritual care with staff	I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.
21	Q51	Spirit	Aff	Adapt	Feeling spiritually supported	I have someone I can talk to about the meaning of illness or dying.
22	Q57	Spirit	Aff	Adapt	Feeling life will have purpose after death	*I worry about having purpose in my life after my family member is gone.
23	Q45	Spirit	Beh	Adapt	Coping with emotions	I am practicing activities which give me strength such as: spending time in nature.
24	Q65, 66, 67	Pract	Beh	Oblig	Organizing affairs	My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.
25	Q68	Pract	Aff	Adapt	Having support for family affairs	I have someone I can contact if I need help managing my family member's affairs.

Revised Item #	Previous Item #	Domain	Trait	Core Concept	Indicator	Revised Item
26	Q62	Pract	Cog	Control	Knowing how to contact family/friends after death	I know how to notify family and friends when my family member dies.
27	Q59	Pract	Beh	Oblig	Arranging after-death services for the body	After-death services are arranged for my family member, such as: burial or cremation.
28	Q70	Pract	Beh	Adapt	Feeling confident you can manage your personal household affairs	I believe I can manage my personal affairs after my family member is gone, for example: finances, housing.
29	Q64, 69	Pract	Cog	Oblig	Knowing about after-death processes	I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.
30	Q60	Pract	Beh	Oblig	Arranging practices to close the person's life	I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.

Note: Abbreviations. Domains/subscales: Med=medical; Rel=relationships/personal; Spirit=spiritual; Pract=practical. Traits: Cog=cognitive; Beh=behaviour; Aff= affective; Global= all traits; Core Concepts, Control=managing the situation; Oblig=fulfilling obligations; Adapt=adapting to loss. *=reverse coded (i.e., negatively worded) item. 1=Item previously included in spiritual domain, moved to relationship/personal domain.

Chapter 6

Evaluation of the Caring Ahead: Preparing for End-of-Life with Dementia Questionnaire[5]

[5] Durepos, P., Akhtar-Danesh, N., Sussman, T., Ploeg, J., & Kaasalainen, S., Evaluation of the caring ahead: Preparing for end-of-life with dementia questionnaire. Prepared for submission to*: Journal of Pain and Symptom Management, September 2020.*

Abstract

Context Persons with dementia and their family caregivers are often not supported within a palliative approach which results in suboptimal care at end-of-life. New holistic measurement tools are needed to identify caregivers with limited preparedness for end-of-life and assess the effectiveness of strategies supporting a palliative approach.

Objectives The objective of this study was to evaluate evidence for the validity and reliability of the new Caring Ahead: Preparing for End-of-Life with Dementia multidimensional questionnaire, which aims to measure current caregiver death preparedness.

Methods We used a cross-sectional survey design for instrument evaluation and validation. Data were collected through the postal mail using a paper-format 30-item questionnaire from a sample of 134 family caregivers of persons with dementia living in congregate living facilities (long-term care and assisted living facilities accommodating a high level of needs). Principal components analysis with factor extraction and correlations with a single-global preparedness item were assessed for evidence of validity. Reliability coefficients were calculated based on a test-retest with 32 participants and the internal consistency of factor subscales.

Results The final revised questionnaire consisted of 20-items with four underlying preparedness factors: 1) Actions (7 items), 2) Dementia Knowledge (5 items), 3)

Communication (4 items) and 4) Emotions and Support Needs (4 items). The four-factor subscales demonstrated strong internal consistency (Cronbach's alpha > 0.7), item-total correlations > 0.5 and Intraclass Coefficients > 0.7 in the test-retest. Correlations between factor subscales and a single-global preparedness item (0.44-0.55, p<0.001) provided evidence for concurrent validity.

Conclusion The study findings support preliminary evidence for internal structure and concurrent validity and reliability of the Caring Ahead questionnaire. This questionnaire makes an important contribution to clinicians, researchers and policy-makers working to improve a palliative approach for family caregivers of persons with dementia.

Key Message This article describes the evaluation of psychometrics of the new Caring Ahead: Preparing for End-of-Life with Dementia questionnaire developed to assess death preparedness in family caregivers of persons with dementia. Results indicate preliminary evidence of the questionnaire's factor structure, concurrent validity and reliability.

Introduction

The global prevalence of dementia is currently estimated at 50 million and is expected to continue to rise as the population ages[1]. Dementia is an unpredictable, often progressive, life-limiting neurological disorder that impacts both the person living with dementia and at least three family members/friends[2]. The majority of care for persons with dementia is provided by family members and friends who act as informal (i.e., unpaid) caregivers, providing physical, emotional and financial care[3]. The burden associated with caregiving increases as dementia progresses, accumulating at end-of-life and negatively impacting caregiver's bereavement[4,5]. Due to the life-limiting nature and unpredictable trajectory of dementia, a palliative approach focused on optimizing quality-of-life, smoothing transitions, and preparing caregivers for end-of-life is strongly recommended[6].

The majority of deaths from dementia occur in congregate living facilities like long-term care [LTC] and persons with dementia and their caregivers often do not receive a palliative approach[7,8]. As many as 50% of family/friend caregivers have reported feeling unprepared for the death of their family member with dementia, even after a long duration of illness[9,10]. This is concerning because negative outcomes (e.g., complicated grief, depression and anxiety) are prevalent in caregivers of persons with dementia and are even greater when they are not prepared for the death[11,4]. Fortunately, feelings of death preparedness (i.e., readiness and awareness) can be offset if families are provided with support and information early on in the trajectory of dementia[12-16].

A single-global preparedness item, "If your loved one were to die soon, how prepared would you be for his/her death?" (p.127)[16,17] has previously been used to measure preparedness, explore the effectiveness of interventions and determine the relationship between preparedness and outcomes in bereavement. However, a single-item measure is limited when exploring multiple dimensions of preparedness to discern areas of need[18]. Therefore, a multidimensional, holistic questionnaire is needed to act as an outcome measure for strategies supporting a palliative approach[19-20]. Hence, the authors completed a mixed methods study guided by the Instrument Development and Construct Validation Framework [IDCV][23] to develop a holistic, patient-reported questionnaire measuring death preparedness with evidence for face and content validity (Onwuegbuzie, 2010).

In 2006, Hebert et al. published the 'Theoretical Framework for End-of-Life'[14] hypothesizing that death preparedness had three underlying traits (i.e., cognitive, behavioural and affective) and four domains (i.e., medical, psychosocial, spiritual and practical). Expanding upon Hebert et al.'s (2006)[14] work and clarifying the concept of preparedness through a concept analysis, the authors developed the 'Caregiver Preparedness for EOL of Persons with Dementia' model[24]. Preparedness was defined as: "a self-perceived cognitive, behavioural and affective quality or state to maintain self-efficacy and control in the face of loss and death" (p4)[24]. To operationalize preparedness as a theoretical construct and generate measurable indicators (i.e., items) for a questionnaire[23,25] the authors completed qualitative semi-structured interviews with bereaved caregivers. Three core concepts comprising preparedness were identified: 'A Sense of Control: Managing the Situation', 'Doing Right: Fulfilling Moral and Legal Obligations' and 'Coming to Terms: Adapting to Loss,' as well as 114 preparedness indicators[26]. Through a Delphi-survey of professional experts, caregivers and subsequent pilot-interviewing, the authors developed the 30-item Caring Ahead questionnaire[27].

Therefore, the aims of this study were to evaluate/generate evidence for: 1) validity (internal structure and concurrent); and 2) reliability (internal consistency and stability over time) in the Caring Ahead questionnaire. This paper follows the recommended guidelines for the reporting of reliability and agreement studies [GRRAS] from the Equator Network[28].

Methods

A cross-sectional survey design was used to perform a field-test[23] and evaluate the initial psychometric properties of a questionnaire to assess preparedness for death in family caregivers of persons with dementia (see Figure 1). A pen and paper questionnaire format was selected because literature suggests it is accessible and preferred by caregivers over 65 years of age who comprised a large proportion of our target sample[29,30,25]. This study was approved by the Hamilton Integrated Research Ethics Board #4503.

Recruitment and Data Collection

Participants were eligible for participation if they were: family/friend caregivers over 18 years old, could read English, and were providing emotional, physical or financial care to a person living with dementia in a congregate living facility (i.e., residential facility providing 24-hour care to meet moderate to high needs)[29,23,31]. A sample of 100 to 200 participants was recommended as adequate for statistical analysis based on correlation in this study[32] (p310). Participants were recruited through advertising, scripted telephone calls and emails to potential participants from administrative/clinical staff and family councils in long-term care homes, provincial/national associations for caregivers, persons with dementia, seniors and long-term care facilities (e.g., British Columbia Caregivers; Alzheimer Society; AdvantAge Non-Profit homes). A study website and social media (e.g., Facebook, Twitter) were also used for advertising and recruitment[29].

Potential participants were contacted by a person known to them (e.g., staff, family council member, LTC volunteer) to minimize distress and researcher intrusion[33]. If interested in participating, the authors mailed participants the pen-paper Caring Ahead questionnaire along with a demographic form, implied consent statement, emotional support resource list and a postage paid envelope for the questionnaire return[33]. Initial participants enrolled in the study were asked to complete a second mailed copy of the questionnaire after the first questionnaire was returned in order to evaluate reliability over time[34,25]. A sample of 30 participants was perceived as adequate to calculate intra-rater agreement and the test-retest was stopped when this sample size was obtained[25].

In total, 191 participants agreed to participate in the study, five questionnaires were returned to sender due to wrong address and 134 questionnaires were completed (response rate 72%). Within this sample, 36 participants were asked to participate in a test-retest, 32 agreed and returned a 2nd copy of the questionnaire (response rate 89%). Two questionnaires were deleted due to missing data, therefore 164 data points were analyzed during factor analysis[25].

Caring Ahead Questionnaire

The Caring Ahead questionnaire originally consisted of 30-item statements with a 7-point, bipolar Likert scale for item response (see Supplement A). Item anchors ranged from ‘strongly disagree’ to ‘strongly agree’. The 7-point scale was selected to support variability in responses[25]. Items were arranged according to four theoretical domains of preparedness: medical (nine items), relationship/personal (nine items), spiritual (five items) and practical (seven items)[14,24]. Items aimed to sample cognitive, behavioural and affective underlying preparedness traits[14,24]. A single-global preparedness item was included with the questionnaire to evaluate concurrent validity[23,16,25].

Analysis

Data collected were entered into SPSS Version 26[35] (IBM Corp., 2018) and 5% percent of data were proofed for accuracy by a second member of the research team[25]. Descriptive statistics were examined including item mean scores, medians, standard deviations and distribution. To address missing data, cases missing values on $\geq$2 items (i.e., 5% of variables) were removed from the data set (n=2) and for cases with one missing value (n=6) the mean of the subscale was imputed[25].

Substantive Structure Validity. We first explored the substantive (i.e., internal) structure validity of the 30-item questionnaire to identify items that would reduce the validity, reliability and factorability of the questionnaire[36.37]. Three items demonstrating low inter-item correlations ≤ 0.3 (Item 23, 24, 26) within the inter-item correlation matrix, and one item with inadequate Measure of Sampling Adequacy (MSA<0.7), 'Life Purpose Concern' (Item 29) were deleted. Factorability of the remaining 26-items were confirmed (Kaiser-Meyer Olkin Measure of Sampling Adequacy=0.87, Bartlett's Test of Sphericity p<0.001)[37]. Therefore, a preliminary, exploratory Principal Components Analysis [PCA] with factor extraction was conducted. Six additional items with low communalities (<0.3), low factor loadings <0.4, cross-loadings onto two factors, loadings onto a factor with ≤ 3 items and/or low corrected item-total correlations <0.5 were deleted[36,37,25].

Exploratory PCA with Promax rotation and factor extraction was then performed with the remaining 20-item questionnaire revealing a six-factor solution with Eigenvalues >1.0[37]. After examining the scree plot, the PCA was repeated with Promax and four factors were extracted with Eigenvalues ≥ 1.2[37]. The scree plot was reviewed and factors with: Eigenvalues greater than 1.0, explaining at least 5% of variance, and at least four loading items were extracted. Factor loadings less than 0.3 were suppressed[37] (Pett, 2003). Once the solution stabilized, PCA was repeated with Principal Axis Factoring for comparison[37]. Based on Classical Test Theory, a subscale score for each extracted factor was calculated by summing each participant's item scores[25,37].

Concurrent Validity. To examine concurrent validity, participants subscale scores (based on the extracted factors) would normally be examined for correlation with a 'gold standard' measure of preparedness for death[25]. However, because no 'gold standard' exists correlations were examined between subscale scores and a single-global preparedness item, "If your loved one were to die soon, how prepared would you be for his/her death?"[16]

Reliability. Cronbach's alpha, a reliability coefficient, was calculated to assess the internal consistency of each factor subscale and is ideally greater than 0.7[25,37]. To examine the scale reliability and stability over time, an intra-class coefficient (target greater than 0.7) for each component scale was calculated using a 2-way mixed effects absolute agreement ANOVA model[36,25].

Results

Characteristics of Sample

Participants were 62 years old on average (SD 11.4), female (78%), adult children/children-in-law of the person with dementia (70%) and in addition to being Canadian, were of European or British descent (71%). Care recipients were 85 years old on average (SD 8.4), female (63%), and had been living in a congregate living facility for an average of 2.9 years (SD 2.6) in Ontario, Canada (96%). The majority of care recipients had Alzheimer's Disease (41%) and had lived with dementia for 6.4 years (SD 4.1)(see Table 1). The full range of item responses (1-7) was received for each item. Across the sample, item skewness ranged between -2.96 (SE=0.21) and -0.71 (SE 0.21). Item kurtosis ranged between -0.88 (SE 0.42) and 9.29 (SE 0.42).

The highest scoring item indicating preparedness (M 6.46, SD 1.11) was obtained for Item 10, 'I understand that dementia (and Alzheimer's) leads to death.'

Within the Dementia Knowledge subscale. In contrast, the items with the lowest score, indicating low levels of preparedness were Item 15 (M 5.02, SD 2.09), “Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management” (Communication subscale) and Item 11, ‘I have learned what the dying process may be like for my family member’ (M 5.09, SD 1.84) (Dementia Knowledge subscale). Overall, the highest item mean scores were demonstrated for Dementia Knowledge (M 5.93, SD, 1.06), followed by Actions (M5.80, SD 1.11), Communication (M 5.72, SD 1.27) and Emotions and Support Needs (M 5.52, SD 1.36) subscale (Table 3).

Substantive Structure Validity

The four-factor model extracted through PCA with Promax rotation explained 61.7% of the cumulative variance. Factor subscales were labelled as: 1) Actions, 37.7% (7 items); 2) Dementia Knowledge, 9.6% (5 items); 3) Communication, 7.1% (4 items); 4) Emotions and Support Needs, 6.4% (4 items). All items demonstrated moderate factor loadings (0.48-0.80) and corrected item-total correlations >5.0 (see Table 2). Low to moderate factor correlations (0.38-0.53) suggested the four factors were unique[37].

A three-factor model was also considered which explained 55.8% of the cumulative variance, maintained the same ‘Dementia Knowledge’ and ‘Emotions and Support Needs’ subscales and combined the ‘Actions’ with ‘Communication’. Based on conceptual and empirical literature surrounding the importance of communication at end-of-life, previous study findings[26,27] and the greater cumulative variance explained, the authors selected the extracted four-factor model and subscales for further validity and reliability testing.

Concurrent Validity

Participant's subscale scores on the Caring Ahead questionnaire were compared to a single-global preparedness item response to explore concurrent validity[23,25]. Pearson correlations were weak to moderate, ranging from 0.43-0.55 (p=0.01)(see Table 4). The positive, significant relationship provided evidence for concurrent validity of the new questionnaire[25,37].

Reliability

The internal consistency (i.e., Cronbach's alpha statistics) for the four subscales was found to be: Actions a=0.85, Dementia Knowledge a=0.78, Communication a=0.86 and Emotions and Support Needs a=0.80 respectively. Item-item correlations within the subscales ranged from 0.22 to 0.77 suggesting little item redundancy[25,37]. Item-total correlations were each greater than 0.5 indicating each item contributed to the internal consistency of the subscale[25,37]. The test-retest was completed by 32 participants with an average of 28.9 (SD 24.5) days elapsing between tests, with the majority completing the retest within two weeks. The calculated ICC (average measures) for each subscale was greater than the recommended 0.7 and 95% Confidence Intervals, suggesting questionnaire stability over time[25,37] (see Table 3).

Discussion

This study aimed to evaluate the psychometric properties of the new Caring Ahead: Preparing for End-of-Life with Dementia questionnaire. Factor analysis with PCA, and subscale correlations with an existing measure generated evidence for substantive (i.e., internal) structure and concurrent validity for the questionnaire[23,25,37]. Assessment of internal consistency and completion of a test-retest resulted in strong reliability coefficients indicating evidence for the questionnaire's consistency and stability over time[25]. Overall, this evaluation study provided preliminary evidence for the use of the Caring Ahead questionnaire with caregivers of persons with dementia living in congregate living facilities like LTC.

To our knowledge, this was the first study to evaluate the psychometrics of a multi-dimensional questionnaire specifically developed to measure current caregiver preparedness for end-of-life in dementia. Factor analysis with PCA revealed an acceptable and meaningful 4-factor internal structure, which explained greater than the recommended 50% of cumulative variance[25,37]. Factor subscales identified included: 'Actions', 'Dementia Knowledge', 'Communication' and 'Emotions and Support Needs'. The moderate correlations between subscales suggested the uniqueness and value of each subscale, with little item redundancy. Elsewhere, 3-underlying preparedness factors have been hypothesized: cognitive, affective and behavioural[14,23,24]. Alternatively, in this study the four-factor preparedness model separated behavioural indicators (i.e., 'Actions' and 'Communication') into two distinct factors. This is significant because Actions and Communication behaviours may have different impacts on overall preparedness.

A nationwide survey of bereaved family members conducted by Mori et al. (2018)[39] also distinguished between caregiver actions and communication to prepare for death with the family member to ascertain the prevalence and impact of these behaviours separately. The authors found that 76% of the sample had engaged in actions to prepare for death, such as increasing the time spent with the family member, helping them to see persons prior to death, and repairing the relationship[39]. Only 46% of the sample had talked about death (e.g., asking what the patient wanted for funeral arrangements/financial affairs). As expected, acting and communicating together were associated with lower prevalence of depression (OR 0.41, p=0.02). However, caregivers who had communicated but not acted were the most likely to experience depression (OR 1.90, p=0.022) and complicated grief (OR 1.25, p=0.68), although complicated grief was not significantly different from those had not acted or communicated. In contrast, caregivers who had acted were the least likely to experience complicated grief and depression, whether they had communicated (OR 0.39, p=0.02) or not (OR, 0.421, p=0.03)[39]. These findings suggest that acting in preparation for death has a greater impact on caregiver well-being in bereavement than communication. Thus, it is likely critical for the Caring Ahead questionnaire to differentiate between actions and communication.

Some questionnaire items developed to sample specific underlying traits were also found to load onto alternative, but fitting factors in this study. For example, items perceived as sampling the cognitive trait such as Item 16, ‘knowing the family member’s preferences’ (Table 2) aligned with the ‘Communication’ factor, suggesting that caregivers had communicated with their family member and were aware of their preferences. Similarly, Item 6, 'I believe I can fulfill my responsibilities' was perceived as sampling the affective trait (i.e., attitudes, beliefs, emotions). However, in the current study this item loaded onto the 'Actions' subscale, suggesting that role confidence indicated 'active' preparedness behaviours (e.g., planning and completing tasks). Lastly, the items 'Grief Process' and 'After-Death Policies' were previously perceived as sampling the cognitive trait. It was interesting in this study that these items loaded onto the 'Emotions and Support Needs' (i.e., affective subscale).

The loading of items onto factors other than those anticipated may have occurred because: 1) underlying traits were overlapping and 2) items sampling underlying traits and items sampling associated functions grouped together. While traits are defined as underlying characteristics, functions refer to the functional ability to perform a task[40]. Studies of personality scales aimed at assessing underlying traits and function[40,41] have reported that behavioural, cognitive and affective traits are not distinct, and that factors/scales often grouped items sampling both personality traits, and functional abilities relative to the personality trait. In our study, the 'Grief Process' and 'After-Death Policies' may have indicated functional abilities related to affective traits of 'Spiritual and Emotional Support'. Nuzum et al., (2019)[40] concluded that underlying traits do overlap, and that functions and traits are complementary.

The lack of an existing ‘gold standard’ preparedness for death questionnaire limited evaluation for criterion validity in this study. Weak-moderate significant correlations were found between subscale scores and a single-global preparedness item suggesting evidence for concurrent validity[23,25]. Strong evidence for reliability was demonstrated by subscale internal consistency (Cronbach’s alpha >0.7) and test-retest statistics (Intraclass Coefficients >0.7).

Limitations

The current study is not without limitations. The study sample may not be representative of the entire population of caregivers because we did not incorporate a randomized sampling strategy[25]. In particular, there was a greater number of adult-child caregiver participants compared to spouses, a small number of caregivers representing minorities and a higher proportion of caregivers identifying as female than other genders. Future studies should aim to increase sampling of both spousal caregivers and minorities. In addition, selection bias may have occurred due to the recruitment strategies used. Volunteer participants were primarily female. In contrast, at LTC sites and the Alzheimer Society where caregivers were approached to participate by someone known to them (e.g., Family Council Member), there was a higher proportion of males recruited. This suggests that multiple strategies are required to recruit persons of differing gender identities. Due to the smaller sample of spouses, minorities and male caregivers, the study findings may not be generalizable to all groups[31]. In addition, participants who were recruited through their attendance of programs at the Alzheimer Society may have had greater questionnaire scores than the entire population if they are receiving greater education and knowledge around dementia and support, for example. Lastly, although response rates were acceptable (>60%), response rates may have been higher if the Covid-19 pandemic had not occurred immediately following a large mailing of questionnaires to enrolled participants in February 2020. As per study protocol, reminder questionnaires would normally have been sent two weeks following the initial mailing, however due to outbreaks in study sites we did not feel it was ethical to send questionnaire reminders.

Implications for Practice

This study provided preliminary evidence for the validity and reliability of the Caring Ahead questionnaire and provides guidance for its future refinement (see Supplement C). Due to the negative outcomes in bereavement associated with limited preparedness, we encourage clinicians (particularly in congregate living facilities like LTC) to begin using this questionnaire as a tool to guide practice and for assessment. Further testing is needed to evaluate the predictive capabilities of the questionnaire, and determine sensitivity to change (e.g., as a result of interventions). However, clinicians can begin using the questionnaire to assess caregiver actions, knowledge and emotions/levels of support. In addition, clinicians can use the questionnaire to guide communication with caregivers and ascertain their knowledge of the person with dementia’s preferences, whether they have discussed end-of-life care with other family members, and to begin planning care in accordance with their goals and end-of-life wishes. The 20-item questionnaire may also provide a beneficial tool for clinicians to administer to caregivers prior to family meetings/annual care conferences to ascertain feelings of preparedness and areas of need.

In conclusion, this study provided an initial validation of the Caring Ahead: Preparing for End-of-Life in Dementia questionnaire. With the efforts being made to improve end-of-life care in LTC homes, this tool will make an important contribution to practicing clinicians, policy-makers, educators and researchers. We anticipate further validation studies and questionnaire refinements to better serve family caregivers of persons with dementia.

Disclosures and Acknowledgements

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References

1. World Health Organization. Dementia. 2019. Available from: https://www.who.int/news-room/fact-sheets/detail/dementia. Accessed May 25, 2020.
2. Cahill S, O'Shea E, Pierce M. Creating excellence in dementia care: a research review for Ireland's national dementia strategy. 2012. Available from: http://hdl.handle.net/10147/215312. Accessed May 25, 2020.
3. Mitchell S. Care of patients with advanced dementia. In Morrison R, Yaffe K, Wilterdink J. (eds.) Up to date. Wolters Kluwer, Up to Date Inc; 2019.
4. Nielsen M, Neergaard M, Jensen A, Vedsted P, Bro F, Guldin M., Predictors of complicated grief and depression in bereaved caregivers: a nationwide prospective cohort study. J Pain Symptom Manage 2017;53:540-550.
5. Vick J, Ornstein K, Szanton S, et al. Does caregiving strain increase as patients with and without dementia approach the end of life?. J Pain Symptom Manage 2019;57:199-208.
6. Van der Steen JT, Radbruch L, Hertogh CM et al. White paper defining optimal palliative care in older people with dementia: a delphi study and recommendations from the European Association for Palliative Care. Palliative Med 2014;28:197-209.
7. McCleary L, Thompson GN, Venturato L, et al., Meaningful connections in dementia end of life care in long term care homes. BMC Psych 2018;18:307.

https://doi.org/10.1186/s12888-018-1882-9

8. Thompson G, Shindruk C, Wickson-Griffiths A, et al. “Who would want to die like that?” Perspectives on dying alone in a long-term care setting. Death Stud 2019;43:509-520.
9. Hovland-Scafe CA, Kramer BJ. Preparedness for death: how caregivers of elders with dementia define and perceive its value. Gerontologist. 2016;gnw092.
10. Terzakis K. Preparing Family Members for the Death of a Loved One in Long-Term Care. Ann Longterm Care 2019;27:25-31.
11. Lobb EA, Kristjanson LJ, Aoun SM, et al. Predictors of complicated grief: a systematic review of empirical studies. Death Stud 2010;34:673-698.
12. Barry L, Kasl S, Prigerson H. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. Am J Geriatr Psychiatry 2002;10:447-457.
13. Breen LJ, Aoun SM, O'Connor M, et al. Family caregivers’ preparations for death: a qualitative analysis. J Pain Symptom Manage 2018;55:1473-1479.
14. Hebert R, Prigerson H, Schulz R, Arnold R. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. J Palliat Med 2006;9: 1164-1171.
15. Kim Y, Carver CS, Spiegel D, et al. Role of family caregivers' self‐perceived preparedness for the death of the cancer patient in long‐term adjustment to bereavement. Psychooncology 2017;26:484-492.

16. Schulz R, Boerner K, Klinger J, et al. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. J Palliat Med 2015;18:127-133.
17. Hauksdottir A, Valdimarsdottir U, Fürst CJ, et al. Health care-related predictors of husbands' preparedness for the death of a wife to cancer—a population-based follow-up. Ann Oncol 2010;21:354-361.
18. Diamantopoulos A, Sarstedt M, Fuchs C, et al. Guidelines for choosing between multi-item and single-item scales for construct measurement: a predictive validity perspective. J Acad Market Sci 2012;40:434–449.
19. Hebert R, Schulz R, Copeland V, Arnold R. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. J Pain Symptom Manage 2009;37:3-12.
20. Moore KJ, Crawley S, Vickerstaff V, et al. Is preparation for end of life associated with pre-death grief in caregivers of people with dementia? Int Psychogeriatr 2020;1-11. doi:10.1017/S1041610220000289
21. Nielsen MK, Neergaard MA, Jensen AB, et al. Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. Clin Psych Rev 2016;44:75-93.
22. Durepos P, Ploeg J, Akhtar-Danesh N, et al. Caregiver preparedness for death in dementia: an evaluation of existing tools. Aging Ment Health 2019;1-10. DOI: 10.1080/13607863.2019.1622074

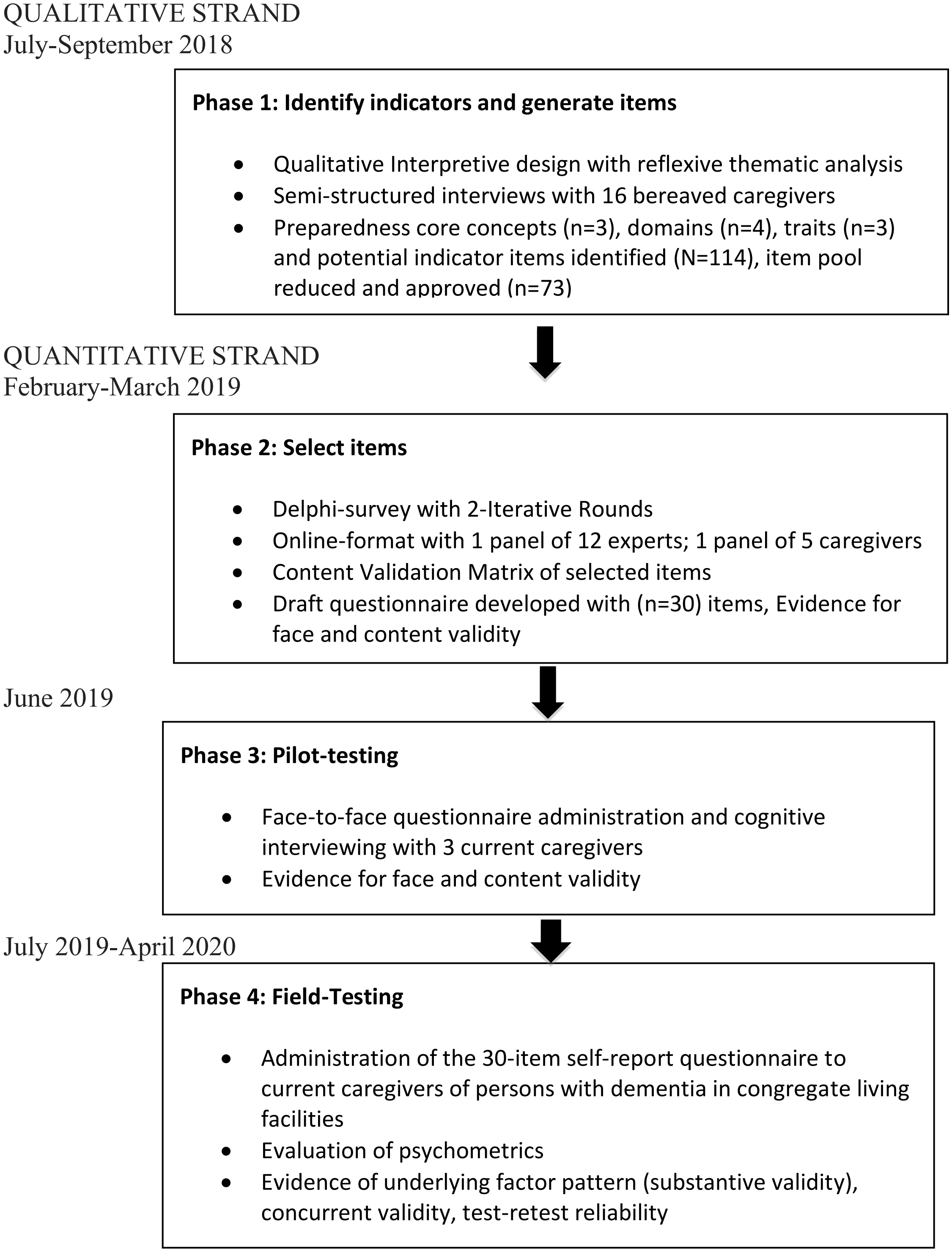
23. Onwuegbuzie AJ, Bustamante RM, Nelson JA. Mixed research as a tool for developing quantitative instruments. J Mixed Methods Res, 2010;4:56-78.
24. Durepos P, Sussman T, Ploeg J, et al. What Does Death Preparedness Mean for Family Caregivers of Persons with Dementia? A J Hospice Palliat Med 2018;36:436-446.
25. Streiner D, Norman G, Cairney J. Health measurement scales: A practical guide to their development and use, 5th ed. Oxford: Oxford University Press, 2015:75-252.
26. Durepos P, Sussman T, Ploeg J, et al. "A crazy roller coaster at the end:" A qualitative study of death preparedness with caregivers of persons with dementia. *Sage Open Nursing, 6:* 1-11. doi.org/10.1177/2377960820949111
27. Durepos P, Akthar-Danesh N, Ploeg J, et al. Caring Ahead: Mixed Methods Development of a Questionnaire to Measure Preparedness for End-of-Life in Dementia. Submitted to Palliat Med 2020.
28. Kottner J, Audigé L, Brorson S, et al. Guidelines for reporting reliability and agreement studies (GRRAS) were proposed. IJNS 2011;48:661-671.
29. Dillman DA, Smyth JD, Christian LM. Internet, phone, mail and mixed-mode surveys: the tailored design method. 4th ed. New Jersey: John Wiley & Sons, 2014:161-176.
30. Kusumoto Y, Kita Y, Kusaka S, et al. Difference between tablet methods and paper questionnaire methods of conducting a survey with community-dwelling elderly. JPTS 2017;29:2100-2102.

31. Patton M. Qualitative research and evaluation methods. 4th ed. DC: Sage Publications Inc, 2015:
32. Munro BH. Statistical Methods for Health Care Research. 4th ed. Pennsylvania: Lippincott Williams & Wilkins, 2001:310.
33. Chambers E, Gardiner C, Thompson J, et al. Patient and carer involvement in palliative care research: An integrative qualitative evidence synthesis review. Palliat Med 2019;33:969-984.
34. Michels CT, Boulton M, Adams A, et al. Psychometric properties of carer-reported outcome measures in palliative care: a systematic review. Palliat Med, 2016;30(1), 23-44.
35. IBM Corp. IBM SPSS Statistics for Macintosh, Version 26.0. Armonk, NY: IBM Corp, 2019.
36. Field A. Discovering Statistics using SPSS: (And sex and drugs and rock 'n' roll). 4th ed. London: SAGE Publishing Inc, 2013:443-459.
37. Pett M, Lackey N, Sullivan J. Making sense of factor analysis: The use of factor analysis for development in health care research. California: SAGE Publishing Inc, 2003:71-206.
38. Martin W, Bridgmon K. Quantitative and statistical research methods: from hypothesis to results. New Jersey: Wiley & Sons Inc, 2012.
39. Mori M, Yoshida S, Shiozaki M, et al. "What I Did for My Loved One Is More Important than whether we talked about death": A nationwide survey of bereaved family members. J Palliat Med 2018;21:335-341.

40. Nuzum H, Shapiro J, Clark A. Affect, behavior, and cognition in personality and functioning: An item-content approach to clarifying empirical overlap. Psychol Assess 2019;31:905-912. http://dx.doi.org/10.1037/pas0000712

41. Clark LA, Ro E. Three-pronged assessment and diagnosis of personality disorder and its consequences: Personality functioning, pathological traits, and psychosocial disability. PD:TRT 2014;5:55–69. http://dx.doi.org/10.1037/per0000063

Figure 1. Mixed methods design: Exploratory, sequential quantitative dominant status, instrument-variant design (qual -> QUAN)



QUALITATIVE STRAND
July-September 2018

Phase 1: Identify indicators and generate items

- Qualitative Interpretive design with reflexive thematic analysis
- Semi-structured interviews with 16 bereaved caregivers
- Preparedness core concepts (n=3), domains (n=4), traits (n=3) and potential indicator items identified (N=114), item pool reduced and approved (n=73)

QUANTITATIVE STRAND
February-March 2019

Phase 2: Select items

- Delphi-survey with 2-Iterative Rounds
- Online-format with 1 panel of 12 experts; 1 panel of 5 caregivers
- Content Validation Matrix of selected items
- Draft questionnaire developed with (n=30) items, Evidence for face and content validity

June 2019

Phase 3: Pilot-testing

- Face-to-face questionnaire administration and cognitive interviewing with 3 current caregivers
- Evidence for face and content validity

July 2019-April 2020

Phase 4: Field-Testing

- Administration of the 30-item self-report questionnaire to current caregivers of persons with dementia in congregate living facilities
- Evaluation of psychometrics
- Evidence of underlying factor pattern (substantive validity), concurrent validity, test-retest reliability

Table 1. Sample Characteristics (n=134)*

CAREGIVERS	n (%)
Age (years); Mean (SD)	61.7 (11.4)
Gender	
Female	104 (78.2)
Male	29 (21.8)
Relationship	
Spouse	32 (24.1)
Adult Child/In-Law	93 (69.9)
Other	9 (6.7)
Education	
Less than High School	3 (2.3)
High School	18 (13.5)
College or University	86 (64.7)
Graduate School	26 (19.5)
Annual Household Income	
Less than 50,000	25 (18.8)
51-100,000	48 (36.1)
101-150,000	27 (20.3)
Greater than 150,000	13 (9.8)
Prefer Not to Say	20 (15.0)
Ethnic Origin	
British Isles	47 (35.3)
Europe and France	49 (36.8)
Asia	4 (3.0)
Caribbean and Latin America	2 (1.5)
First Nations	3 (2.3)
None/Canadian	28 (21.1)
Race	
White	124 (93.2)
Black	1 (0.8)
South Asian	2 (1.5)
East Asian	2 (1.5)
Hispanic	1 (0.8)
First Nations	3 (2.3)
Religious Affiliation	
Catholic	33 (24.8)
Protestant	48 (36.1)
Jewish	1 (0.8)
Buddhist	1 (0.8)
Agnostic	1 (0.8)

CAREGIVERS	n (%)
Non-Practicing Catholic	3 (2.3)
None	48 (36.1)
CARE RECIPIENTS	n (%)
Age; Mean (SD)	85.1 (8.40)
Gender	
Female	84 (63.2)
Male	49 (36.8)
Religious Affiliation	
Catholic	46 (34.5)
Protestant	53 (39.8)
Jewish	1 (0.8)
Non-Practicing Catholic	1 (0.8)
None	32 (24.1)
Type of Dementia	
Alzheimer's	54 (40.6)
Vascular	18 (13.5)
Mixed	13 (9.8)
Lewy Body	9 (6.8)
Fronto-Temporal	4 (3.0)
Korsakoff's	2 (1.5)
Unknown	26 (19.5)
Other	7 (5.3)
Years with Dementia; Mean (SD)	6.4 (4.1)
Years in Congregate Living; Mean (SD)	2.9 (2.6)
Congregate Living Location	
Ontario	128 (96.2)
British Colombia	3 (2.3)
Saskatchewan	1 (0.8)
Europe	1 (0.8)

Note. Congregate living refers to facilities providing residential 24-hour care for moderate to high level needs. *One participant excluded from analysis due to missing data.

Table 2. Four-Factor Loading Model; 61.7% of Cumulative Variance Explained (n=166)*

Item	Factor			
	Actions	Dementia Knowledge	Communication	Emotions and Support Needs
Making the Most of Time	0.80			
Life Review	0.80			
Affairs	0.79			
Closure Activities	0.76			
Memorial	0.71			
Role Confidence	0.69			
After-Death Services	0.60			
Changes to Expect		0.96		
Treatment Decisions		0.81		
No Cure		0.79		
Dying Process		0.68		
Understand Health Status		0.66		
Goals of Care Discuss with Staff			0.85	
Family Friends Discuss			0.81	
Death Preferences Discuss with Staff			0.73	
Know Preferences			0.54	
Spiritual Support				0.92
Emotional Support				0.89
Grief Process	0.41			0.54
After-Death Policies/Process				0.48

Note. Principal Component Analysis Extraction Method, Promax with Kaiser Normalization Rotation Method. *2 participants excluded for missing data. Two decimal digits are provided to illustrate slight differences in values.

Table 3. Subscale Statistics and Reliability Coefficients

Subscale	# of Items	Subscale Items	Subscale Total	Cronbach's Alpha	Test ReTest ICC (95% CI)
		Mean (SD)	Mean (SD)		
Actions	7	5.8 (1.1)	52.1 (10.0)	0.85	0.89 (0.77-0.95)
Dementia Knowledge	5	5.9 (1.1)	29.7(5.3)	0.86	0.95 (0.89-0.98)
Communication	4	5.7 (1.3)	22.9 (5.1)	0.78	0.87 (0.73-0.94)
Emotions and Support Needs	4	5.5 (1.4)	22.1 (5.4)	0.80	0.91 (0.80-0.96)

Note. Abbreviation: ICC=Intraclass Coefficient. Subscale statistics (M, SD) and Cronbach's alpha calculated with 133 participants, Test Re-Test Average Measures ICC calculated with 31 participants using a Two-Way Mixed Effects Model with Absolute Agreement. Two decimal places are provided for Cronbach's Alpha and the ICC to illustrate slight differences in coefficients.

Table 4. Subscale Correlations with Single-Global Preparedness Item

Subscale	Single Global Preparedness Item
Actions	0.54**
Dementia Knowledge	0.54**
Communication	0.43**
Emotions and Support Needs	0.55**

Note. Abbreviation.CG=Caregiver; CR=Care Recipient. **Correlation significant at the 0.01 level (2-tailed). Two decimal places are provided for coefficients to illustrate slight differences between values.

Supplement A. Original 30-item Caring Ahead questionnaire with item abbreviations and single-global preparedness item

Medical Preparations	**Strongly Disagree**						**Strongly Agree**
[Understand Health Status] I believe I understand my family member's current health status.	1	2	3	4	5	6	7
[Changes to Expect] I believe I know what changes to expect as dementia advances, for example: swallowing, eating difficulties.	1	2	3	4	5	6	7
[Treatment Decisions] I understand I may be faced with decisions such as: transferring to hospital, treating infections.	1	2	3	4	5	6	7
[Know Preferences] I believe I know what treatments my family member would choose.	1	2	3	4	5	6	7
[Goals of Care Discuss] I have shared my family member's wishes with health care providers, for example: focusing on living longer, maximizing comfort.	1	2	3	4	5	6	7
[EOL Preferences Discuss] Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.	1	2	3	4	5	6	7
[Family Friends Discuss] I have discussed end-of-life care preferences with the important people in my family member's life, for example: friends, family.	1	2	3	4	5	6	7
[Dying Process] I have learned what the dying process may be like for my family member.	1	2	3	4	5	6	7
[No Cure] I understand that dementia (and Alzheimer's) is a condition that leads to death.	1	2	3	4	5	6	7

Relationships and Personal Preparations	**Strongly Disagree**						**Strongly Agree**
[Role Confidence] I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.	1	2	3	4	5	6	7
[More Involved] I would like to be more involved in planning care with health care providers. *Negatively worded	1	2	3	4	5	6	7
[Caregiving Acceptance] I accept that I am doing my best for my family member.	1	2	3	4	5	6	7
[Emotional Support] I have someone to go to for emotional support about my family member's health.	1	2	3	4	5	6	7
[Grief Process] I understand what my grief process may be like after my family member has died.	1	2	3	4	5	6	7
[Conflict] I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers. *Negatively worded.	1	2	3	4	5	6	7
[Making the Most of Time] I am making the most of my time with my family member, for example: by saying what I need to say to them.	1	2	3	4	5	6	7
[Closure Activities] I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.	1	2	3	4	5	6	7
[Life Review] I am spending time reflecting on my family member's life, for example: by sharing stories.	1	2	3	4	5	6	7

Spiritual Preparations	**Strongly Disagree**						**Strongly Agree**
[Honour Traditions] I have a plan to honour traditions or practices my family member would want, for example: personal, cultural, spiritual, religious.	1	2	3	4	5	6	7
[Traditions Discuss] I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.	1	2	3	4	5	6	7
[Spiritual Support] I have someone I can talk to about the meaning of illness or dying.	1	2	3	4	5	6	7
[Life Purpose Concern] I worry about having purpose in my life after my family member has died. *Negatively worded.	1	2	3	4	5	6	7
[Personal Activities] I am practicing activities which give me strength such as: spending time in nature.	1	2	3	4	5	6	7

Practical Preparations	**Strongly Disagree**						**Strongly Agree**
[Affairs] My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.	1	2	3	4	5	6	7
[Affairs Support] I have someone I can contact if I need help managing my family member's affairs.	1	2	3	4	5	6	7
[Notify Family] I know how to notify family and friends when my family member dies.	1	2	3	4	5	6	7
[After-Death Services] After-death services are arranged for my family member such as: burial or cremation.	1	2	3	4	5	6	7
[Personal Affairs] I believe I can manage my personal affairs after my family member has died, for example: finances, housing.	1	2	3	4	5	6	7
[After-Death Policies] I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.	1	2	3	4	5	6	7
[Memorial] I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.	1	2	3	4	5	6	7

Overall Preparedness [Single-Global Item]	**Not Prepared** **Prepared** **At All** **As** **Much** **As** **Possible**						
*If your loved one were to die soon, how prepared would you be for his/her death?	1	2	3	4	5	6	7

Note. *Re-printed with permission of the authors, Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. Journal of Palliative Medicine, 18(2), 127-1. Original questionnaire printed in 14-pt font.

Supplement B. Item Statistics (n=134)*

Item		Mean	SD
1	Making the Most of Time	5.8	1.5
2	Life Review	5.5	1.5
3	Affairs	6.4	1.2
4	Closure Activities	5.3	1.6
5	Memorial	5.7	1.6
6	Role Confidence	6.3	1.3
7	After-Death Services	5.6	2.2
8	Changes to Expect	5.7	1.5
9	Treatment Decisions	6.3	1.1
10	No Cure	6.5	1.1
11	Dying Process	5.1	1.9
12	Understand Health Status	6.2	1.1
13	Goals of Care Discuss with Staff	6.0	1.5
14	Family Friends Discuss	5.6	1.7
15	Death Preferences Discuss with Staff	5.0	2.1
16	Know Preferences	6.2	1.2
17	Spiritual Support	5.4	1.7
18	Emotional Support	5.6	1.8
19	Grief Process	5.3	1.6
20	After-Death Policies/Processes	5.7	1.8
Deleted Items			
21	*Traditions Discuss with Staff*	*4.2*	*2.0*
22	*Conflict Expected*	*4.5*	*2.2*
23	*Honour Traditions*	*5.8*	*1.7*
24	*Personal Activities*	*5.2*	*1.7*
25	*Desire More Involvement*	*2.6*	*1.8*
26	*Ways to Notify Family*	*6.3*	*1.3*
27	*Personal Affairs in Order*	*6.6*	*1.0*
28	*Affairs Support*	*6.0*	*1.7*
29	*Life Purpose Concern*	*5.3*	*2.1*
30	*Caregiving Acceptance*	*6.3*	*0.9*
Concurrent Validity Measure			
31	Single Global Preparedness Item	5.9	1.2

Note. Italicized items not included in the factor model. *1 participant excluded for missing data.

Supplement C. Revised Caring Ahead questionnaire proposed for use.

Caring Ahead: Preparing for End-of-Life with Dementia questionnaire

Instructions:

Caring for a family member or friend with dementia can be very challenging, especially as end-of-life approaches. This questionnaire asks sensitive questions to help understand the knowledge, actions, communication and support you have to prepare for the death of your family member or friend. Please circle one number to show how strongly you agree or disagree with each question statement. Please take your time and reach out for emotional support when needed. Please share your responses with your health care provider.

	Dementia Knowledge Preparations	**Strongly Disagree**						**Strongly Agree**
1.	I believe I understand my family member's current health status.	1	2	3	4	5	6	7
2.	I believe I know what changes to expect as dementia advances, for example: swallowing, eating difficulties.	1	2	3	4	5	6	7
3.	I understand I may be faced with decisions such as: transferring to hospital, treating infections.	1	2	3	4	5	6	7
4.	I have learned what the dying process may be like for my family member.	1	2	3	4	5	6	7
5.	I understand that dementia (and Alzheimer's) is a condition that leads to death.	1	2	3	4	5	6	7

	Communication Preparations	**Strongly Disagree**						**Strongly Agree**
6.	I believe I know what treatments my family member would choose.	1	2	3	4	5	6	7
7.	I have shared my family member's wishes with health care providers, for example: focusing on living longer, maximizing comfort.	1	2	3	4	5	6	7
8.	Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.	1	2	3	4	5	6	7
9.	I have discussed end-of-life care preferences with the important people in my family member's life, for example: friends, family.	1	2	3	4	5	6	7

	Action Preparations	**Strongly Disagree Strongly Agree**
10.	I am making the most of my time with my family member, for example: by saying what I need to say to them.	1 2 3 4 5 6 7
11.	I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.	1 2 3 4 5 6 7
12.	I am spending time reflecting on my family member's life, for example: by sharing stories.	1 2 3 4 5 6 7
13.	I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.	1 2 3 4 5 6 7
14.	My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.	1 2 3 4 5 6 7
15.	After-death services are arranged for my family member such as: burial or cremation.	1 2 3 4 5 6 7
16.	I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.	1 2 3 4 5 6 7

	Emotions and Support Needs Preparations	**Strongly Disagree**						**Strongly Agree**
17.	I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.	1	2	3	4	5	6	7
18.	I understand what my grief process may be like after my family member has died.	1	2	3	4	5	6	7
19.	I have someone to go to for emotional support about my family member's health.	1	2	3	4	5	6	7
20.	I have someone I can talk to about the meaning of illness or dying.	1	2	3	4	5	6	7

Overall Preparedness [Single-Global Item]	**Not Prepared At All**						**Prepared As Much As Possible**
*If your loved one were to die soon, how prepared would you be for his/her death?	1	2	3	4	5	6	7

Proposed Scoring Instructions: Sum items to create a total score for each subscale. Divide the subscale total by the number of items to calculate an average subscale score.

Dementia Knowledge (Items 1-5)	Total Score out of 35: ________________ Average Score out of 7: ________________
Communication (Items 6-9)	Total Score out of 28: ________________ Average Score out of 7: ________________
Actions (Items 10-16)	Total Score out of 49: ________________ Average Score out of 7: ________________
Emotions and Support Needs (17-20)	Total Score out of 28: ________________ Average Score out of 7: ________________

Chapter 7

Discussion and Conclusion

In this chapter there is a discussion of the key contributions from this dissertation, implications, study strengths and limitation. The purpose of this study was to develop and evaluate a holistic questionnaire aimed at measuring preparedness for death with family caregivers [CG] of persons with dementia, with evidence for validity and reliability. The study was informed by two published papers included as introductory chapters: a concept analysis (Chapter 2) and review of existing preparedness instruments (Chapter 3). The main body of this dissertation was comprised of three manuscripts submitted or prepared for journal review including: a qualitative study exploring core concepts, facilitators and barriers to preparedness (Chapter 4); a Delphi-survey and pilot-testing for questionnaire development (Chapter 5); and a cross-sectional study for field-testing and evaluating questionnaire psychometrics (Chapter 6). The key findings from this dissertation include: core concepts and contextual factors influencing preparedness; observable, measurable behavioural indicators of preparedness; and evidence of validity and reliability for a 20-item Caring Ahead: Preparing for EOL with Dementia questionnaire.

Major Contributions

Research into the concept and impact of preparedness for death is relatively new, largely growing out of research into circumstances defining a good death (Barry et al., 2002; Steinhauser et al., 2000). Despite researchers' growing awareness of the impact of preparedness for death on CGs' well-being, core concepts of preparedness have not been identified; and a multidimensional instrument to measure death preparedness in dementia (or any diagnosis) does not exist. Therefore, the major contributions of this study include: 1) the identification of novel core concepts and indicators of preparedness for death, and 2) the development of a holistic, multi-item questionnaire to assess caregiver preparedness for the death of someone with dementia.

Novel core concepts and indicators of preparedness. Findings from the concept analysis in Chapter 2 (Durepos et al., 2018) were used to evaluate the adequacy and congruence of existing preparedness questionnaires to measure preparedness for end-of-life in CGs of persons with dementia. Subsequently, limitations in the content validity of existing preparedness questionnaires related to death/dying, dementia, the affective trait (i.e., acceptance, emotion-based coping) and practical domain (i.e., EOL planning, after-death services and burial) were demonstrated by the review in Chapter 3 (Durepos et al., 2019). Therefore, an important contribution of this study was the generation of novel, holistic indicators of preparedness that addressed gaps in existing questionnaires.

Through interviews with 16 bereaved CGs for the qualitative phase of this study, three core concepts of preparedness were revealed: 1) adapting to loss, 2) managing the situation, and 3) fulfilling obligations. Novel items related to spirituality, grief and loss and rituals/traditions at EOL were generated to address these core concepts. Behaviours associated with adapting to loss and fulfilling obligations focus on meaning-making activities for life completion, relationship closure/reconciliation, life review and planning for after-death rituals. However, measures and frameworks addressing the spiritual and existential aspect of preparedness are lacking. Interventions targeting meaning-making and existential processes have been found to reduce mental health concerns and to promote well-being in bereavement (Austin, Macleod, Siddall, McSherry & Egan, 2017; Neimeyer, 2019; Smeaton & Maher, 2016). Therefore, exploring CGs' engagement in meaning-making activities and integrating spiritual care into interventions at EOL may be key to promoting preparedness.

A holistic questionnaire. The major contribution of this study was the development of a holistic, multidimensional questionnaire to measure preparedness that has evidence for validity and reliability. Through a modified Delphi-survey, five caregivers and 12 diverse professional experts selected and refined 30 items to sample preparedness on the Caring Ahead questionnaire (Chapter 5) (Durepos et al., 2020a). An evaluation of the questionnaire psychometric properties through a cross-sectional survey of 134 current CGs then revealed preliminary evidence for validity (i.e., substantive structure and concurrent) as well as reliability (i.e., internal consistency and stability) (Chapter 6).

A four-factor model explaining 62% of the cumulative variance was produced with factors labelled as: Actions, Dementia Knowledge, Communication, Emotions and Support Needs. The strongest (and arguably the most important) underlying component of preparedness was Actions (Pett et al., 2003; Streiner, et al., 2015). Items included in the Actions subscale indicated caregivers' active engagement and completion of tasks to prepare themselves and act as a surrogate to prepare their family member for death. The 'Actions' subscale reflected psychosocial (e.g., making the most of time), spiritual (e.g., life review) and practical (e.g., affairs) preparedness domains that contributed to overlapping cognitive, affective and behavioural traits. Based on the psychometric properties, a revised questionnaire with 20-items organized according to four subscales was produced from this thesis and is available for use.

An important finding based on the evaluation of the questionnaire was that items sampling the medical domain of preparedness did not load onto the strongest factor subscale: Actions. Rather, items perceived as sampling medical preparedness loaded onto the 'Dementia Knowledge' subscale. These findings suggest that the medical domain of preparedness, although often the focus of communication and interventions may not have the greatest impact on feelings of preparedness or outcomes in bereavement. Mori et al., (2018) similarly reported that CGs who acted to prepare for EOL had better outcomes than CGs who communicated.

Implications

Research

Researchers have previously reported that limitations in existing preparedness measures may have contributed to negative and/or non-statistically significant findings in correlation and intervention studies (Hudson, Aranda & Hayman-White, 2005; Moore et al., 2020). In a recent study by Moore et al. (2020) for example, the authors developed a study specific questionnaire incorporating five preparedness indicators to examine the relationship between pre-death grief and preparedness. Although strong theoretical and empirical evidence exists for a relationship between caregivers' mental health pre-death, preparedness and well-being in bereavement (Hebert et al, 2009; Holm, Arestedt, Ohlen, Alvariza, 2019; Nielsen et al., 2017), negative findings were reported. The authors speculated that the preparedness indicators selected may have had limited content validity, and the addition of a multidimensional preparedness questionnaire might have resulted in positive findings (Moore et al., 2020).

As such, the items generated to sample preparedness, the final 20-item questionnaire and four associated subscales should support researchers to: 1) investigate relationships between distinct preparedness subscales and outcomes in bereavement; and 2) design, tailor and evaluate interventions aimed at promoting preparedness. Because no multi-dimensional questionnaire previously existed to assess preparedness for death in CGs, the internal structure of preparedness had not been explored through factor analysis. Researchers can now use four distinct subscales within the Caring Ahead questionnaire to advance understanding of preparedness and improve care for CGs. Further insight into the concept of preparedness should guide researchers to design and tailor interventions to address all domains, traits and core concepts of preparedness. In particular, the emergence of CG 'Actions' as the strongest loading factor underlying the questionnaire should guide researchers to incorporate tasks for EOL preparation and activities for meaning-making into interventions.

Future research with the Caring Ahead questionnaire should include testing of the revised 20-item questionnaire with a larger, population-based probability sample to produce a population-based estimate of preparedness (degrees and areas), and to compare/contrast/replicate findings from this study (Onwuegbuzie et al., 2010). The predictive validity of the questionnaire also needs to be explored by evaluating correlations between subscale scores and CG outcomes in bereavement (e.g., complicated grief) that are currently predicted by a single-global preparedness item. The reliability co-efficient suggested stability in responses, however the sensitivity of the questionnaire to measure change also needs to be evaluated by administering the questionnaire to CGs at multiple time points, and before/after interventions.

In addition, hypotheses based on the conceptual understanding of preparedness generated from this study should be tested to explore evidence for the construct validity of the questionnaire (Onwuegbuzie et al., 2010). For example, higher scores on the Caring Ahead questionnaire should have a negative correlation with pre-death depression and grief based on the conceptual model of preparedness (Supiano et al., 2020). In general, future research should focus on generating and exploring evidence for validity and reliability that will support the uptake of the questionnaire into research, practice, policy and education (Onwuegbuzie et al., 2010).

Policy

The rise in national/international dementia strategies (Cahill, 2020; Chertkow, 2018) and initiatives to improve access to palliative care around the globe (Callaway & Foley, 2018; Morrison, 2018) demonstrate the urgent need to improve care for CGs of persons with dementia. However, quality indicators for a palliative approach are not standardized and vary between organizations/regions and nations, making it difficult to monitor and compare the effectiveness of interventions (Michels, Boulton, Adams, Wee & Peters, 2016). Policy-makers are therefore seeking new holistic, outcome measures and standardized indicators to evaluate strategies supporting a palliative approach (Amador et al., 2019; Murtagh et al., 2018; Virdun, Luckett, Lorenz & Phillips, 2018). The Framework for Palliative Care in Canada, for example, specifically calls for measures to evaluate and monitor the effectiveness of policies for a palliative approach (Canadian Institutes of Health Information [CIHI], 2018).

Therefore, the caregiver-reported, holistic outcome measure produced in this thesis should make an important contribution for policy-makers. Uptake of the Caring Ahead questionnaire could provide a new standardized indicator for the quality of healthcare services delivered at EOL (that are notoriously challenging to evaluate) (Michels et al., 2016). Lastly, findings from this thesis should enable the evaluation of policies and programs prior to death in order to focus on preventing rather than treating negative outcomes for CGs in bereavement (Murtagh et al., 2018).

Theory

The conceptualization of preparedness for this study began with and expanded upon Hebert et al.'s (2006) Theoretical Framework of Preparedness for End-of-Life. The findings of this thesis served to clarify and operationalize preparedness as a theoretical construct by contributing a conceptual model and a multidimensional questionnaire (Durepos et al., 2018; 2020c). As a final step in Rodgers' Evolutionary method for concept analysis and instrument development, hypotheses based on the conceptual model and questionnaire should be tested to explore evidence for predictive, convergent and construct validity (Onwuegbuzie et al., 2010; Rodgers, 2000). A lack of evidence may suggest that the theory or questionnaire needs to be modified (Streiner et al., 2015).

Findings in this thesis relate to existing theories of grief and bereavement. The Dual-Process Model of Coping with Bereavement [DPM] aims to describe adaptive coping strategies for loss that predict adaptation to bereavement (Stroebe & Schut, 1999; 2010). According to the DPM, bereaved persons oscillate between the use of confrontation or avoidant coping strategies focused on reconstructing meaning in loss and meaning in restoration (i.e., the consequences of bereavement). Stroebe and Schut (2010) explain that the use of confrontation and avoidant coping strategies as well as the reconstruction of meaning in loss and restoration are all necessary to adapt to bereavement.

Indicators and preparedness items generated for the questionnaire in this thesis focus both on reconstructing meaning in the loss experience (e.g., by making the most of time together) and by reconstructing meaning for restoration (e.g., by having sources of life purpose) and therefore align with the DLM model (Stroebe & Schut, 2010). However, indicators of preparedness included on the Caring Ahead questionnaire focus primarily on active, confrontation coping strategies (e.g., meaning-making, communicating, planning, organizing). Coping strategies referred to as ‘avoidant’ (e.g., worrying, wishful-thinking, negative interpretation of events/suffering) were not sampled on the Caring Ahead questionnaire, and these strategies may have an important impact on feelings of preparedness (Stroebe & Schut, 1999; 2010). Without items to sample avoidant coping strategies, the questionnaire could over or underestimate preparedness, and therefore further testing of the model (and questionnaire) is needed.

The Meaning Reconstruction Theory also provides an explanatory model of mourning with meaning-making and reconstruction activities similar to those in the Caring Ahead questionnaire (Durepos et al., 2020c; Gillies & Neiymeyer, 2006; Park, 2010; Supiano et al., 2020). According to Gillies and Neiymeyer (2006), the process for meaning-making and meaning reconstruction involves: 1) coming to terms with loss, 2) realizing personal growth and benefits, and 3) reorganizing identity. Active, purposeful engagement in this process is described as promoting constructive 'good' grief (i.e., healthy and adaptive) whereas process barriers lead to complicated grief (i.e., intrusive, prolonged, debilitating) for CGs (Supiano et al., 2020). Outcomes associated with meaning-making and reconstruction clearly mirror those predicted by CG preparedness (Nielsen et al., 2017).

Findings from a study by Supiano et al. (2020) reported that bereaved and current CGs of persons with dementia who participated in meaning-making and meaning reconstruction activities (e.g., positive memory construction, relationship resolution, shared grief processes with family members) demonstrated higher levels of preparedness. Evidence for relationships within the Meaning Reconstruction Theory (Gillies & Neimeyer, 2006; Park, 2010), aligns with and supports the validity of the findings from this thesis. As such, meaning-making and meaning-reconstruction may represent the most important aspect of preparedness and propositions relative to these hypotheses require further exploration.

Education

This study generated new knowledge surrounding the unique journey of CGs in dementia and important healthcare provider-related factors perceived as influencing death preparedness. This knowledge could be used to enhance education for nursing students and increase competency to deliver a palliative approach. Healthcare providers in Canada and globally have reported limited self-efficacy to deliver a palliative approach (Hunter et al., 2019) and to care for persons with dementia (Annear, 2017). These limitations point to gaps in nursing education surrounding grief, bereavement and death, as well as dementia (Bristol, 2017).

Advanced practice nursing roles in mental health, aging and palliative care in particular are rising with required skills in geriatric assessment, psychotherapy and grief/bereavement counselling. Thus, enhancing undergraduate and graduate nursing curriculum by including content on death preparedness and additional theories surrounding bereavement, grief, death and caregiving is needed to improve students' knowledge and competency in delivering a palliative approach and dementia care (Bristol, 2017; Hutti & Limbo, 2019).

The ideal time to dispel the many myths held by nurses about persons with dementia and a palliative approach is while they are receiving their formal education (Bristol, 2017; Pallium, 2020; Pereira, Downer, Giddings, Hanvey, Riordan & Gravelle-Ray, 2018). It is a common and widespread myth amongst practicing nurses that caregiving for a long period of time results in preparedness for death (Pallium, 2020). Caregivers who participated in qualitative interviews in this study confirmed that the length of time of caregiving does not influence preparedness (Chapter 4) (Durepos et al., 2020a). It is therefore essential to educate students that CGs providing care for a long period of time may require even more support than CGs of persons with other illnesses at EOL.

Experiential learning opportunities may help to build students' knowledge of preparedness and competency to deliver a palliative approach. Examples of innovative (experiential) strategies used to teach concepts of bereavement, death and grief in the literature have included: integrating spiritual bereavement skills into an advanced nursing practicum (Bristol, 2017), incorporating bereaved persons as educators to teach principles of end-of-life care (Snaman, 2018), and simulating a bereavement scenario (Colwell, 2017). Overall, the new knowledge of preparedness and caregiving generated from this study along with the Caring Ahead questionnaire (as a tool for a palliative approach) could be incorporated into curriculum to enhance nursing education.

Nursing Practice

The findings from this study validated the perceived importance of competency for a palliative approach and communication between nurses and CGs described in the literature (Kulasegaram, Thompson, Sussman, & Kaasalainen, 2018). This thesis study also highlighted that a major purpose of nursing practice and communication should be to facilitate feelings of preparedness by helping CGs to:

maintain a sense of control, fulfill obligations, and adapt to loss (Durepos et al., 2020a). A lack of communication was perceived as inhibiting critical aspects of preparedness by: limiting trusting relationships with healthcare providers, impairing caregivers' understanding of their family member's health, and reducing the quality of care that CGs felt obligated to provide (Chapter 5) (Durepos et al., 2020a). Unfortunately, communication in clinical practice is often reduced to a one-way process of relaying information to caregivers (Kulasegaram et al., 2018).

As such, the Caring Ahead questionnaire could be a useful tool to guide and facilitate communication between CGs and nurses/other healthcare providers. In a study by Shirado et al. (2013), Caregivers of persons with cancer perceived that healthcare providers had promoted death preparedness by: being knowledgeable about treatments; respecting the ideas of patients/family members to improve the patient's physical condition; adapting treatment goals to the circumstances; discussing specific achievable goals and pacing the explanation with the state of the family's preparation. These behaviours and the content of discussion correspond with items selected for the Caring Ahead questionnaire (Durepos et al., 2020b). For example, the questionnaire item, "I have shared my family member's wishes for end-of-life with healthcare providers…" can act as a reminder for nurses/healthcare providers to, 'discuss specific achievable goals' as recommended (Shirado et al., 2013).

Nurses are also leaders in residential care facilities (where the majority of persons with advanced dementia reside) and are engaged in quality improvement initiatives to optimize fiscal spending and improve resident and caregiver outcomes with limited resources (Boyd, 2018; Nasu, 2020). Currently, only 22% of residents living in residential care are receiving a palliative approach and the majority are receiving suboptimal EOL care (CIHI, 2018). Content within the Caring Ahead questionnaire could support the implementation of new quality improvement initiatives by nurses and healthcare providers in practice. In addition, uptake of the questionnaire in clinical practice could provide nurses with the means to evaluate the effectiveness of initiatives aimed at improving EOL care.

Strengths and Limitations

Strategies to promote the trustworthiness (i.e., credibility, transferability and confirmability), validity and reliability of the findings were implemented appropriate for each research design (Patton, 2015; Streiner et al., 2015). In addition, across this mixed methods study strategies to develop a questionnaire with evidence for face, content, concurrent and substantive validity were implemented and informed by the IDCV framework (Onwuegbuzie et al., 2010). Face validity of the Caring Ahead questionnaire was promoted through data transformation which involved translating the qualitative findings (Durepos et al., 2020a) into quantitative questionnaire items that were relevant and important to the target population (Durepos et al., 2020b). Content or 'item' validity refers to the extent to which items sample the content that should be measured by the questionnaire (Onwuegbuzie et al., 2010). Content validity was promoted by comparing the items selected in the quantitative Delphi-survey to a construct validation matrix to ensure the questionnaire was conceptually adequate (Durepos et al., 2020b).

Concurrent validity (i.e., the extent to which participant scores on a questionnaire are related to scores on an established questionnaire) was examined through correlations between global-preparedness and factor subscale scores (Onwuegbuzie, et al., 2010). Lastly, substantive validity assesses evidence that the questionnaire samples underlying hypothesized traits (Onwuegbuzie et al., 2010). Evidence for substantive validity was generated through integrated data reduction which involved reducing the dimensionality of the quantitative data collected for questionnaire evaluation and considering the extracted factors in light of existing theories and previous study phase findings.

Additional strengths of this study included: 1) the moderate sample size and engagement of diverse CGs during each study phase from a wide array of residential care facilities; and 2) the use of mixed methods which allowed the findings from one study phase to inform and complement findings from the subsequent phase. A total sample of 166 unique participants contributed to this study with only two CGs participating in Phase 1 and 2. Onwuegbuzie et al. (2010) recommends that the sample of participants be expanded and new persons recruited during each study phase to validate, 'legitimize' and expand upon the findings from the previous phase. As such, data collected from new participants in each study phase provided additional perspectives and? concrete examples of preparedness characteristics that validated and expanded upon findings from previous participants. The moderate sample size should support the transferability and generalizability of findings to similar CGs. Lastly, the qualitative and quantitative phases of data collection and analysis enabled the comparison of findings generated through alternative, complementary methods (i.e., reflexive thematic analysis, content validation index and exploratory factor analysis) (Onwuegbuzie et al., 2010). The use of mixed methods supports confidence for inferences that can be drawn from the study findings.

Limitations for this study included the recruitment of primarily female, non-minority adult-child CGs from Ontario, Canada. Adult child-CGs do report different experiences related to caregiving and EOL than spousal CGs (Schulz et al., 2015), therefore larger sample sizes of spousal CGs are needed to examine patterns and differences in preparedness. It is possible that spousal CGs were less likely to participate in the study because of higher levels of burden or grief than adult-child CGs or may have been approached less by leaders in LTC for fear of causing distress. As a result, the questionnaire and findings may not be generalizable or transferable to all CGs. In addition, data were not obtained from CGs who opted not to enroll in the study, therefore persons who participated may be different from those who did not, again limiting the generalizability of the findings.

Factor analysis was conducted with 134 participants and 166 data points. However, one item (‘Life Purpose Concern’) was discarded that did not meet the Measure for Sampling Adequacy (Pett et al., 2003). Concern about life purpose after caregiving ends has been described as greater amongst spousal CGs and may be an important predictor of complicated grief (Durepos et al., 2017; Orzeck, 2018;

Supiano et al., 2020). Therefore, this item should be examined further in the future, as it may contribute to content and substantive validity of the questionnaire and assist with discriminating between spousal and adult-child CGs.

General data to describe length of time since diagnosis and time living in a residential care facility were collected. However, specific clinical information describing the stage of the dementia, abilities and/or symptoms of persons with dementia were not collected during the questionnaire evaluation in Phase 3 (Chapter 6). The goal of this study was not to evaluate associations between levels of preparedness and stage/symptoms of dementia. In addition, we aimed to minimize the amount of data collected from participants to avoid response burden (Streiner et al., 2015).

During the test re-test completed in Phase 3 of this study (Chapter 6), times varied between the initial and secondary administration of the questionnaire and extended beyond the two-week recommended period for a test-retest (Streiner et al., 2010). However, because the questionnaire was administered by postal mail, a secondary questionnaire could not be sent until the first was returned. The reliability co-efficient suggested stability in responses but the impact of time on item responses (and sensitivity to change) should be further investigated.

Conclusion

In summary, findings from this thesis and the development of the Caring Ahead: Preparing for EOL with Dementia questionnaire aim to make contributions to research, policy, theory, education and practice. New insight into preparedness core concepts and novel indicators should support the design of interventions and creation of practice guidelines that focus on enabling CGs to; manage the situation and meet the needs of the person with dementia; fulfill moral and legal societal obligations; and adapt to loss. Integrating these core concepts into interventions and practice should promote all aspects of CG preparedness.

Furthermore, assessing CGs' degrees and areas of preparedness with the Caring Ahead questionnaire should enable researchers, healthcare providers and policy-makers to identify CGs in need of support, target specific needs and evaluate the effectiveness of interventions. By identifying CGs and tailoring interventions to promote limited areas of preparedness, the well-being of CGs should be promoted. It is important to remember that preparedness is a relatively 'new', complex and dynamic theoretical construct influenced by personal beliefs and context. It is therefore the responsibility of the nurse and healthcare provider to explore the preferences and values of each unique person and tailor a palliative approach that supports preparedness.

References

Achora, S., & Labrague, L. J. (2019). An integrative review on knowledge and attitudes of nurses toward palliative care: Implications for practice. *Journal of Hospice & Palliative Nursing*, *21*(1), 29-37.

Amador, S., Sampson, E. L., Goodman, C., Robinson, L., & SEED Research Team. (2019). A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliative Medicine*, *33*(4), 415-429.

Annear, M. J., Toye, C., Elliott, K. E. J., McInerney, F., Eccleston, C., & Robinson, A. (2017). Dementia knowledge assessment scale (DKAS): confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, *17*(1), 168.

Austin, P., Macleod, R., Siddall, P., McSherry, W., & Egan, R. (2017). Spiritual care training is needed for clinical and non-clinical staff to manage patients' spiritual needs. *Journal for the Study of Spirituality, 7*(1), 50-63.

Barry, L. C., Kasl, S. V., & Prigerson, H. G. (2002). Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The American Journal of Geriatric Psychiatry,* 10(4), 447-457.

Boyd, M., Frey, R., Balmer, D., Robinson, J., McLeod, H., Foster, S., ... & Gott, M. (2019). End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. *BMC Geriatrics, 19*(1), 137.

Bremer, P., Cabrera, E., Leino-Kilpi, H., Lethin, C., Saks, K., Sutcliffe, C., ... & Right Time Place Care Consortium. (2015). Informal dementia care: Consequences for caregivers' health and health care use in 8 European countries. *Health Policy, 119*(11), 1459-1471.

Bristol, S. T., Lloyd, S. L., & Bristol, A. A. (2017). Integrating spiritual bereavement skills into an advanced practice curriculum. *Journal of Nursing Education, 56*(7), 439-442.

Cahill, S. (2020). WHO's global action plan on the public health response to dementia: some challenges and opportunities.

Callaway, M. V., & Foley, K. M. (2018). The International Palliative Care Initiative. *Journal of Pain and Symptom Management*, *55*(2), S1-S5.

Canadian Hospice Palliative Care Association. *The way forward national framework: A roadmap for an integrated approach to care.* Available from: http://www.hpcintegration.ca/media/60044/TWF-framework-doc- Eng-2015-final-April1.pdf

Canadian Institute for Health Information (2018). *Access to palliative care in Canada.* Ottawa, ON: CIHI.

Chertkow, H. (2018). An action plan to face the challenge of dementia: international statement on dementia from IAP for health. *The Journal of Prevention of Alzheimer's Disease*, *5*(3), 207-212.

Colwell, P. (2017). Building confidence in neonatal bereavement: The use of simulation as an innovative educational approach. *Journal of Neonatal Nursing, 23*(2), 65-74.

Corey, K. L., & McCurry, M. K. (2018). When caregiving ends: the experiences of former family caregivers of people with dementia. *The Gerontologist*, *58*(2), e87-e96.

Dassel, K. B., & Carr, D. C. (2016). Does dementia caregiving accelerate frailty? Findings from the Health and Retirement Study. *The Gerontologist*, *56*(3), 444-450.

Durepos, P., Sussman, T., Ploeg, J., Akhtar-Danesh, N., Punia, H., & Kaasalainen, S. (2018). What does death preparedness mean for family caregivers of persons with dementia? *American Journal of Hospice and Palliative Medicine, 36*(5), 436- 446. /doi.org/10.1177/1049909118814240

Durepos, P., Ploeg, J., Akhtar-Danesh, N., Sussman, T., Orr, E., & Kaasalainen, S. (2019). Caregiver preparedness for death in dementia: An evaluation of existing tools. *Aging & Mental Health,* 1-10. https://www.tandfonline.com/doi/full/10.1080/13607863.2019.1622074

Durepos, P., Ploeg, J., Sussman, T., Akhtar-Danesh, N., & Kaasalainen, S. (2020a) “A crazy roller coaster at the end”: A qualitative study of death preparedness with caregivers of persons with dementia. *SAGE Open Nursing, 6:* 1-11. doi.org/10.1177/2377960820949111

Durepos, P., Akhtar-Danesh, N., Ploeg, J., Sussman, T., & Kaasalainn, S. (2020b) Caring ahead: Mixed methods development of a questionnaire to measure preparedness for end-of-life in dementia. *Submitted to: Palliative Medicine, April 2020.*

Durepos, P., Sussman, T., Akhtar-Danesh, N., Ploeg, J., & Kaasalainen, S. (2020c). Evaluation of the caring ahead: Preparing for end-of-life in dementia questionnaire. *Prepared for submission to: Journal of Pain and Symptom Management, September 2020.*

Durepos, P., Wickson-Griffiths, A., Hazzan, A. A., Kaasalainen, S., Vastis, V., Battistella, L., & Papaioannou, A. (2017). Assessing palliative care content in dementia care guidelines: a systematic review. *Journal of Pain and Symptom Management*, *53*(4), 804-813. https://doi.org/10.1016/j.jpainsymman.2016.10.368

Durepos, P., Kaasalainen, S., Carroll, S., Papaioannou, A. (2017). Perceptions of a psychoeducation program for caregivers of persons with dementia at end of life: A qualitative study. *Aging and Mental Health,* 0:1-9. https://doi.org/10.1080/13607863.2017.1399347

Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology, 19*(1), 31–65. doi:10.1080/10720530500311182

Health Canada (2018). *Framework on palliative care in Canada.* Ottawa, ON: Health Canada.

Hebert, R., Prigerson, H., Schulz, R., & Arnold R. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine, 9*(5), 1164-1171.

Holm, M., Årestedt, K., & Alvariza, A. (2019). Associations between pre-death and post-death Grief in family caregivers in palliative home care. *Journal of Palliative Medicine. 22*(12), 1530-1535.

Hunter, P. V., McCleary, L., Akhtar-Danesh, N., Goodridge, D., Hadjistavropoulos, T., Kaasalainen, S., ... & Wickson-Griffiths, A. (2019). Mind the gap: is the Canadian long-term care workforce ready for a palliative care mandate?. *Ageing & Society*, 1-21.

Hutti, M. H., & Limbo, R. (2019). Using theory to inform and guide perinatal bereavement care. *The American Journal of Maternal/Child Nursing, 44*(1), 20-26

Kulasegaram, P., Thompson, G., Sussman, T., & Kaasalainen, S. (2018). End-of-life care communication training programs for long-term care staff: A scoping review. *Journal of Pain and Symptom Management*, *56*(6), e80.

Michels, C. T., Boulton, M., Adams, A., Wee, B., & Peters, M. (2016). Psychometric properties of carer-reported outcome measures in palliative care: A systematic review. *Palliative Medicine*, *30*(1), 23-44.

Mitchell, S.L. (2018). UpToDate: Palliative care of patients with advanced dementia. https://www.uptodate.com/contents/palliative-care-of-patients-with- advanced-dementia

Moore, K. J., Crawley, S., Vickerstaff, V., Cooper, C., King, M., & Sampson, E. L. (2020). Is preparation for end of life associated with pre-death grief in caregivers of people with dementia?. *International Psychogeriatrics*, 1-11.

Mori, M., Yoshida, S., Shiozaki, M., Morita, T., Baba, M., Aoyama, M., ... & Miyashita, M. (2018). "What I did for my loved one is more important than whether we talked about death": A nationwide survey of bereaved family members. *Journal of Palliative Medicine, 21*(3), 335-341.

Morrison, R. S. (2018). A national palliative care strategy for Canada. *Journal of Palliative Medicine*, *21*(S1), S-63.

Murtagh, F. E., Pinto, C., Bristowe, K., Witt, J., Davies, J. M., de Wolf-Linder, S., ... & Daveson, B. (2018). Perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and lessons for implementation: A multi-method qualitative study. *Annals of Palliative Medicine*, *7*(s3).

Nasu, K., Konno, R., & Fukahori, H. (2020). End-of-life nursing care practice in long-term care settings for older adults: A qualitative systematic review. *International Journal of Nursing Practice, 26*(2), e12771.

Neimeyer, R. A. (2019). Meaning reconstruction in bereavement: Development of a research program. *Death Studies, 43*(2), 79-91.

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers?

A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, *44*, 75-93.

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Vedsted, P., Bro, F., & Guldin, M. B. (2017). Predictors of complicated grief and depression in bereaved caregivers: A nationwide prospective cohort study. *Journal of Pain and Symptom Management, 53*(3), 540-550.

Orzeck P. (2016). Identities in transition: Women caregivers in bereavement. *Journal of Social Work and End-of-Life in Palliative Care,* 12(1-2), 145-161

Pallium Canada. (2020). *Palliative care myths episode 1 and 2.* [Film]. Pallium Canada.

Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin, 136*(2), 257–301. doi:10.1037/a0018301

Pereira, J., Downer, K., Giddings, G., Hanvey, L., Riordan, B., & Gravelle-Ray, N. (2018). *Leap Renewal. National standardized interprofessional education.* https://www.pallium.ca/wp-content/uploads/2019/07/LEAP-Renewal-%E2%80%93-National-Standardized-Interprofessional-Education.pdf

Pett, M., Lackey, N., & Sullivan J. (2003). *Making sense of factor analysis: The use of factor analysis for development in health care research*. California: SAGE Publishing Inc:71-206.

Rodgers BL Concept analysis: An evolutionary view. In: Rodgers BL, Knafl KA, eds. *Concept Development in Nursing.* Philadelphia: Saunders; 2000, 7-37.

Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine*, *18*(2), 127-133.

Shirado, A., Morita, T., Akazawa, T., et al. (2013). Both maintaining hope and preparing for death: Effects of physicians' and nurses' behaviors from bereaved family members' perspectives. *Journal of Pain and Symptom Management,* 45(5):848-858.

Smeaton, E., & Maher, C. (2016). Supporting spiritual engagement for people living with dementia. *Health and Social Care Chaplaincy, 4*(2), 130-141.

Snaman, J. M., Kaye, E. C., Spraker-Perlman, H., Levine, D., Clark, L., Wilcox, R., ... & Baker, J. N. (2018). Incorporating bereaved parents as faculty facilitators and educators in teaching principles of palliative and end-of-life care. *American Journal of Hospice and Palliative Medicine®, 35*(12), 1518-1525.

Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of internal medicine*, *132*(10), 825-832.

Streiner, D.L., Norman, G.R., Cairney, J. (2015). *Health measurement scales: A practical guide to their development and use.* Oxford, UK: Oxford University Press.

Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *OMEGA-Journal of Death and Dying*, *61*(4), 273-289.

Stroebe, M. S., & Schut, H. (1999). The Dual Process Model of coping with bereavement: Rationale and description. *Death Studies, 23,* 197-224.

Supiano, K. P., Luptak, M., Andersen, T., Beynon, C., Iacob, E., & Wong, B. (2020). If we knew then what we know now: The preparedness experience of pre-loss and post-loss dementia caregivers. *Death Studies*, 1-12.

Tang, W., Friedman, D. B., Kannaley, K., Davis, R. E., Wilcox, S., Levkoff, S. E., ... & Belza, B. (2019). Experiences of caregivers by care recipient's health condition: A study of caregivers for Alzheimer's disease and related dementias versus other chronic conditions. *Geriatric Nursing*, *40*(2), 181-184.

Terzakis, K. (2019). Preparing family members for the death of a loved one in long-term care. *Annals of Long-term Care*, *27*(2), 25-31.

van der Steen, J.T., Radbruch, L., Hertogh, C.M. et al. (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine, 28*(3), 197-209.

Virdun, C., Luckett, T., Lorenz, K. A., & Phillips, J. (2018). National quality indicators and policies from 15 countries leading in adult end-of-life care: a systematic environmental scan. *BMJ Supportive & Palliative care*, *8*(2), 145-154.

World Health Organization [WHO] (2019). Dementia key facts. Retrieved from: https://www.who.int/news-room/fact-sheets/detail/dementia

Appendices

Appendix A
Summary of Papers

Title	Purpose	Design and Methods	Main Findings
1) What Does Death Preparedness Mean for Family Caregivers of Persons with Dementia? Chapter 2	- Define preparedness attributes, antecedents, consequences	- Rodgers' Evolutionary Concept Analysis - 63 articles included	- 7 attributes of preparedness, antecedents & consequences - 'Preparedness for End-of-Life in Dementia Conceptual' model - Theoretical definition of preparedness
2) Caregiver Preparedness for Death in Dementia: An Evaluation of existing tools. Chapter 3	- Review and evaluate existing preparedness questionnaires	- Literature Review and Content Analysis - Evaluation of: Conceptual basis, population, setting, timing, psychometrics, Congruence with purpose - 7 questionnaires included	- 70% did not sample all preparedness domains/traits Gaps in content: - Affective trait - Practical domain - Dementia - Preparedness
3) "A Crazy Roller Coaster at the End": A Qualitative Study of Death Preparedness Chapter 4	- Explore caregivers' end-of-life experiences - Identify core concepts, barriers & facilitators of preparedness	- Interpretive Description and Reflexive Thematic Analysis - Semi-structured interviews - 16 bereaved CGs from 6 LTC homes	3 core concepts: - A sense of control, - Doing right, - Coming to Terms - Influential factors, facilitators, barriers and behavioural indicators generate

Title	Purpose	Design and Methods	Main Findings
4) Caring Ahead: Mixed Methods Development of a Questionnaire to Measure Preparedness for End-of-Life in Dementia. Chapter 5	- Identify & select indicators/items - Develop a questionnaire - Pilot-test	- Cross-sectional quantitative Delphi-survey and Content Analysis - 5 CGs and 12 Professional Delphi participants - Cognitive interviewing with 3 CGs	- 104 indicators translated from Phase 1 findings - 30-item questionnaire developed - Items refined through pilot-testing
5) Evaluation of the Caring Ahead: Preparing for End-of-Life in Dementia Questionnaire. Chapter 6	- Evaluate questionnaire psychometrics - Generate evidence for validity & reliability - Field-test	- Cross-sectional quantitative survey - 134 CGs, 166 data points - Descriptive Statistics, Factor Analysis, Correlation Analysis, Test-Retest, Cronbach's Alpha	Validity: - Internal Structure: 4 factor loading model: Actions, Dementia Knowledge, Communication, Emotions & Support Needs - Concurrent: Correlation with Single- Global Item ($p=0.05$) Reliability: - Test ReTest ICC > 0.7 - Cronbach's Alpha a > 0.7

Appendix B

Mixed methods design: Exploratory, sequential quantitative dominant status, instrument-variant design (qual -> QUAN)

QUALITATIVE STRAND
July-September 2018

Phase 1: Identify indicators and generate items

- Qualitative Interpretive design with reflexive thematic analysis
- Semi-structured interviews with 16 bereaved caregivers
- Preparedness core concepts (n=3), domains (n=4), traits (n=3) and potential indicator items identified (N=114), item pool reduced and approved (n=73)

QUANTITATIVE STRAND
February-March 2019

Phase 2: Select items

- Delphi-survey with 2-Iterative Rounds
- Online-format with 1 panel of 12 experts; 1 panel of 5 caregivers
- Content Validation Matrix of selected items
- Draft questionnaire developed with (n=30) items, Evidence for face and content validity

June 2019

Phase 3: Pilot-testing

- Face-to-face questionnaire administration and cognitive interviewing with 3 current caregivers
- Evidence for face and content validity

July 2019-April 2020

Phase 4: Field-Testing

- Administration of the 30-item self-report questionnaire to 134 current caregivers of persons with dementia in congregate living facilities
- Evaluation of psychometrics
- Evidence of underlying factor pattern, concurrent validity, test re-test reliability with 32 participants

Appendix C
Personal Relationship to the Study

After graduating from a Bachelor of Science in Nursing program in 2003, I embarked on a career as a critical care nurse in a high acuity, regional, neurotrauma intensive care unit. By 2012, I had witnessed much suffering, limited quality-of-life and invasive life-prolonging care amongst the patients and family members in my care. These experiences left me with feelings of existential and moral distress. As a result, I decided to return to graduate school to focus on a palliative approach that aimed to improve quality rather than length of life.

While pursuing my Master's degree two major events occurred that led to this study: 1) I came across Hebert et al.'s (2006) Theoretical Framework of Preparedness for End-of-Life while completing a project for a quantitative research methods class in October, 2012; and 2) I became involved in a psychoeducation program for family caregivers of persons with dementia through a clinical practicum in a specialized behavioural health unit in January, 2013.

Becoming involved with the psychoeducation program for family caregivers was one of the most meaningful and important experiences of my life. Over 12 months, I learned first-hand about the rewards and challenges that family caregivers experience both while their family member is living (and in an institution) and after their family member is deceased. The family caregivers became my formal and informal mentors along with the gifted social workers that led the program. I am still in touch and bonded to the caregivers from the program, although all the family members with dementia are now deceased. This program became the focus of my Master's thesis and one of the major findings was the perceived importance and benefits of being prepared for end-of-life for caregivers of persons with dementia. Family caregivers believe in this research and I have a responsibility to serve them.

The emphasis on preparedness as a priority to caregivers also resonated with my experiences in clinical practice. As a nurse in critical care, I believed and was taught that preparing family members for the future was a key aspect and responsibility of my role. I could rarely 'fix' persons' illnesses or provide curative care. However, I could always support families, try to prepare them for decision-making, caregiving, loss, grief, end-of-life and be a companion on their journey.

Just a few hours after the defense of my Master's thesis in July 2016, my supervisor Dr. Kaasalainen and I were discussing topics for my Ph.D. She suggested that the development or validation of an instrument was a very worthwhile endeavor for a dissertation. Immediately I blurted out that I wanted to develop a questionnaire to measure preparedness for end-of-life for family caregivers of persons with dementia based on Hebert et al.'s (2006) theoretical framework. I knew that preparedness was a priority for family caregivers in dementia, and I knew that many measurement tools negated aspects of spiritual and end-of-life care that are extremely important to well-being. I believe strongly in a palliative approach, that there is great need to shift to care focused on quality-of-life, that dying is a natural part of life that can bring about positive transformations and growth, and that preparing and embracing end-of-life benefits patients, caregivers and healthcare providers. For all of these reasons, I remain extremely passionate about this research after six years and since embarking on the ‘Caring Ahead’ journey I have never looked back.

Appendix D

Phase 3: Information and Consent Statement

PARTICIPANT INFORMATION SHEET

Title of Study: Caring Ahead: Development of a Questionnaire to Measure Preparedness for End-of-Life in Family Caregivers of Persons with Dementia

Student Investigator: Pamela Durepos, RN, PhD Student, School of Nursing, Faculty of Health Sciences, McMaster University
Principal Investigator: Dr. Sharon Kaasalainen, RN, PhD, Professor, School of Nursing,Faculty of Health Sciences, McMaster University

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You are being invited to participate in a research study conducted by Ms. Pamela Durepos because you have experience providing care to a family member or friend with dementia. This is a student research project conducted under the supervision of Dr. Sharon Kaasalainen at McMaster University. This study will help the student learn more about how family and friend caregivers prepare and cope with the end of the person with dementia's life. The student will also develop skills in research design, collection and analysis of data, and writing a research paper.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you.

WHY IS THIS RESEARCH BEING DONE?

Often family caregivers of people with dementia do not feel prepared for the loss of their family member or friend. This can affect their ability to adjust and cope for a long time after the death has occurred. A palliative approach may help caregivers to feel more prepared, but we currently do not have a questionnaire to measure what information and support family caregivers have, and if planning is effective at helping caregivers feel more ready for loss.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to learn about the needs of family or friend caregivers preparing for end-of-life in dementia. Family caregivers together with researchers have developed a questionnaire titled ‘Caring Ahead’ which aims to measure how prepared caregivers feel for the loss of their family member with dementia in different areas (e.g., practical, spiritual, medical). In the future, the questionnaire will be used to identify caregivers who need support in preparing for end-of-life, and highlight the areas where support is needed most. The questionnaire will help us to understand if Palliative Care and Advance Care Planning are helping caregivers feel prepared for death, or if new practices are needed to meet their needs.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?
If you volunteer to participate in this study, we will ask you to complete 1 copy of the ‘Caring Ahead questionnaire. Participants receive the questionnaire by mail, and return it to the student researcher Pam Durepos in a postage paid envelope. More than 1 family member can also complete a questionnaire so please contact us if anyone else in your family would like to participate.

The questionnaire will take approximately 15 minutes to complete. The questionnaire will ask you to rate how strongly you agree or disagree with 31 statements about preparing for the loss of your family member or friend (e.g., funeral planning, having difficult conversations, understanding your family member’s health). You will also be asked to complete a short questionnaire about your age, gender and demographics.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

By participating in this study, you may benefit by becoming more aware of your own feelings and preparations for the loss of your family or friend. The questionnaire may help you reflect on plans, conversations or actions you want to take. Your participation will help us understand if the questionnaire includes appropriate statements to measure preparedness. If the questionnaire is accurate, it will help us design more effective supports to help family caregivers.

The findings of this study will be shared in Canada and internationally through research journal publications, conference presentations, public seminars and workshops with long-term care homes. Results may also be posted on websites such as the Alzheimer Society of Canada. The questionnaire ‘Caring Ahead’ will be available for use after testing by researchers, nurses and others throughout the world that are working to help family caregivers in dementia, and potentially in other diseases.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

Completing the questionnaire and thinking about the death of your family member or friend may be difficult. You may experience feelings of sadness or grief. Your questionnaire will not be shared with health care providers, therefore we encourage you to reach out to family, friends and professionals (e.g., your family doctor) for support and help with grief. The researchers are also available to help connect you to resources.

If you complete and return the questionnaire you are giving your consent to participate in this study. Participation in this study is completely voluntary and you may choose not to participate. All questions are also voluntary and you may choose not to answer or to withdraw from this study at any time. Any decision not to participate or to withdraw from the study will have no impact on your relationships or care. Information about grief and supportive services (e.g., counselors, support groups) is included with the questionnaire.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your data will not be shared with anyone except with your consent or as required by law. All of the information you share in the questionnaires is confidential. Only members of the research team will have access to your information. Your identity will be protected by replacing your name and any identifying information with a code, known only to the research team. All information will be kept in a locked cabinet, stored in password protected, encrypted
the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board, may consult your research data. By returning the questionnaire, you authorize such access.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure. All information that is gathered in this study will be kept confidential. You will not be identified in any published results of the study. All information that you give will be kept in a locked cabinet at McMaster University for up to 7 years, after which it will be destroyed. Only
members of the research team will have access to the information.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you volunteer to be in this study, you may withdraw at any time and this will in no way affect you. You have the option to withdraw from the study or remove your data from the study, by contacting Pamela Durepos at 905-484-3546, lapospm@mcmaster.ca. You may also refuse to answer any questions you don't want to answer and still remain in the study.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

Initially we interviewed 16 bereaved family caregivers and then surveyed 17 caregivers and professionals to create the questionnaire. In this last phase of the study we will recruit over 200 current family caregivers to test the questionnaire.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

Participants will not receive any pay.

IMPLIED CONSENT STATEMENT

By returning this survey, you are agreeing to have your confidential responses used for research purposes. Your responses to the survey will help the research team learn more about the information and support that family caregivers have or need to feel more prepared for end-of-life. Should you have any questions about this study or if anyone else in your family would like to complete a questionnaire as well, please don't hesitate to contact:

Pamela Durepos, RN, PhD Student
lapospm@mcmaster.ca or caringahead@gmail.com
905-484-3546 or 1-833-998-1280
www.caringahead.com

Dr. Sharon Kaasalainen, School of Nursing, McMaster University
kaasal@mcmaster.ca
(905) 525-9140 extension 22291.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 420

Appendix E

Phase 3: Caring Ahead questionnaire for evaluation

Questionnaire Instructions and Study Results

Thank you for agreeing to participate in this study. The questionnaire statements are very sensitive and may bring up difficult emotions. Please take your time and reach out for support if needed. Please return the questionnaire and demographic sheet to us using the envelope provided.

In this questionnaire, ‘end-of-life’ refers to the last stage of someone’s life (approximately one year or two) and death. On the questionnaire, please select one number indicating how much you agree or disagree with each statement.

Caring Ahead: Preparing for End-of-Life with Dementia

Medical Preparations	**Strongly Disagree**						**Strongly Agree**
1. I believe I understand my family member's current health status.	1	2	3	4	5	6	7
2. I believe I know what changes to expect as dementia advances, for example: swallowing, eating difficulties.	1	2	3	4	5	6	7
3. I understand I may be faced with decisions such as: transferring to hospital, treating infections.	1	2	3	4	5	6	7
4. I believe I know what treatments my family member would choose.	1	2	3	4	5	6	7
5. I have shared my family member's wishes with health care providers, for example: focusing on living longer, maximizing comfort.	1	2	3	4	5	6	7
6. Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.	1	2	3	4	5	6	7
7. I have discussed end-of-life care preferences with the important people in my family member's life, for example: friends, family.	1	2	3	4	5	6	7
8. I have learned what the dying process may be like for my family member.	1	2	3	4	5	6	7
9. I understand that dementia (and Alzheimer's) is a condition that leads to death.	1	2	3	4	5	6	7

Relationships and Personal Preparations	**Strongly Disagree**						**Strongly Agree**
10. I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.	1	2	3	4	5	6	7
11. I would like to be more involved in planning care with health care providers.	1	2	3	4	5	6	7
12. I accept that I am doing my best for my family member.	1	2	3	4	5	6	7
13. I have someone to go to for emotional support about my family member's health.	1	2	3	4	5	6	7
14. I understand what my grief process may be like after my family member has died.	1	2	3	4	5	6	7
15. I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers.	1	2	3	4	5	6	7
16. I am making the most of my time with my family member, for example: by saying what I need to say to them.	1	2	3	4	5	6	7
17. I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.	1	2	3	4	5	6	7
18. I am spending time reflecting on my family member's life, for example: by sharing stories.	1	2	3	4	5	6	7

Spiritual Preparations	**Strongly Disagree**						**Strongly Agree**
19. I have a plan to honour traditions or practices my family member would want, for example: personal, cultural, spiritual,religious.	1	2	3	4	5	6	7
20. I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.	1	2	3	4	5	6	7
21. I have someone I can talk to about the meaning of illness or dying.	1	2	3	4	5	6	7
22. I worry about having purpose in my life after my family member has died.	1	2	3	4	5	6	7
23. I am practicing activities which give me strength such as: spending time in nature.	1	2	3	4	5	6	7

Practical Preparations	**Strongly Disagree**						**Strongly Agree**
24. My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.	1	2	3	4	5	6	7
25. I have someone I can contact if I need help managing my family member's affairs.	1	2	3	4	5	6	7
26. I know how to notify family and friends when my family member dies.	1	2	3	4	5	6	7
27. After-death services are arranged for my family member such as: burial or cremation.	1	2	3	4	5	6	7
28. I believe I can manage my personal affairs after my family member has died, for example: finances, housing.	1	2	3	4	5	6	7
29. I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.	1	2	3	4	5	6	7
30. I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.	1	2	3	4	5	6	7

Overall Preparedness		**Not Prepared At All**						**Prepared As Much As Possible**
31.	*If your loved one were to die soon, how prepared would you be for his/her death?	1	2	3	4	5	6	7

*Re-printed with permission of the authors, Schulz, R., Boerner, K., Klinger, J., & Rosen, J. (2015). Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. *Journal of Palliative Medicine*, *18*(2), 127-1

Appendix F

Phase 3: Demographic Collection Sheet

Please complete the following questions by placing a 'check-mark' in boxes or filling in the blanks.

1. What is your age (in years)? _______

2. What is your gender identity?
   - ☐ Male
   - ☐ Other
   - ☐ Female
   - ☐ Prefer not to say

3. What is your highest level of education?
   - ☐ Less than High School
   - ☐ High School
   - ☐ College / University
   - ☐ Graduate School
   - ☐ Other ____________

4. What is your annual household income?
   - ☐ Less than 50,000
   - ☐ 51-100,000
   - ☐ 101-150,000
   - ☐ Greater than 151,000
   - ☐ Prefer not to say

5. What is your ethnic origin (other than Canadian)? (e.g., British, South Asian)
   ____

6. Are you a member of a visible minority? (e.g., Black, Hispanic)
   - ☐ Yes, if so what minority? _____
   - ☐ No

7. Do you have a religious or spiritual affiliation? (e.g., Christian, Agnostic, Muslim)
   - ☐ Yes, if so what is your affiliation? ____________ _____
   - ☐ No

8. What is your relationship to the family member/friend you provide care for?
   - ☐ Spouse / Partner
   - ☐ Adult Child of the Person with Dementia
   - ☐ Other, Please Explain (e.g., daughter-in-law)__________

9. What is the age of your family member/friend (in years)?
____

10. What is the gender identity of your family member/friend?
    - ☐ Male
    - ☐ Other
    - ☐ Female
    - ☐ Prefer not to say

11. Does your family member have a religious or spiritual affiliation? (e.g., Christian, Agnostic, Muslim)
    - ☐ Yes, if so what is their affiliation?
      ____
    - ☐ No

12. How long has your family member/friend had dementia (in years)? ____

13. What type of dementia does your family member/friend have?
    - ☐ Alzheimer's
    - ☐ Vascular / Stroke
    - ☐ Mixed
    - ☐ Lewy Body
    - ☐ Fronto-Temporal
    - ☐ Other, Please explain
      ____
    - ☐ Korsakoff's
    - ☐ Unknown/ Unsure

14. How long has your family member/friend lived in a care facility (in years)?
____

15. What city and province / territory is the care facility located in? ____

Appendix G

Resources & Support for Coping with Grief, Stress & Care Planning

Caring for someone with dementia and thinking about end of life can be difficult. Please consider reaching out to a health care provider or fellow caregiver (e.g., physician, nurse, social worker, Family Council, Director of Care/Home Administrator in the care facility) and/or services for support:

Alzheimer Society (multiple branches)	'Dementia in the Later Stages Class', information, free counselling, support	https://alzheimer.ca/ 1-800-616-8816
Caregiver Coalitions (chapters in most provinces / territories)	Information, support	www.ontariocaregiver.ca 1-833-416-2273 https://www.familycaregiversbc.ca/ 1-877-520-3267 www.caregiversalberta.ca 1-877-453-5088 Manitoba www.ccc-ccan.ca
Crisis Services Canada	Free counselling	www.crisisservicescanada.ca 1-833-456-4566 (24-7) Text 45645 (4pm-12am)
Center for Loss and Life Transition	Information	www.centerforloss.com
Canadian Mental Health Association	Free counselling	https://cmhanl.ca Toll free 1-888-737-4668
Speak Up	Free advance care planning resources for families	http://www.advancecareplanning.ca/ 1-800-349-3111 ext 31

Appendix H
Ethics Approval Certificate from Hamilton Integrated Research Ethics Board

HiREB
Hamilton Integrated Research Ethics Board

Amendment Approval
Jun-07-2019 HiREB Project #: 4503

Project Submission Title: Caring Ahead: Development and Evaluation of a Questionnaire to Measure Preparedness for Death in Family Caregivers of Persons with Dementia

Local Principal Investigator: Dr. Sharon Kaasalainen
Document(s) Approved:

Document Name	Document Date	Document Version
Caring Ahead Study Questionnaire Phase 3	Apr-26-2019	1
Durepos_Proposal V8 Clean	May-16-2019	8 Clean
Grief and Mental Health Supports	Apr-26-2019	1
Participant Demographics Phase 3	Apr-26-2019	1
Participant Mailing Address Information	Apr-26-2019	1
Phase 3 Abbreviated Flyer	Apr-26-2019	1
Phase 3 Contact Information for Recruitment	May-03-2019	1
Phase 3 Face to Face Pilot Test Guide	Apr-26-2019	1
Phase 3 Information Sheet V-5 Clean	Apr-26-2019	5 Clean
Phase 3 Letter and Lay Summary for Recuitment Sites	May-03-2019	1 Clean
Phase 3 Participant Consent and Information Sheet V-5 Clean	Apr-26-2019	5 Clean
Phase 3 Participant Recruitment Letter V2 Clean	May-16-2019	2 Clean
Phase 3- Permission to Share Contact Information Script	Apr-26-2019	1
Phase 3 Questionnaire Instructions for Participants	Apr-26-2019	1

Document Name	**Document Date**	**Document Version**
Phase 3 Recruitment Flyer	**Apr-26-2019**	**1**
Phase 3 Recruitment Script Telephone V2 Clean	**May-16-2019**	**2 Clean**
Phase 3 Reminder Phone Script	**Apr-26-2019**	**1**
Summary of Changes Amendment 3 V5	**May-16-2019**	**5**

Document(s) Acknowledged:

Document Name	**Document Date**	**Document Version**
Family Council Letter of Support 1	**Apr-26-2019**	**1**
Family Council Letter of Support 2	**Apr-26-2019**	**1**
Family Council Letter of Support 3	**Apr-26-2019**	**1**

This amendment has been reviewed and approved as submitted:
[ ] Full Research Ethics Board
[X] Research Ethics Board Executive [ ] Student Research Committee

Dr. Mark Inman, MD, PhD
Chair, Hamilton Integrated Research Ethics Board

The Hamilton Integrated Research Ethics Board (HiREB) represents the institutions of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton and the Faculty of Health Sciences at McMaster University and operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada