

# Caring ahead: Mixed methods development of a questionnaire to measure caregiver preparedness for end-of-life with dementia

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## Abstract

**Background:** Family caregivers of persons with dementia often feel unprepared for end-of-life and preparedness predicts caregiver outcomes in bereavement. Existing questionnaires assessing preparedness have limitations. A multi-dimensional questionnaire assessing family caregiver preparedness for the end-of-life of persons with dementia is needed to identify caregivers at risk for negative outcomes in bereavement and evaluate the quality of strategies within a palliative approach.

**Aim:** To develop a multi-dimensional questionnaire titled ‘Caring Ahead’ to assess feelings of preparedness for end-of-life in family caregivers of persons with dementia.

**Design:** A mixed methods, sequential design employed semi-structured interviews, a Delphi-survey and pilot-testing of the questionnaire, June 2018 to July 2019.

**Setting/population:** Participants included five current and 16 bereaved family caregivers of persons with symptoms advanced dementia from long-term care homes in Ontario, Canada; and 12 professional experts from clinical and academic settings in Canada, Europe, United States.

**Results:** Interviews generated three core concepts and 114 indicators of preparedness sampling cognitive, affective and behavioural traits in four domains (i.e., medical, psychosocial, spiritual, practical). Indicators were translated and reduced to a pool of 73 potential questionnaire items. 30-items were selected to create the ‘Caring Ahead’ preparedness questionnaire through a Delphi-survey. Items were revised through a pilot-test with cognitive interviewing.

**Conclusions:** Family caregivers’ feelings of preparedness for end-of-life need to be assessed and the quality of strategies within a palliative approach evaluated. Future psychometric testing of the Caring Ahead questionnaire will evaluate evidence for validity and reliability.

## Keywords

Caregiver, death preparedness, dementia, questionnaire, mixed methods, palliative care, death and dying, outcome measure, long-term care

### What is already known about this topic?

- Family caregiving for persons with dementia is associated with negative outcomes in bereavement.
- Negative outcomes are predicted by family caregivers’ preparedness for end-of-life.
- Preparedness is modifiable through strategies supporting a palliative approach.
- Existing questionnaires used to assess preparedness have limitations.

### What this paper adds?

- Core concepts of preparedness for end-of-life included managing the situation, fulfilling obligations and adapting to loss.
- Indicators of preparedness included engaging in life review, reconciling with the person with dementia, knowing what the dying process may be like, communicating about goals and preferences with healthcare professionals and having affairs in order.

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### Implications for practice and research

- Further research is needed to evaluate psychometrics of the Caring Ahead questionnaire.
- Healthcare professionals should assess preparedness to identify caregivers of persons with advanced dementia in need of support.
- Researchers should design/evaluate interventions to address preparedness core concepts and indicators.

## Introduction

Family caregivers of persons with dementia can experience unique challenges and barriers to accessing care that impact their well-being into bereavement.<sup>1–3</sup> New dementia and palliative care frameworks aim to address inequities by promoting the early introduction of a palliative approach.<sup>4–7</sup> Approximately half of deaths of persons with dementia occur in long-term care institutions making long-term care the ideal location to introduce a palliative approach.<sup>7,8</sup>

A palliative approach focuses on providing holistic care to promote quality-of-life and prepare persons with life-limiting illnesses and their families for end-of-life.<sup>9</sup> Guidelines for dementia care often negate aspects of care essential to a palliative approach such as end-of-life management, grief/loss and spiritual care.<sup>10,11</sup> Up to 50% of family caregivers report feeling unprepared for end-of-life and death preparedness predicts well-being in bereavement.<sup>12–17</sup> Caregiver death preparedness (i.e., readiness for death) can be modified through strategies supporting a palliative approach.<sup>13–17</sup> However, outcome measures used to evaluate strategies within a palliative approach are often limited to the documentation of resuscitation status.<sup>11,18,19</sup> Assessing preparedness rather, could provide a holistic, outcome measure to evaluate the effectiveness of strategies.

Caregiver death preparedness is a multi-dimensional, dynamic 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’ (p. 4).<sup>20</sup> The Theoretical Framework of Preparedness for End-of-Life<sup>21</sup> and the Caregiver Preparedness for End-of-Life with Dementia model<sup>20</sup> describe preparedness as having medical, psychosocial, spiritual and practical domains with underlying cognitive, affective and behavioural traits (see Figure 1). Preparedness has been linked to end-of-life conversations, which supports the assessment of preparedness as a holistic outcome measure for strategies supporting a palliative approach.<sup>20–24</sup>

Despite the complexity of preparedness, the construct is often assessed with a single-item or a generic questionnaire such as the Preparedness for Caregiving Scale.<sup>25,26</sup> This is problematic because single-items are unidimensional, require abstract-thinking and are

occasion-specific.<sup>27–29</sup> Generic questionnaires are also less responsive to detecting change over time than condition-specific questionnaires and do not assess specific content and concerns, which reduces face and content validity.<sup>26–30</sup> In contrast, multi-item, condition-specific questionnaires investigate dimensionality, explore variance in core concepts and individual items and avoid occasion-specific effects.<sup>27–30</sup> Hence, a multi-item, condition-specific questionnaire is needed to assess caregiver preparedness for end-of-life of persons with dementia and act as an outcome measure for strategies supporting a palliative approach.

## Methods

### Aims

In this study we aimed to develop a multi-dimensional questionnaire to assess caregiver preparedness for the end-of-life of persons with dementia.

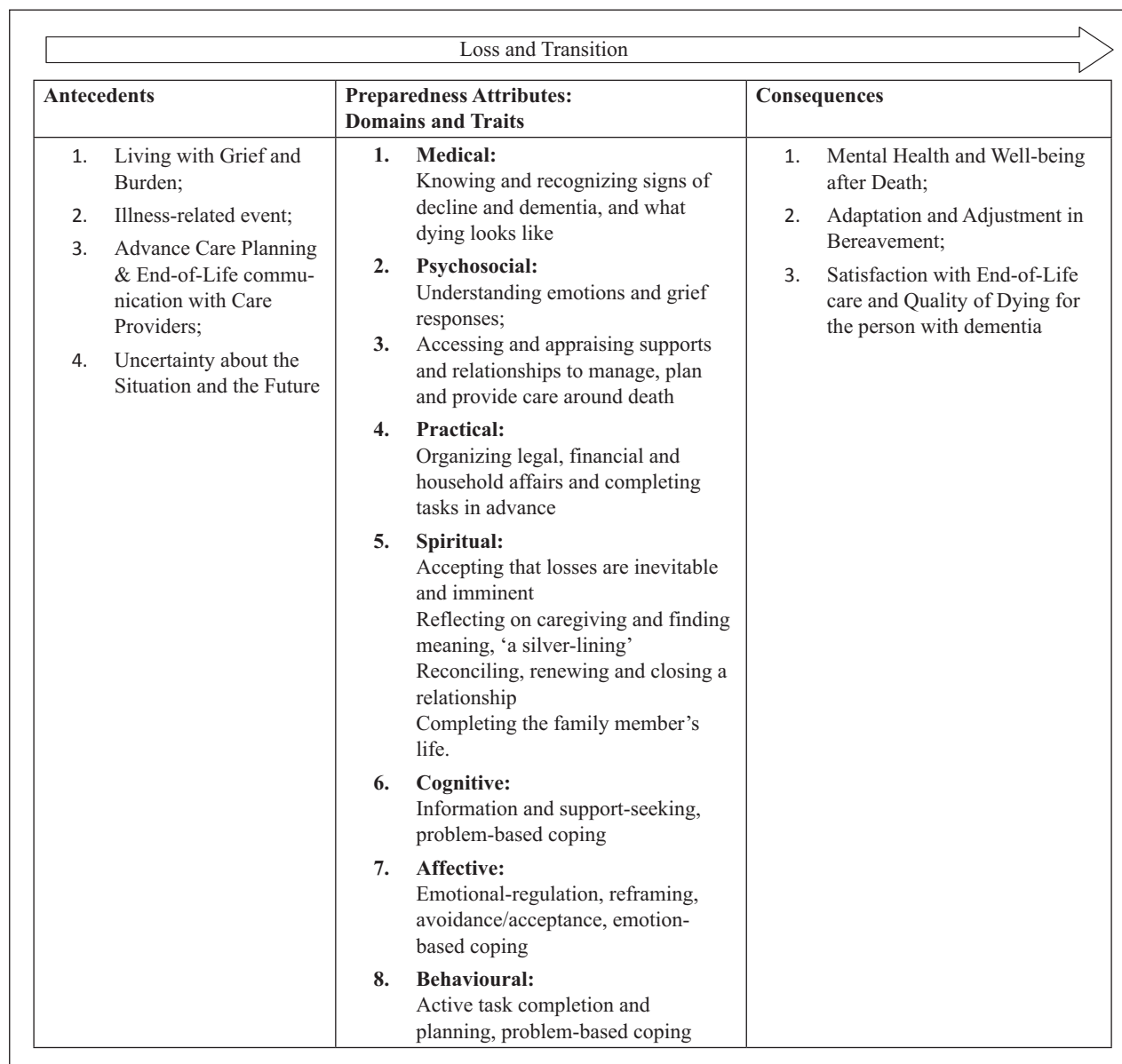
### Design

This sequential mixed methods study was guided by the Instrument Development and Construct Validation framework.<sup>31</sup> We used three phases (qualitative → QUANTITATIVE) to: (1) generate questionnaire items; (2) select questionnaire items and (3) evaluate questionnaire face validity and response process (Figure 2). The protocol was approved by the Hamilton Integrated Research Ethics Board (#4503).

### Phase 1

*Design.* A qualitative, interpretive descriptive approach was first used to explore core concepts of preparedness beyond the surface, identify behavioural indicators and generate questionnaire items in summer, 2018.<sup>31–35</sup>

*Population/setting.* Purposive and maximum variation sampling were used to recruit 16 bereaved caregivers for interviews from six long-term care homes in Ontario, Canada.<sup>32</sup> To minimise researcher intrusion and participant distress, participants were recruited with the aid of partners (e.g., long-term care Director) who acted as gatekeepers and asked participants for permission to share their contact information with us.<sup>36,37</sup> Participants



**Figure 1.** 'Caregiver preparedness for end-of-life with dementia' model.

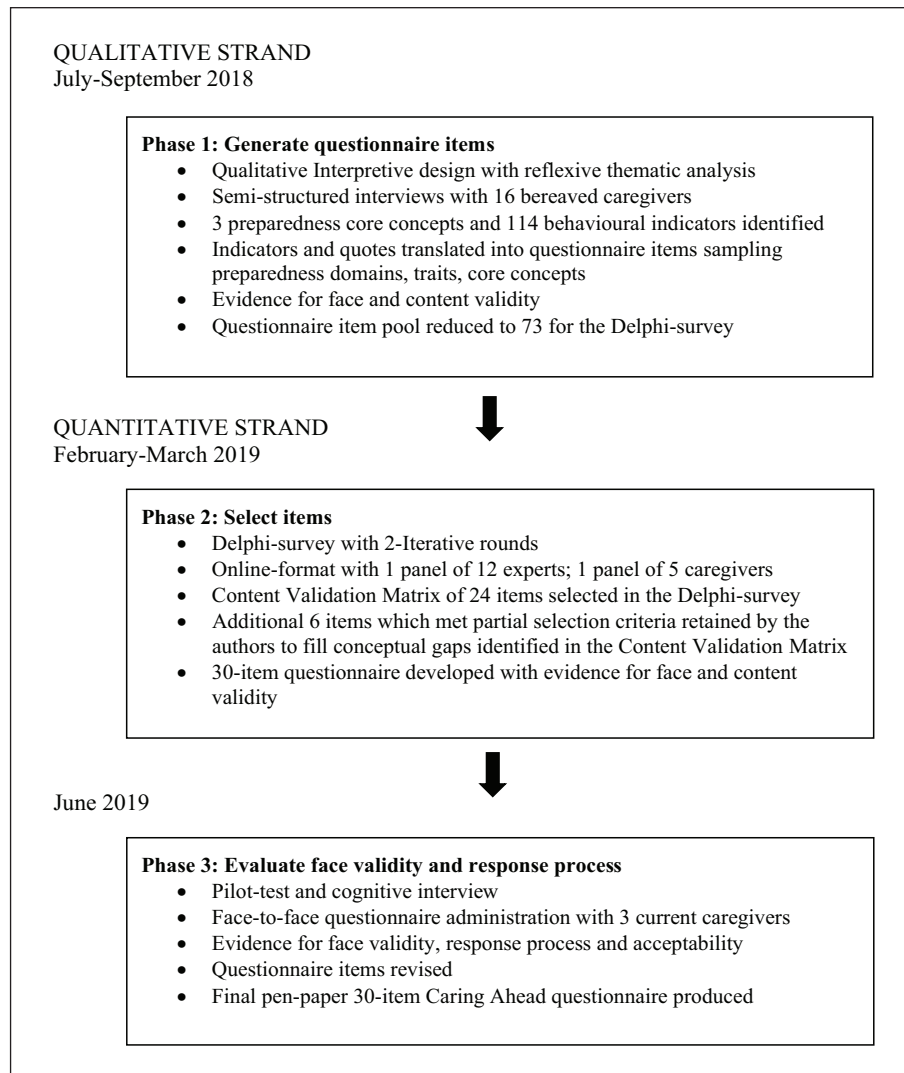
Source: Reprinted with permission from Durepos et al.<sup>20</sup>

were English-speaking, primarily female (57%), bereaved (10 months on average), adult-child caregivers (70%) who had cared for a person with dementia living in long-term care. Participants described persons with dementia as having symptoms of late-stage dementia prior to death (e.g., difficulty swallowing, frequent infections, immobility, incontinence, limited verbalisation and facial recognition).<sup>1</sup>

*Data collection.* A semi-structured interview guide with questions organised around preparedness domains (i.e., medical, psychosocial, spiritual, practical preparations) was used to conduct in-person or telephone interviews.<sup>20,21</sup>

Participants were asked to describe events, activities and feelings of preparedness which occurred during the last year of the person's life. Informed, written consent was obtained and participants were provided with a list of supportive resources.<sup>35-37</sup> Interviews were audio-recorded, transcribed and proofed.

*Analysis.* We followed Braun and Clarke's (2014) process for reflexive thematic analysis. We used an iterative, inductive, data-driven approach to: (1) organise the data with surface-level codes; (2) identify behaviours perceived as facilitating and indicating caregiver preparedness during the year prior to death; (3) search



**Figure 2.** Mixed methods design: exploratory, sequential quantitative dominant status, instrument-variant design (qualitative → QUANTITATIVE).

for, define and agree upon overarching themes that represented core concepts of preparedness.<sup>34</sup> Authors independently analysed three transcripts and met together to agree upon codes and themes. PD then analysed the remaining transcripts extracting participant quotes as evidence and met frequently with the authors to ensure the findings were data-driven.<sup>34,35</sup> We then translated the behavioural indicators and facilitators into potential questionnaire items sampling preparedness core concepts, domains, and traits based on participants' direct-quotes.<sup>20,21,30-32</sup>

### Phase 2

*Design.* A cross-sectional Delphi-survey was next completed to generate consensus and select/revise items for the questionnaire in winter, 2019.<sup>38,39</sup>

*Population/setting.* Purposive, convenience and maximum variation sampling was used to recruit seventeen panelists (including five caregivers and 12 professional experts) via email to participate in the Delphi-survey. Caregiver panelists included participants from Phase 1 who had requested further participation and volunteers within the Alzheimer Society or Canadian Frailty Network known to the authors (response rate 63%). Professional expert panelists were reputable academics or clinicians in the field of dementia, caregiving and palliative care contacted via publicly available emails (response rate 55%).<sup>30</sup> A sample of 15–20 participants has been described as adequate for a Delphi-survey and no panelist attrition occurred between rounds.<sup>38,39</sup> Caregiver panelists were English-speaking, 59 years old on average, 60% were female, 80% were adult-children of a person with dementia, and 60% were bereaved. Expert panelists had an average of 20 years of experience (see Table 1).

**Table 1.** Phase 2 Delphi-survey panelists.

Caregiver panel (n = 5)		Mean (SD)	N (%)
Age (years)		58.8 (11.2)	
Gender identity	Female		3 (60)
	Male		2 (40)
Relationship	Spouse		1 (20)
	Adult child		2 (40)
	Adult child in-law		2 (40)
Caregiver status	Bereaved		3 (60)
	Current		2 (40)
Expert panel (n = 12)		Mean (SD)	N (%)
Age (years)		49.8 (13.7)	
Gender identity	Female		10 (83)
	Male		2 (17)
Years of experience		20.2 (12.6)	
Discipline	Medicine		2 (17)
	Nursing		2 (17)
	Psychology		2 (17)
	Health research		1 (7)
	Social work		2 (17)
	Spiritual care		2 (17)
	Law		1 (7)
Setting	Clinical/community		6 (50)
	Academic/research		6 (50)
Country	Canada		8 (67)
	Europe		1 (8)
	USA		3 (25)

**Data collection.** The survey was piloted with one caregiver, one expert nurse researcher and two graduate students.<sup>38,39</sup> We used LimeSurvey, a secure online survey platform to administer the survey with implied consent.<sup>40</sup> In Round 1, panelists rated the importance of items using a 7-point Likert scale with anchors (1 = Strongly Disagree, 7 = Strongly Agree) and suggested changes to item wording.<sup>38,39</sup> In Round 2, panelists were provided with the item Content Validation Index (CVI), of each panel's (i.e., expert and caregiver) median scores and the original wording of revised items. Panelists then provided a dichotomous rating (rate 0/1) to 'accept or reject' items selected based on consensus in Round 1 and re-rated items (from 1 to 7) that had met partial criteria for consensus. The survey was stopped after Round 2 when the item pool was reduced.<sup>30,38,39</sup>

**Analysis.** Criteria for item selection consensus was defined as: CVI  $\geq$  0.8 and a median score of  $\geq$  6 from both panels. Consensus from both panels equally values perspectives and using multiple selection criteria efficiently reduces items.<sup>38,39</sup> Content analysis of panelist comments guided item revision and exclusion.<sup>31</sup> Upon completion of the Delphi-survey, a draft questionnaire comprised of the selected items was compared to a Content Validation

Matrix to ensure that the questionnaire adequately sampled three core concepts, four domains and four traits of preparedness.<sup>20,21,30,31,38</sup>

### Phase 3

**Design.** A cross-sectional pilot-test and cognitive interview with the developed questionnaire was conducted to explore face validity and response process in spring, 2019.<sup>30,31,41,42</sup>

**Population/setting.** Purposive and criterion sampling and advertising flyers were used to recruit three current caregivers from three long-term care homes in Ontario.<sup>30</sup> Participants were female, between 35 and 68 years old and included one spouse and two adult-children. Persons with dementia were living in long-term care and were described as having symptoms of advanced dementia.<sup>1</sup>

**Data collection and analysis.** Participants provided informed, written consent for the in-person questionnaire pilot-test and cognitive interview. Cognitive interviewing is a process whereby participants: complete a questionnaire with an interviewer; explain their interpretation of questions (i.e., response process) by 'thinking-aloud' and make suggestions to increase items' face validity.<sup>30,31,41,42</sup> A semi-structured interview guide with questions such as, 'what does this statement mean to you?' was followed and field notes were recorded to document participants' interpretations and suggestions. Field notes were analysed through content analysis to categorise and compare recommendations.<sup>41</sup>

## Results

### Phase 1 Findings

Three core concepts of preparedness emerged from interviews with bereaved caregiver participants including: (1) managing the situation to meet the needs of the person with dementia, (2) fulfilling obligations to meet the moral and legal needs of society and (3) adapting to loss to meet the emotional needs of the caregiver. One hundred and fourteen behaviours perceived as indicating and facilitating preparedness such as planning, organising, knowing, coping and accepting were identified and translated into a pool of questionnaire items sampling perceived core concepts, domains and traits of preparedness.<sup>20,21</sup> Through discussions with one caregiver and one expert (nurse researcher in dementia/caregiving) the pool of items was subsequently reduced to 73 for the Delphi-survey (see Table 2). The 'psychosocial' domain label was replaced with 'relationships and personal' to reduce jargon.<sup>30</sup> Items were organised according to one primary domain to reduce respondents' cognitive workload and less sensitive

**Table 2.** Phase 1 findings: Preparedness indicators, quotes and potential questionnaire items ( $n = 73$ ) sampling preparedness domains, traits and core concepts.

Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
Medical	Q1	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	Beh	Control
	Q2	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	Cog	Control
	Q3	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 Alzheimer's) is a life-threatening (fatal) condition with no cure	Cog	Control
	Q4	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 time something comes up so we can make that decision.'	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	Cog	Control
	Q5	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	Cog	Control
	Q6	Understanding medical information provided by staff	'The nurses and doctors were also very good at dumbing things down because they do it a lot'	Can understand, for example: printed pamphlets, face to face discussion	Cog	Control
	Q7	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	Cog	Control
	Q8	Recognising 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 recognise decline in my family member's health, for example: eating less, less social, behaviour changes (more or less)	Aff	Control
	Q9	Knowing the person with dementia'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 example: to focus on lengthening life, comfort/quality of life, or a combination of both	Cog	Oblig
	Q10	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	Beh	Control
	Q11	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	Beh	Control
	Q12	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	Beh	Control

(Continued)



Table 2. (Continued)

Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
	Q13	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	Beh	Control
	Q14	Knowing the 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	Cog	Control
	Q15	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	Beh	Control
	Q16	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	Beh	Control
	Q17	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.	Cog	Control
	Q18	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	Beh	Control
	Q19	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	Beh	Control
	Q20	Global medical preparedness		Overall, I feel prepared for medical changes which might occur when my family member is dying	Global	Control
Relationship/personal	Q21	*Limited support from family for care	'Surround yourself with support. . .When you're alone you're just anxious. . .You don't know what your loved one is going to need'	I do not feel I will receive enough support from family and friends around my family member's death, for example: making decisions, providing hands-on care	Aff	Adapt
	Q22	*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'	*Reverse worded item I expect there will be conflicts (i.e., disagreements) in my family around my family member's death	Aff	Adapt
	Q23	Confident to meet needs of the person with dementia	'This is my speciality. . .we were checking all the boxes. . .'	*Reverse worded item I feel confident in my responsibilities for my family member in their care facility, for example: decision-maker, companion, hands-on-care provider	Aff	Control
	Q24	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	Beh	Control

(Continued)

Table 2. (Continued)

Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
	Q25	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' 'The charge nurse. . . had her finger on everything'	I feel I have some control over the care of my family member	Beh	Control
	Q26	Trusting staff with care	'You can't rely on the staff'	I feel confident that care providers will provide quality end-of-life care for my family member	Aff	Control
	Q27	*Limited collaboration with staff	'Communication is the key to everything right? I mean when you feel informed you feel a little more in control' '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 do not feel satisfied with the relationship I have with my family member's care providers *Reverse worded item	Aff	Control
	Q28	Feeling staff are accessible	'They basically said, 'we need you to come pick up your mom's furniture'. . . it was really upsetting. . . not an hour after the funeral' '[Staff] helped to prepare us every step of the way'	I feel confident that I can speak to care providers when I would like to	Aff	Control
	Q29	Feeling emotionally supported by staff	'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 was surprised that I was so grief stricken by it'	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	Aff	Adapt
	Q30	*Feeling concern over conflicts with staff	'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 expect to have conflict (i.e., disagreements) with care providers around my family member's death	Aff	Adapt
	Q31	Having supportive resources to prepare for death	'Everybody should take advantage of counselling' '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'	*Reverse worded item Overall, care providers are supportive in helping me prepare for my family member's death	Global	Control
	Q32	Recognising your emotions		I recognise that I may be grieving before my family member with dementia has died	Cog	Adapt
	Q33	Knowing what emotions to expect		I understand that I may experience strong emotions that are normal when my family member dies, for example: intense grief, numbness, relief or shock	Cog	Adapt
	Q34	Feeling capable to cope with emotions		I feel confident that I can cope with emotions (e.g., grief) I may experience	Beh	Adapt
	Q35	Having access to emotional support		I can access additional emotional support if I need to, for example: from a support group or counsellors	Aff	Adapt
	Q36	Reconciling and closing the relationship with the PWD		I have said the things I needed to say to my family member	Beh	Adapt

(Continued)



Table 2. (Continued)

Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
Spiritual	Q37	Accepting changing relationship	'I was ready to let that go'	I feel prepared to let go of my family member	Aff	Adapt
	Q38	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	Beh	Oblig
	Q39	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	Aff	Adapt
	Q40	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	Aff	Adapt
	Q41	*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	Aff	Adapt
	Q42	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	Beh	Adapt
	Q43	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	Aff	Adapt
	Q44	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	Aff	Adapt
	Q45	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 it was so peaceful. . . and it meant so much just to be outside'	I can practice activities which help me to feel at peace if I want, for example: spending time in nature, reflective time or prayer	Beh	Adapt
	Q46	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	Aff	Adapt
	Q47	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	Cog	Oblig
	Q48	Discussing plans for traditions/practices with staff	'There was pressure. . . but one person at long-term care 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	Beh	Control
	Q49	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	Aff	Adapt
	Q50	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	Aff	Oblig
	Q51	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	Aff	Adapt

(Continued)

Table 2. (Continued)

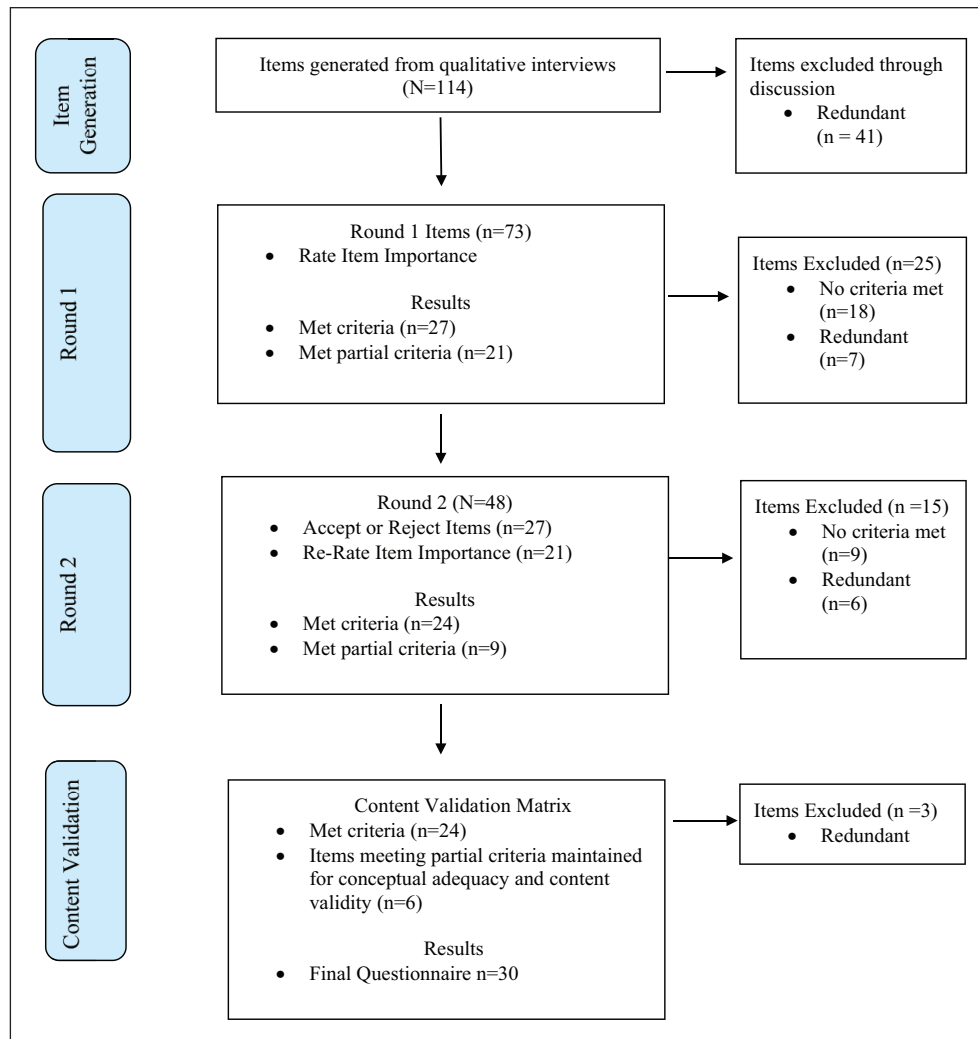
Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
	Q52	Believing a spiritual relationship with the person with dementia can continue after death	'Their light kind of lives in everybody. . . There's probably not a week that goes by that something doesn't come up with my 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	Aff	Adapt
	Q53	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	Aff	Adapt
	Q54	Planning ways to complete and value the person with dementia's life	'I had thought about the memorial through the last year. . . I gave the Eulogy and that gave me a lot of satisfaction. . . just writing it helped me focus my feelings'	I have a plan to remember my family member, for example: obituary, donation, sharing their belongings	Beh	Oblig
	Q55	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	Aff	Adapt
	Q56	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	Aff	Adapt
	Q57	*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	Aff	Adapt
	Q58	Feeling spiritually prepared for death	'I was calling God to take her. So she was in no more 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'	Overall, I feel at peace with my family member dying	Global	Adapt
Practical	Q59	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	Beh	Oblig
	Q60	Arranging practices to close the person with dementia'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	Beh	Oblig
	Q61	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	Beh	Control
	Q62	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	Cog	Control

(Continued)

Table 2. (Continued)

Domain	Question item	Behavioural indicator	Quote	Potential item	Trait	Core concept
	Q63	*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	Aff	Adapt
	Q64	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. . .'	*Reverse worded item I understand the policies in the care facility for after my family member's death, for example: removing belongings, final payments and timeline	Cog	Oblig
	Q65	Organising 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 organised, for example: will, insurance, birth certificate	Beh	Oblig
	Q66	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	Beh	Oblig
	Q67	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	Cog	Oblig
	Q68	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	Aff	Adapt
	Q69	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	Cog	Oblig
	Q70	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	Beh	Adapt
	Q71	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	Aff	Control
	Q72	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	Beh	Adapt
	Q73	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	Global	Oblig

Preparedness traits. Beh: behaviour; Aff: affective; Cog: cognitive; core concepts; Control: managing the situation, maintaining a sense of control; Oblig: fulfilling obligations; Adapt: adapting to loss. Indicators were translated into a pool of potential questionnaire items three based on participant's direct quotes and aimed to adequately sample the perceived three core concepts, three underlying traits and four domains of preparedness.



**Figure 3.** Phase 2 Delphi-survey item flow.

Source: Moher et al.<sup>43</sup>

items were positioned at the beginning of the questionnaire to minimise potential distress during the next phase.<sup>30,42</sup>

### Phase 2 Findings

Twenty-four questionnaire items met selection criteria in the Delphi-survey. A Content Validation Matrix of the 24-items revealed conceptual gaps, therefore the authors retained an additional six items which met partial criteria from the item pool.<sup>30,31</sup> Hence, a thirty-item questionnaire was developed as a result of the Delphi-survey (see Figure 3 for item flow). Caregiver panelists requested pertinent examples be included with items (e.g., aware of changes to expect such as problems with swallowing). In contrast, expert panelists recommended the deletion of examples from items to avoid causing distress (e.g., pneumonia, moving houses) and the use of ‘softer’ language (e.g., ‘I am confident’ changed to ‘I believe’ (see Supplemental File A).

### Phase 3 Findings

During the pilot-test, three current caregiver participants reported that the questionnaire content was acceptable (not distressing), relevant and applicable and the length was appropriate (not burdensome). Based on participants’ redundant response process and consistent recommendations ambiguous items were clarified (Question [Q]2, Q8, Q14, Q22, Q28), preferred language was incorporated (Q5, Q9) and inclusivity was enhanced (Q7, Q19). Specifically, participants recommended adding examples and using universal direct language to clarify items. The item ‘knowing what the dying process may be like’ was revised to clarify ‘for my family member with dementia’ (Q8). Examples were added to clarify changes to expect as dementia progresses such as ‘swallowing, eating difficulties’ (Q2).

In terms of language, the words ‘wishes’ was preferred over the word ‘goals’ (Q5) and the words ‘has died’ perceived as more appropriate and direct than the words ‘is

**Table 3.** Phase 3 findings: final questionnaire items ( $n = 30$ ).

Medical preparations ( $n = 9$ )	
1	I believe I understand my family member's current health status.
2	I believe I know what changes to expect as dementia advances, for example: <b>swallowing, eating difficulties.</b>
3	I understand I may be faced with decisions such as: transferring to hospital, treating infections.
4	I believe I know what treatments my family member would choose.
5	*I have shared my family member's <b>wishes</b> with health care providers, for example: focusing on living longer, maximising comfort.
6	*Health care providers and I have discussed our end-of-life care preferences for my family member, for example: location, pain management.
7	I have discussed end-of-life care preferences with the <b>important people in my family member's life, for example: friends, family.</b>
8	*I have learned what the dying process may be like <b>for my family member.</b>
9	I understand that dementia (and Alzheimer's) is a condition <b>that leads to death.</b>
Relationships and personal preparations ( $n = 8$ )	
10	I believe I can carry out my responsibilities, for example: decision-maker, companion, advocate.
11	I would like to be more involved in planning care with health care providers.
12	I accept that I am doing my best for my family member.
13	I have someone to go to for emotional support about my family member's health.
14	*I understand what my grief process may be like after my family member <b>has died.</b>
15	*I worry that disagreements will make my family member's death more difficult, for example: with family, friends, health care providers.
16	I am making the most of my time with my family member, for example: by saying what I need to say to them.
17	*I am helping my family member with activities they would want near end-of-life, for example: seeing old friends.
18	I am spending time reflecting on my family member's life, for example: by sharing stories.
Spiritual preparations ( $n = 5$ )	
19	I have a plan to honour traditions or <b>practices</b> my family member would want, for example: <b>personal</b> , cultural, spiritual, religious.
20	I have discussed our family's practices or traditions with health care providers, for example: privacy, prayers, opening a window.
21	*I have someone I can talk to about the meaning of illness or dying.
22	I worry about having purpose in my life after my family member <b>has died.</b>
23	*I am practicing activities which give me strength such as: spending time in nature.
Practical preparations ( $n = 6$ )	
24	My family member's affairs are in order, for example: decision-maker, will, banking, credit cards, insurance.
25	I have someone I can contact if I need help managing my family member's affairs.
26	I know how to notify family and friends when my family member dies.
27	After-death services are arranged for my family member such as: burial or cremation.
28	I believe I can manage my personal affairs after my family member <b>has died</b> , for example: finances, housing.
29	I am aware of after-death policies I will need to follow, for example: moving belongings in long-term care.
30	I am thinking about memorials appropriate for our family such as: gathering, funeral, celebration, private time.

Bolded words were revised based on the pilot-test and cognitive interviews.

\*Indicates items met partial criteria for selection in the Delphi-survey and were retained from the pool by the authors to adequately address all preparedness core concepts, domains and traits.

gone' (Q9). Participants explained that many persons with dementia were cognitively unaware or 'gone' for years before death, making this an inappropriate euphemism. Participants did not all identify with the examples of traditions so 'personal traditions' was added (Q19), and lastly the reference to 'my family' was revised to 'important people in my family member's life' (Q7) to be more inclusive (see Table 3 for final revised questionnaire items).

## Discussion

### Main findings

The purpose of this mixed methods study was to develop a multi-dimensional, condition-specific questionnaire to assess preparedness for end-of-life in family caregivers of persons with dementia. Core concepts and indicators of preparedness were identified and items selected, revised

and piloted through three study phases to develop the 'Caring Ahead' questionnaire. The final questionnaire included 30-items translated from preparedness indicators and participant quotes. Questionnaire items are organised in four domains: medical, relationships/personal, spiritual and practical; aim to sample three core concepts: managing the situation, fulfilling obligations and adapting to loss; and three traits of preparedness: cognitive, affective and behavioural.

### *Limitations*

Study limitations included the small sample size in the Delphi-survey compared to other Delphi-studies which have reported sample sizes over 50.<sup>44</sup> The Delphi-survey response rate (57%) was also lower than the recommended 70% and could result in response bias and instability.<sup>30,38,39</sup> 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.<sup>38,39</sup> The sample small of caregivers (n=3) recruited to pilot-test the questionnaire in Phase 3 of this study was less than the suggested sample size of five participants for cognitive interviewing and questionnaire development studies and is therefore a limitation.<sup>41</sup> However, demographic variability amongst the participants and redundancy in item responses were demonstrated, which suggests reliability in the questionnaire item response process.<sup>30,31,35</sup> Future studies will evaluate questionnaire psychometrics with 200 caregivers to align with sample sizes in the majority of instrument development studies.<sup>45</sup>

Study participants were primarily female and white, which may influence the transferability of the questionnaire to caregivers of other genders, cultures/races. Similar sample demographics have been reported in other instrument development studies including the Caregiver Grief Scale<sup>46</sup> and the Carer Support Needs Assessment Tool<sup>47</sup> which suggests this is a common phenomenon. Targeted recruitment of diverse participants in future studies is needed to explore transferability, sex and gender-based analysis.<sup>48</sup> Lastly, persons with dementia were living in long-term care and were described by participants as having symptoms of advanced dementia. Therefore, further research is needed to explore the transferability (i.e., acceptability, content and face validity) of the questionnaire for caregivers of persons with early stages of dementia or outside of long-term care.

### *What this study adds*

New insight into indicators and core concepts of preparedness was gleaned through this study that helped to produce the Caring Ahead questionnaire with current evidence for face and content validity. These findings should assist

healthcare professionals and researchers to assess caregivers' feelings of preparedness, identify caregivers in need of support, design and evaluate strategies aligned with a palliative approach. However, future research is needed to evaluate questionnaire psychometrics (i.e., content, construct, predictive validity and reliability) in a larger sample and with different populations.

Unique preparedness indicators described by participants in this study such as: fulfilling rituals/traditions, facilitating life completion and reconciling with persons with dementia highlight the importance for healthcare professionals and researchers to explore all areas of preparedness and not focus narrowly on the medical domain. Preparedness indicators identified in this study also reflected problem and emotion-focused coping behaviours (e.g., learning/knowing, planning, organising) that have been previously reported as facilitating feelings of preparedness for death.<sup>49-51</sup> Evidence exists for associations between coping behaviours such as emotional-support, acceptance, problem-focused coping included as indicators on the Caring Ahead questionnaire and positive mental health outcomes (e.g., reduced depression and anxiety).<sup>52</sup> Therefore, the Caring Ahead questionnaire may predict caregiver outcomes in bereavement.

Sensitive strategies to minimise intrusion and distress were used to recruit and retain participants in this study such as gatekeeping (i.e., person known to potential participants asks for permission to share contact information with researchers) and providing question examples for the interview/Delphi/pilot-test.<sup>36,37</sup> Similar strategies should be employed by researchers and healthcare professionals administering the questionnaire in the future. The Serious Illness Conversation guide for example, recommends that healthcare professionals plan ahead for serious discussions and (1) assess the person's level of knowledge; (2) ask for permission to discuss the future/serious illness and (3) ascertain information preferences.<sup>53</sup>

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.<sup>54</sup> 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. Euphemisms have been reported as: obscuring the truth, contributing to miscommunications, paternalistic and used to avoid end-of-life discussions.<sup>54-57</sup> Healthcare professionals' 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.<sup>55</sup> Hence, caregivers of persons with dementia may be more at risk of experiencing miscommunications which reduce preparedness for death. Healthcare professionals and researchers should therefore communicate with



universal terms such as 'dying' and 'end-of-life' in order to normalise and not obscure approaching death.

## Conclusion

The 30-item 'Caring Ahead' questionnaire which aims to assess 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 long-term care is currently underway. Once tested, this questionnaire can be used by healthcare professionals, researchers and policy-makers to identify family caregivers with limited areas of preparedness and as a holistic outcome measure for strategies supporting a palliative approach.

## Author contributions

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

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## Supplemental material

Supplemental material for this article is available online.

## References

- Mitchell S. Care of patients with advanced dementia. In: Morrison R, Yaffe K and Wilterdink J (eds) *Up to date*. Alphen aan den Rijn, Netherlands: Wolters Kluwer, Up to Date Inc, 2019.
- Karg N, Graessel E, Randzio O, et al. 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 Geriatr* 2018; 18(1): 189.
- Kim Y and Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health* 2008; 20(5): 483–503.
- Health Canada. Framework on palliative care in Canada, <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> (2018, accessed 9 April 2020).
- Public Health Agency of Canada. A dementia strategy for Canada: together we aspire, [https://www.canada.ca/content/dam/phacaspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy\\_ENG.pdf](https://www.canada.ca/content/dam/phacaspc/images/services/publications/diseases-conditions/dementia-strategy/National%20Dementia%20Strategy_ENG.pdf) (2019, accessed 9 April 2020).
- World Health Organization. Global action plan on the public health response to dementia, <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=8A33E0C7F683E7AB2723BCD0FFE4A44C?sequence=1> (2017, accessed 9 April 2020).
- Canadian Hospice Palliative Care Association. The way forward national framework: a roadmap for an integrated approach to care, <http://www.hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf> (2015, accessed 9 April 2020).
- 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. *Palliat Med* 2014; 28(3): 197–209.
- World Health Organization. WHO definition of palliative care, <https://www.who.int/cancer/palliative/definition/en/> (2020, accessed 9 April 2020).
- Durepos P, Wickson-Griffiths A, Hazzan AA, et al. Assessing the palliative care content of dementia care guidelines: a systematic review. *J Pain Symptom Manag* 2016; 53(4): 804–813.
- McMahan RD, Knight SJ, Fried TR, et al. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manag* 2013; 46(3): 355–365.
- Dasch B, Bausewein C and Feddersen B. Place of death in patients with dementia and the association with comorbidities: a retrospective population-based observational study in Germany. *BMC Palliat Care* 2018; 17(1): 80.
- Terzakis K. Preparing family members for the death of a loved one in long-term care. *Ann Longterm Care* 2019; 27(2): 25–31.
- Lobb EA, Kristjanson LJ, Aoun SM, et al. Predictors of complicated grief: a systematic review of empirical studies. *Death Stud* 2010; 34(8): 673–698.
- 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 Psychol Rev* 2016; 44: 75–93.
- Henriksson A, Hudson P, Öhlen J, et al. Use of the preparedness for caregiving scale in palliative care: a rasch evaluation study. *J Pain Symptom Manag* 2015; 50(4): 533–541.
- Barry L, Kasl S and Prigerson H. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *The Am J Geriatr Psychiatry* 2002; 10(4): 447–457.

18. Blondo PD, Lee LD, Davison SN, et al. How healthcare systems evaluate their advance care planning initiatives: results from a systematic review. *Palliat Med* 2016; 30(8): 720–729.
19. Dixon J, Karagiannidou M and 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. *J Pain Symptom Manag* 2018; 55(1): 132–150.
20. Durepos P, Sussman T, Ploeg J, et al. What does death preparedness mean for family caregivers of persons with dementia? *Am J Hosp and Palliat Care* 2018; 36(5): 436–446.
21. Hebert R, Prigerson H, Schulz R, et al. 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.
22. Hovland CA and Kramer BJ. Barriers and facilitators to preparedness for death: experiences of family caregivers of elders with dementia. *J Soc Work End Life Palliat Care* 2019; 15(1): 55–74.
23. Gonella S, Basso I, Dimonte V, et al. Association between end-of-life conversations in nursing homes and end-of-life care outcomes: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2018; 20(3): 249–261.
24. 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(2): 127–133.
25. Archbold PG, Stewart BJ, Greenlick MR, et al. Mutuality and preparedness as predictors of caregiver role strain. *Res Nurs Health* 1990; 13(6): 375–384.
26. Durepos P, Ploeg J, Akhtar-Danesh N, et al. Caregiver preparedness for death in dementia: an evaluation of existing tools. *Aging Ment Health* 2020; 24(10): 1671–1680.
27. 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 Mark Sci* 2012; 40: 434–449.
28. Gnambts T and Buntins K. The measurement of variability and change in life satisfaction. *Eur J Psychol Assess* 2017; 33: 224–238.
29. Page TE, Farina N, Brown A, 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.
30. Streiner D, Norman G and Cairney J. *Health measurement scales: a practical guide to their development and use*. 5th ed. Oxford: Oxford University Press, 2015.
31. Onwuegbuzie AJ, Bustamante RM and Nelson JA. Mixed research as a tool for developing quantitative instruments. *J Mix Methods Res* 2010; 4(1): 56–78.
32. Durepos P, Ploeg J, Sussman T, et al. “A crazy roller coaster at the end”: a qualitative study of death Preparedness with caregivers of persons with dementia. *SAGE Open Nurs* 2020; 6: 2377960820949111.
33. O’Cathain A, Murphy E and Nicholl J. The quality of mixed methods studies in health services research. *J Health Serv Res Policy* 2008; 13(2): 92–98.
34. Braun V, Clarke V and Rance N. How to use thematic analysis with interview data (process research). In: Vossler A and Moller N (eds) *The counselling & psychotherapy research handbook*. London: Sage Publications Inc, 2014.
35. Thorne S. *Interpretive description: qualitative research for applied practice*. 2nd ed. New York, NY: Routledge, 2016.
36. Aoun S, Slatyer S, Deas K, et al. Family caregiver participation in palliative care research: challenging the myth. *J Pain Symptom Manag* 2017; 53(5): 851–861.
37. Butler AE, Copnell B and Hall H. Researching people who are bereaved: managing risks to participants and researchers. *Nurs Ethics* 2019; 26(1): 224–234.
38. Jünger S, Payne SA, Brine J, et al. Guidance on conducting and reporting delphi studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliat Med* 2017; 31(8): 684–706.
39. Jorm A. Using the delphi expert consensus method in mental health research. *Aust N Z J Psychiatry* 2015; 49(10): 887–897.
40. Limesurvey GmbH. *LimeSurvey: an open source survey tool, computer software*. Hamburg: Limesurvey GmbH. <http://www.limesurvey.org> (2020, accessed 9 April 2020).
41. Peterson CH, Peterson NA and Powell KG. Cognitive interviewing for item development: validity evidence based on content and response processes. *Meas Eval Couns Dev* 2017; 50(4): 217–223.
42. Roberts K, Holland J, Prigerson HG, et al. Development of the bereavement risk inventory and screening questionnaire (BRISQ): item generation and expert panel feedback. *Palliat Support Care* 2017; 15(1): 57–66.
43. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6(7): e1000097.
44. Sudore RL, Heyland DK, Lum HD, et al. Outcomes that define successful advance care planning: a delphi panel consensus. *J Pain Symptom Manage* 2018; 55(2): 245–255.
45. 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.
46. Meichsner F, Schinköthe D and Wilz G. The caregiver grief scale: development, exploratory and confirmatory factor analysis and validation. *Clin Gerontol* 2016; 39(4): 342–361.
47. Ewing G and Grande G. Development of a carer support needs assessment tool (CSNAT) for end-of-life care at home: a qualitative study. *Palliat Med* 2012; 27(3): 244–256.
48. Arbel I, Bingham KS and Dawson DR. A scoping review of literature on sex and gender differences among dementia spousal caregivers. *Gerontologist* 2019; 59(6): e802–e815.
49. Hebert R, Schulz R, Copeland V, et al. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manag* 2009; 37(1): 3–12.
50. Hovland-Scafe CA and Kramer BJ. Preparedness for death: how caregivers of elders with dementia define and perceive its value. *Gerontologist* 2016; 57: 1093–1102.

51. Rodríguez-Pérez M, Abreu-Sánchez A, Rojas-Ocaña MJ, et al. Coping strategies and quality of life in caregivers of dependent elderly relatives. *Health Qual Life Outcomes* 2017; 15(71): 1–8.
52. Gilhooly KJ, Gilhooly MLM, Sullivan MP, et al. A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatr* 2016; 16(106): 1–8.
53. Daubman BR, Bernacki R, Stoltenberg M, et al. Best practices for teaching clinicians to use a serious illness conversation guide. *Palliat Med Rep* 2020; 1(1): 135–142.
54. Rawlings D, Tieman JJ, Sanderson C, et al. Never say die: death euphemisms, misunderstandings and their implications for practice. *Int J Palliat Nurs* 2017; 23(7): 324–330.
55. Devlin M and Maida V. The demon in deeming: medical paternalism and linguistic issues in the palliative care setting. *Can Fam Physician* 2017; 63(3): 191.
56. Pallium Canada. The words we use, <https://www.pallium.ca/videos/> (2019, accessed 9 April 2020).
57. Wentlandt K, Toupin P, Novosedlik N, et al. used by health care professionals to describe dying at an acute care hospital. *J Pain Symptom Manage* 2018; 56(3): 337–343.