

July 2021

Developing Country-specific Questions about End-of-life Care for Nursing Home Residents with Advanced Dementia using the Nominal Group Technique with Family Caregivers

Laura Bavelaar^a, Maria Nicula^b, Sophie Morris^c, Sharon Kaasalainen^b, Wilco P. Achterberg^a, Martin Loucka^d, Karolina Vlckova^d, Genevieve Thompson^e, Nicola Cornally^f, Irene Hartigan^f, Andrew Harding^g, Nancy Preston^g, Catherine Walshe^g, Emily Cousins^h, Karen Harrison Dening^{h,i}, Kay De Vries^h, Kevin Brazil^c, Jenny T. van der Steen^{a,j*}

^a Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, the Netherlands

^b School of Nursing, McMaster University, Ontario, Canada

^c School of Nursing and Midwifery, Queen's University Belfast, Belfast, Northern Ireland, the UK

^d Center for Palliative Care, Prague, the Czech Republic

^e College of Nursing, University of Manitoba, Manitoba, Canada

^f Catherine McAuley School of Nursing and Midwifery, University College Cork, Cork, Ireland

^g Division of Health Research, Lancaster University, Lancaster, the UK

^h School of Nursing and Midwifery, De Montfort University, Leicester, the UK

ⁱ Dementia UK, London, the UK

^j Department of Primary and Community Care, Radboud university medical center, Nijmegen, the Netherlands

Correspondence during the submission process: Laura Bavelaar, L.Bavelaar@lumc.nl

*Corresponding author at: Jenny T. van der Steen, jtvandersteen@lumc.nl, +31715268497

Department of Public Health and Primary Care, Leiden University Medical Center, Hippocratespad 21, Postbox 9600, 2300 RC, Leiden, the Netherlands

July 2021

Highlights

- We developed country-specific question prompt lists about dementia palliative care
- In five countries, family caregivers were consulted to finalize a list of questions
- All caregivers selected: *“Can you tell me more about palliative care in dementia?”*
- Included topics differed across countries, namely artificial nutrition and fluids

Abstract

Objective: We aimed to develop question prompt lists (QPLs) for family caregivers of nursing home residents with advanced dementia in the context of a study involving Canada, the Czech Republic, Italy, the Netherlands, the United Kingdom and Ireland, and to explore cross-national differences.

QPLs can encourage family caregivers to ask questions about their relative’s end-of-life care.

Methods: We used nominal group methods to create country-specific QPLs. Family caregivers read an information booklet about end-of-life care for people with dementia, and generated questions to ask healthcare professionals. They also selected questions from a shortlist. We analysed and compared the QPLs using content analysis.

Results: Four to 20 family caregivers per country were involved. QPLs ranged from 15-24 questions.

A quarter (24%) of the questions appeared in more than one country’s QPL. One question was included in all QPLs: *“Can you tell me more about palliative care in dementia?”*.

Conclusion: Family caregivers have many questions about dementia palliative care, but the local context may influence which questions specifically. Local end-user input is thus important to customize QPLs.

Practice implications: Prompts for family caregivers should attend to the unique information preferences among different countries. Further research is needed to evaluate the QPLs’ use.

Keywords

Dementia, Family caregiver, Patient engagement, Shared decision making, End-of-life care, Nursing home

1. Introduction

Healthcare professionals are increasingly adopting patient-centered care that is sensitive to the patient's preferences and needs [1]. This requires patients to be engaged in the decision-making process, to be informed about the positive and negative features of each option and to be aware of their own values and preferences that can guide the decision [2].

Patient engagement in the context of advanced dementia can be challenging. There are numerous quality and ethical issues, such as the cognitive ability of the person with dementia to understand and contribute to the conversation [3, 4]. Consequently, family caregivers -for example partners or adult children- are expected to represent their relatives with dementia when they are no longer able to express own wishes [5]. However, family caregivers may lack a good understanding of dementia and end-of-life care [6, 7]. To address this issue, Arcand and colleagues developed an informational booklet about comfort care for nursing home residents with advanced dementia: the Comfort Care Booklet [8]. The aim of the booklet is to prepare family caregivers for the end of life and reassure them about the patient's comfort. The Comfort Care Booklet has been translated and adapted for use in various countries [9-13]. The Comfort Care Booklets were developed by healthcare professionals with input from patients and family caregivers. Involving end-users can lead to more user-friendly information [14].

Although family caregivers welcome information about dementia and end-of-life care, information provision itself is not enough: there is a need for follow-up conversations with healthcare professionals [15]. As families will often not explicitly share their information and support needs with healthcare providers, they need assistance in expressing these needs so that they can be met [15]. An aid to increase patient or family caregiver engagement is a question prompt list (QPL) [16]. A QPL is a list of typical questions, that can encourage individuals to ask questions about their

relative's care. Thus, healthcare professionals can provide personally relevant information. Hyatt, Lipson-Smith and colleagues [17] found that patients with cancer experienced a QPL to be supportive to their care, but also recommended that QPLs should be culturally-tailored and patient-driven. For example, the development of a QPL for patients with cancer in the US and Australia led to two different versions as some aspects were deemed less acceptable or useful in the US compared with Australia [18].

Currently, available QPLs about illness and treatment to support decision making (e.g. [19-22]) are mostly tailored for patients with cancer. A QPL to support family caregivers of nursing home residents with advanced dementia is not internationally available. Therefore, the objective of this study was to develop a QPL for family caregivers of nursing home residents with advanced dementia. The purpose of the new QPLs was to complement the Comfort Care Booklet [8-13] by encouraging question asking and aid conversations about care.

In this study, we consult current and bereaved family caregivers in five countries to ensure family-driven and culturally-tailored QPLs for dementia. We assessed differences between countries in the resulting QPLs to examine importance of the local context.

2. Methods

This study is part of an international EU Joint Programme – Neurodegenerative Disease Research (JPND) project to support family caregivers of nursing home residents with advanced dementia in decision making, called 'mySupport study', involving Canada, the Czech Republic, Italy, the Netherlands, the UK and Ireland. The QPLs were developed with the targeted consultation of family caregivers. The aim of the development process was to agree on the final QPLs with 20-25 questions. This process took 13 months and was divided into three phases as described below and depicted in Figure 1. An evaluation of the QPLs in practice was outside the scope of the current study and will be addressed during the larger mySupport study [23].

Phase one

Phase one (July 2019 – September 2019) involved an elderly care physician, two researchers specialized in palliative care, a researcher trained in psychology and a researcher educated in neuroscience. This team selected a set of questions from three available QPLs (two about dementia care and one about palliative care). The QPLs originated in three different countries (Australia [24], Canada [25], the Netherlands [26]), providing a transnational overview of questions (248 questions in total, 206 without duplicates).

The team aimed to reduce the number of questions to < 50 and to include at least one question per topic discussed in the Comfort Care Booklets: dementia, end-of-life decision making, symptom relief, and end of life. Questions were deemed appropriate for inclusion if they were relevant to the nursing home setting and within the scope of the Comfort Care Booklets. 'Nursing home' is used to refer to a collective institutional setting in which care is provided to older adults 24 hours a day, including nurses and medical staff. Question selection took place in three consensus rounds and was informed by the inclusion criteria in Box 1. In the Netherlands, three researchers (LB, WPA, JTvds) independently selected questions and discussed to reach consensus. In parallel, two researchers from the UK followed the same procedure (SM, KB). Next, the results of these two independent consensus rounds were discussed between the researchers from the two countries in a third consensus round. A preliminary selection of 39 questions was thus completed in preparation for Phase two.

Phase two

Phase two (November 2019 – July 2020) involved the targeted consultation of end-users of the QPLs. End-users in each country independently compiled the final selection of questions for the QPL to address local needs. End-users were defined as current or bereaved family caregivers of people with dementia. The eligibility requirements were: over 18 years of age; sufficient capacity of the local

July 2021

language to read the Comfort Care Booklet and participate in the discussion; and able to agree to terms and conditions of participation. The consultation protocol was reviewed by local ethics committees in Canada (Hamilton Integrated Research Ethics Board: 2019-5837-GRA) and the Netherlands (Medical Ethical Committee Leiden-Den Haag-Delft: N19.114) and written informed consent was obtained from all participants. In the Czech Republic, Ireland and the UK, the consultation was considered 'Public and Patient Involvement' and therefore the process was exempt from review by ethics committees and formal consent procedures. In Italy, the consultation could not be performed due to COVID-19.

Convenience recruitment strategies included local invitations and snowballing. In Canada, family caregivers involved at the nursing home that participates in the larger project were invited by the site's social service coordinator. The Czech team recruited participants using the Facebook page of the Center for Palliative Care and by using the snow-ball method, that is: participants invited others from their social networks to participate. In collaboration with Alzheimer Nederland, the Dutch team invited family caregivers who are part of the Alzheimer panel from a west and middle region over email. The team in Ireland posted flyers in public spaces and on Facebook, and invited potential participants via personal and professional networks. In the UK, researchers recruited family caregivers through their local patient and public involvement connections around Leicester and through the network of a family caregiver that was involved in previous projects in Lancaster.

The consultation process was structured in the four steps (see below) of a nominal group technique [27, 28]. Although normally conducted in a group setting, the first two steps were adapted to allow family caregivers to complete them individually at home. This was done to ensure that participants were sufficiently prepared for the group discussion. The group discussion was virtually conducted in some cases using email, phone calls or videoconferencing (see Supplementary information Text S1). The steps were conducted as follows:

Silent-generation step (individually at home)

July 2021

Upon reading the Comfort Care Booklet, family caregivers wrote down any questions that came to mind and that they would wish to discuss with a healthcare professional. They also wrote down their reasoning for posing these questions.

Round-robin step (individually at home)

Afterwards, the family caregivers selected approximately 15 questions of the 39 pre-selected questions that they felt may arise when a family member reviews the Comfort Care Booklet. Finally, the family caregivers could add any outstanding questions that were not yet addressed; once again, they wrote down their rationale for posing these questions.

Discussion/item clarification step

A moderator presented all individually generated and selected questions to the family caregivers at the group discussion. The moderator was not involved in the preliminary question selection to minimize bias in the facilitation of the discussion. Family caregivers read all the questions as a group and discussed each item's similarities, differences, and reasons for its inclusion in the final list.

Observers took notes on reasons for inclusion and exclusion of questions.

Voting step

After the group discussion, participants voted on which items to include in the QPL by raising hands or highlighting them on a collective list. The 20-25 questions that received the most votes were included in the final list. The research team mapped the questions from the final list onto the relevant sections of the Comfort Care Booklet to ensure that there was at least one question per topic.

Phase three

Phase three (June 2020 – August 2020) involved two researchers (MN, Canadian and LB, Dutch), who compared the final QPLs from each country to highlight similarities and differences across contexts using conventional content analysis [29]. First, LB and MN familiarized themselves with all of the questions. They then inductively derived a set of codes from the questions and labelled each

question with a code. Next, codes were sorted into themes when referring to a similar overarching topic. Finally, code names were adjusted after defining the themes, and themes were refined after adjusting the codes. Reasons for including questions that were available in field notes or participants' answer sheets were collected and also underwent a content analysis to explore any cross-national differences in the rationale for including questions in the QPLs.

To ensure validity and rigor [30], all steps of the analyses were independently performed by two individual coders (LB, MN). Codes, themes and interpretations were discussed at each step to reach consensus.

3. Results

Phase one

Out of the 206 questions, the UK team selected 33 and the Dutch team 49. Ten questions were selected by both teams, totaling 72 questions. The two teams agreed on the in- and exclusion of 75% (186/248) of the questions. Cross-national differences were apparent during the consensus discussion. For example, questions about life termination and prognosis seemed inappropriate to the UK team because they were difficult to answer adequately, and end of life and euthanasia were not considered topics that people tend to discuss. They were pressing to the Dutch team because people will often ask about these issues and there was a concern of creating taboo when excluding such questions. Table 1 shows the 39 questions that were pre-selected by the research teams upon reaching consensus.

Phase two

Table 2 shows an overview of the nominal group for each country. Forty-three people participated, ranging from 4 to 20 per country. The ages ranged from 25 to 87 years, and the majority (72%) was female. The participants were current or bereaved family caregivers (n = 41) or living with dementia (n = 2). Six participants had professional experience with dementia. The group discussions took 40 to

July 2021

140 minutes. The characteristics of the moderators and observers are included in the supplementary information (Table S1). The group discussion resulted in a final list of questions in each of the countries. Canada decided upon 15, the Czech Republic had 20, Ireland had 22, and the Netherlands and the UK each had 24 (Table 1 and Supplementary information Table S2).

Phase three

Questions were scanned for overlap and similarity, leading to a list of 76 distinct questions from the total of 105 selected questions. Almost a quarter (24%, 18/76 questions) were selected by more than one country. Question 2 from the pre-selected list of 39 questions was selected by all groups:

“Can you tell me more about palliative care in dementia?”

For 55/105 questions (52%) the reason for inclusion was clearly described in the field notes or participants' answer sheets. The Czech Republic (70%), Canada (67%) and the Netherlands (63%) had more information about the rationale available than the UK (37%) and Ireland (32%). The reasons that were provided for selecting questions were aggregated into the following six themes, in order of frequency: just obtaining information, preparation for end of life, reassurance, preparation for shared decision making, informing staff about the resident's needs and informing staff about the family caregiver's needs (Table 3). The reason provided most often per country was just obtaining information in the UK, preparation for end of life in Ireland, and just obtaining information and preparation for shared decision making in the Czech Republic. In the Netherlands, informing staff about the resident's needs was directly followed by reassurance and just obtaining information. Canada had mentioned reassurance, just obtaining information and preparation for end of life at equal frequency.

The inductive content analysis of the QPLs resulted in 18 codes (Table 4). The most common codes were communication with staff, care protocols, palliative care information, and roles and responsibilities. The codes were aggregated into seven broader themes. These include Request for

(services or) information about (1) Symptoms and Disease, (2) Treatment, (3) Death, (4) Care staff, (5) Care setting, (6) Request for the increase or use of patient values and wishes, or (7) Request for information about shared decision-making. Overall, the three most common themes across all countries were Requests for Services or Information pertaining to Care Setting (5), Treatment (2), and Care Staff (4).

Symptoms and Disease: Questions about symptoms and disease focused on the prognosis of the person with dementia in terms of upcoming death or the signs and symptoms related to dementia stages, and disease-related complications such as problems with nutrition or hydration. Questions about how the disease or various methods of treatment would affect the resident's nutrition and hydration were only included in the Czech QPL. The reasons for including questions from this theme mainly related to preparation for end of life and just obtaining information.

Treatment: Questions in this theme consisted of general questions about treatment options or information about palliative care, but also specific questions about pain management options, and treatment options for pneumonia or problems with nutrition or hydration. All five countries submitted questions that were related to this theme. Most Dutch questions on treatment were specific to learning more about palliative care and comfort care. The Czech Republic focused more on treatment of specific conditions with pneumonia and problems with nutrition or hydration. The rationale for including questions from this theme focused on just obtaining information.

Controlling Death Circumstances: The questions in this theme were about controlling the circumstances of death such as active life termination and choosing the place of death. Family members from all the countries, except for Ireland, asked questions that were specific to changes (in setting or treatment) or preferences for circumstances at the end-of-life. There was limited information about the reasons for including questions from this theme, which varied.

Care Setting: Care setting-related questions concerned possibilities in terms of specialist services that could be accessed (spiritual, support, medical specialists). It also included questions about how day-to-day care is being managed, about general policies in the care facility and about

the logistical procedures that coordinate care and responsibilities. All countries—except the Czech Republic—asked a large proportion of questions about the services and coordination offered by the nursing home. Canada focused on specialist services, while Ireland was the only group that submitted questions regarding the specific policies and protocol that the home followed, such as security measures and visiting policies. The reasons for including questions within this theme related to reassurance and preparation for end of life.

Care Staff: These questions related to concerns about communication with staff, including whom to contact (and how), and concerns about staff competence in providing palliative care. While all groups expressed the need for clear information on communication with staff, the UK group had the highest proportion of questions related to this. The questions surrounding staff competence were only asked by the UK and Czech Republic groups. Questions from this theme were included for various reasons; reassurance and informing staff about the resident's needs were mentioned most often.

Patient Values and Wishes: The questions in this theme were about specific preference statements such as living wills. This theme also contained questions about values guiding decisions such as the patient's dignity. The questions pertaining to dignity were most often asked in the Czech Republic, Ireland and the Netherlands. The questions were asking for reassurance that the patient's dignity would not be compromised as a result of the treatment options or otherwise. The reasons for including question from this theme varied, informing staff about the resident's needs was mentioned most frequently.

Shared Decision-Making: This theme consisted of questions about the shared decision-making process and the roles and responsibilities of different people involved in this process. Questions related to the status of clinicians' and families' perspectives and living wills. Although none of the countries' QPLs concentrated on this topic, at least one question from each group was about shared decision-making. The rationale for including questions from this theme most often related to informing staff about the family caregiver's needs.

4. Discussion and Conclusion

4.1. Discussion

We have developed question prompt lists about end-of-life care in collaboration with family caregivers of nursing home residents with dementia in Canada, the Czech Republic, the Netherlands, Ireland and the UK. QPLs for this area were not internationally available. Despite cross-country differences, all lists contained a question requesting more information about palliative care in dementia and another question about the roles and responsibilities of the people involved in shared decision making. Overall, the questions focused mainly on treatment.

During the pre-selection phase, the UK and Dutch researchers had different perspectives on ‘appropriateness’, focusing on sensitivity versus not avoiding taboo subjects respectively. After the consultation phase, the Dutch, Irish and Canadian QPLs focused on questions related to palliative treatment and the care setting. The UK QPL focused on communication with care staff and staff competence. A large part of questions selected in the Czech QPL were about symptoms and disease. The cross-country differences may reflect socio-cultural differences and how well palliative care is established locally. The focus of the Dutch QPL on palliative care may portray that palliative care for people with dementia may be less well-known (and had not been part of Dutch dementia plans [31]). The Dutch participants indeed often provided ‘just obtaining information’ as reason for selecting questions, but reassurance and informing staff about the resident’s needs were also frequently mentioned. The Irish QPL lacked questions about controlling death circumstances. This suggests that this topic felt less appropriate to the Irish family caregivers. However, the Irish family caregivers most often provided ‘preparation for end of life’ as a reason to include questions. The large number of questions about communication with staff in the UK QPL could indicate that patient engagement in healthcare is well established in the UK [32]. As the reason most often provided for including questions was ‘just obtaining information’, this could also suggest that family caregivers

prefer being informed by staff members in personal conversations rather than searching for information themselves. The Canadian QPL focused on questions about specialist services and care protocols. One interpretation could be that the family caregivers had experienced that care coordination and accessibility to services can be improved [33]. The reasons for selecting questions varied.

The Czech QPL seemed to be the most different from the other countries, indicating concern about the quality of palliative care in dementia and questions regarding nutrition and hydration. The main reasons for question selection among Czech family caregivers included just obtaining information and preparation for shared decision making. Cross-national work indicated that artificial feeding and fluids is a sensitive topic [34] and recommendations on nutrition and hydration from the European Association for Palliative Care received only moderate consensus [35]. The concerns surrounding the quality of palliative care in dementia might relate to the poor resources for palliative care in the Czech Republic, where palliative care is not well known [36] and not yet officially acknowledged as necessary for people with dementia [37]. This could also explain the focus on curative treatment in the questions, rather than palliative options.

It is important to note some limitations of this study. Differences in how and when the group discussions were conducted, due to COVID-19 or local practice, may have influenced the results. Adapting the group discussion from an onsite activity to a thread of emails [38], phone calls [39] or videoconferencing [40] could have impacted the engagement process. Furthermore, group sizes differed between the countries. The resulting QPLs are based on input from a convenience sample of family caregivers and may not be representative of general cross-country differences. Possibly, (larger) cultural differences within groups rather than between countries have affected the results. The consultation process took place prior to the pandemic in Canada and the Netherlands, but during the pandemic in the Czech Republic, Ireland and the UK. This could have affected the type of questions that were pertinent to family caregivers. Also, we did not have clear information on the

rationale for selecting questions for almost half of the questions. Finally, the use and acceptability of the QPLs in real-time practice settings have not yet been evaluated.

However, we can explore the quality of the QPLs. According to the International Patient Decision Aids Standards (IPDAS) Collaboration [41], decision aids should contain the six key elements of shared decision making: (1) situation diagnosis, (2) choice awareness, (3) option clarification, (4) harms and benefits discussion, (5) patient preferences deliberation and (6) making the decision [42]. Interestingly, the themes and codes derived from the content analysis overlap strongly with these six elements of shared decision making, with two exceptions: questions about care staff and care setting are not included among the six elements. Care staff and care setting form the context of shared decision making, which is thus not well represented by the six elements. The importance of the relational context of shared decision making has been proposed before [43], but the care setting has not been included in shared decision making definitions yet [44]. Our results mirror the findings of Thompson and colleagues [15] that family caregivers need general information about nursing home life in addition to specific information about treatment and disease, to support them in decision making.

4.2. Conclusion

Given divergent preferences for sample questions, engaging end-users such as family caregivers of persons with advanced dementia in the development of materials is vital, especially when these materials aim to increase family caregiver engagement. Cultural differences may influence the information needs of family caregivers and should therefore be considered. The family caregivers in this study expressed a general need to be informed about palliative care in dementia, and about the process of shared decision making. The differences in questions generated between the countries underpin the value of cross-country exercises when developing materials for implementation into practice.

4.3. Practice implications

July 2021

Person-centered care calls for patient and family engagement, that requires facilitation via communication tools such as QPLs. QPLs can be used by families to prepare for advance care planning conversations with healthcare professionals by reflecting on the questions, or provide possible topics to help start conversations about care and reassure families that their information needs will be met. Healthcare professionals need to be aware of the different informational needs of their patients and their families, possibly related to their cultural background. Service planning and training programs for healthcare professionals should have more attention for shared decision making and general information provision about dementia palliative care, as these subjects raised many questions across the countries. This study also highlighted areas where further guidance is needed, such as artificial hydration and nutrition in advanced dementia in the Czech Republic. More research is necessary to explore the use of QPLs in conversations in healthcare and possible cross-country differences in these conversations.

Declaration of interest

None

Informed consent

Informed consent was obtained according to country-specific guidelines. I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Funding

This is an EU Joint Programme -Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND -www.jpnd.eu: Canada, Canadian Institutes of Health Research; the Czech Republic, Ministry of Education, Youth and Sport; Netherlands, Netherlands Organisation for Health Research and Development; Republic

July 2021

of Ireland, Health Research Board; the UK, Alzheimer's Society. Funders had no role in study design, management or dissemination.

Contributors and authorship

Laura Bavelaar: Conceptualization, Methodology, Formal analysis, Writing – Original draft **Maria Nicula:** Formal analysis, Writing – Original Draft **Sophie Morris:** Writing – Review & Editing **Sharon Kaasalainen:** Writing – Review & Editing **Wilco Achterberg:** Writing – Review & Editing **Martin Loucka:** Writing – Review & Editing **Karolina Vlckova:** Writing – Review & Editing **Genevieve Thompson:** Writing – Review & Editing **Nicola Cornally:** Writing – Review & Editing **Irene Hartigan:** Writing – Review & Editing **Andrew Harding:** Writing – Review & Editing **Nancy Preston:** Writing – Review & Editing **Catherine Walshe:** Writing – Review & Editing **Emily Cousins:** Writing – Review & Editing **Karen Harrison Dening:** Writing – Review & Editing **Kay de Vries:** Writing – Review & Editing **Kevin Brazil:** Writing – Review & Editing **Jenny van der Steen:** Conceptualization, Methodology, Writing – Review & Editing

Acknowledgements

Special thanks to the family caregivers and persons with dementia who participated in the nominal groups. We also like to thank Theresa Orsini, Danielle Just, Emily Di Sante, Lucie Zackova, Erlen Bruls, Bram Tilburgs and Dominica Lisiecka for their help as moderators or observers at the group discussions.

References

1. M. Park, M. Lee, H. Jeong, M. Jeong, M., Y. Go. Patient-and family-centered care interventions for improving the quality of health care: a review of systematic reviews, *Int. J. Nurs. Stud.* 87 (2018) 69-83. <https://doi.org/10.1016/j.ijnurstu.2018.07.006>.
2. L. Dudley, C. Gamble, J. Preston, D. Buck, The EPIC Patient Advisory Group, B. Hanley, P. Williamson, B. Young, 2015. What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials, *PLoS ONE*, 10, e0128817. <https://doi.org/10.1371/journal.pone.0128817>.
3. E. Mariani, M. Vernooij-Dassen, R. Koopmans, Y. Engels, R. Chattat. Shared decision-making in dementia care planning: barriers and facilitators in two European countries, *Aging Ment. Health* 21 (2017) 31-9, <https://doi.org/10.1080/13607863.2016.1255715>.
4. J. Bethell, E. Comisso, H.M. Rostad, M. Puts, J. Babineau, A. Grinbergs-Saull, A., M.B. Wighton, J. Hammel, E. Doyle, S. Nadeau, K.S. McGilton. Patient engagement in research related to dementia: a scoping review, *Dementia* 17 (2018) 944-75. <https://doi.org/10.1177/1471301218789292>.
5. G. Bollig, E. Gjengedal, J.H. Rosland. They know!—Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes, *Palliative Med.* 30 (2016) 456-70. <https://doi.org/10.1177/0269216315605753>.
6. A. Robinson, C. Eccleston, M. Annear, K.E. Elliott, S. Andrews, C. Stirling, M. Ashby, C. Donohue, S. Banks, C. Toye, F. McInerney. Who knows, who cares? Dementia knowledge among nurses, care workers, and family members of people living with dementia, *J. Palliat. Care* 30 (2014) 158-65. <https://doi.org/10.1177/082585971403000305>.
7. J. Gabbard, D. Johnson, G. Russell, S. Spencer, J.D. Williamson, L.E. McLouth, K.G. Ferris, K. Sink, G. Brenes, M. Yang. Prognostic awareness, disease and palliative understanding among

caregivers of patients with dementia, *Am. J. Hosp. Palliat. Me.* 37 (2020), 683-91.

<https://doi.org/10.1177/1049909119895497>.

8. M. Arcand, C. Caron, *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain - A Guide for Caregivers*, Centre de santé et de services sociaux - institut universitaire de gériatrie de Sherbrooke, 2005.
9. J.T. van der Steen, C.M. Hertogh, T. de Graas, *Zorg rond het levenseinde voor mensen met de ziekte van Alzheimer of een andere vorm van dementie: Een handreiking voor familie en naasten* [Care around the end of life for people with Alzheimer's disease or another type of dementia: A guide for family and friends], second ed., VUmc, EMGO, Amsterdam, 2011.
10. L. Volicer, H. Vanková, *Palliativní péče konci života u lidí s Alzheimerovou nemocí či jiným neurodegenerativním onemocněním* [End-of-life palliative care in people with Alzheimer's disease or another neurodegenerative disease], 3rd Medical Faculty of Charles University, Prague, 2017.
11. K. Brazil, G. Carter, *Providing Comfort Care to People with Dementia During Their Last Days of Life - A guide for family and friends*, ninth ed., Queen's University Belfast, School of Nursing and Midwifery, Northern Ireland, 2017.
12. T. Spadin, F. Toscani, *Cure Palliative alla fine della vita - Una guida per chi si prende cura di persone con malattia di Alzheimer o altre patologie cerebrali degenerative* [Palliative care at the end of life: A guide for those who care for people with Alzheimer's disease or other degenerative brain diseases], Fondazione Maestroni e AIMA Associazione Italiana Malattia di Alzheimer, Milano, 2008.
13. N. Cornally, I. Hartigan, D. Lisiecka, T. Foley, C. Buckley, S. Timmons, C. Sweeney, R. O'Caomh, *Providing Comfort Care to People with Advanced Dementia. - A guide for family and friends*, Republic of Ireland, 2019.
14. M. Hughes, C. Duffy. *Public involvement in health and social sciences research: a concept analysis*, *Health Expect.* 21 (2018) 1183-90. <https://doi.org/10.1111/hex.12825>.

15. G. Thompson, T. Hack, K. Rodger, P. St. John, H. Chochinov, S. McClement, 2020. Clarifying the information and support needs of family caregivers of nursing home residents with advancing dementia, *Dementia* 1471301220927617.
<https://doi.org/10.1177/1471301220927617>.
16. K. Brandes, A.J. Linn, P.N. Butow, J.C. van Weert. The characteristics and effectiveness of question prompt list interventions in oncology: a systematic review of the literature, *Psycho-Oncol.* 24 (2015) 245-52. <https://doi.org/10.1002/pon.3637>.
17. A. Hyatt, R. Lipson-Smith, K. Gough, P. Butow, M. Jefford, T.F. Hack, S. Hale, E. Zucchi, S. White, U. Ozolins, P. Schofield. Culturally and linguistically diverse oncology patients' perspectives of consultation audio-recordings and question prompt lists, *Psycho-oncol.* 27 (2018) 2180-8. <https://doi.org/10.1002/pon.4789>.
18. A. Walczak, B. Mazer, P.N. Butow, M.H. Tattersall, J.M. Clayton, P.M. Davidson, J. Young, S. Ladwig, R.M. Epstein. A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation, *Palliative Med.* 27 (2013) 779-88.
<https://doi.org/10.1177/0269216313483659>.
19. Q. Guo, H.M. Chochinov, S. McClement, G. Thompson, T. Hack. Development and evaluation of the Dignity Talk question framework for palliative patients and their families: A mixed-methods study, *Palliative Med.* 32 (2018) 195-205.
<https://doi.org/10.1177/0269216317734696>.
20. C. Caminiti, F. Diodati, S. Filiberti, B. Marcomini, M.A. Annunziata, M. Ollari, R. Passalacqua, 2010. Cross-cultural adaptation and patients' judgments of a Question Prompt List for Italian-speaking cancer patients, *BMC Health Serv. Res.* 10, 16.
<https://doi.org/10.1186/1472-6963-10-16>.
21. I. Henselmans, H.W. van Laarhoven, P. van Maarschalkerweerd, H.C. de Haes, M.G. Dijkgraaf, D.W. Sommeijer, P.B. Ottevanger, H.B. Fiebrich, S. Dohmen, G.J. Creemers, F.Y. de Vos, E.M.A. Smets, 2020. Effect of a Skills Training for Oncologists and a Patient

Communication Aid on Shared Decision Making About Palliative Systemic Treatment: A Randomized Clinical Trial, *The oncologist* 25, e578.

<https://doi.org/10.1634/theoncologist.2019-0453>

22. R. Glynne-Jones, P. Ostler, S. Lumley-Graybow, I. Chait, R. Hughes, J. Grainger, T.J. Leverton. Can I look at my list? An evaluation of a 'prompt sheet' within an oncology outpatient clinic, *Clin. Oncol.* 18 (2006), 395-400. <https://doi.org/10.1186/s13012-018-0740-y>.
23. I. Hartigan, K. Brazil, S. Kaasalainen, T. Sussman, J. Van Der Steen, M. Loucka, P. Di Giulio, E. Meehan, N. Cornally. mySupport: A Transnational Effectiveness-Implementation Study of the Family Carer Decision Support Intervention to Improve End of Life Care in Long-Term Care, *Age Ageing* 48 (2019) iii17–65. <https://doi.org/10.1093/ageing/afz103.216>.
24. Palliative Care Australia, Asking questions can help: an aid for people seeing the palliative care team, Medical Psychology Research Unit, The University of Sydney, 2006.
25. G. Thompson, Preparing for the Future: Learning about Dementia and Care near the End of Life, Dignity in Care: Manitoba Palliative Care Research, 2015. (unpublished)
26. J.T. Van der Steen, C.C.M Juffermans, F. Gillissen, Y.M. van der Linden, R.T.C.M Koopmans, Gesprekshulp de latere levensfase bij dementie: Tijdige informatie en voorbeeldvragen voor mensen met dementie en hun naasten [Talking about the later stages of life in dementia: timely information and example questions for people with dementia and their loved ones], LUMC, Leiden, 2019. (pilot version).
27. S.S. McMillan, M. King, M.P. Tully. How to use the nominal group and Delphi techniques, *Int. J. Clin. Pharm-Net.* 38 (2016) 655-62. <https://doi.org/10.1007/s11096-016-0257-x>
28. M. Gallagher, T.I.M Hares, J. Spencer, C. Bradshaw, I.A.N. Webb. The nominal group technique: a research tool for general practice?, *Fam. Pract.* 10 (1993) 76-81. <https://doi.org/10.1093/fampra/10.1.76>.

29. H.F. Hsieh, S.E. Shannon. Three approaches to qualitative content analysis, Qual. Health Res. 15 (2005) 1277-88. <https://doi.org/10.1177/1049732305276687>.
30. J.M. Morse. Critical analysis of strategies for determining rigor in qualitative inquiry, Qual. Health Res. 25 (2015) 1212-22. <https://doi.org/10.1177/1049732315588501>.
31. M. Nakanishi, J.T. van der Steen. National dementia plans to address escalating global palliative care needs, Palliative Med. 34 (2020) 966-7. .
32. R. Osborn, D. Squires. International perspectives on patient engagement: results from the 2011 Commonwealth Fund Survey, J. Ambul. Care Manage. 35 (2012) 118-28. <https://doi.org/10.1097/JAC.0b013e31824a579b>.
33. P. Stolee, J. Ashbourne, J. Elliott, S. Main, N. Holland, C. Edick, C., C. Ropp, C. Tong, S. Bodemer. Whole Person, Whole Journey: Developing a Person-Centred Regional Dementia Strategy, Can. J. Aging (2020) 1-15. <https://doi.org/10.1017/S071498082000015X>.
34. J.T. van der Steen, C.M. Hertogh, T. de Graas, M. Nakanishi, F. Toscani, M. Arcand. Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive topics revised before implementation, J. Med. Ethics 39 (2013) 104-9. <https://doi.org/10.1136/medethics-2012-100903>.
35. J.T. Van der Steen, L. Radbruch, C.M. Hertogh, M.E. de Boer, J.C. Hughes, P. Larkin, A.L. Francke, S. Jünger, D. Gove, P. Firth, R.T. Koopmans, L. Volicer, on behalf of the European Association for Palliative Care (EAPC). 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. 28 (2014) 197-209. <https://doi.org/10.1177/0269216313493685>.
36. STEM/MARK. Umírání a péče o nevléčitelně nemocné II – výzkumná zpráva. [Dying and caring for the terminal ill]. 2013. <https://www.umirani.cz/sites/default/files/custom-files/cesta-domu-zprava-umirani-a-pece-o-nevylecitelne-nemocne-2013.pdf> . Accessed 22 June 2021.

37. D. Hradcova. Relational approach to ethics and quality improvement in institutional care for people with dementia, *Ann. Palliat. Med.* 6 (2017) 319-26.
<https://doi.org/10.21037/apm.2017.06.20>.
38. N. James. Using email interviews in qualitative educational research: Creating space to think and time to talk, *Int. J. Qual. Stud. Educ.* 29 (2016) 150-63.
<https://doi.org/10.1080/09518398.2015.1017848>
39. G. Novick. Is there a bias against telephone interviews in qualitative research?, *Res. Nurs. Health* 31 (2008) 391-8. <https://doi.org/10.1002/nur.20259>.
40. S. Weller. Using internet video calls in qualitative (longitudinal) interviews: Some implications for rapport, *Int. J. Soc. Res. Method.* 20 (2017) 613-25.
<https://doi.org/10.1080/13645579.2016.1269505>.
41. N. Joseph-Williams, R. Newcombe, M. Politi, M.A. Durand, S. Sivell, D. Stacey, A. O'Connor, R.J. Volk, A. Edwards, C. Bennett, M. Pignone, R. Thomson, G. Elwyn. Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process, *Med. Decis. Making* 34 (2014) 699-710. <https://doi.org/10.1177/0272989X13501721>.
42. T.H. Wieringa, R. Rodriguez-Gutierrez, G. Spencer-Bonilla, M. De Wit, O.J. Ponce, M.F. Sanchez-Herrera, N.R. Espinoza, Y. Zisman-Ilani, M. Kunneman, L.J. Schoonmade, V.M. Montori, F.J. Snoek. Decision aids that facilitate elements of shared decision making in chronic illnesses: a systematic review, *Syst. Rev.* 8 (2019) 121.
<https://doi.org/10.1186/s13643-019-1034-4>.
43. M.S. Matthias, M.P. Salyers, R.M. Frankel. Re-thinking shared decision-making: context matters, *Patient Educ. Couns.* 91 (2013) 176-9. <https://doi.org/10.1016/j.pec.2013.01.006>.
44. G. Makoul, M.L. Clayman. An integrative model of shared decision making in medical encounters, *Patient Educ. Couns.* 60 (2006) 301-12.
<https://doi.org/10.1016/j.pec.2005.06.010>.

Figure 1. Outline of the three-phase process for developing country specific question prompt lists.

[See File: “Figure 1 Outline of the three-phase process for developing country specific question prompt lists”]

QPL = question prompt list; AU = Australia, CA = Canada, CZ = the Czech Republic, IT = Italy, NL = the Netherlands, ROI = Republic of Ireland, UK = the United Kingdom

**In Italy, Phase 2 could not be performed due to the large impact of COVID-19*

Box 1. Criteria for question pre-selection by research team (Phase 1)

1. The question is not already answered in the Comfort Care Booklet.
2. The question probes for relevant information or more personal or in-depth information.
3. The question is of cultural, care practice or legislative relevance to at least one of the participating countries.
4. The question is not purely medical or medical-technical, and can thus be addressed by a long-term care staff member from the relevant occupation (for example, by a nurse or a social worker).
5. The question cannot be answered or on the contrary, is already covered by the Comfort Care Booklet, but is still pressing to family caregivers (according to literature and researchers’ experience in practice) and bringing it to the table would be beneficial.

Table 1. List of pre-selected questions (Phase 1) and selection per country (Phase 2)

Question	Selected by
1 Can you tell me more about palliative care in dementia?	CA [†] , CZ, NL, ROI, UK
2 What changes can I expect, still, such as worsening of symptoms or behavior?	CA [†] , CZ, ROI, UK*
3 When there is no solution for very unpleasant symptoms such as pain or shortness of breath, will the doctor have other options (such as lower the level of consciousness, put to sleep by means of 'palliative sedation'), so my/our loved one is less aware of them, or can we discuss the level of awareness we prefer?	CA*, CZ, NL, UK*
4 What do you want to know about my loved one, so you can provide appropriate and quality care, now and later on?	CA*, NL, UK
5 What role might I or other family members be expected to play in decision making such as decisions about to transfer to hospital or change medication?	CA, CZ*, ROI*
6 Is it possible to record wishes regarding end-of-life care now, and if so: how, and how often are these being reviewed?	CA*, NL, UK*
7 Can you tell me what "comfort care" means?	CA [†] , CZ, NL*
8 Can you tell me how much time is left?	CA* CZ, UK
9 Can you warn me, the relative, when death is near?	CA [†] , CZ*, ROI*
10 Can my loved one be admitted into a hospice?	CA, CZ*, UK
11 I would like to talk about how my family member would want to be cared for. When can I discuss this and with whom?	NL, UK
12 Can you arrange for me to talk with someone from my culture, someone who may understand me better?	NL, UK
13 Can someone help me to communicate with other members of my family about what is happening?	ROI, UK
14 How do we ensure positive experiences?	CZ, ROI
15 What are advantages and disadvantages of resuscitation in this case?	ROI*, UK
16 What spiritual or religious care is available to us?	NL, ROI*
17 Is it feasible for my loved one to die at home?	CZ*, UK
18 What should or can I, the relative, do at the moment of death and afterwards?	NL, ROI [†]
19 What is the best way for me and my family member to communicate our needs, concerns, and questions to the staff?	CA*
20 How can I make arrangements to meet with the doctor?	UK*
21 Is it possible for me to see someone else if I don't get along with the nurse or doctor? How do I go about this?	UK
22 What are the worst days going to be like, and what are the best days going to be like?	CZ
23 Can you alleviate symptoms and provide some comfort?	NL
24 How do we ensure incontinence does not affect dignity?	NL
25 My loved one has dementia but also other medical conditions. How might this affect their care at the end of life?	UK
26 Do people die from dementia?	
27 What might the final days and hours of my family member's life look like?	ROI [†]
28 Who can help me sit up with my dying loved one/relative? Are there volunteers we can call in?	CA*
29 What if my loved one/relative dies when I am not there?	NL
30 What possibilities are there not to prolong life in a natural way?	NL
31 Can we ask for life-terminating treatment, if things really go worse?	NL
32 What can help me or my loved one accept that my loved one is no longer able to do things, or know things (cope with/prepare for losses)?	
33 How confidential is the information? For example: are other family members allowed to know about medical problems or behavior problems?	
34 When could hospitalization be necessary and when is it not a good idea?	
35 Can you help me to work out questions I may wish to ask my other doctors/specialists?	
36 Are medications necessary [for the problem] or can we try something else first?	
37 How do I recognize that I am overburdened?	
38 How might your care of my family member change in his/her final days?	
39 What aftercare is available to me, like speaking to the doctor again?	

*The original question was rephrased by the participants †The original questions were combined into one question

Table 2. Nominal group information (Phase 2)

	Month, year of phase 2	Number of participants in phase 2	Duration of group discussion (minutes)	Setting of group discussion	Number of questions in final QPL
CA	Nov 2019 – Jan 2020	4	140	Nursing home	15
CZ**	Feb 2020 – April 2020	5*	120	Online (home)	20
NL	Nov 2019 – Dec 2019	20	(i): 135 (ii): 120	(i): Alzheimer Nederland Offices (ii): LUMC conference room	24
ROI**	March 2020 – July 2020	6*	(i): 40 (ii): 60	(i): Health care facility conference room (ii): Family caregiver's garden	22
UK**	March 2020 – June 2020	8	60 (video call)	Video call, phone, email (home)	24

**Number of participants providing individual input; 2 Czech participants and 1 Irish participant could not join the group discussion. **Group discussions had to be performed in alternative formats to accommodate for COVID-19 restrictions. (i) = group discussion 1, (ii) = group discussion 2*

Table 3. Family caregivers' reasons for selecting questions

Reason	Explanation
<i>Just obtaining information</i>	The answers to these questions are important for people to know and could address misunderstandings; the answer does not necessarily influence preparations or plans
<i>Preparation for end of life</i>	The answers to these questions would allow for family caregiver to obtain knowledge that will inform preparation for end of life
<i>Reassurance</i>	The answers to these questions would allow for family caregivers to feel better about (future) scenarios by soothing concerns and providing confirmation
<i>Preparation for shared decision making</i>	The answers to these questions could set up the family caregiver to prepare for or make decisions in an informed manner
<i>Informing staff about the resident's needs</i>	Asking these questions would allow the family caregiver to inform or prepare staff about the resident's needs and wishes
<i>Informing staff about the family caregiver's needs</i>	Asking these questions would allow the family caregiver to inform or prepare staff about their own needs and wishes for support and involvement

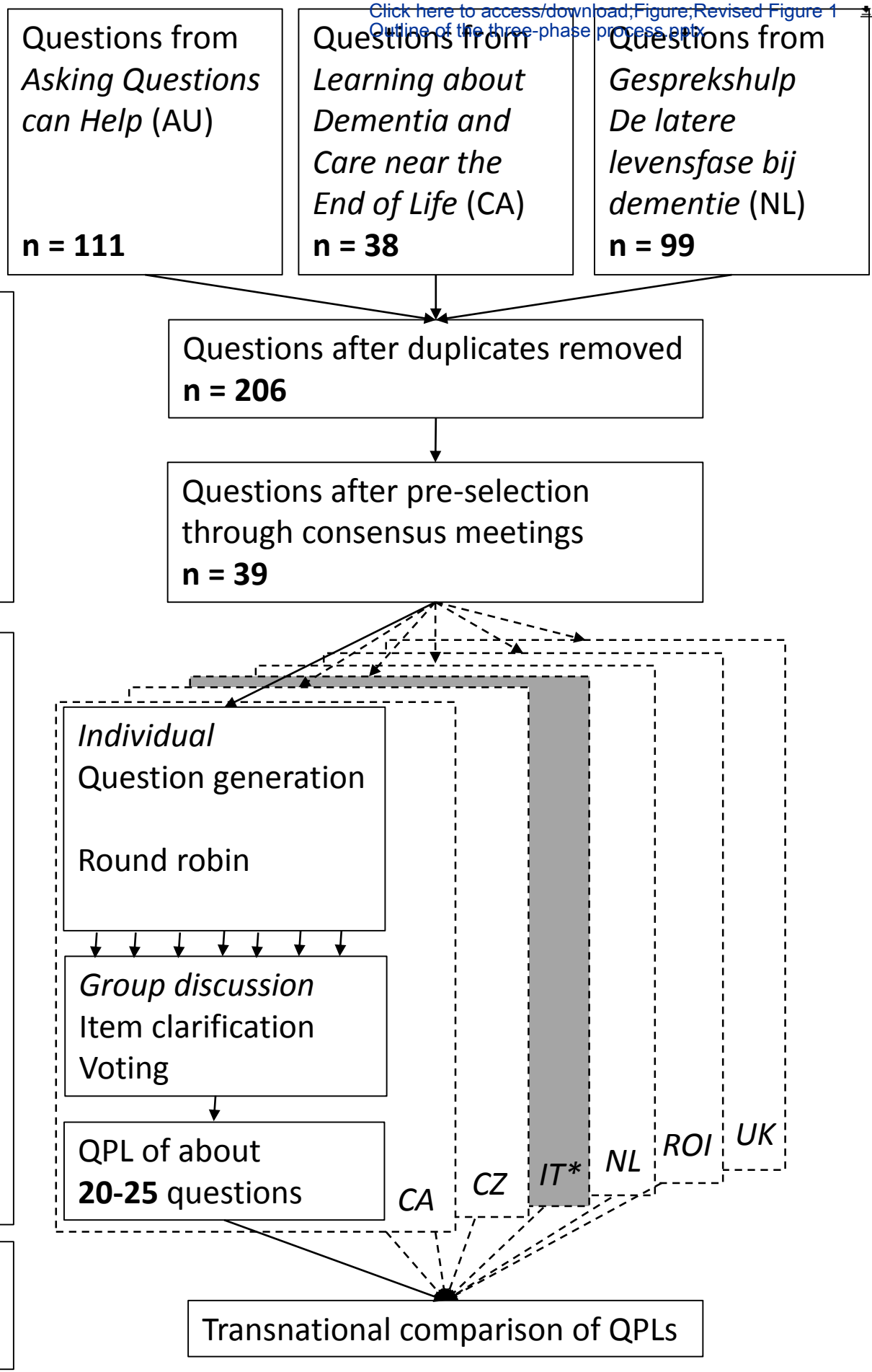
Table 4. Themes and codes derived from the question prompt lists, with example questions (Phase 3)

Themes	Codes	Example questions (country)
1. Request for (services or) information about symptoms and disease	<i>Prognosis: death</i>	How close is my loved one to the end of their life? (ROI)
	<i>Dementia trajectory</i>	What changes can I expect, still, such as worsening of symptoms or behavior? (CZ, ROI, UK)
	<i>Pneumonia</i>	What is the association between pneumonia and introducing a PEG? (CZ)
	<i>Nutrition/hydration</i>	How can swallowing disorder be alleviated while food intake is conserved? (CZ)
2. Request for (services or) information about treatment	<i>Pain management</i>	What pain management is available and which one do you advise and why? (NL)
	<i>Treatment options</i>	What are some alternatives to medication that can be provided at this LTC? (CA)
	<i>Palliative care information</i>	Can you tell me more about palliative care in dementia? (CA, CZ, NL, ROI, UK)
3. Requests for (services or) information about death	<i>Intervention risks and benefits</i>	What are the advantages and disadvantages of going to hospital? (ROI)
	<i>Controlling death circumstances</i>	Can we ask for life-terminating treatment, if things really go worse? (NL)
	<i>Staff competence</i>	What training/support is given to care staff to enable them to support my loved one? (UK)

<p>4. Requests for (services or) information about care staff</p>	<p><i>Communication with staff</i></p>	<p>Is it possible for me to see someone else if I don't get along with the nurse or doctor? How do I go about this? (UK)</p>
<p>5. Requests for (services or) information about care setting</p>	<p><i>Long term care setting policy</i> <i>Care protocols</i> <i>Specialist services</i> <i>Coordination of care</i></p>	<p>Who is appropriate to come visit and how often? (ROI) Do staff continue care, such as patient turning/repositioning, at the end of life? (CA) Does this long-term care facility have a "palliative team"? (CA) If equipment is needed, where will it come from and how quickly can it be obtained? For example, wheelchair, mattress, syringe driver, etc. (UK)</p>
<p>6. Request for the increase or use of patient values and wishes</p>	<p><i>Living will</i> <i>Dignity</i></p>	<p>How can I support my loved one to make a will? (UK) How are we going to protect dignity during personal care? (ROI)</p>
<p>7. Request for information about shared decision-making</p>	<p><i>Roles and responsibilities</i></p>	<p>Who has the final say? The physician, the nurse or I (the relative or mandatory)? (NL)</p>

Figure

[Click here to access/download;Figure, Revised Figure 1 Outline of the three-phase process only](#)



Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Contributors and authorship

Laura Bavelaar: Conceptualization, Methodology, Formal analysis, Writing – Original draft **Maria**

Nicula: Formal analysis, Writing – Original Draft **Sophie Morris:** Writing – Review & Editing **Sharon**

Kaasalainen: Writing – Review & Editing **Wilco Achterberg:** Writing – Review & Editing **Martin**

Loucka: Writing – Review & Editing **Karolina Vlckova:** Writing – Review & Editing **Genevieve**

Thompson: Writing – Review & Editing **Nicola Cornally:** Writing – Review & Editing **Irene Hartigan:**

Writing – Review & Editing **Andrew Harding:** Writing – Review & Editing **Nancy Preston:** Writing –

Review & Editing **Catherine Walshe:** Writing – Review & Editing **Emily Cousins:** Writing – Review &

Editing **Karen Harrison Dening:** Writing – Review & Editing **Kay de Vries:** Writing – Review & Editing

Kevin Brazil: Writing – Review & Editing **Jenny van der Steen:** Conceptualization, Methodology,

Writing – Review & Editing