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Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

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ABSTRACT

Objectives In oncology and palliative care, patient question prompt lists (QPLs) increased patients' involvement in decision making and improved outcomes if physicians actively endorsed asking questions. Therefore, we aim to evaluate practitioners' perceptions of acceptability and possible use of a QPL about palliative and end-of-life care in dementia.

Methods A multidisciplinary team drafted a QPL and (bereaved) family caregivers and experts improved it. A mixed-methods design comprised evaluation through a survey and interviews with practitioners. The practitioners were mostly general practitioners and elderly care physicians and recruited from two academic medical training centres in west and east of the Netherlands. The main survey outcome was acceptability measured with a 15-75 acceptability scale with ≥45 meaning "acceptable."

Results The survey response rate was 21% (66/320). The QPL was regarded as acceptable (mean 51, SD 10) but 64% felt it was too long. Thirty-five percent would want training to be able to answer the questions. Those who felt unable to answer (31%) found the QPL less acceptable (mean 46 vs. 54 for others; $p=0.015$). We identified three themes from nine interviews: (1) enhancing conversations through discussing difficult topics, (2) pro-actively engaging in end-of-life conversations and (3) possible implementation.

Conclusion Confidence of physicians to be able to address questions about end-of-life care is crucial when implementing a QPL in practice, but may require training. To facilitate discussions of advance care planning and palliative care, families and persons with dementia should also be empowered to access the QPL themselves.

Keywords

Advance care planning, dementia, end of life care, shared decision making, decision aids

Article summary – Strengths and limitations of this study

- Practitioners' perceptions regarding concrete tools to support advance care planning are highly relevant as the literature reports many barriers to advance care planning including from the side of the physician and other practitioners. There are specific sensitivities around advance care planning with dementia-some related cognitive decline. Physicians should have confidence to provide such tools, in particular tools striving to empower patient and family.
- We employed a mixed-methods design with early integration of the quantitative survey and qualitative interview findings. This allowed for integration of relevant secondary analyses of the quantitative data based on a question that emerged from the qualitative interviews.
- We assessed perceptions of physicians only.
- The responding physicians may represent a sample with an above average interest in the topic of advance care planning or in dementia care.

INTRODUCTION

In long-term care, an ongoing dialogue between patient, family (caregivers) and the healthcare team in the form of advance care planning (ACP) can improve the quality of end-of-life care.[1-3] With dementia, timely ACP is crucial to enable persons to participate because of the cognitive decline and rather unpredictable disease trajectory.[3-5]

However, in practice there are numerous barriers to early ACP initiation. Some people do not want to talk about the future, but rather live one day at a time.[5,6] Moreover, healthcare professionals (practitioners) may struggle to find the right moment or hold very different beliefs regarding when to best initiate the ACP discussion.[6-8] Interventions to increase ACP often address either the practitioner or the family.[9-11]

Several decision aids have been developed to enhance ACP and improve the quality of decision making including a family booklet for dementia at the end of life that was found acceptable and useful by physicians, nurses and family in multiple countries.[12-14] However, the booklet only contains information, while explicit example questions provided by a question prompt list (QPL) can empower people to ask questions that are specific to their individual information needs. QPLs may also prompt patient and family to ask about sensitive topics that they might not otherwise think of or feel comfortable with. Research in oncology and palliative care indicates that QPLs increased question asking during medical consultations especially if physicians also encourage patients to use the QPL, enhance participation in decision making and sometimes improve psychological outcomes such as anxiety in a longer term.[15,16]

Similarly, a QPL specifically for persons with dementia and their family might alter the dynamics of discussions on end-of-life care. Therefore, we developed a QPL for persons with dementia and their family and addressed the research question of what are perceptions on acceptability and possible use of the QPL among practitioners involved with advance care planning in dementia care.

METHODS

We performed a mixed-methods evaluation study of a QPL among practitioners because their perceptions are crucial for implementation strategies in practice and preparing for trials.[17] We used validated instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

Patient and public involvement in QPL development

A multidisciplinary team drafted an initial QPL in the form of a booklet with information and sample questions. The QPL's goals were to: help elicit perceptions and beliefs about the end of life, help think about what to ask professionals, encourage conversations and facilitate decision making. The contents was based on the earlier booklet,[12-14] an Australian QPL for persons with dementia and their family[18] and a Canadian QPL for family of nursing home residents with dementia.[19] The first draft was presented to a panel of older people and experts in grief and bereavement, spiritual caregiving and ethics, cultural issues, layout, and lay language use (a professional language center reducing the level to B1),[20] and their feedback was used to improve the QPL (Box 1).

Evaluation procedures

The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice. These professions are responsible for primary care for persons with dementia, with elderly care physicians usually being on the staff of a nursing home, or also practicing in the community in collaboration with GPs.[21]

The QPL and survey were distributed on paper during meetings at educational centres or sent via postal mail in June 2018. We provided two copies of each, for the physician themselves and for a colleague. Completing and returning the survey on the QPL served as informed consent for the study's survey part. We sent one general reminder via e-mail. We offered an optional accredited (1-hour) educational exercise that involved developing a strategy for future implementation of the QPL in practice with feedback from the researchers.

Survey

The questionnaire examined physician's perception of the acceptability of the QPL (primary outcome), the usefulness and quality of contents (secondary outcomes) and possible barriers to implementation in practice. We assessed acceptability with a slightly adapted validated 15-item scale of statements[13,14] (Supplement 1) based on acceptability decision aid evaluation methodology.[22] Usefulness and quality of content was assessed by asking physicians to rate the contents[13,14] and statements of anticipated benefits based on the QPL's goals. Barriers to optimal use of the QPL were assessed based on earlier questionnaires on barriers to symptom relief in dementia and perceptions of ACP among general practitioners and elderly care physicians.[17,22-25]

All items were rated on 1 to 5-point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree'') except for quality of content for which extremes were labelled ''poor'' and ''excellent.''[14] The 15 acceptability items were summed to calculate an acceptability score ranging 15-75 points. We regarded (mean) total scores of 45 (mean item score 3) and higher as acceptable, and scores of 60 and higher as highly acceptable.[14] The survey data were managed in Castor EDC (2018) (Castor, Amsterdam) and for analysis exported to SPSS version 23 (2018) (SPSS Corp. Inc., Chicago, IL). We used descriptive statistics to present the results and we compared professions with appropriate tests (in footnote to tables).

Interviews

At the end of the survey, physicians could indicate whether they were willing to be approached for an additional qualitative interview by providing their contact details. We selected physicians for an interview based on a particularly high or low acceptability scores (purposive sampling). We aimed to perform about 10 to 12 individual interviews for probable saturation for our specific aim.[26,27] Before the interview, participants signed an informed consent form modelled after the template of the Dutch Central Committee on Research Involving Human Subjects (CCMO). Interviewees were offered a gift card of 30 euros. Semi-structured face-to-face interviews (7) were held by SH-male Master student working in nursing homes, JTS-female PhD epidemiologist (double interview) and female MD-researcher AK who had not been involved in QPL development (one, and one with SH).

The interviews were guided by an interview guide (Supplement 2) that contained key questions addressing the participant's views on the QPL, their personal approach to end-of-life conversations and considerations regarding possible implementation of the QPL. If relevant, specific questions were asked based on reviewing participant's survey responses in an open manner. All interviews were audio-recorded, and SH transcribed verbatim while guaranteeing confidentiality through procedures consistent with the GDPR. Interview data were managed and coded in Atlas.ti (version 7.5.18, 2012). We used inductive thematic analyses to analyse the interviews along with open-ended items of the survey (whether they agreed with the QPL's contents and format, any missing information or questions, any other comments). The three researchers who conducted the interviews, coded the first interviews and discussed and agreed upon the coding (188 codes and 11 interrelated subthemes available at request). We selected citations to represent and illustrate the themes consistent with good research practice.[28]

RESULTS

Survey participants

We approached all residents and supervisors (160) to participate, providing a copy of the questionnaire also for a colleague (i.e. 320 in total). Between June and December 2018, 66 (21%) were returned completed by 18 general practitioners including two general practice-based assistant practitioners and 46 elderly care physicians, one geriatrician and one geriatric nurse.

The majority (73%) of the participants were female, with a mean of 21 years' experience and over half (56%) cared for persons with dementia on a daily basis (table 1). Elderly care physicians were more likely to see persons daily (70% vs. 22%) and in more advanced stages of dementia (70% vs. 11%).

Survey–acceptability and possible use

Table 2 shows that the physicians judged the QPL as acceptable (mean acceptability score 51), however, with a high standard deviation (10), but there was no difference in acceptability score between GPs and elderly care physicians. Mean usefulness was 7.2 points on the 1–10 scale. The contents were mostly appreciated (mean quality 64 points, SD also 10; Supplement 1: most, care for relatives; least, the introduction about illness and care). Although few participants thought there were too many example questions (9%), 64% of the physicians found the QPL too long and 59% felt there was too much information.

The survey items on barriers and benefits did not show clear patterns, but 49% believed that persons in early stages of dementia could not use the QPL themselves (table 3). When available, most (59%) would give the QPL to the individual and their family and 26% to family only (14% would not give it to anyone). Most (56%) physicians anticipated the QPL will increase provision of palliative care, and 21% anticipated more requests to hasten death, which was concerning to about half of them (10% overall).

Table 4 shows that almost one-third (31%) of the physicians found they were unable to answer all example questions in the QPL adequately, despite the instruction with this item recognizing that for some questions, there is no, or no certain answer. Overall one-third of participants (35%) felt a need for training to answer the QPL's example questions; more often GPs than elderly care physicians (72% vs. 20%).

Interviewees

We invited five physicians with a high acceptability score (55-64), four others (score 24, 35 or no score but negative comments), and one with combined GP/elderly care background and all were interviewed at their workplace July-November 2018. Of the physicians (seven female, three male), three were trainees, four were supervisors; seven were elderly care physicians, one GP, one both, and one geriatrician. Eight were individual interviews, and we interviewed one dyad of supervisor and trainee. The interviews lasted on average 46 (SD 15) minutes.

Interview themes

We identified three major themes with the last three interviews pointing to saturation: (1) enhancing conversations through discussing difficult topics; (2) pro-actively engaging in end-of-life discussions in practice; and (3) considering possible implementation of the QPL.

(1) Enhancing conversations through discussing difficult topics

The physicians who rated the QPL as highly acceptable anticipated added value in end-of-life discussions, mainly to enhance the conversations. They expected that it would encourage the person and family to consider questions about dementia and care options:

> *"I think if the patient has it [the question prompt list], he or she will have some questions of his/her own before we have this conversation. So I think the doctor will be triggered and get more questions from the client side, yes." (elderly care physician in training 2, positive; citation a)*

Moreover, they felt that having an overview of topics that could be discussed would be helpful for themselves:

> *"I was pleasantly surprised because I think something like this is very useful. It actually provided a very good guide for the things you actually want to know from a patient." (elderly care physician-in training 1, positive; citation b)*

On the other hand, both physicians with a high and a low acceptability score were concerned about possible information overload, leading to confusion, or even fear:

> *"I'm afraid that because of its extensiveness, it won't be used that much and that would be a pity because the subjects that are raised are all very relevant." (elderly care physician and GP 6, positive; citation c)*

> *"Yes, I think that because of the amount of information, people will start thinking and can also get, well, confused." (elderly care physician in training 1, positive; citation d)*

> *"Because for example, a feeding tube is also touched upon here, but it is mentioned very briefly and then: well, that often doesn't help. I think it can also sometimes cause people to get confused if there is information that is perhaps a little too concise and consequently raises expectations of: gosh, it might be worthwhile; that it can also generate unrest in such a conversation." (elderly care physician-in training 8, negative; citation e)*

> *"But sometimes you... Maybe it's a good thing not to know things and not to ask about them (elderly care physician supervisor 7, negative; citation f)*

Another issue was whether terms such as "care goals" and "advance care planning", although explained in the QPL, should be used at all.

> *"...you keep hammering on care goals, what's your care goal. That is our problem, we want to label everything a goal or a problem, why should you call it a care goal, you could say: we would like to know, what is important for you to have a good life." (elderly care physician 4, supervisor, negative; citation g)*

Some physicians' had concerns regarding specific questions in the QPL such as those about life expectancy, progression of the disease over time, and religious matters. While participants felt these questions would be meaningful for the person, some physicians felt they had no clear answers, and they reasoned that this might result in persons with dementia and family becoming more anxious.

> *"A slightly more critical look is needed at some of the questions being asked, questions that make me wonder, what doctor can answer that." (elderly care physician 4, supervisor, negative; citation h)*

(2) Pro-actively engaging in end-of-life discussions in practice

The physicians would normally employ various approaches in initiating conversations about the end of life. Most mentioned they start with asking general non-threatening questions, and through the answers, consider whether the person with dementia or family is ready to further discuss more sensitive or confrontational topics at that time, or to postpone the discussion:

> *"You explore: what is a person's attitude to life and what can the person handle and in that way you try, you basically ask questions. And that's how you try to find a starting point (...) you are very careful, you don't go in like 'wham' " (elderly care physician-in training 1, positive; citation i)*

However, some physicians take a more pro-active yet confrontational approach with specific examples that people can imagine and understand easily:

> *"You're actually describing the situations, is that what you'd want in that case? For example, resuscitation, because that is also a difficult concept to explain: we will bring you back from the dead, actually you are already dead, but then we bring you back from the dead, but that can cause a lot of brain damage. Then they say "brain damage, why?"; we often use the term [living like a] 'vegetable' [in Dutch: 'kasplant'], that's an association." (elderly care physician 3, positive; citation j)*

> *"'Vegetable'[...] is very easily accepted as a word. It is clear to 99% of people."(elderly care physician 5, supervisor, positive; citation k)*

The most important factor in how to approach the person and family was their educational level, according to the interviewees, which was corroborated by comments to open-ended survey items. The more highly educated would be equipped for the conversation through a better understanding of the subject, where others would need more guidance and explanation. The physicians believed those with a lower education level may hold misconceptions regarding treatment and care and have more trouble processing the QPL.

> *"That depends. Around here we have quite a few highly educated people, so shared decision making is very doable. People are well-informed, they read up [on the topic]." (elderly care physician 3, positive; citation l)*

> *"Yes, and I think it can be very confusing for some people. But maybe that's with the poorly educated population I occasionally work with in mind, that this is a lot and difficult to grasp. [...] then you ask do you want to be resuscitated and people say yes, but they have no idea... They think if they say no, they'll get an injection tomorrow and that's it, those are people's perceptions sometimes". (elderly care physician-in training 1, positive; citation m, continued citation d).*

Apart from educational level, some participants mentioned the relevance of the setting in which the QPL conversation takes place. Nursing home residents with dementia and family may have had more opportunity to think about the end of life, regarding specific treatment and values and preferences relating to care. Therefore, the more sensitive topics regarding end of life may be easier to discuss:

> *"People in nursing homes have already faced much more dependency, so most of them have thought about it. In primary healthcare this is much more difficult, because people who are never ill think they will live forever, and then suddenly they are confronted with it". (elderly care physician 4, supervisor, negative; citation n)*

A good connection based on trust was regarded as an important factor to improve the quality of end-of-life discussions:

> *"..you get to know your client over a long period of time, you get to know the family over a long period of time, the care staff get to know someone over a long period of time, because that's also important... yes, these are people you know well, that's the advantage of being a GP, that you have a connection with a person". (GP 1, negative; citation o)*

(3) Considering possible implementation of the QPL

The interviewees selected for being positive about the QPL would like to the QPL used by physicians and nurse practitioners. Some physicians would want the QPL to be used as early as possible in general practice, with the general practice-based assistant practitioner being the right person to not only give the QPL to patients and families, but also start the conversation about possible future care options, supervised by the GP:

> *"Maybe this is not a job for the GP? Maybe for the general practice-based assistant practitioner. They often have more time and they know the people better, are more accessible and they can probably explain things in everyday language. " (elderly care physician 3, positive; citation p)*

The physicians who found the QPL less acceptable envisioned barriers to implementation and were not considering possible solutions. They mentioned lack of time if there would be many questions or stated that the format is not viable:

> *"I think that you can have a really good conversation with two or three questions, and that you have to be careful it doesn't turn into an hour of conversation, because we simply don't have that kind of time. (GP 1, negative; citation q)*

> *"I think it [the length of the list] is such a major drawback that I think, I don't know ……. that I also find it hard to figure out how to make it work." (elderly care physician 4, supervisor, negative; citation r)*

Integration of survey and interview results

Some interviewees expressed concerns about not being able to provide good, or specific answers to certain questions in the QPL. For example, they mentioned not being able to answer a question on life expectancy and the progression of the disease. Based on the interview findings, we hypothesized that lack of self-efficacy or fear of not having the answer might be a decisive factor in using or appreciating the QPL. We then did a post-hoc secondary analysis of the survey data and found that the average acceptability score of those who felt they could not give answers to all example questions was lower, compared to those who felt they could (46 vs. 54; p=0.015), with a higher standard deviation (13 vs. 8).

DISCUSSION

Main findings and interpretation

This is the first study to assess practitioners' acceptability and views on a QPL about end-of-life issues specifically designed for persons living with dementia and their families. Physicians (and a few other practitioners) who provide long-term and end-of-life care for persons with dementia rated the QPL to be acceptable and the quality of the contents as good. However, many found the amount of information problematic, and were concerned it could be overwhelming. Importantly, the physicians were divided about whether the QPL would be too difficult for use by persons with dementia themselves due to the cognitive impairment associated with dementia, and they also differed in the extent to which they would confront persons with dementia and family with sensitive or difficult issues about end of life. Some physicians felt it would be better to ask initial screening questions to probe the persons' readiness to discuss these issues before providing a QPL.

When comparing the physician acceptability score of the QPL to earlier research in which we evaluated a family booklet with information only about dementia at the end of life, the mean acceptability score for the QPL was lower (56 versus 51, respectively).[14] The QPL also targets persons with dementia themselves in a community setting, rather than family only. In a secondary analysis prompted by the interview findings, we found lower acceptability of the QPL by physicians who were concerned about their ability to answer questions in the QPL adequately. Physicians may not feel comfortable to discuss some topics included in the QPL, perhaps also including around hastening death.

Strengths and limitations of the study

The mixed-methods design allowed for a richer understanding of the quantitative survey data, in particular regarding barriers and concerns, and also provided an efficient iterative approach of analysing the quantitative data based on a question that emerged from the qualitative interviews. The response to the survey was low although usual for physician surveys. We did not assess the acceptability of the QPL by persons living with dementia and their families, and further research in this area is warranted.

What this study adds: implications and conclusions

Training is required to increase confidence of physicians to be able to address questions from family and persons with dementia about end-of-life care when implementing a QPL in practice. This may generalize to other countries as other work has shown that many Dutch elderly care physicians but also many GPs in Northern Ireland are reluctant to initiate ACP with people in the early stages of dementia.[8] Shared decision making is worthwhile in situations where there is choice based on individual preferences.[29] Persons with dementia may hold a neutral or negative stance regarding ACP[,3,11] and a first extra step, before starting a decision-making process with a person with dementia is to agree on the necessity to make a decision.[30] Therefore, a prudent approach, probing readiness to engage in ACP, as adopted by some physicians, makes sense. On the other hand, persons with dementia and family may need proactive encouragement and support from physicians or other practitioners to discuss ACP so that they don't miss out on the opportunity to participate in decisions about their future care. This can help empower persons with dementia and avoid regret and crisis later on for family when making difficult decisions on behalf of the person with dementia.[31] A QPL may help persons with dementia and family to select exactly the topics they find relevant at that time, and this could also inform the practitioner about readiness to discuss end of life. QPLs have the potential to alter the dynamics of conversations and empower persons with dementia in encounters with professional caregivers. These are worthwhile endeavours for persons with dementia who essentially would like to be part of society, appreciated, and their identity recognized.[32,33] Further, shared decision-making about goals for future care as the persons' dementia progresses is important because not all goals of care can be achieved, and there may also be trade-offs between goals for the family and the person with dementia.[29,33-35] To empower persons with dementia and their family, implementation strategies should also circumvent possible gatekeeping to include free access so they can ask practitioners and thus take initiative to start conversations.

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Author contributions

The author's responsibilities were as follows:
Development of the question prompt list: JTS, CCMJ, MMG, JMC, GNT, RTCMK, YML
Project design: JTS, SH, WPA, MMG
Data collection: JTS, SH
Paper writing: JTS, SH
Critique and review of the final manuscript: all.

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Conflict of interest disclosure

The Department advised on research review design and data collection. There was no influence on study analysis, decision to publish or preparation of the manuscript. The author(s) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Patient consent for publication

Not applicable.

Patient and public involvement

Patient representatives were involved in question prompt list development. Patients were not involved in the practitioners' evaluation study.

Patient consent for publication

Not applicable.

Data sharing statement

The de-identified survey participant data may be requested from the corresponding author upon reasonable request.

Ethics approval

As a tool evaluation study among practitioners, this project did not involve patients or patient data. Therefore, ethics committee approval was not required. The protocol was approved by the Scientific Committee of the Department of Public Health and Primary Care of Leiden University Medical Center, the Netherlands, number WC-2018-10.

Supplemental material

1. Interview guide
2. Tables with individual items and item scores

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Box 1 Overview of topics covered in the question prompt list (QPL)

Talking about the later stages of life in dementia:
Timely information and example questions for people with dementia and their relatives

Part 1: About illness and care

- Dementia and changes in health
- Care goals, palliative care and end-of-life decisions

Part 2: About treatment and choices with health problems

- Decisions about treatments and agreements (advance care planning)
- Treatment and care for common problems
  - Food and fluid intake and swallowing problems
  - Pneumonia and other infections
  - Shortness of breath
  - Pain and discomfort
  - Restlessness and challenging behaviour
  - Incontinence
  - Depressive symptoms, anxiety and apathy
  - Feelings of loss and existential issues
  - Other illnesses and what these may require
- Resuscitation and euthanasia
- Choice of location of care and change of living environment

Part 3: Relatives

- Care for you as a relative
- The dying phase and the period after death

Table 1 Physicians' characteristics and dementia care practice patterns (n=66)*

Female sex, %	73
Age, mean (SD)	48 (11)
Experience as a physician, mean (SD)	21 (11)
Resident trainee, %	17
Supervisor,%	53
Care for dementia patients; frequency, %	
at least daily	56
at least weekly	34
at least monthly	6
at least every 2 months	3
at least every 6 months	0
< every 6 months	0
Care for dementia patients; stage of disease, %	
mostly early stage (mild dementia)	8
both early and late (moderate or advanced) stage, about equally distributed	39
mostly late (moderate or advanced) stage	53
Estimation of dementia patients dying in the past year, %	
0	2
1 – 4	27
5 – 9	25
10 – 19	34
20 or more	13

SD: standard deviation; GP: general practitioner

Significant differences (p<0.05) between GPs and elderly care practitioners were not observed for sex, trainee or supervisor status (Chi-square), age and experience (t-test). With the hierarchical gamma test there were differences between the last three items; elderly care physicians cared for dementia patients more frequently (e.g. daily 70% vs. 22%), cared for patients in later stages (e.g. advanced stage 70% vs. 11%) and more patients with dementia died in their practice in the past year (e.g. 20 or more 17% vs. 0).

* Two of 66 respondents missed characteristics other than sex and age. GP (n=18) included two general practice-based assistant practitioners (often nurses or social workers, referred in the Netherlands as "praktijkondersteuner huisarts", POH). Elderly care practitioners (n=48) included 46 elderly care physicians, a geriatrician and a geriatric nurse. Experience refers to experience as a physician and was missing for the general practice-based assistant practitioners (POH) and the nurse.

Table 2 Evaluation of acceptability and the contents of the question prompt list (n=66)

Acceptability score, mean (SD)*	51 (10)
Usefulness for persons with dementia and family, mean (SD)†	7.2 (1.7)
Quality of the content of the question prompt list, mean (SD)‡	64 (10)
Length, %	
too long	64
too short	2
just right	34
Amount of information, %	
too much	59
too little	0
just right	41
Balance in proportions of information versus example questions, %	
too much information	20
too many example questions	9
just right	70

SD: standard deviation

No differences (p<0.05, t-test or Chi-square as appropriate) were observed between GPs and elderly care practitioners for any of the items, including after adjustment for sex, experience and stage of dementia cared for most (first three outcome items, linear regression). Missing values: 2, except for usefulness, 1.

[*] Theoretical range score: 15 – 75. Cronbach's alpha in this sample was 0.94. The acceptability score covers: informing families, supporting decision making, communication with families, satisfaction with care, use in practice, and use in training (see Supplement 1, tables S1 and S2 for individual items and item scores).

[†] Theoretical range score: 0 – 10.

[‡] Theoretical range score: 16 – 80 (see Supplement 1, table S3 for item scores).

Table 3 Barriers, benefits and views about use, % (n=66)

Range of perceived barrier scores (means and SDs 5 items)[*]	2.4-2.9 (0.89-1.1)
Goals and anticipated benefits of use (means and SDs 7 items)[*]	3.1-3.9 (0.79-0.94)
Do you think dementia patients can use the QPL themselves?	
yes, but only in early stages of the disease (MMSE>20)	49
yes, in early but also in moderate stages of the disease (MMSE>10)	2
no, (almost) no one with dementia can	49
When the QPL is available, I will give it to…	
patients and relatives	59
relatives	26
I will not give the QPL to anyone	14
QPL will lead to earlier or more frequent providing of palliative care	
yes	56
no	44
This QPL will lead to more requests to hasten death	
yes, and I do not have any objection	11
yes, and I object to that	10
no	79

SD: standard deviation; QPL: question prompt list; MMSE: Mini-Mental State Examination.

[*] Items are shown in Supplement 1, Tables S4 and S5. Agreement is scaled on the same scale as the acceptability scale, from 1 to 5 point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree''). No differences ($p<0.05$, Chi-square or t-test as appropriate) were observed between GPs and elderly care physicians for any of the items, except for the barrier item "The hectic pace of practice will prevent me from using the question prompt list" (higher barrier score for GPs). Missing values: use themselves 1, give it to 2, palliative care 2, hasten death 3.

Table 4 Confidence in using the question prompt list (n=66)

I am able to answer all the questions asked in the question prompt list, %[*]	
yes	69
no	31
Need for training, % confirmed	35
Training on subject / content	19
Training in conversation techniques	5
Training on subject / content and conversation techniques	11

Differences (Chi-square) were observed between GPs and elderly care practitioners (first item, p=0.015, unable to answer, elderly care physicians 22% vs. GPs 56%; second item, p=0.001, any training elderly care physicians 20% vs. GPs 72%).

[*] The item included this explanation: "this does not mean that you have a ready-made answer to all questions, but that you think you can respond adequately to all questions"

Supplement 1. Acceptability and all scale item scores: Tables with individual items and item scores

S1. Acceptability scale adaptations (track changes) compared to acceptability scale for evaluation of a family booklet[12-14]

Use of the question prompt list in practice

This section is about your expectations when using the question prompt list in your practice. Could you please indicate the extent to which you agree or disagree with each statement? (*circle the number that applies*)

	strongly DISagree		→		**strongly agree**
a. This question prompt list~~booklet~~ will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	1	2	3	4	5
b. This question prompt list~~booklet~~ will result in them~~my patients' families~~ making more informed decisions	1	2	3	4	5
c. This question prompt list~~booklet~~ is suitable for helping ~~patients' familie~~to~~s~~ make value laden choices	1	2	3	4	5
d. Th~~e~~is question prompt list~~booklet~~ will positively affect my relationships with the person with dementia and the families	1	2	3	4	5
e. This~~e~~ question prompt list~~booklet~~ will improve the quality of discussions with ~~families~~ them	1	2	3	4	5
f. This question prompt list~~e booklet~~ will increase ~~family~~ satisfaction of the person with dementia and the family with my care	1	2	3	4	5
g. This question prompt list~~booklet~~ will increase shared understanding of ~~patient's~~ preferences of the person with dementia	1	2	3	4	5
h. This question prompt list~~booklet~~ will increase ~~family~~ consensus on decision making between the person with dementia and family, and within families	1	2	3	4	5
i. This question prompt list~~booklet~~ complements my usual approach	1	2	3	4	5
j. This question prompt list~~booklet~~ will be easy for me to use	1	2	3	4	5
k. I would decide to adopt this question prompt list ~~it~~ even before experimenting with it	1	2	3	4	5
l. Using this question prompt list~~booklet~~ will save me time.	1	2	3	4	5

m. This question prompt list~~booklet~~ is likely to be used by most of my colleagues	1	2	3	4	5
n. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for physicians*	1	2	3	4	5
o. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for nurses*	1	2	3	4	5

~~* Includes training before and after certification~~

S2. Acceptability of the question prompt list item scores (n=66 respondents)*

	mean	**SD**
a. This question prompt list will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	3.7	0.93
b. This question prompt list will result in them making more informed decisions	**4.0**	0.72
c. This question prompt list is suitable for helping to make value laden choices	3.6	0.89
d. This question prompt list will positively affect my relationships with the person with dementia and the families	3.4	0.92
e. This question prompt list will improve the quality of discussions with them	3.7	0.86
f. This question prompt list will increase satisfaction of the person with dementia and the family with my care	3.3	0.89
g. This question prompt list will increase shared understanding of preferences of the person with dementia	3.7	0.89
h. This question prompt list will increase consensus on decision making between the person with dementia and family, and within families	3.5	0.87
i. This question prompt list complements my usual approach	3.5	**1.2**
j. This question prompt list will be easy for me to use	3.0	**1.0**
k. I would decide to adopt this question prompt list even before experimenting with it	**2.5**	**1.1**
l. Using this question prompt list will save me time.	**2.7**	0.99
m. This question prompt list is likely to be used by most of my colleagues	**2.9**	0.94
n. This question prompt list should be used as a teaching aid in training or continued medical education for physicians	3.8	0.96
o. This question prompt list should be used as a teaching aid in training or continued medical education for nurses	3.8	0.89

Interpretation: summed scores range 15-75 with ≥45 meaning “acceptable.” This equates to item scores ≥3. Summed scores of ≥60 mean “highly acceptable” and this equates to item scores ≥4. Cronbach’s alpha 0.94. Bold indicates either not acceptable (red) or highly acceptable (green), and large variation (red, > 1 SD). No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs, except for the items f (mean 3.2 SD 0.88 for elderly care physicians vs. 3.7 SD 0.84 for GPs) and j (mean 3.2 SD 0.93 for elderly care physicians vs. 2.6 SD 1.1 for GPs).

*Number of missing values of 66, per item: 2 (because 2 respondents did not complete the scale), except for item c (a total of 3 missing values) and item m (a total of 4 missing values).

S3. Quality of the content of the question prompt list

	mean	**SD**	**N***
Part 1: About illness and care			
Dementia and changes in health			
information	3.7	0.84	65
questions	3.5	**1.0**	65
Care goals, palliative care and end-of-life decisions			
information	3.8	0.99	65
questions	3.7	0.80	63
Part 2: About treatment and choices with health problems			
Decisions about treatments and agreements (advance care planning)			
information	4.0	0.85	64
questions	4.0	0.84	65
Treatment and care for common problems			
information	4.0	0.82	64
questions	3.9	0.81	64
Resuscitation and euthanasia			
information	**4.0**	0.91	63
questions	**4.0**	0.87	62
Choice of location of care and change of living environment			
information	**4.1**	0.72	64
questions	**4.0**	0.73	64
Part 3: Relatives			
Care for you as a relative			
information	**4.3**	0.67	64
questions	**4.2**	0.61	64
The dying phase and the period after death			
information	**4.2**	0.77	63
questions	**4.1**	0.74	62

Bold indicates either close to poor (red, mean rating 1 to 2; did not occur) or close to excellent (green, mean rating 4-5), and large variation (red, > 1 SD).

No differences (p<0.05, t-test) were observed between elderly care physicians and GPs.

[*] One missing value (n=65) was due to a respondent who did not rate any quality item–but did complete the acceptability scale as the primary outcome.

S4. Perceived barriers to implementation of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
The hectic pace of practice will prevent me from using the question prompt list	2.8	**1.1**	64
This question prompt list will cause the person living dementia or the family to be anxious	2.9	**1.1**	64
I don't expect people living with dementia and family will want to use the question prompt list	2.5	0.93	64
Going through the question prompt list gives me enough inspiration for conversations: it is not necessary to hand it out to people living with dementia and family	2.4	**1.1**	64
The advantages of working with the conversation aid will not outweigh the time and effort invested	2.6	0.89	64

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD).
No differences (p<0.05, t-test) were observed between elderly care physicians and GPs, except for the item "The hectic pace of practice will prevent me from using the question prompt list" (mean 2.5 SD 1.0 for elderly care physicians vs. 3.6 SD 0.98 for GPs).

S5. Goals achieved and anticipated benefits of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
Question prompt list goals achieved			
This question prompt list will help the (capable) person living with dementia and the family organise their thoughts about the later stage of life	3.8	0.84	64
This question prompt list will help them formulate important questions about dementia and end-of-life care, making it easier to ask the health care professional questions	3.9	0.81	64
This question prompt list will help them to have conversations with healthcare professionals and also conversations with each other	3.8	0.79	64
This question prompt list will make choices about care and treatment easier for them	3.2	0.91	64
Other possible benefits of the question prompt list			
This question prompt list will help them to get information that is important to them in a timely manner	3.7	0.82	63
This question prompt list will make a person living with dementia or family feel supported and understood as to what they go through, and they will be better prepared for the future	3.6	0.94	63
Thanks to this question prompt list they can get the best possible personalized care.	3.1	0.88	62

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD; did not occur).
No differences (p<0.05, t-test) were observed between elderly care physicians and GPs.

Supplement 2. Interview guide

Interview guide for evaluation of the question prompt list ”Talking about the later stages in life in dementia” Translated from Dutch by a professional translator.

INTRODUCTION

First of all, thank you for your willingness to participate in this interview, after you have already assessed the question prompt list in a questionnaire. The purpose of this interview is to elaborate on what you think of the question prompt list and how it might be applied. It would be helpful to refer to the question prompt list you received from us during the interview. Of course we can provide a copy if you don’t have it with you. We will also ask you about your views on openly discussing end-of-life care and palliative care in dementia in general.

The interviews will be recorded. Your information will be treated confidentially and analyzed in the secure environment of LUMC. The data used for any publication will not be traceable to your personal data. If you agree, please sign the informed consent form.

Do you have any questions before we begin?

THE QUESTION PROMPT LIST

1. What do you think of the question prompt list in its current form?
   Possible follow-up question: Which themes are missing?
2. What do you like about the question prompt list?
3. What don’t you like about the question prompt list?
   Possible follow-up questions: Do you have tips on how to improve these points? If so, what are they?
4. Are there parts or factors in this question prompt list that could impede the conversation between you and the patient and (loved one) (family)?
   a. **If yes**: Which?
   b. **If no**: Do you feel that the question prompt list as a whole facilitates conversations?
   Possible follow-up question: How can these impeding factors be reduced or resolved?

For interviewer, to the participant:
Explain that the subject of the questions will now shift from the question prompt list to discussing sensitive subjects with persons living with dementia and family/loved ones. Also indicate that there will be more questions about the question prompt list later.

DISCUSSING SENSITIVE SUBJECTS

1. How difficult (or easy) do you find talking about the course of dementia and end of life (care) with patients and family/loved ones?
   a. *(**if little experience**): Which subjects seem most difficult to discuss? What do you think is the easiest way to make them discussible? Do you think this will become easier over the years (experience)?*
   b. *(**if very experienced**): Is it easier for you now than at the beginning of your career? What factors played a role? **If yes**: How do you deal with difficult subjects now and how is that different from the beginning of your career?*
2. Do you think the subjects highlighted in the question prompt list are easy to discuss in general?
3. Are there any subjects you find difficult to discuss with patient and family?
   a. **If yes**: Which subjects?
   b. **If no:** Are all subjects easy to discuss for you?
   Possible follow-up questions: Does this have to do with your experience regarding these conversations? (if not yet discussed under 1., and then elaborate in same manner) Does the question prompt list (also) contain certain example questions that you find difficult to answer?
   Possible follow-up question: What would you need to be able to answer these questions?
   Possible follow-up question: How to act when resistance is sensed from patient/family?
4. Have you (personally) found ways to make certain subjects easier to discuss in these types of conversations?
   a. ***If yes**: How do you go about it?*
   b. ***If no**: What do you need to change/improve your approach?*
5. Will the question prompt list contribute to initiating/starting the conversation with the patient and family/loved ones? And will it influence the moment of initiation?

IMPLEMENTATION IN PRACTICE

1. When a final version is available, would you want to apply this question prompt list? Why/Why not? ***If yes**: How would you want to apply the question prompt list?*
2. Are there any particular preconditions that must be met in order to be able to use this question prompt list?
3. Could this question prompt list also be applied by other healthcare professionals? ***If yes**: By whom, and would you recommend it?*
4. Do you think that question prompt lists should be used more frequently in the future in other fields or for other diseases, when available? ***If yes**: What fields/diseases?*

QUESTIONS BASED ON QUESTIONNAIRE RESPONSES

Explanation of goal:
In the final part of the interview, we would like to hear the physician's opinion, based on certain answers he/she provided in the questionnaire. As the answers to the questionnaires will vary from person to person, our goal is to record a few specific questions based on the answers to make sure all of the physician's perspectives and opinions are heard. This allows us to highlight as many different perspectives as possible.

Questions will partly have the same structure (but may deviate):

- In the questionnaire your answer to question [?] was [?]. We would really like to know what reasoning led to this answer. Can you please elaborate on your answer?
- **When physician is positive**: How do you think [?] can influence the conversations between physicians and persons with dementia and family/loved ones?
- **When physician is negative**: What should be changed in your opinion? What do you feel is necessary to do this?

1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Topic	Item No.	Guide Questions/Description	Reporting (reported in section, para) Note, page numbers refer to PDF MERGE PAGE NUMBERS
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Interviews were conducted by JTS, SH, and physician AK named in the Acknowledgement section (Methods, before last para; page 6, line 3-7)
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	SH-Master student working in nursing homes a JTS-PhD epidemiologist AK-MD researcher who had not been involved in QPL development (Methods, before last para; page 6, line 3-7)
Occupation	3	What was their occupation at the time of the study?	See item 2
Gender	4	Was the researcher male or female?	JTS and AK are females, SH male (Methods, before last para; page 6, line 3-7)
Experience and training	5	What experience or training did the researcher have?	JTS has experience with qualitative research. SH and AK are novice qualitative researchers with no PhD title (yet), supervised by JTS. We did not include these details in the reporting of the mixed-methods study to leave room to reporting of the survey as well.
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No, we selected interviewees based on survey ratings linked to IDs without immediately seeing any names, and none of the interviewees happened to be known to the interviewers. We did not include this detail in the text but we reported selection of interviewees "based on a particularly high or a low acceptability score." (Methods, before last para; page 5, line 56-58)
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The participants knew we wanted to evaluate the question prompt list they read and evaluated by completing the survey before the interview. (The Methods section is structured around the survey performed first and interviews afterwards; page 5)
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons	No other characteristics than those under no 1-7.

		and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was used with no specific methodological orientation (page 6, line 16)
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling (Methods, before last para; page 5 line 58)
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	If willing to be interviewed, the participants left contact details on the last page of the survey (telephone number or email or both according to their preference, but we did not specify contact details as we judged the choice offered for a preferred way of contacting practitioners not the most relevant detail). (Methods, before last para; page 5, line 54-55)
Sample size	12	How many participants were in the study?	10 interviewees (Results, para Interviewees; page 7, line 44-45)
Non-participation	13	How many people refused to participate or dropped out? Reasons?	None (Results, para Interviewees; page 7, line 44-45)
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	We traveled to the physician's workplace. (Results, para Interviewees; page 7, line 46)
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No-one else was present; we mentioned the interviewers with item 1.
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	We describe gender, profession, trainee / supervisor status (Results, para Interviewees; page 7, line 46-50)
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The interview topic guide was translated to English and provided as a Supplemental file (referred to page 6, line 8). It was not pilot tested but some late adaptations were based on interesting findings in the survey as this is a mixed-methods study.
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No, we felt this was not necessary for individual or dyadic interviews with practitioners on defined topics.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	The interviews were all audio recorded (Methods, last para; page 6, line 13)

Field notes	20	Were field notes made during and/or after the interview or focus group?	Limited field notes were made. We did not include this detail in the manuscript to leave room to report the Methods of the survey.
Duration	21	What was the duration of the interviews or focus group?	Interviews were held with a median duration of 46 minutes (SD 15) (Results, para Interviewees; page 7, line 50)
Data saturation	22	Was data saturation discussed?	The last three interviews contributed little to the findings. (Results, Interview themes, first para; page 7, line 53)
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to busy physicians.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	The three interviewers coded the first interviews together, and other interviews were coded by SH. (Methods, last para; page 6, line 17-20)
Description of the coding tree	25	Did authors provide a description of the coding tree?	188 codes and 11 subthemes are available upon request - available in Dutch only (mentioned in the Methods, last para; page 6, line 20-21)
Derivation of themes	26	Were themes identified in advance or derived from the data?	We inductively identified themes (Methods, last para; page 6, line 15)
Software	27	What software, if applicable, was used to manage the data?	We used Atlas.ti version 7.5.18, 2012 (Methods, last para; page 6, line 15)
Participant checking	28	Did participants provide feedback on the findings?	No, the interview was a one-time effort for busy physicians. However, physicians who choose to develop an implementation plan for an accreditation point, received feedback on the plan. (Methods, fourth para; page 5, line 31-33)
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotes indicated with letters are included in the text of the Results section, each with a participant number, profession, and trainee or supervisor status (text in italics pages 8-10)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	We selected exemplary quotes (reference for standard / good research practice in Methods; page 6, line 21)
Clarity of major themes	31	Were major themes clearly presented in the findings?	We presented three major themes (page 7, line 53-56)
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Subthemes are included under the main themes in narrative format (pages 8-10). Purposive sampling of physicians with particular positive and negative acceptability

			scores (page 5, line 56-58) helped to identify and understand divergent approaches to discuss end of life and different perceptions on usefulness and implementation. We did not comment on this strength in the Discussion, to leave room to discuss survey results integrated with interview results.

2. Survey reporting checklist

https://www.equator-network.org/reporting-guidelines/good-practice-in-the-conduct-and-reporting-of-survey-research/

Kelley et al. 2003

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Reporting

When reporting survey research, it is essential that a number of key points are covered (though the length and depth of reporting will be dependent upon journal style). These key points are presented as a 'checklist' below:

1. Explain the purpose or aim of the research, with the explicit identification of the research question.

   Aim (abstract; page 3 line 8-10): To evaluate practitioners' perceptions of acceptability and possible use of a QPL [question prompt list] about palliative and end-of-life care in dementia.

   Question (last sentence of introduction; page 4 line 31-33): what are perceptions on acceptability and possible use of the QPL among physicians involved with advance care planning in dementia care?

2. Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (the literature review).

   In brief (Introduction, page 4):

-in practice there are numerous barriers to early ACP initiation (references to systematic reviews)
-available booklets provide sensitive information but may not engage patient with dementia and family enough
-QPL can empower people to ask their physician questions and research has shown benefits for patients in oncology (reference to systematic review) and palliative care (reference to Clayton et al.; see also second of two bullet points "What is already known on the topic")

3. Describe in (proportionate) detail how the research was done.

a. State the chosen research method or methods, and justify why this method was chosen.

First paragraph of Methods (page 5, line 6-10): We performed a mixed-methods evaluation study of a QPL among practitioners because … We used validated quantitative instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

b. Describe the research tool. If an existing tool is used, briefly state its psychometric properties and provide references to the original development work. If a new tool is used, you should include an entire section describing the steps undertaken to develop and test the tool, including results of psychometric testing.

For the primary outcome, acceptability of the QPL, we referred to an available scale that in turn was developed based on generic decision aid evaluation methodology. We included the full scale in a Supplementary file (referred to page 5, line 38), showing how we rephrased to refer to a QPL instead of a booklet. The Supplementary file also shows any missing values of items (2 to 4), also as an indicator of feasibility. Properties of the acceptability scale are described in the articles on booklet evaluation we refer to, and we added Cronbach's alpha (0.94) for the current study as a Footnote to Table 2 (page 19, line 36) and to the Table in the Supplement. Regarding the usefulness and quality of the contents as secondary outcomes, we referred to a list of barriers developed based on previous work (references included; page 5, line 41-44) and we used a simple 0-10 usefulness scale. For the quality of the contents, we used the same items based on

booklet and generic decision aid methodology (with references; page 5, line 39-40).

c. Describe how the sample was selected and how data were collected, including:

   i. How were potential subjects identified?

      Methods: "The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice." (page 5, line 21-23)

   ii. How many and what type of attempts were made to contact subjects?

      Methods: there was "one general reminder via e-mail" (page 5, line 31)

   iii. Who approached potential subjects?

      The academic medical center granted access to the research team to send the survey. (page 5, line 21-23)

   iv. Where were potential subjects approached?

      General practitioners and elderly care physicians. (page 5, line 21-23)

   v. How was informed consent obtained?

      Methods: "Completing and returning the survey on the QPL served as informed consent for this study" (page 5, line 30-31)

   vi. How many agreed to participate?

      Results: 66 of (160 * 2) copies of the surveys were returned. (page 7, line 7-9)

   vii. How did those who agreed differ from those who did not agree?

      Because of privacy regulation, we could not perform a non-response analysis. The response rate did not differ between the two academic centers (21% and 20%). We choose to not include this detail to leave room for reporting on the qualitative interviews.

   viii. What was the response rate?

      21% (66/160*2) (page 7, line 7-9)

4. Describe and justify the methods and tests used for data analysis.

   Methods: we used descriptive statistics to present the results and compared subgroups with appropriate tests (page 5, line 52-53). Footnotes to the Table specify we used the hierarchical gamma test, Chi-square, and t-tests to compare

characteristics between GPs and elderly care physicians, and adjusted for physician characteristics for continuous outcomes with linear regression.

5. Present the results of the research. The results section should be clear, factual, and concise.

   We used two headings for the survey results: “Survey participants,” and “Survey-acceptability and use” (page 7). Similarly, we used two heading for the interview results: “Interviewees” and “Interview themes” (page 7). The final Results paragraph for the mixed-methods study is called “Integration of survey and interview results” (page 10).

6. Interpret and discuss the findings. This ‘discussion’ section should not simply reiterate results; it should provide the author’s critical reflection upon both the results and the processes of data collection. The discussion should assess how well the study met the research question, should describe the problems encountered in the research, and should honestly judge the limitations of the work.

   To comply with this requirement, we used the structured Discussion with headings “Main findings and interpretation,” “Strengths and limitations of the study,” and “What this study adds: implications and conclusions” (page 12). The study showed practitioners’ perceptions on acceptability and possible use of the QPL.

7. Present conclusions and recommendations.

   In brief, the practitioners generally found the QPL acceptable and rated the contents as good, yet they had many concerns on how to use it in practice, and some were concerned they could not answer the questions that patient and family may select and ask them. To move forward, practitioners need training and patient and family should be able to access the question prompt list themselves to circumvent possible gatekeeping.

The researcher needs to tailor the research report to meet:

- The expectations of the specific audience for whom the work is being written.

  We assumed a basic understanding of palliative care and advance care planning.

- The conventions that operate at a general level with respect to the production of reports on research in the social sciences.

  We report for a health care audience, policy makers and researchers interested in palliative care in dementia, advance care planning, and promoting conversations about death and dying.

BMJ Open

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

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For peer review only

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

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ABSTRACT

Objectives In oncology and palliative care, patient question prompt lists (QPLs) with sample questions for patient and family increased patients' involvement in decision making and improved outcomes if physicians actively endorsed asking questions. Therefore, we aim to evaluate practitioners' perceptions of acceptability and possible use of a QPL about palliative and end-of-life care in dementia.

Methods Mixed-methods evaluation study of a QPL developed with family caregivers and experts comprising a survey and interviews with practitioners. The practitioners were mostly general practitioners and elderly care physicians and recruited from two academic medical training centres in the Netherlands. The main survey outcome was acceptability measured with a 15-75 acceptability scale with ≥45 meaning "acceptable."

Results The survey response rate was 21% (66/320). The QPL was regarded as acceptable (mean 51, SD 10) but 64% felt it was too long. Thirty-five percent would want training to be able to answer the questions. Those who felt unable to answer (31%) found the QPL less acceptable (mean 46 vs. 54 for others; $p=0.015$). We identified three themes from nine interviews: (1) enhancing conversations through discussing difficult topics, (2) pro-actively engaging in end-of-life conversations and (3) possible implementation.

Conclusion Acceptability of the QPL was adequate, but physicians feeling confident to be able to address questions about end-of-life care is crucial when implementing it in practice, and may require training. To facilitate discussions of advance care planning and palliative care, families and persons with dementia should also be empowered to access the QPL themselves.

Keywords

Advance care planning, dementia, end of life care, shared decision making, decision aids

Strengths and limitations of this study

- We employed a mixed-methods design which allowed for integration of relevant secondary analyses of the quantitative data based on a question that emerged from the qualitative interviews.
- We did not assess perceptions of persons with dementia and family; we assessed perceptions of physicians only.
- The responding physicians may represent a sample with an above average interest in the topic of advance care planning or in dementia care.

INTRODUCTION

In long-term care, an ongoing dialogue between patient, family (caregivers) and the healthcare team in the form of advance care planning (ACP) can improve the quality of end-of-life care.[1-3] With dementia, timely ACP is crucial to enable persons to participate because of the cognitive decline and rather unpredictable disease trajectory.[3-5]

However, in practice there are numerous barriers to early ACP initiation. Some people do not want to talk about the future, but rather live one day at a time.[5,6] Moreover, healthcare professionals (practitioners) may struggle with moral dilemmas around, for example, best interest judgements.[7] Practitioners may also hold very different beliefs regarding when to best initiate the ACP discussion,[6,8,9] which may relate to different conceptualisations of what ACP entails.[10] Interventions to increase ACP often address either the practitioner or the family.[11-13]

Several decision aids have been developed to enhance ACP and improve the quality of decision making including a family booklet for dementia at the end of life that was found acceptable and useful by physicians, nurses and family in multiple countries.[14-16] However, the booklet only contains information, while explicit example questions provided by a question prompt list (QPL) can empower people to ask questions that are specific to their individual information needs. QPLs may also prompt patient and family to ask about sensitive topics that they might not otherwise think of or feel comfortable with. Research in oncology and palliative care indicates that QPLs increased question asking during medical consultations especially if physicians also encourage patients to use the QPL, enhance participation in decision making and sometimes improve psychological outcomes such as anxiety in a longer term.[17,18]

Similarly, a QPL specifically for persons with dementia and their family might alter the dynamics of discussions on end-of-life care. Therefore, we developed a QPL for persons with dementia and their family and addressed the research question of what are perceptions on acceptability and possible use of the QPL among practitioners involved with advance care planning in dementia care.

METHODS

We performed a mixed-methods evaluation study of a QPL among practitioners because their perceptions are crucial for implementation strategies in practice and preparing for trials.[19] We used validated instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

Patient and public involvement (in QPL development)

In 2018, a multidisciplinary team drafted an initial QPL in the form of a booklet with information and sample questions. The QPL's goals were to: help elicit perceptions and beliefs about the end of life, help think about what to ask professionals, encourage conversations and facilitate decision making. The contents was based on the earlier booklet,[14-16] an Australian QPL for persons with dementia and their family[20] and a Canadian QPL for family of nursing home residents with dementia.[21] Content about euthanasia was specific for the Netherlands as in the earlier booklet.[22] In the Netherlands, the general public finds euthanasia in dementia more often acceptable than physicians do and there are many questions around usefulness and acceptability of a euthanasia living will.[23,24]

The first draft of the QPL was presented to two panels of older people affiliated with the academic centers, many of whom had experience with dementia in various roles and experts in grief and bereavement, spiritual caregiving and ethics, cultural issues, layout, and lay language use (a professional language center reducing the level to B1).[25] We provided the three goals we wanted to achieve with the QPL and solicited for any feedback. We collated and discussed their feedback which was used to improve the QPL, in particular the information provided, simplifying it and addressing the reader more personally and empathically (Box 1). The 2018 version comprised 76 questions in total, 2 to 11 sample questions per topic (Supplement 1).

Evaluation procedures

The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice. These professions are responsible for primary care for persons with dementia, with elderly care physicians usually being on the staff of a nursing home, or also practicing in the community in collaboration with GPs.[26] Further, we thus sampled for large variation in experience and a population of practitioners who may be early adopters.

The QPL and survey were distributed on paper during meetings at educational centres or sent via postal mail in June 2018. We provided two copies of each, for the physician themselves and for a colleague. Completing and returning the survey on the QPL served as informed consent for the study's survey part. We sent one general reminder via e-mail. We offered an optional accredited (1-hour) educational exercise that involved developing a strategy for future implementation of the QPL in practice with feedback from the researchers.

Survey

The questionnaire examined physician's perception of the acceptability of the QPL (primary outcome), the usefulness and quality of contents (secondary outcomes) and possible barriers to implementation in practice. We assessed acceptability with a slightly adapted validated 15-item scale of statements[15,16] (Supplement 2) based on acceptability decision aid evaluation methodology.[27] Usefulness and quality of content was assessed by asking physicians to rate the contents[15,16] and statements of anticipated benefits based on the QPL's goals. Barriers to optimal use of the QPL were assessed based on earlier questionnaires on barriers to symptom relief in dementia and perceptions of ACP among general practitioners and elderly care physicians.[19,27-30]

All items were rated on 1 to 5-point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree") except for quality of content for which extremes were labelled ''poor'' and ''excellent."[16] The 15 acceptability items were summed to calculate an acceptability score ranging 15-75 points. We regarded (mean) total scores of 45 (mean item score 3) and higher as acceptable, and scores of 60 and higher as highly acceptable.[16] The survey data were managed in Castor EDC (2018) (Castor, Amsterdam) and for analysis exported to SPSS version 23 (2018) (SPSS Corp. Inc., Chicago, IL). We used descriptive statistics to present the results and we compared professions with appropriate tests (in footnote to tables).

Interviews

In line with an explanatory sequential mixed-methods design,[31] at the end of the survey, physicians could indicate whether they were willing to be approached for an additional qualitative interview by providing their contact details. We selected physicians for an interview based on a particularly high or low acceptability scores (purposive sampling). We aimed to perform about 10 to 12 individual interviews for probable saturation for our specific aim.[32,33] Before the interview, participants signed an informed consent form modelled after the template of the Dutch Central Committee on Research Involving Human Subjects (CCMO). Interviewees were offered a gift card of 30 euros. Semi-structured face-to-face interviews (7) were held by SH-male Master student working in nursing homes, JTS-female PhD epidemiologist (double interview) and female MD-researcher AK who had not been involved in QPL development (one, and one with SH).

The interviews were guided by an interview guide (Supplement 3) that contained key questions addressing the participant's views on the QPL, their personal approach to end-of-life conversations and considerations regarding possible implementation of the QPL. If relevant, specific questions were asked based on reviewing participant's survey responses in an open manner. Not all questions were asked and in later interviews, we asked more about personal strategies employed to introduce ACP triggered by discussing both the QPL as a concrete tool and end-of-life conversations more generally. All interviews were audio-recorded, and SH transcribed verbatim while guaranteeing confidentiality through procedures consistent with the GDPR. Interview data were managed and coded in Atlas.ti (version 7.5.18, 2012). We used inductive thematic analyses to analyse the interviews along with open-ended items of the survey (whether they agreed with the QPL's contents and format, any missing information or questions, any other comments). The three researchers who conducted the interviews, coded the first interviews and discussed and agreed upon the coding (188 codes and 11 interrelated subthemes available at request). We selected citations to represent and illustrate the themes consistent with good research practice.[34]

RESULTS

Survey participants

We approached all residents and supervisors (160) to participate, providing a copy of the questionnaire also for a colleague (i.e. 320 in total). Between June and December 2018, 66 (21%) were returned completed by 18 general practitioners including two general practice-based assistant practitioners and 46 elderly care physicians, one geriatrician and one geriatric nurse. The response rates of the Leiden (21%; 40/190) and Nijmegen center (20%; 26/130) were similar.

The majority (73%) of the participants were female, with a mean of 21 years' experience and over half (56%) cared for persons with dementia on a daily basis (table 1). Elderly care physicians were more likely to see persons daily (70% vs. 22%) and in more advanced stages of dementia (70% vs. 11%).

Survey–acceptability and possible use

Table 2 shows that the physicians judged the QPL as acceptable (mean acceptability score 51), however, with a high standard deviation (10), but there was no difference in acceptability score between GPs and elderly care physicians. Mean usefulness was 7.2 points on the 1–10 scale. The contents were mostly appreciated (mean quality 64 points, SD also 10; Supplement 2: most, care for relatives; least, the introduction about illness and care). Although few participants thought there were too many example questions (9%), 64% of the physicians found the QPL too long and 59% felt there was too much information.

The survey items on barriers and benefits did not show clear patterns, but 49% believed that persons in early stages of dementia could not use the QPL themselves (table 3). When available, most (59%) would give the QPL to the individual and their family and 26% to family only (14% would not give it to anyone). Most (56%) physicians anticipated the QPL will increase provision of palliative care, and 21% anticipated more requests to hasten death, which was concerning to about half of them (10% overall).

Table 4 shows that almost one-third (31%) of the physicians found they were unable to answer all example questions in the QPL adequately, despite the instruction with this item recognizing that for some questions, there is no, or no certain answer. Overall one-third of participants (35%) felt a need for training to answer the QPL's example questions; more often GPs than elderly care physicians (72% vs. 20%).

Interviewees

We invited five physicians with a high acceptability score (55-64), four others (score 24, 35 or no score but negative comments), and one with combined GP/elderly care background and all were interviewed at their workplace July-November 2018. Of the physicians (seven female, three male), three were trainees, four were supervisors; seven were elderly care physicians, one GP, one both, and one geriatrician. Eight were individual interviews, and we interviewed one dyad of supervisor and trainee. The interviews lasted on average 46 (SD 15) minutes.

Interview themes

We identified three major themes with the last three interviews (with highly critical elderly care physicians and the only geriatrician) pointing to saturation: (1) enhancing conversations through discussing difficult topics; (2) pro-actively engaging in end-of-life discussions in practice; and (3) considering possible implementation of the QPL.

(1) Enhancing conversations through discussing difficult topics

The physicians who rated the QPL as highly acceptable anticipated added value in end-of-life discussions, mainly to enhance the conversations. They expected that it would encourage the person and family to consider questions about dementia and care options:

> *"I think if the patient has it [the question prompt list], he or she will have some questions of his/her own before we have this conversation. So I think the doctor will be triggered and get more questions from the client side, yes." (elderly care physician in training 2, positive; citation a)*

Moreover, they felt that having an overview of topics that could be discussed would be helpful for themselves:

> *"I was pleasantly surprised because I think something like this is very useful. It actually provided a very good guide for the things you actually want to know from a patient." (elderly care physician-in training 1, positive; citation b)*

On the other hand, both physicians with a high and a low acceptability score were concerned about possible information overload, leading to confusion, or even fear:

> *"I'm afraid that because of its extensiveness, it won't be used that much and that would be a pity because the subjects that are raised are all very relevant." (elderly care physician and GP 6, positive; citation c)*
>
> *"Yes, I think that because of the amount of information, people will start thinking and can also get, well, confused." (elderly care physician in training 1, positive; citation d)*
>
> *"Because for example, a feeding tube is also touched upon here, but it is mentioned very briefly and then: well, that often doesn't help. I think it can also sometimes cause people to get confused if there is information that is perhaps a little too concise and consequently raises expectations of: gosh, it might be worthwhile; that it can also generate unrest in such a conversation." (elderly care physician-in training 8, negative; citation e)*
>
> *"But sometimes you... Maybe it's a good thing not to know things and not to ask about them (elderly care physician supervisor 7, negative; citation f)*

Another issue was whether terms such as "care goals" and "advance care planning", although explained in the QPL, should be used at all.

> *"...you keep hammering on care goals, what's your care goal. That is our problem, we want to label everything a goal or a problem, why should you call it a care goal, you could say: we would like to know, what is important for you to have a good life." (elderly care physician 4, supervisor, negative; citation g)*

Some physicians' had concerns regarding specific questions in the QPL such as those about life expectancy, progression of the disease over time, and religious matters. While participants felt these questions would be meaningful for the person, some physicians felt they had no clear answers, and they reasoned that this might result in persons with dementia and family becoming more anxious.

> *"A slightly more critical look is needed at some of the questions being asked, questions that make me wonder, what doctor can answer that." (elderly care physician 4, supervisor, negative; citation h)*

(2) Pro-actively engaging in end-of-life discussions in practice

The physicians would normally employ various approaches in initiating conversations about the end of life. Most mentioned they start with asking general non-threatening questions, and through the answers, consider whether the person with dementia or family is ready to further discuss more sensitive or confrontational topics at that time, or to postpone the discussion:

> *"You explore: what is a person's attitude to life and what can the person handle and in that way you try, you basically ask questions. And that's how you try to find a starting point (...) you are very careful, you don't go in like 'wham' " (elderly care physician-in training 1, positive; citation i)*

However, some physicians take a more pro-active yet confrontational approach with specific examples that people can imagine and understand easily:

> *"You're actually describing the situations, is that what you'd want in that case? For example, resuscitation, because that is also a difficult concept to explain: we will bring you back from the dead, actually you are already dead, but then we bring you back from the dead, but that can cause a lot of brain damage. Then they say "brain damage, why?"; we often use the term [living like a] 'vegetable' [in Dutch: 'kasplant'], that's an association." (elderly care physician 3, positive; citation j)*

> *"'Vegetable'[...] is very easily accepted as a word. It is clear to 99% of people."(elderly care physician 5, supervisor, positive; citation k)*

The most important factor in how to approach the person and family was their educational level, according to the interviewees, which was corroborated by comments to open-ended survey items. The more highly educated would be equipped for the conversation through a better understanding of the subject, where others would need more guidance and explanation. The physicians believed those with a lower education level may hold misconceptions regarding treatment and care and have more trouble processing the QPL.

> *"That depends. Around here we have quite a few highly educated people, so shared decision making is very doable. People are well-informed, they read up [on the topic]." (elderly care physician 3, positive; citation l)*

> *"Yes, and I think it can be very confusing for some people. But maybe that's with the poorly educated population I occasionally work with in mind, that this is a lot and difficult to grasp. [...] then you ask do you want to be resuscitated and people say yes, but they have no idea... They think if they say no, they'll get an injection tomorrow and that's it, those are people's perceptions sometimes". (elderly care physician-in training 1, positive; citation m, continued citation d).*

Apart from educational level, some participants mentioned the relevance of the setting in which the QPL conversation takes place. Nursing home residents with dementia and family may have had more opportunity to think about the end of life than persons (still) living in a community setting, regarding specific treatment and values and preferences relating to care. Therefore, the more sensitive topics regarding end of life may be easier to discuss:

> *"People in nursing homes have already faced much more dependency, so most of them have thought about it. In primary healthcare this is much more difficult, because people who are never ill think they will live forever, and then suddenly they are confronted with it". (elderly care physician 4, supervisor, negative; citation n)*

A good connection based on trust was regarded as an important factor to improve the quality of end-of-life discussions:

> *"..you get to know your client over a long period of time, you get to know the family over a long period of time, the care staff get to know someone over a long period of time, because that's also important... yes, these are people you know well, that's the advantage of being a GP, that you have a connection with a person". (GP 1, negative; citation o)*

(3) Considering possible implementation of the QPL
The interviewees selected for being positive about the QPL would like to the QPL used by physicians and nurse practitioners. Some physicians would want the QPL to be used as early as possible in general practice, with the general practice-based assistant practitioner being the right person to not only give the QPL to patients and families, but also start the conversation about possible future care options, supervised by the GP:

> *"Maybe this is not a job for the GP? Maybe for the general practice-based assistant practitioner. They often have more time and they know the people better, are more accessible and they can probably explain things in everyday language. " (elderly care physician 3, positive; citation p)*

The physicians who found the QPL less acceptable envisioned barriers to implementation and were not considering possible solutions. They mentioned lack of time if there would be many questions or stated that the format is not viable:

> *"I think that you can have a really good conversation with two or three questions, and that you have to be careful it doesn't turn into an hour of conversation, because we simply don't have that kind of time. (GP 1, negative; citation q)*
>
> *"I think it [the length of the list] is such a major drawback that I think, I don't know ……. that I also find it hard to figure out how to make it work." (elderly care physician 4, supervisor, negative; citation r)*

Integration of survey and interview results
Some interviewees expressed concerns about not being able to provide good, or specific answers to certain questions in the QPL. For example, they mentioned not being able to answer a question on life expectancy and the progression of the disease. This emerged as an important issue that could affect adoption of the QPL. Therefore, based on the interview findings, we

hypothesized that lack of self-efficacy or fear of not having the answer might be a decisive factor in using or appreciating the QPL. We then did a post-hoc secondary analysis of the survey data and found that the average acceptability score of those who felt they could not give answers to all example questions was lower, compared to those who felt they could (46 vs. 54; p=0.015), with a higher standard deviation (13 vs. 8).

DISCUSSION

Main findings and interpretation

This is the first study to assess practitioners' acceptability and views on a QPL about end-of-life issues specifically designed for persons living with dementia and their families. Physicians (and a few other practitioners) who provide long-term and end-of-life care for persons with dementia rated the QPL to be acceptable and the quality of the contents as good. However, many found the amount of information problematic, and were concerned it could be overwhelming. Importantly, the physicians were divided about whether the QPL would be too difficult for use by persons with dementia themselves due to the cognitive impairment associated with dementia, and they also differed in the extent to which they would confront persons with dementia and family with sensitive or difficult issues about end of life. Some physicians felt it would be better to ask initial screening questions to probe the persons' readiness to discuss these issues before providing a QPL.

When comparing the physician acceptability score of the QPL to earlier research in which we evaluated a family booklet with information only about dementia at the end of life, the mean acceptability score for the QPL was lower (56 versus 51, respectively).[16] The QPL also targets persons with dementia themselves in a community setting, rather than family only. In the secondary analysis prompted by the interview findings, we found lower acceptability of the QPL by physicians who were concerned about their ability to answer questions in the QPL adequately. The physicians, although associated with an academic center and probably with an interest in the topic, may not feel comfortable to discuss some topics included in the QPL, perhaps also including around hastening death.[24]

Strengths and limitations of the study

The mixed-methods design allowed for a richer understanding of the quantitative survey data, in particular regarding barriers and concerns, and also provided an efficient iterative approach of analysing the quantitative data based on a question that emerged prominently from the qualitative interviews, additional to interviewing about completed surveys. The response to the survey was low but within the range of responses commonly observed for physician surveys, while trends point to declining response rates.[35-37] The concerns we identified from respondents, who were probably interested physicians connected with an academic center, may not be generalizable and may underestimate concerns in physicians caring for persons with dementia.

We did not assess the acceptability of the QPL by persons living with dementia and their families, and further research in this area is warranted. In other research, on a lengthy QPL in palliative care more generally, despite its length, patients and professionals would not drop any topic or question for choice.[38] Indeed, the physicians in the evaluation study suggested adding questions rather than deleting any, the revised version including 7 more questions and new, practical tips (Supplement 1). Further research should determine various modes of delivery, for example, deciding together in advance to limit the conversation to one or two topics.

What this study adds: implications and conclusions

Training is required to increase confidence of physicians to be able to address questions from family and persons with dementia about end-of-life care when implementing a QPL in practice. Training should focus on increasing self-efficacy in addressing difficult questions, and for this, training of actual conversations with actors or e-simulated patients may be effective.[39,40] This may generalize to other countries as other work has shown that many Dutch elderly care physicians but also many GPs in Northern Ireland are reluctant to initiate ACP with people in the early stages of dementia.[9] Shared decision making is worthwhile in situations where there is choice based on individual preferences.[41] Persons with dementia may hold a neutral or negative stance regarding ACP[3,13] and a first extra step, before starting a decision-making process with a person with dementia is to agree on the necessity to make a decision.[42] Therefore, a prudent approach, probing readiness to engage in ACP, as adopted by some physicians, makes sense. On the other hand, persons with dementia and family may need proactive encouragement and support from physicians or other practitioners to discuss ACP so that they don't miss out on the opportunity to participate in decisions about their future care. This can help empower persons with dementia and avoid regret and crisis later on for family when making difficult decisions on behalf of the person with dementia.[43] Further research should include evaluations of use in practice, including formal evaluations from persons with dementia and family.

A QPL may help persons with dementia and family to select exactly the topics they find relevant at that time, and this could also inform the practitioner about readiness to discuss end of life. They should be offered choice from a collection of structured sample questions, but if overwhelming, they may decide in advance with their professional caregivers which topic to discuss (first). QPLs have the potential to alter the dynamics of conversations and empower persons with dementia in encounters with professional caregivers. These are worthwhile endeavours for persons with dementia who essentially would like to be part of society, appreciated, and their identity recognized.[44,45] Further, shared decision-making about goals for future care as the persons' dementia progresses is important because not all goals of care can be achieved, and there may also be trade-offs between goals for the family and the person with dementia.[41,45-47] To empower persons with dementia and their family, implementation strategies should also circumvent possible gatekeeping to include free access so they can ask practitioners and thus take initiative to start conversations.

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Author contributions

The author's responsibilities were as follows:
Development of the question prompt list: JTS, CCMJ, MMG, JMC, GNT, RTCMK, YML
Project design: JTS, SH, WPA, MMG
Data collection: JTS, SH
Paper writing: JTS, SH
Critique and review of the final manuscript: all.

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Conflict of interest disclosure

The Department advised on research review design and data collection. There was no influence on study analysis, decision to publish or preparation of the manuscript. The author(s) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Patient consent for publication

Not applicable.

Patient and public involvement

Patient representatives were involved in question prompt list development. Patients were not involved in the practitioners' evaluation study.

Patient consent for publication

Not applicable.

Data sharing statement

The de-identified survey participant data may be requested from the corresponding author upon reasonable request. are available upon reasonable request. Interview recordings and transcripts are not available as they might render physicians recognizable to insiders.

Ethics approval

As a tool evaluation study among practitioners, this project did not involve patients or patient data. Therefore, ethics committee approval was not required. The protocol was approved by the Scientific Committee of the Department of Public Health and Primary Care of Leiden University Medical Center, the Netherlands, number WC-2018-10.

Supplemental material

1. Question prompt list "Talking about the later stages of life in dementia" sample questions, tips and "things to think about"
2. Interview guide
3. Tables with individual items and item scores

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Box 1 Overview of topics covered in the question prompt list (QPL)*

Talking about the later stages of life in dementia:
Information and example questions
for people with dementia and their relatives

Part 1: About illness and care

- Dementia and changes in health
- Care goals, palliative care and end-of-life decisions

Part 2: About treatment and choices

- Decisions about treatments and agreements [advance care planning]
- Treatment and care for common problems
    - Eating and drinking and swallowing problems
    - Pneumonia and other infections
    - Shortness of breath
    - Pain and feeling uncomfortable
    - Restlessness and challenging behaviour / behavioural problems
    - (Incontinence [in later version only])
    - Depression, anxiety and lack of initiative Feelings of loss and existential questions
    - Other illnesses and what these may require
- End-of-life decisions regarding prolonging or shortening life Choice of location of care and change of living environment

Part 3: About and for the relative

- Care for you as a relative
- The dying phase and after death

* Topics of the 2018 evaluation version. For adaptations in response to the evaluation, see Supplement 1

Table 1 Physicians' characteristics and dementia care practice patterns (n=66)*

Female sex, %	73
Age, mean (SD)	48 (11)
Experience as a physician, mean (SD)	21 (11)
Resident trainee, %	17
Supervisor,%	53
Care for dementia patients; frequency, %	
at least daily	56
at least weekly	34
at least monthly	6
at least every 2 months	3
at least every 6 months	0
< every 6 months	0
Care for dementia patients; stage of disease, %	
mostly early stage (mild dementia)	8
both early and late (moderate or advanced) stage, about equally distributed	39
mostly late (moderate or advanced) stage	53
Estimation of dementia patients dying in the past year, %	
0	2
1 – 4	27
5 – 9	25
10 – 19	34
20 or more	13

SD: standard deviation; GP: general practitioner

Significant differences ($p<0.05$) between GPs and elderly care practitioners were not observed for sex, trainee or supervisor status (Chi-square), age and experience (t-test). With the hierarchical gamma test there were differences between the last three items; elderly care physicians cared for dementia patients more frequently (e.g. daily 70% vs. 22%), cared for patients in later stages (e.g. advanced stage 70% vs. 11%) and more patients with dementia died in their practice in the past year (e.g. 20 or more 17% vs. 0).

[*] Two of 66 respondents missed characteristics other than sex and age. GP (n=18) included two general practice-based assistant practitioners (often nurses or social workers, referred in the Netherlands as "praktijkondersteuner huisarts", POH). Elderly care practitioners (n=48) included 46 elderly care physicians, a geriatrician and a geriatric nurse. Experience refers to experience as a physician and was missing for the general practice-based assistant practitioners (POH) and the nurse.

Table 2 Evaluation of acceptability and the contents of the question prompt list (n=66)

Acceptability score, mean (SD)[*]	51 (10)
Usefulness for persons with dementia and family, mean (SD)[†]	7.2 (1.7)
Quality of the content of the question prompt list, mean (SD)[‡]	64 (10)
Length, %	
too long	64
too short	2
just right	34
Amount of information, %	
too much	59
too little	0
just right	41
Balance in proportions of information versus example questions, %	
too much information	20
too many example questions	9
just right	70

SD: standard deviation

No differences (p<0.05, t-test or Chi-square as appropriate) were observed between GPs and elderly care practitioners for any of the items, including after adjustment for sex, experience and stage of dementia cared for most (first three outcome items, linear regression). Missing values: 2, except for usefulness, 1.

[*] Theoretical range score: 15 – 75. Cronbach's alpha in this sample was 0.94. The acceptability score covers: informing families, supporting decision making, communication with families, satisfaction with care, use in practice, and use in training (see Supplement 2, tables S1 and S2 for individual items and item scores).

[†] Theoretical range score: 0 – 10.

[‡] Theoretical range score: 16 – 80 (see Supplement 2, table S3 for item scores).

Table 3 Barriers, benefits and views about use, % (n=66)

Range of perceived barrier scores (means and SDs 5 items)*	2.4-2.9 (0.89-1.1)
Goals and anticipated benefits of use (means and SDs 7 items)*	3.1-3.9 (0.79-0.94)
Do you think dementia patients can use the QPL themselves?	
yes, but only in early stages of the disease (MMSE>20)	49
yes, in early but also in moderate stages of the disease (MMSE>10)	2
no, (almost) no one with dementia can	49
When the QPL is available, I will give it to…	
patients and relatives	59
relatives	26
I will not give the QPL to anyone	14
QPL will lead to earlier or more frequent providing of palliative care	
yes	56
no	44
This QPL will lead to more requests to hasten death	
yes, and I do not have any objection	11
yes, and I object to that	10
no	79

SD: standard deviation; QPL: question prompt list; MMSE: Mini-Mental State Examination.

* Items are shown in Supplement 2, Tables S4 and S5. Agreement is scaled on the same scale as the acceptability scale, from 1 to 5 point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree''). No differences (p<0.05, Chi-square or t-test as appropriate) were observed between GPs and elderly care physicians for any of the items, except for the barrier item "The hectic pace of practice will prevent me from using the question prompt list" (higher barrier score for GPs). Missing values: use themselves 1, give it to 2, palliative care 2, hasten death 3.

Table 4 Confidence in using the question prompt list (n=66)

I am able to answer all the questions asked in the question prompt list, %[*]	
yes	69
no	31
Need for training, % confirmed	35
Training on subject / content	19
Training in conversation techniques	5
Training on subject / content and conversation techniques	11

Differences (Chi-square) were observed between GPs and elderly care practitioners (first item, p=0.015, unable to answer, elderly care physicians 22% vs. GPs 56%; second item, p=0.001, any training elderly care physicians 20% vs. GPs 72%).

[*] The item included this explanation: “this does not mean that you have a ready-made answer to all questions, but that you think you can respond adequately to all questions”

Supplement 1. Question prompt list “Talking about the later stages of life in dementia” sample questions, tips and “things to think about”

- Translated from Dutch to English by a professional bi-lingual translator. The Dutch question prompt list additionally presents brief information on each of the topics.
- The pilot version used in the evaluation study with practitioners in 2018 was improved in 2019 based on the evaluation, and again with input from family caregivers and professional caregivers in 2020. Where versions differ, the 2018 text is presented in the lightest grey shade, 2019 in dark grey and 2020 text and unchanged text is presented in black [explanation added after the first questions].
- Changes are indicated with grey mark. The 2018 version included 76 questions. The 2020 and 2019 versions comprise 83 similar questions. After the evaluated 2018 version, various tips and nine questions were added (highlighted blue), one question was deleted, and two were combined in a single question (both highlighted green).
- The 2020 version also offers the sample questions as a separate list to facilitate preparing for a conversation with a health care provider.
- The 2020 question prompt list and separate list are available in Dutch from: https://www.lumc.nl/org/unc-zh/onderzoek/Palliatievezorgbijdementie/Ontwikkelengesprekshulpdementie/
- Reference: van der Steen JT, Juffermans CCM, Gilissen F, van der Linden YM, Koopmans RTCM. 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 relatives]. 2nd Edition. Leiden, The Netherlands: LUMC, 2020.

Talking about the later stages of life in dementia:

information and example questions
for people with dementia and their relatives
timely information and example questions
for people with dementia and their relatives
timely information and example questions for people with dementia and their relatives

Part 1 About illness and care
Part 1 About illness and care in general
Part 1 About illness and care in general
1. Dementia and changes in health
2. Care goals, palliative care and end-of-life decisions
Part 2 About treatments and choices
Part 2 About treatments and choices regarding health issues
Part 2 About treatments and choices regarding health issues
3. Decisions about treatments and agreements [advance care planning]
4. Treatment and care for common problems
5. Choice of location of care and change of living environment
5. Choice of location of care and change of living environment
6. Choice of location of care and change of living environment
6. End-of-life decisions regarding prolonging or shortening life
6. Resuscitation and euthanasia
5. Resuscitation and euthanasia

Part 3 About and for the relative
Part 3 The relative
Part 3 The relative
7. Care for you as a relative
8. The dying phase and after death
8. The dying phase and the period after death
8. The dying phase and the period after death

Tips

✓ There are many questions you could put to your health care professional.
If you have difficulty choosing a question at this point, you could start off with this one:
In your opinion, what is important for us to know about care now and in the future?

✓ There are many questions you could put to your health care professional.
If you have difficulty choosing a question at this point, you could start off with this one:
In your opinion, what is important for us to know about care now and in the future?

✓ People who have experience with dementia often say that it is important to start thinking in advance about decisions and support that will be needed in the future. This is in part so you can call in assistance from health care providers on time.

✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.

✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.

✓ Please don’t hesitate to ask your care provider questions. Asking questions or expressing concerns may provide reassurance or clarification [of uncertainties].

1. Dementia and changes in health

- *Can you tell me more about the type of dementia I have? [unchanged, same in 3 versions]*

- *What changes can I expect, and in particular: what changes in behaviour? [2018 version]*
- *What changes can be expected, and in particular: what changes in behaviour? [change in 2019]*
- *What changes can be expected, and in particular: what changes in behaviour? [2020 = 2019]*

- *How long does it take before the symptoms clearly become worse?*
- *How long does it usually take before the symptoms clearly become worse?*
- *How long does it usually take before the symptoms clearly become worse?*

- *Can you explain how I can recognize the final stage of life?*
- *How can I make sure I can do the things I enjoy for as long as possible?*
- *How can I make sure I can do the things I enjoy for as long as possible?*

- *How long do I have?*
- *Can you tell me how much time I have left?*
- *Can you tell me how much time I have left?*

2. Care goals, palliative care and end-of-life decisions

Things to think about

What is important to me in terms of the care?
What is important to me in terms of the care?
What is important to me when I am in need of care?

What should the care focus on (i.e. which 'care goal' am I looking for?)

- *Can you tell me what palliative care in dementia is?*
- *Can you tell me more about palliative care in dementia?*
- *Can you tell me more about palliative care in dementia?*

- *Which palliative care is available in my situation?*

- *Who can help me formulate care goals? [newly introduced in 2019 version]*
- *Who can help me formulate care goals? [same in 2020 version, etc.]*

- *Who can I contact about care and care goals in which type of situation, and how?*

- *What care, matching my care goal, is available for me?*

Tips

✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it. So do not let the term palliative care put you off when you are thinking about future care.
✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it.
✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. You can start preparing for 'later' now.

✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.
✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.
✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. If you and others know what the preferences and wishes are, this can bring peace now and later.

✓ Start talking about what is important for the present. This is often easy to start with.
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✓ Start talking about what is important for the present. This is often easier to start with.

✓ When the end of life is in sight, the importance of supporting and being there for each other, of feeling connected increases.

3. Decisions about treatments and agreements [advance care planning]

Things to think about

The most important question is: 'Which type of care best suits me or my loved one in this stage of life?'

- *I would like to talk about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*

- *What do you want to know about me, so you can provide quality care that suits me, now and later on?*

- *Is it possible to record my wishes regarding end-of-life care now, and if so: how?*

- *Which documents or plans are significant for me and what do I need to know about them?*

- *How confidential is the information about me? For example: who is allowed to know about my medical problems or behaviour problems?*

- *What is my role in the decision-making? And what is the role of my relatives?*

- *Who makes the decisions for me when I am no longer able to?*

- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that?*
- *How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*

- *What should I or my relative do in case we disagree with each other about a decision, or when we disagree with the doctor?*

- *Will I be able to change previously arranged agreements? And can my relatives do this when I am no longer able to?*

Tips

✓ It is important to make arrangements regarding finances, care and wellbeing at an early stage

✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.
✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.
✓ You and your relatives may have different principles and needs. It helps to identify these differences and discuss them together.

✓ What should always be central is the wish of the person with dementia even if it is an earlier wish. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.
✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.
✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia. In other words: ultimately determine the most suitable course of action at that particular point in time, taking into consideration the previously expressed wishes.

✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.
✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.

4. Treatment and care for common problems

Things to think about

Which are treatments I definitely do NOT want to undergo?

What (action) do I want (taken) when I am in serious pain?
What do I want when I am in serious pain?
What do I want when I am in serious pain?

When there is no solution for burdensome symptoms, do I want the doctor to lower my level of consciousness (‘*palliative sedation’*), so I am less aware of them?
When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of ‘*palliative sedation’*), so I am less aware of them?
When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of ‘*palliative sedation’*), so I am less aware of them?

Do I also want to record these things, for example with the general practitioner?

What can help me accept that I am no longer able to do things, or know things (with experiencing losses)?
What can help me accept that I am no longer able to do things, or know things (cope with loss)?
What can help me accept that I am no longer able to do things, or know things (cope with loss)?

Questions about restlessness and challenging behaviour / behaviour problems

- *Where does the behaviour come from, for example refusing care?*

- *How can the problem behaviour be reduced?*

- *What might help in case of unsafe behaviour?*
- *What might help in case of unsafe behaviour?*

- *Are medications necessary or can we try something else first?*

- *Which potentially helpful medications are available?*

- *What side effects can these medications have?*

- *Can the use of medications be stopped when the problem behaviour is gone?*

Questions about incontinence
Questions about incontinence

- *What can help in case of incontinence?*
- *What can help in case of incontinence?*

- *How do we ensure incontinence does not affect dignity?*
- *How do we ensure incontinence does not affect dignity?*

Questions about feelings of depression, anxiety and lack of initiative

- *How can you diminish my depression or alleviate my anxiety?*
- *How can you diminish depression or alleviate anxiety?*
- *How can you diminish depression or alleviate anxiety?*

- *Which psychosocial interventions are available?*

- *How can my need for contact be met when I am no longer able to make contact?*

Questions about feelings of loss and existential questions

- *How can I and my relatives adequately cope with experiences of loss?*
- *How do we cope adequately with experiences of loss?*
- *How do we cope adequately with experiences of loss?*

- *Which type of spiritual care (based on world view, spiritual beliefs, religion), is available that is suitable for me?*

- *How do we ensure that every day brings positive and meaningful experiences?*

Questions about eating and drinking problems [order of paragraphs revised after 2019 version, which until then started with this paragraph; the paragraph title includes swallowing problems]

- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do about my eating, drinking, or swallowing problems?*

- *How can I reduce the risk of choking on food and drink?* [bullet 1 and 2 reversed order after 2018 version]

- *Would soft or pureed food, or thickened liquids help?*

- *Would a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*

Questions about infections [the paragraph title is Pneumonia and other infections]

- *Can I prevent pneumonia? What would help reduce the risk of developing pneumonia?*

- *What can you do in case of pneumonia or bladder infection?*

- *Are antibiotics a good option in my case?*
- *Are antibiotics suitable in my case?*
- *Are antibiotics suitable in my case?*

- *What about going to the hospital?*
- *What about going to the hospital?*

- *What are the options to alleviate symptoms, to make me more comfortable?*
- *Can you alleviate symptoms and provide some comfort?*
- *Can you alleviate symptoms and provide some comfort?*

Questions about shortness of breath

- *What can you do for me when I am short of breath?*
- *What can you do in case of shortness of breath?*
- *What can you do in case of shortness of breath?*

- *Could I suffocate?*
- *Could I suffocate?*

- *Can morphine make me die sooner?*
- *Will morphine make me die sooner?*
- *Will morphine make me die sooner?*

Questions about pain and feeling uncomfortable

- *How will you determine whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*

- *What is the cause of the pain or discomfort?*
- *What is the cause of the pain or feeling uncomfortable?*
- *What is the cause of the pain or feeling uncomfortable?*

- *How can you alleviate the pain?*

- *Can I get addicted to morphine?*

Questions about other illnesses and what these may require

- *Which medications or medical checks will remain necessary for me?*

- *Do the different medications that I need work well together?*

- *How do the other illnesses affect the care in later stages or at the end of life?*

Tips

✓ Stay focused on the *care goal*, for example comfort or prolonging life

✓ Stay focused on the *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.

✓ Stay focused on the jointly determined *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.

✓ You can raise existential with your health care professional to find support, even if you are not religious.

✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.

✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.

5. Choice of location of care and change of living environment

Things to think about

How important is remaining at home for me when I compare it, for example, to my safety and the care that my relatives will then have to provide?

How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?

How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?

Are there any situations in which I would not want to be taken to hospital?

Are there any situations in which I would not want to be taken to hospital?

How do we look at the end of life, for example: where and who will be present?

Questions about choosing the care location and living environment

- *Do you think I will be able to stay at home, and what does this depend on?*

- *Which help is available so I can stay at home for as long as possible?*
- *Which help is available so I can stay at home for as long as possible?*

- *When is hospitalisation necessary?*
- *When could hospitalisation be necessary and when is it not a good idea?*
- *When could hospitalisation be necessary and when is it not a good idea?*

- *Can I be admitted to a hospice, or a nursing home or residential home?*
- *Can I be admitted to a hospice, or a nursing home?*
- *Can I be admitted to a hospice, or a nursing home?*

- *Which (other) options are there when staying at home is no longer possible?*

Questions for you when you change living environment and health care provider

- *How can I make sure that a change goes as smoothly as possible?*
- *What will be done to secure my safety in the new environment?*
- *Who works in the new environment and which health care professional does what?*
- *How often will I see the doctor here?*
- *How do I make sure that the health care professional gets to know me, my background and my preferences?*

Tips

✓ Accept help such as home help when necessary. Do not hesitate and please don’t wait too long.

✓ Accept help such as home help when necessary. Do not hesitate and please don’t wait too long.

✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.

✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.

✓ Ask your GP or acquaintances about good nursing homes. For example, not all small-scale nursing homes are equipped to provide good quality care.

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✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.

✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.

✓ To check whether a care facility like a nursing home or residential home is suitable for you, you could visit several to take in the atmosphere.

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✓ To check whether a care facility like a nursing home is suitable for you, you could visit several to take in the atmosphere.

✓ Investing in good contact with the new health care professionals, who need to get to know you and your relatives, is helpful.

✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.

✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.

✓ If you want to share it, a life book, for example [www.sprekenoververgeten.nl, [locally relevant example] can also help health care professionals get to know you.

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✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

6. Resuscitation and euthanasia [order of topics in 2020 version; in the 2018 and 2019 versions, this topic was placed before topic 5]

Things to think about

How do I feel about prolonging or shortening life?
How do I feel about prolonging or shortening my life?
How do I feel about prolonging or shortening my life?

Questions about resuscitation

- *What are advantages and disadvantages of resuscitation in my case?*
- *How can I document that I do not want to be resuscitated, or do not want resuscitation under certain circumstances?*

Questions about euthanasia

- *Is euthanasia an option in my situation?*
- *Is euthanasia an option at a later stage when I am no longer able to say that that is what I want?*
- *Can my relative or the doctor decide about euthanasia?*

- *Can my relative or the doctor decide about euthanasia?*

- *What possibilities are there to not prolong life in a more natural way?*

- *What possibilities are there to not prolong life in a more natural way?*

7. Care for you as a relative

Things to think about

How do I as the relative prepare for the deterioration of my loved one with dementia?

What takes most of my energy, and what can I do to improve that?

- *How can I best support my loved one who has dementia?*
- *What emotions am I likely to experience?*
- *Which support am I entitled to, and where can I get it?*
- *What can I do to prevent becoming overburdened?*
- *How do I recognise that I am overburdened?*

Tips

- ✓ Make sure that you as the relative always get enough rest. This benefits everyone.
- ✓ In addition to your GP, also inform your employer that you are a family caregiver, because this is something that needs to be taken into account.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ The Alzheimer’s telephone helpline lends a sympathetic ear and offers advice on coping with dementia. The Alzheimer's telephone helpline can be reached via the free phone number 0800 5088, 7 days a week from 9:00 am to 11:00 pm.

8. The dying phase and the period after death

Things to think about

What do we want the final moments to be like?

- *Can you warn me, as the relative, when death is near?*

- *Who can help me sit up with my dying loved one?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*

- *What if my loved one dies when I am not there?*

- *What spiritual or religious care is available?*
- *What spiritual or religious care is available to us?*
- *What spiritual or religious care is available to us?*

- *How does a person feel when he does not eat or drink anything?*

- *What can you do about the loud breathing due to mucous build-up?*

- *What should or can I, the relative, do at the moment of death and afterwards?*

- *Do I, as the relative, get an opportunity to speak to the doctor again?*

- *What aftercare is available to me?*

Tips

- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor how necessary it is, despite the emotions that may be present.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary, despite the emotions you may be experiencing. Remember that doctors are generally in ‘treatment-mode’.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary and what will happen if it is decided to discontinue treatment. Despite the emotions you may be experiencing. Remember that doctors are generally in ‘treatment-mode’.

- ✓ Many nursing homes provide relatives the opportunity to spend the night there during the final days. If this is what you want, ask about it on time.

Supplement 2. Acceptability and all scale item scores: Tables with individual items and item scores

S1. Acceptability scale adaptations (track changes) compared to acceptability scale for evaluation of a family booklet[12-14]

Use of the question prompt list in practice

This section is about your expectations when using the question prompt list in your practice. Could you please indicate the extent to which you agree or disagree with each statement? (*circle the number that applies*)

	strongly DISagree		→		**strongly agree**
a. This question prompt list~~booklet~~ will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	1	2	3	4	5
b. This question prompt list~~booklet~~ will result in them~~my patients' families~~ making more informed decisions	1	2	3	4	5
c. This question prompt list~~booklet~~ is suitable for helping ~~patients' familie~~to~~s~~ make value laden choices	1	2	3	4	5
d. Th~~e~~is question prompt list~~booklet~~ will positively affect my relationships with the person with dementia and the families	1	2	3	4	5
e. Thi~~se~~ question prompt list~~booklet~~ will improve the quality of discussions with ~~families~~ them	1	2	3	4	5
f. This question prompt list~~e booklet~~ will increase ~~family~~ satisfaction of the person with dementia and the family with my care	1	2	3	4	5
g. This question prompt list~~booklet~~ will increase shared understanding of ~~patient's~~ preferences of the person with dementia	1	2	3	4	5
h. This question prompt list~~booklet~~ will increase ~~family~~ consensus on decision making between the person with dementia and family, and within families	1	2	3	4	5
i. This question prompt list~~booklet~~ complements my usual approach	1	2	3	4	5
j. This question prompt list~~booklet~~ will be easy for me to use	1	2	3	4	5
k. I would decide to adopt this question prompt list ~~it~~ even before experimenting with it	1	2	3	4	5
l. Using this question prompt list~~booklet~~ will save me time.	1	2	3	4	5

m. This question prompt list~~booklet~~ is likely to be used by most of my colleagues	1	2	3	4	5
n. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for physicians*	1	2	3	4	5
o. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for nurses*	1	2	3	4	5

~~* Includes training before and after certification~~

S2. Acceptability of the question prompt list item scores (n=66 respondents)*

	mean	**SD**
a. This question prompt list will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	3.7	0.93
b. This question prompt list will result in them making more informed decisions	**4.0**	0.72
c. This question prompt list is suitable for helping to make value laden choices	3.6	0.89
d. This question prompt list will positively affect my relationships with the person with dementia and the families	3.4	0.92
e. This question prompt list will improve the quality of discussions with them	3.7	0.86
f. This question prompt list will increase satisfaction of the person with dementia and the family with my care	3.3	0.89
g. This question prompt list will increase shared understanding of preferences of the person with dementia	3.7	0.89
h. This question prompt list will increase consensus on decision making between the person with dementia and family, and within families	3.5	0.87
i. This question prompt list complements my usual approach	3.5	**1.2**
j. This question prompt list will be easy for me to use	3.0	**1.0**
k. I would decide to adopt this question prompt list even before experimenting with it	**2.5**	**1.1**
l. Using this question prompt list will save me time.	**2.7**	0.99
m. This question prompt list is likely to be used by most of my colleagues	**2.9**	0.94
n. This question prompt list should be used as a teaching aid in training or continued medical education for physicians	3.8	0.96
o. This question prompt list should be used as a teaching aid in training or continued medical education for nurses	3.8	0.89

Interpretation: summed scores range 15-75 with ≥45 meaning "acceptable." This equates to item scores ≥3. Summed scores of ≥60 mean "highly acceptable" and this equates to item scores ≥4. Cronbach's alpha 0.94. Bold indicates either not acceptable (red) or highly acceptable (green), and large variation (red, > 1 SD).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs, except for the items f (mean 3.2 SD 0.88 for elderly care physicians vs. 3.7 SD 0.84 for GPs) and j (mean 3.2 SD 0.93 for elderly care physicians vs. 2.6 SD 1.1 for GPs).

*Number of missing values of 66, per item: 2 (because 2 respondents did not complete the scale), except for item c (a total of 3 missing values) and item m (a total of 4 missing values).

S3. Quality of the content of the question prompt list

	mean	**SD**	**N***
Part 1: About illness and care			
Dementia and changes in health			
information	3.7	0.84	65
questions	3.5	**1.0**	65
Care goals, palliative care and end-of-life decisions			
information	3.8	0.99	65
questions	3.7	0.80	63
Part 2: About treatment and choices with health problems			
Decisions about treatments and agreements (advance care planning)			
information	4.0	0.85	64
questions	4.0	0.84	65
Treatment and care for common problems			
information	4.0	0.82	64
questions	3.9	0.81	64
Resuscitation and euthanasia			
information	**4.0**	0.91	63
questions	**4.0**	0.87	62
Choice of location of care and change of living environment			
information	**4.1**	0.72	64
questions	**4.0**	0.73	64
Part 3: Relatives			
Care for you as a relative			
information	**4.3**	0.67	64
questions	**4.2**	0.61	64
The dying phase and the period after death			
information	**4.2**	0.77	63
questions	**4.1**	0.74	62

Bold indicates either close to poor (red, mean rating 1 to 2; did not occur) or close to excellent (green, mean rating 4-5), and large variation (red, > 1 SD).

No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs.

*One missing value (n=65) was due to a respondent who did not rate any quality item–but did complete the acceptability scale as the primary outcome.

S4. Perceived barriers to implementation of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
The hectic pace of practice will prevent me from using the question prompt list	2.8	**1.1**	64
This question prompt list will cause the person living dementia or the family to be anxious	2.9	**1.1**	64
I don't expect people living with dementia and family will want to use the question prompt list	2.5	0.93	64
Going through the question prompt list gives me enough inspiration for conversations: it is not necessary to hand it out to people living with dementia and family	2.4	**1.1**	64
The advantages of working with the conversation aid will not outweigh the time and effort invested	2.6	0.89	64

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs, except for the item “The hectic pace of practice will prevent me from using the question prompt list” (mean 2.5 SD 1.0 for elderly care physicians vs. 3.6 SD 0.98 for GPs).

S5. Goals achieved and anticipated benefits of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
Question prompt list goals achieved			
This question prompt list will help the (capable) person living with dementia and the family organise their thoughts about the later stage of life	3.8	0.84	64
This question prompt list will help them formulate important questions about dementia and end-of-life care, making it easier to ask the health care professional questions	3.9	0.81	64
This question prompt list will help them to have conversations with healthcare professionals and also conversations with each other	3.8	0.79	64
This question prompt list will make choices about care and treatment easier for them	3.2	0.91	64
Other possible benefits of the question prompt list			
This question prompt list will help them to get information that is important to them in a timely manner	3.7	0.82	63
This question prompt list will make a person living with dementia or family feel supported and understood as to what they go through, and they will be better prepared for the future	3.6	0.94	63
Thanks to this question prompt list they can get the best possible personalized care.	3.1	0.88	62

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD; did not occur).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs.

Supplement 3. Interview guide

Interview guide for evaluation of the question prompt list ”Talking about the later stages in life in dementia” Translated from Dutch by a professional translator.

INTRODUCTION

First of all, thank you for your willingness to participate in this interview, after you have already assessed the question prompt list in a questionnaire. The purpose of this interview is to elaborate on what you think of the question prompt list and how it might be applied. It would be helpful to refer to the question prompt list you received from us during the interview. Of course we can provide a copy if you don't have it with you. We will also ask you about your views on openly discussing end-of-life care and palliative care in dementia in general.

The interviews will be recorded. Your information will be treated confidentially and analyzed in the secure environment of LUMC. The data used for any publication will not be traceable to your personal data. If you agree, please sign the informed consent form.

Do you have any questions before we begin?

THE QUESTION PROMPT LIST

1. What do you think of the question prompt list in its current form?
   Possible follow-up question: Which themes are missing?
2. What do you like about the question prompt list?
3. What don't you like about the question prompt list?
   Possible follow-up questions: Do you have tips on how to improve these points? If so, what are they?
4. Are there parts or factors in this question prompt list that could impede the conversation between you and the patient and (loved one) (family)?
   a. **If yes**: Which?
   b. **If no**: Do you feel that the question prompt list as a whole facilitates conversations?
   Possible follow-up question: How can these impeding factors be reduced or resolved?

For interviewer, to the participant:
Explain that the subject of the questions will now shift from the question prompt list to discussing sensitive subjects with persons living with dementia and family/loved ones. Also indicate that there will be more questions about the question prompt list later.

DISCUSSING SENSITIVE SUBJECTS

1. How difficult (or easy) do you find talking about the course of dementia and end of life (care) with patients and family/loved ones?
    a. *(**if little experience**): Which subjects seem most difficult to discuss? What do you think is the easiest way to make them discussible? Do you think this will become easier over the years (experience)?*
    b. *(**if very experienced**): Is it easier for you now than at the beginning of your career? What factors played a role? **If yes**: How do you deal with difficult subjects now and how is that different from the beginning of your career?*
2. Do you think the subjects highlighted in the question prompt list are easy to discuss in general?
3. Are there any subjects you find difficult to discuss with patient and family?
    a. **If yes**: Which subjects?
    b. **If no:** Are all subjects easy to discuss for you?
    Possible follow-up questions: Does this have to do with your experience regarding these conversations? (if not yet discussed under 1., and then elaborate in same manner) Does the question prompt list (also) contain certain example questions that you find difficult to answer?
    Possible follow-up question: What would you need to be able to answer these questions?
    Possible follow-up question: How to act when resistance is sensed from patient/family?
4. Have you (personally) found ways to make certain subjects easier to discuss in these types of conversations?
    a. ***If yes**: How do you go about it?*
    b. ***If no**: What do you need to change/improve your approach?*
5. Will the question prompt list contribute to initiating/starting the conversation with the patient and family/loved ones? And will it influence the moment of initiation?

IMPLEMENTATION IN PRACTICE

1. When a final version is available, would you want to apply this question prompt list? Why/Why not? ***If yes**: How would you want to apply the question prompt list?*
2. Are there any particular preconditions that must be met in order to be able to use this question prompt list?
3. Could this question prompt list also be applied by other healthcare professionals? ***If yes**: By whom, and would you recommend it?*
4. Do you think that question prompt lists should be used more frequently in the future in other fields or for other diseases, when available? ***If yes**: What fields/diseases?*

QUESTIONS BASED ON QUESTIONNAIRE RESPONSES

Explanation of goal:

In the final part of the interview, we would like to hear the physician's opinion, based on certain answers he/she provided in the questionnaire. As the answers to the questionnaires will vary from person to person, our goal is to record a few specific questions based on the answers to make sure all of the physician's perspectives and opinions are heard. This allows us to highlight as many different perspectives as possible.

Questions will partly have the same structure (but may deviate):

- In the questionnaire your answer to question [?] was [?]. We would really like to know what reasoning led to this answer. Can you please elaborate on your answer?
- **When physician is positive**: How do you think [?] can influence the conversations between physicians and persons with dementia and family/loved ones?
- **When physician is negative**: What should be changed in your opinion? What do you feel is necessary to do this?

1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Topic	**Item No.**	**Guide Questions/Description**	**Reporting (reported in section, para)** **Note, page numbers refer to PDF MERGE PAGE NUMBERS**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Interviews were conducted by JTS, SH, and physician AK named in the Acknowledgement section (Methods, before last para; page 6, line 3-7)
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	SH-Master student working in nursing homes a JTS-PhD epidemiologist AK-MD researcher who had not been involved in QPL development (Methods, before last para; page 6, line 3-7)
Occupation	3	What was their occupation at the time of the study?	See item 2
Gender	4	Was the researcher male or female?	JTS and AK are females, SH male (Methods, before last para; page 6, line 3-7)
Experience and training	5	What experience or training did the researcher have?	JTS has experience with qualitative research. SH and AK are novice qualitative researchers with no PhD title (yet), supervised by JTS. We did not include these details in the reporting of the mixed-methods study to leave room to reporting of the survey as well.
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No, we selected interviewees based on survey ratings linked to IDs without immediately seeing any names, and none of the interviewees happened to be known to the interviewers. We did not include this detail in the text but we reported selection of interviewees "based on a particularly high or a low acceptability score." (Methods, before last para; page 5, line 56-58)
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The participants knew we wanted to evaluate the question prompt list they read and evaluated by completing the survey before the interview. (The Methods section is structured around the survey performed first and interviews afterwards; page 5)
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons	No other characteristics than those under no 1-7.

		and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was used with no specific methodological orientation (page 6, line 16)
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling (Methods, before last para; page 5 line 58)
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	If willing to be interviewed, the participants left contact details on the last page of the survey (telephone number or email or both according to their preference, but we did not specify contact details as we judged the choice offered for a preferred way of contacting practitioners not the most relevant detail). (Methods, before last para; page 5, line 54-55)
Sample size	12	How many participants were in the study?	10 interviewees (Results, para Interviewees; page 7, line 44-45)
Non-participation	13	How many people refused to participate or dropped out? Reasons?	None (Results, para Interviewees; page 7, line 44-45)
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	We traveled to the physician's workplace. (Results, para Interviewees; page 7, line 46)
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No-one else was present; we mentioned the interviewers with item 1.
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	We describe gender, profession, trainee / supervisor status (Results, para Interviewees; page 7, line 46-50)
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The interview topic guide was translated to English and provided as a Supplemental file (referred to page 6, line 8). It was not pilot tested but some late adaptations were based on interesting findings in the survey as this is a mixed-methods study.
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No, we felt this was not necessary for individual or dyadic interviews with practitioners on defined topics.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	The interviews were all audio recorded (Methods, last para; page 6, line 13)

Field notes	20	Were field notes made during and/or after the interview or focus group?	Limited field notes were made. We did not include this detail in the manuscript to leave room to report the Methods of the survey.
Duration	21	What was the duration of the interviews or focus group?	Interviews were held with a median duration of 46 minutes (SD 15) (Results, para Interviewees; page 7, line 50)
Data saturation	22	Was data saturation discussed?	The last three interviews contributed little to the findings. (Results, Interview themes, first para; page 7, line 53)
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to busy physicians.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	The three interviewers coded the first interviews together, and other interviews were coded by SH. (Methods, last para; page 6, line 17-20)
Description of the coding tree	25	Did authors provide a description of the coding tree?	188 codes and 11 subthemes are available upon request - available in Dutch only (mentioned in the Methods, last para; page 6, line 20-21)
Derivation of themes	26	Were themes identified in advance or derived from the data?	We inductively identified themes (Methods, last para; page 6, line 15)
Software	27	What software, if applicable, was used to manage the data?	We used Atlas.ti version 7.5.18, 2012 (Methods, last para; page 6, line 15)
Participant checking	28	Did participants provide feedback on the findings?	No, the interview was a one-time effort for busy physicians. However, physicians who choose to develop an implementation plan for an accreditation point, received feedback on the plan. (Methods, fourth para; page 5, line 31-33)
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotes indicated with letters are included in the text of the Results section, each with a participant number, profession, and trainee or supervisor status (text in italics pages 8-10)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	We selected exemplary quotes (reference for standard / good research practice in Methods; page 6, line 21)
Clarity of major themes	31	Were major themes clearly presented in the findings?	We presented three major themes (page 7, line 53-56)
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Subthemes are included under the main themes in narrative format (pages 8-10). Purposive sampling of physicians with particular positive and negative acceptability

			scores (page 5, line 56-58) helped to identify and understand divergent approaches to discuss end of life and different perceptions on usefulness and implementation. We did not comment on this strength in the Discussion, to leave room to discuss survey results integrated with interview results.

2. Survey reporting checklist

https://www.equator-network.org/reporting-guidelines/good-practice-in-the-conduct-and-reporting-of-survey-research/

Kelley et al. 2003

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Reporting

When reporting survey research, it is essential that a number of key points are covered (though the length and depth of reporting will be dependent upon journal style). These key points are presented as a 'checklist' below:

1. Explain the purpose or aim of the research, with the explicit identification of the research question.

   Aim (abstract; page 3 line 8-10): To evaluate practitioners' perceptions of acceptability and possible use of a QPL [question prompt list] about palliative and end-of-life care in dementia.

   Question (last sentence of introduction; page 4 line 31-33): what are perceptions on acceptability and possible use of the QPL among physicians involved with advance care planning in dementia care?

2. Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (the literature review).

   In brief (Introduction, page 4):

-in practice there are numerous barriers to early ACP initiation (references to systematic reviews)
-available booklets provide sensitive information but may not engage patient with dementia and family enough
-QPL can empower people to ask their physician questions and research has shown benefits for patients in oncology (reference to systematic review) and palliative care (reference to Clayton et al.; see also second of two bullet points "What is already known on the topic")

3. Describe in (proportionate) detail how the research was done.

a. State the chosen research method or methods, and justify why this method was chosen.

   First paragraph of Methods (page 5, line 6-10): We performed a mixed-methods evaluation study of a QPL among practitioners because … We used validated quantitative instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

b. Describe the research tool. If an existing tool is used, briefly state its psychometric properties and provide references to the original development work. If a new tool is used, you should include an entire section describing the steps undertaken to develop and test the tool, including results of psychometric testing.

   For the primary outcome, acceptability of the QPL, we referred to an available scale that in turn was developed based on generic decision aid evaluation methodology. We included the full scale in a Supplementary file (referred to page 5, line 38), showing how we rephrased to refer to a QPL instead of a booklet. The Supplementary file also shows any missing values of items (2 to 4), also as an indicator of feasibility. Properties of the acceptability scale are described in the articles on booklet evaluation we refer to, and we added Cronbach's alpha (0.94) for the current study as a Footnote to Table 2 (page 19, line 36) and to the Table in the Supplement. Regarding the usefulness and quality of the contents as secondary outcomes, we referred to a list of barriers developed based on previous work (references included; page 5, line 41-44) and we used a simple 0-10 usefulness scale. For the quality of the contents, we used the same items based on

booklet and generic decision aid methodology (with references; page 5, line 39-40).

c. Describe how the sample was selected and how data were collected, including:
   i. How were potential subjects identified?
      Methods: "The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice." (page 5, line 21-23)
   ii. How many and what type of attempts were made to contact subjects?
      Methods: there was "one general reminder via e-mail" (page 5, line 31)
   iii. Who approached potential subjects?
      The academic medical center granted access to the research team to send the survey. (page 5, line 21-23)
   iv. Where were potential subjects approached?
      General practitioners and elderly care physicians. (page 5, line 21-23)
   v. How was informed consent obtained?
      Methods: "Completing and returning the survey on the QPL served as informed consent for this study" (page 5, line 30-31)
   vi. How many agreed to participate?
      Results: 66 of (160 * 2) copies of the surveys were returned. (page 7, line 7-9)
   vii. How did those who agreed differ from those who did not agree?
      Because of privacy regulation, we could not perform a non-response analysis. The response rate did not differ between the two academic centers (21% and 20%). We choose to not include this detail to leave room for reporting on the qualitative interviews.
   viii. What was the response rate?
      21% (66/160*2) (page 7, line 7-9)

4. Describe and justify the methods and tests used for data analysis.
   Methods: we used descriptive statistics to present the results and compared subgroups with appropriate tests (page 5, line 52-53). Footnotes to the Table specify we used the hierarchical gamma test, Chi-square, and t-tests to compare

characteristics between GPs and elderly care physicians, and adjusted for physician characteristics for continuous outcomes with linear regression.

5. Present the results of the research. The results section should be clear, factual, and concise.

   We used two headings for the survey results: “Survey participants,” and “Survey-acceptability and use” (page 7). Similarly, we used two heading for the interview results: “Interviewees” and “Interview themes” (page 7). The final Results paragraph for the mixed-methods study is called “Integration of survey and interview results” (page 10).

6. Interpret and discuss the findings. This ‘discussion’ section should not simply reiterate results; it should provide the author’s critical reflection upon both the results and the processes of data collection. The discussion should assess how well the study met the research question, should describe the problems encountered in the research, and should honestly judge the limitations of the work.

   To comply with this requirement, we used the structured Discussion with headings “Main findings and interpretation,” “Strengths and limitations of the study,” and “What this study adds: implications and conclusions” (page 12). The study showed practitioners’ perceptions on acceptability and possible use of the QPL.

7. Present conclusions and recommendations.

   In brief, the practitioners generally found the QPL acceptable and rated the contents as good, yet they had many concerns on how to use it in practice, and some were concerned they could not answer the questions that patient and family may select and ask them. To move forward, practitioners need training and patient and family should be able to access the question prompt list themselves to circumvent possible gatekeeping.

The researcher needs to tailor the research report to meet:

- The expectations of the specific audience for whom the work is being written.

  We assumed a basic understanding of palliative care and advance care planning.

- The conventions that operate at a general level with respect to the production of reports on research in the social sciences.

  We report for a health care audience, policy makers and researchers interested in palliative care in dementia, advance care planning, and promoting conversations about death and dying.

BMJ Open

Practitioners’ perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

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Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

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ABSTRACT

Objectives In oncology and palliative care, patient question prompt lists (QPLs) with sample questions for patient and family increased patients' involvement in decision making and improved outcomes if physicians actively endorsed asking questions. Therefore, we aim to evaluate practitioners' perceptions of acceptability and possible use of a QPL about palliative and end-of-life care in dementia.

Design Mixed-methods evaluation study of a QPL developed with family caregivers and experts comprising a survey and interviews with practitioners.

Setting Two academic medical training centres for primary and long-term care in the Netherlands.

Participants Practitioners (n=66; 73% female; mean of 21 (SD 11) years of experience) who were mostly general practitioners and elderly care physicians.

Outcomes The main survey outcome was acceptability measured with a 15-75 acceptability scale with ≥45 meaning "acceptable."

Results The survey response rate was 21% (66 of 320 participated). The QPL was regarded as acceptable (mean 51, SD 10) but 64% felt it was too long. Thirty-five percent would want training to be able to answer the questions. Those who felt unable to answer (31%) found the QPL less acceptable (mean 46 vs. 54 for others; p=0.015). We identified three themes from nine interviews: (1) enhancing conversations through discussing difficult topics, (2) pro-actively engaging in end-of-life conversations and (3) possible implementation.

Conclusion Acceptability of the QPL was adequate, but physicians feeling confident to be able to address questions about end-of-life care is crucial when implementing it in practice, and may require training. To facilitate discussions of advance care planning and palliative care, families and persons with dementia should also be empowered to access the QPL themselves.

Keywords

Advance care planning, dementia, end of life care, shared decision making, decision aids

Strengths and limitations of this study

- We employed a mixed-methods design which allowed for integration of relevant secondary analyses of the quantitative data based on a question that emerged from the qualitative interviews.
- We did not assess perceptions of persons with dementia and family; we assessed perceptions of physicians only.
- The responding physicians may represent a sample with an above average interest in the topic of advance care planning or in dementia care.

INTRODUCTION

In long-term care, an ongoing dialogue between patient, family (caregivers) and the healthcare team in the form of advance care planning (ACP) can improve the quality of end-of-life care.[1-3] With dementia, timely ACP is crucial to enable persons to participate because of the cognitive decline and rather unpredictable disease trajectory.[3-5]

However, in practice there are numerous barriers to early ACP initiation. Some people do not want to talk about the future, but rather live one day at a time.[5,6] Moreover, healthcare professionals (practitioners) may struggle with moral dilemmas around, for example, best interest judgements.[7] Practitioners may also hold very different beliefs regarding when to best initiate the ACP discussion,[6,8,9] which may relate to different conceptualisations of what ACP entails.[10] Interventions to increase ACP often address either the practitioner or the family.[11-13]

Several decision aids have been developed to enhance ACP and improve the quality of decision making including a family booklet for dementia at the end of life that was found acceptable and useful by physicians, nurses and family in multiple countries.[14-16] However, the booklet only contains information, while explicit example questions provided by a question prompt list (QPL) can empower people to ask questions that are specific to their individual information needs. QPLs may also prompt patient and family to ask about sensitive topics that they might not otherwise think of or feel comfortable with. Research in oncology and palliative care indicates that QPLs increased question asking during medical consultations especially if physicians also encourage patients to use the QPL, enhance participation in decision making and sometimes improve psychological outcomes such as anxiety in a longer term.[17,18]

Similarly, a QPL specifically for persons with dementia and their family might alter the dynamics of discussions on end-of-life care. Therefore, we developed a QPL for persons with dementia and their family and addressed the research question of what are perceptions on acceptability and possible use of the QPL among practitioners involved with advance care planning in dementia care.

METHODS

We performed a mixed-methods evaluation study of a QPL among practitioners because their perceptions are crucial for implementation strategies in practice and preparing for trials.[19] We used validated instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

Patient and public involvement (in QPL development)

In 2018, a multidisciplinary team drafted an initial QPL in the form of a booklet with information and sample questions. The QPL's goals were to: help elicit perceptions and beliefs about the end of life, help think about what to ask professionals, encourage conversations and facilitate decision making. The contents was based on the earlier booklet,[14-16] an Australian QPL for persons with dementia and their family[20] and a Canadian QPL for family of nursing home residents with dementia.[21] Content about euthanasia was specific for the Netherlands as in the earlier booklet.[22] In the Netherlands, the general public finds euthanasia in dementia more often acceptable than physicians do and there are many questions around usefulness and acceptability of a euthanasia living will.[23,24]

The first draft of the QPL was presented to two panels of older people affiliated with the academic centers, many of whom had experience with dementia in various roles and experts in grief and bereavement, spiritual caregiving and ethics, cultural issues, layout, and lay language use (a professional language center reducing the level to B1).[25] We provided the three goals we wanted to achieve with the QPL and solicited for any feedback. We collated and discussed their feedback which was used to improve the QPL, in particular the information provided, simplifying it and addressing the reader more personally and empathically (Box 1). The 2018 version comprised 76 questions in total, 2 to 11 sample questions per topic (Supplement 1).

Evaluation procedures

The academic medical training centres for primary and long-term care of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice. These professions are responsible for primary care for persons with dementia, with elderly care physicians usually being on the staff of a nursing home, or also practicing in the community in collaboration with GPs.[26] Further, we thus sampled for large variation in experience and a population of practitioners who may be early adopters.

The QPL and survey were distributed on paper during meetings at educational centres or sent via postal mail in June 2018. We provided two copies of each, for the physician themselves and for a colleague. Completing and returning the survey on the QPL served as informed consent for the study's survey part. We sent one general reminder via e-mail. We offered an optional accredited (1-hour) educational exercise that involved developing a strategy for future implementation of the QPL in practice with feedback from the researchers.

Survey

The questionnaire examined physician's perception of the acceptability of the QPL (primary outcome), the usefulness and quality of contents (secondary outcomes) and possible barriers to implementation in practice. We assessed acceptability with a slightly adapted validated 15-item scale of statements[15,16] (Supplement 2) based on acceptability decision aid evaluation methodology.[27] Usefulness and quality of content was assessed by asking physicians to rate the contents[15,16] and statements of anticipated benefits based on the QPL's goals. Barriers to optimal use of the QPL were assessed based on earlier questionnaires on barriers to symptom relief in dementia and perceptions of ACP among general practitioners and elderly care physicians.[19,27-30]

All items were rated on 1 to 5-point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree") except for quality of content for which extremes were labelled ''poor'' and ''excellent."[16] The 15 acceptability items were summed to calculate an acceptability score ranging 15-75 points. We regarded (mean) total scores of 45 (mean item score 3) and higher as acceptable, and scores of 60 and higher as highly acceptable.[16] The survey data were managed in Castor EDC (2018) (Castor, Amsterdam) and for analysis exported to SPSS version 23 (2018) (SPSS Corp. Inc., Chicago, IL). We used descriptive statistics to present the results and we compared professions with appropriate tests (in footnote to tables).

Interviews

In line with an explanatory sequential mixed-methods design,[31] at the end of the survey, physicians could indicate whether they were willing to be approached for an additional qualitative interview by providing their contact details. We selected physicians for an interview based on a particularly high or low acceptability scores (purposive sampling). We aimed to perform about 10 to 12 individual interviews for probable saturation for our specific aim.[32,33] Before the interview, participants signed an informed consent form modelled after the template of the Dutch Central Committee on Research Involving Human Subjects (CCMO). Interviewees were offered a gift card of 30 euros. Semi-structured face-to-face interviews (7) were held by SH-male Master student working in nursing homes, JTS-female PhD epidemiologist (double interview) and female MD-researcher AK who had not been involved in QPL development (one, and one with SH).

The interviews were guided by an interview guide (Supplement 3) that contained key questions addressing the participant's views on the QPL, their personal approach to end-of-life conversations and considerations regarding possible implementation of the QPL. If relevant, specific questions were asked based on reviewing participant's survey responses in an open manner. Not all questions were asked and in later interviews, we asked more about personal strategies employed to introduce ACP triggered by discussing both the QPL as a concrete tool and end-of-life conversations more generally. All interviews were audio-recorded, and SH transcribed verbatim while guaranteeing confidentiality through procedures consistent with the GDPR. Interview data were managed and coded in Atlas.ti (version 7.5.18, 2012). We used inductive thematic analyses to analyse the interviews along with open-ended items of the survey (whether they agreed with the QPL's contents and format, any missing information or questions, any other comments). The three researchers who conducted the interviews, coded the first interviews and discussed and agreed upon the coding (188 codes and 11 interrelated subthemes available at request). We selected citations to represent and illustrate the themes consistent with good research practice.[34]

RESULTS

Survey participants

We approached all residents and supervisors (160) to participate, providing a copy of the questionnaire also for a colleague (i.e. 320 in total). Between June and December 2018, 66 (21%) were returned completed by 18 general practitioners including two general practice-based assistant practitioners and 46 elderly care physicians, one geriatrician and one geriatric nurse. The response rates of the Leiden (21%; 40/190) and Nijmegen center (20%; 26/130) were similar.

The majority (73%) of the participants were female, with a mean of 21 years' experience and over half (56%) cared for persons with dementia on a daily basis (table 1). Elderly care physicians were more likely to see persons daily (70% vs. 22%) and in more advanced stages of dementia (70% vs. 11%).

Survey–acceptability and possible use

Table 2 shows that the physicians judged the QPL as acceptable (mean acceptability score 51), however, with a high standard deviation (10), but there was no difference in acceptability score between GPs and elderly care physicians. Mean usefulness was 7.2 points on the 1–10 scale. The contents were mostly appreciated (mean quality 64 points, SD also 10; Supplement 2: most, care for relatives; least, the introduction about illness and care). Although few participants thought there were too many example questions (9%), 64% of the physicians found the QPL too long and 59% felt there was too much information.

The survey items on barriers and benefits did not show clear patterns, but 49% believed that persons in early stages of dementia could not use the QPL themselves (table 3). When available, most (59%) would give the QPL to the individual and their family and 26% to family only (14% would not give it to anyone). Most (56%) physicians anticipated the QPL will increase provision of palliative care, and 21% anticipated more requests to hasten death, which was concerning to about half of them (10% overall).

Table 4 shows that almost one-third (31%) of the physicians found they were unable to answer all example questions in the QPL adequately, despite the instruction with this item recognizing that for some questions, there is no, or no certain answer. Overall one-third of participants (35%) felt a need for training to answer the QPL's example questions; more often GPs than elderly care physicians (72% vs. 20%).

Interviewees

We invited five physicians with a high acceptability score (55-64), four others (score 24, 35 or no score but negative comments), and one with combined GP/elderly care background and all were interviewed at their workplace July-November 2018. Of the physicians (seven female, three male), three were trainees, four were supervisors; seven were elderly care physicians, one GP, one both, and one geriatrician. Eight were individual interviews, and we interviewed one dyad of supervisor and trainee. The interviews lasted on average 46 (SD 15) minutes.

Interview themes

We identified three major themes with the last three interviews (with highly critical elderly care physicians and the only geriatrician) pointing to saturation: (1) enhancing conversations through discussing difficult topics; (2) pro-actively engaging in end-of-life discussions in practice; and (3) considering possible implementation of the QPL.

(1) Enhancing conversations through discussing difficult topics

The physicians who rated the QPL as highly acceptable anticipated added value in end-of-life discussions, mainly to enhance the conversations. They expected that it would encourage the person and family to consider questions about dementia and care options:

> *"I think if the patient has it [the question prompt list], he or she will have some questions of his/her own before we have this conversation. So I think the doctor will be triggered and get more questions from the client side, yes." (elderly care physician in training 2, positive; citation a)*

Moreover, they felt that having an overview of topics that could be discussed would be helpful for themselves:

> *"I was pleasantly surprised because I think something like this is very useful. It actually provided a very good guide for the things you actually want to know from a patient." (elderly care physician-in training 1, positive; citation b)*

On the other hand, both physicians with a high and a low acceptability score were concerned about possible information overload, leading to confusion, or even fear:

> *"I'm afraid that because of its extensiveness, it won't be used that much and that would be a pity because the subjects that are raised are all very relevant." (elderly care physician and GP 6, positive; citation c)*
>
> *"Yes, I think that because of the amount of information, people will start thinking and can also get, well, confused." (elderly care physician in training 1, positive; citation d)*
>
> *"Because for example, a feeding tube is also touched upon here, but it is mentioned very briefly and then: well, that often doesn't help. I think it can also sometimes cause people to get confused if there is information that is perhaps a little too concise and consequently raises expectations of: gosh, it might be worthwhile; that it can also generate unrest in such a conversation." (elderly care physician-in training 8, negative; citation e)*
>
> *"But sometimes you... Maybe it's a good thing not to know things and not to ask about them (elderly care physician supervisor 7, negative; citation f)*

Another issue was whether terms such as "care goals" and "advance care planning", although explained in the QPL, should be used at all.

> *"...you keep hammering on care goals, what's your care goal. That is our problem, we want to label everything a goal or a problem, why should you call it a care goal, you could say: we would like to know, what is important for you to have a good life." (elderly care physician 4, supervisor, negative; citation g)*

Some physicians' had concerns regarding specific questions in the QPL such as those about life expectancy, progression of the disease over time, and religious matters. While participants felt these questions would be meaningful for the person, some physicians felt they had no clear answers, and they reasoned that this might result in persons with dementia and family becoming more anxious.

> *"A slightly more critical look is needed at some of the questions being asked, questions that make me wonder, what doctor can answer that." (elderly care physician 4, supervisor, negative; citation h)*

(2) Pro-actively engaging in end-of-life discussions in practice

The physicians would normally employ various approaches in initiating conversations about the end of life. Most mentioned they start with asking general non-threatening questions, and through the answers, consider whether the person with dementia or family is ready to further discuss more sensitive or confrontational topics at that time, or to postpone the discussion:

> *"You explore: what is a person's attitude to life and what can the person handle and in that way you try, you basically ask questions. And that's how you try to find a starting point (...) you are very careful, you don't go in like 'wham' " (elderly care physician-in training 1, positive; citation i)*

However, some physicians take a more pro-active yet confrontational approach with specific examples that people can imagine and understand easily:

> *"You're actually describing the situations, is that what you'd want in that case? For example, resuscitation, because that is also a difficult concept to explain: we will bring you back from the dead, actually you are already dead, but then we bring you back from the dead, but that can cause a lot of brain damage. Then they say "brain damage, why?"; we often use the term [living like a] 'vegetable' [in Dutch: 'kasplant'], that's an association." (elderly care physician 3, positive; citation j)*

> *"'Vegetable'[...] is very easily accepted as a word. It is clear to 99% of people."(elderly care physician 5, supervisor, positive; citation k)*

The most important factor in how to approach the person and family was their educational level, according to the interviewees, which was corroborated by comments to open-ended survey items. The more highly educated would be equipped for the conversation through a better understanding of the subject, where others would need more guidance and explanation. The physicians believed those with a lower education level may hold misconceptions regarding treatment and care and have more trouble processing the QPL.

> *"That depends. Around here we have quite a few highly educated people, so shared decision making is very doable. People are well-informed, they read up [on the topic]." (elderly care physician 3, positive; citation l)*

> *"Yes, and I think it can be very confusing for some people. But maybe that's with the poorly educated population I occasionally work with in mind, that this is a lot and difficult to grasp. [...] then you ask do you want to be resuscitated and people say yes, but they have no idea... They think if they say no, they'll get an injection tomorrow and that's it, those are people's perceptions sometimes". (elderly care physician-in training 1, positive; citation m, continued citation d).*

Apart from educational level, some participants mentioned the relevance of the setting in which the QPL conversation takes place. Nursing home residents with dementia and family may have had more opportunity to think about the end of life than persons (still) living in a community setting, regarding specific treatment and values and preferences relating to care. Therefore, the more sensitive topics regarding end of life may be easier to discuss:

> *"People in nursing homes have already faced much more dependency, so most of them have thought about it. In primary healthcare this is much more difficult, because people who are never ill think they will live forever, and then suddenly they are confronted with it". (elderly care physician 4, supervisor, negative; citation n)*

A good connection based on trust was regarded as an important factor to improve the quality of end-of-life discussions:

> *"..you get to know your client over a long period of time, you get to know the family over a long period of time, the care staff get to know someone over a long period of time, because that's also important... yes, these are people you know well, that's the advantage of being a GP, that you have a connection with a person". (GP 1, negative; citation o)*

(3) Considering possible implementation of the QPL

The interviewees selected for being positive about the QPL would like to the QPL used by physicians and nurse practitioners. Some physicians would want the QPL to be used as early as possible in general practice, with the general practice-based assistant practitioner being the right person to not only give the QPL to patients and families, but also start the conversation about possible future care options, supervised by the GP:

> *"Maybe this is not a job for the GP? Maybe for the general practice-based assistant practitioner. They often have more time and they know the people better, are more accessible and they can probably explain things in everyday language. " (elderly care physician 3, positive; citation p)*

The physicians who found the QPL less acceptable envisioned barriers to implementation and were not considering possible solutions. They mentioned lack of time if there would be many questions or stated that the format is not viable:

> *"I think that you can have a really good conversation with two or three questions, and that you have to be careful it doesn't turn into an hour of conversation, because we simply don't have that kind of time. (GP 1, negative; citation q)*
>
> *"I think it [the length of the list] is such a major drawback that I think, I don't know ……. that I also find it hard to figure out how to make it work." (elderly care physician 4, supervisor, negative; citation r)*

Integration of survey and interview results

Some interviewees expressed concerns about not being able to provide good, or specific answers to certain questions in the QPL. For example, they mentioned not being able to answer a question on life expectancy and the progression of the disease. This emerged as an important issue that could affect adoption of the QPL. Therefore, based on the interview findings, we hypothesized that lack of self-efficacy or fear of not having the answer might be a decisive factor in using or appreciating the QPL. We then did a post-hoc secondary analysis of the survey data and found that the average acceptability score of those who felt they could not give answers to all example questions was lower, compared to those who felt they could (46 vs. 54; p=0.015), with a higher standard deviation (13 vs. 8).

DISCUSSION

Main findings and interpretation

This is the first study to assess practitioners' acceptability and views on a QPL about end-of-life issues specifically designed for persons living with dementia and their families. Physicians (and a few other practitioners) who provide long-term and end-of-life care for persons with dementia rated the QPL to be acceptable and the quality of the contents as good. However, many found the amount of information problematic, and were concerned it could be overwhelming. Importantly, the physicians were divided about whether the QPL would be too difficult for use by persons with dementia themselves due to the cognitive impairment associated with dementia, and they also differed in the extent to which they would confront persons with dementia and family with sensitive or difficult issues about end of life. Some physicians felt it would be better to ask initial screening questions to probe the persons' readiness to discuss these issues before providing a QPL.

When comparing the physician acceptability score of the QPL to earlier research in which we evaluated a family booklet with information only about dementia at the end of life, the mean acceptability score for the QPL was lower (56 versus 51, respectively).[16] The QPL also targets persons with dementia themselves in a community setting, rather than family only. In the secondary analysis prompted by the interview findings, we found lower acceptability of the QPL by physicians who were concerned about their ability to answer questions in the QPL adequately. The physicians, although associated with an academic center and probably with an interest in the topic, may not feel comfortable to discuss some topics included in the QPL, perhaps also including around hastening death.[24]

Strengths and limitations of the study

The mixed-methods design allowed for a richer understanding of the quantitative survey data, in particular regarding barriers and concerns, and also provided an efficient iterative approach of analysing the quantitative data based on a question that emerged prominently from the qualitative interviews, additional to interviewing about completed surveys. The response to the survey was low but within the range of responses commonly observed for physician surveys, while trends point to declining response rates.[35-37] The concerns we identified from respondents, who were probably interested physicians connected with an academic center, may not be generalizable and may underestimate concerns in physicians caring for persons with dementia.

We did not assess the acceptability of the QPL by persons living with dementia and their families, and further research in this area is warranted. In other research, on a lengthy QPL in palliative care more generally, despite its length, patients and professionals would not drop any topic or question for choice.[38] Indeed, the physicians in the evaluation study suggested adding questions rather than deleting any, the revised version including 7 more questions and new, practical tips (Supplement 1). Further research should determine various modes of delivery, for example, deciding together in advance to limit the conversation to one or two topics.

What this study adds: implications and conclusions

Training is required to increase confidence of physicians to be able to address questions from family and persons with dementia about end-of-life care when implementing a QPL in practice. Training should focus on increasing self-efficacy in addressing difficult questions, and for this, training of actual conversations with actors or e-simulated patients may be effective.[39,40] This may generalize to other countries as other work has shown that many Dutch elderly care physicians but also many GPs in Northern Ireland are reluctant to initiate ACP with people in the early stages of dementia.[9] Shared decision making is worthwhile in situations where there is choice based on individual preferences.[41] Persons with dementia may hold a neutral or negative stance regarding ACP[3,13] and a first extra step, before starting a decision-making process with a person with dementia is to agree on the necessity to make a decision.[42] Therefore, a prudent approach, probing readiness to engage in ACP, as adopted by some physicians, makes sense. On the other hand, persons with dementia and family may need proactive encouragement and support from physicians or other practitioners to discuss ACP so that they don't miss out on the opportunity to participate in decisions about their future care. This can help empower persons with dementia and avoid regret and crisis later on for family when making difficult decisions on behalf of the person with dementia.[43] Further research should include evaluations of use in practice, including formal evaluations from persons with dementia and family.

A QPL may help persons with dementia and family to select exactly the topics they find relevant at that time, and this could also inform the practitioner about readiness to discuss end of life. They should be offered choice from a collection of structured sample questions, but if overwhelming, they may decide in advance with their professional caregivers which topic to discuss (first). QPLs have the potential to alter the dynamics of conversations and empower persons with dementia in encounters with professional caregivers. These are worthwhile endeavours for persons with dementia who essentially would like to be part of society, appreciated, and their identity recognized.[44,45] Further, shared decision-making about goals for future care as the persons' dementia progresses is important because not all goals of care can be achieved, and there may also be trade-offs between goals for the family and the person with dementia.[41,45-47] To empower persons with dementia and their family, implementation strategies should also circumvent possible gatekeeping to include free access so they can ask practitioners and thus take initiative to start conversations.

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Author contributions

The author's responsibilities were as follows:
Development of the question prompt list: JTS, CCMJ, MMG, JMC, GNT, RTCMK, YML
Project design: JTS, SH, WPA, MMG
Data collection: JTS, SH
Paper writing: JTS, SH
Critique and review of the final manuscript: all.

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Conflict of interest disclosure

The Department advised on research review design and data collection. There was no influence on study analysis, decision to publish or preparation of the manuscript. The author(s) declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Patient consent for publication

Not applicable.

Patient and public involvement

Patient representatives were involved in question prompt list development. Patients were not involved in the practitioners' evaluation study.

Patient consent for publication

Not applicable.

Data sharing statement

The de-identified survey participant data may be requested from the corresponding author upon reasonable request. are available upon reasonable request. Interview recordings and transcripts are not available as they might render physicians recognizable to insiders.

Ethics approval

As a tool evaluation study among practitioners, this project did not involve patients or patient data. Therefore, ethics committee approval was not required.

Supplemental material

1. Question prompt list "Talking about the later stages of life in dementia" sample questions, tips and "things to think about"
2. Interview guide
3. Tables with individual items and item scores

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Box 1 Overview of topics covered in the question prompt list (QPL)*

Talking about the later stages of life in dementia:
Information and example questions
for people with dementia and their relatives

Part 1: About illness and care

- Dementia and changes in health
- Care goals, palliative care and end-of-life decisions

Part 2: About treatment and choices

- Decisions about treatments and agreements [advance care planning]
- Treatment and care for common problems
    - Eating and drinking and swallowing problems
    - Pneumonia and other infections
    - Shortness of breath
    - Pain and feeling uncomfortable
    - Restlessness and challenging behaviour / behavioural problems
    - (Incontinence [in later version only])
    - Depression, anxiety and lack of initiative Feelings of loss and existential questions
    - Other illnesses and what these may require
- End-of-life decisions regarding prolonging or shortening life Choice of location of care and change of living environment

Part 3: About and for the relative

- Care for you as a relative
- The dying phase and after death

* Topics of the 2018 evaluation version. For adaptations in response to the evaluation, see Supplement 1

Table 1 Physicians' characteristics and dementia care practice patterns (n=66)*

Female sex, %	73
Age, mean (SD)	48 (11)
Experience as a physician, mean (SD)	21 (11)
Resident trainee, %	17
Supervisor,%	53
Care for dementia patients; frequency, %	
at least daily	56
at least weekly	34
at least monthly	6
at least every 2 months	3
at least every 6 months	0
< every 6 months	0
Care for dementia patients; stage of disease, %	
mostly early stage (mild dementia)	8
both early and late (moderate or advanced) stage, about equally distributed	39
mostly late (moderate or advanced) stage	53
Estimation of dementia patients dying in the past year, %	
0	2
1 – 4	27
5 – 9	25
10 – 19	34
20 or more	13

SD: standard deviation; GP: general practitioner

Significant differences ($p<0.05$) between GPs and elderly care practitioners were not observed for sex, trainee or supervisor status (Chi-square), age and experience (t-test). With the hierarchical gamma test there were differences between the last three items; elderly care physicians cared for dementia patients more frequently (e.g. daily 70% vs. 22%), cared for patients in later stages (e.g. advanced stage 70% vs. 11%) and more patients with dementia died in their practice in the past year (e.g. 20 or more 17% vs. 0).

[*] Two of 66 respondents missed characteristics other than sex and age. GP (n=18) included two general practice-based assistant practitioners (often nurses or social workers, referred in the Netherlands as "praktijkondersteuner huisarts", POH). Elderly care practitioners (n=48) included 46 elderly care physicians, a geriatrician and a geriatric nurse. Experience refers to experience as a physician and was missing for the general practice-based assistant practitioners (POH) and the nurse.

Table 2 Evaluation of acceptability and the contents of the question prompt list (n=66)

Acceptability score, mean (SD)[*]	51 (10)
Usefulness for persons with dementia and family, mean (SD)[†]	7.2 (1.7)
Quality of the content of the question prompt list, mean (SD)[‡]	64 (10)
Length, %	
too long	64
too short	2
just right	34
Amount of information, %	
too much	59
too little	0
just right	41
Balance in proportions of information versus example questions, %	
too much information	20
too many example questions	9
just right	70

SD: standard deviation

No differences ($p<0.05$, t-test or Chi-square as appropriate) were observed between GPs and elderly care practitioners for any of the items, including after adjustment for sex, experience and stage of dementia cared for most (first three outcome items, linear regression). Missing values: 2, except for usefulness, 1.

[*] Theoretical range score: 15 – 75. Cronbach's alpha in this sample was 0.94. The acceptability score covers: informing families, supporting decision making, communication with families, satisfaction with care, use in practice, and use in training (see Supplement 2, tables S1 and S2 for individual items and item scores).

[†] Theoretical range score: 0 – 10.

[‡] Theoretical range score: 16 – 80 (see Supplement 2, table S3 for item scores).

Table 3 Barriers, benefits and views about use, % (n=66)

Range of perceived barrier scores (means and SDs 5 items)*	2.4-2.9 (0.89-1.1)
Goals and anticipated benefits of use (means and SDs 7 items)*	3.1-3.9 (0.79-0.94)
Do you think dementia patients can use the QPL themselves?	
yes, but only in early stages of the disease (MMSE>20)	49
yes, in early but also in moderate stages of the disease (MMSE>10)	2
no, (almost) no one with dementia can	49
When the QPL is available, I will give it to…	
patients and relatives	59
relatives	26
I will not give the QPL to anyone	14
QPL will lead to earlier or more frequent providing of palliative care	
yes	56
no	44
This QPL will lead to more requests to hasten death	
yes, and I do not have any objection	11
yes, and I object to that	10
no	79

SD: standard deviation; QPL: question prompt list; MMSE: Mini-Mental State Examination.

* Items are shown in Supplement 2, Tables S4 and S5. Agreement is scaled on the same scale as the acceptability scale, from 1 to 5 point scale with only the extremes labelled (''strongly disagree'' and ''strongly agree''). No differences ($p<0.05$, Chi-square or t-test as appropriate) were observed between GPs and elderly care physicians for any of the items, except for the barrier item "The hectic pace of practice will prevent me from using the question prompt list" (higher barrier score for GPs). Missing values: use themselves 1, give it to 2, palliative care 2, hasten death 3.

Table 4 Confidence in using the question prompt list (n=66)

I am able to answer all the questions asked in the question prompt list, %[*]	
yes	69
no	31
Need for training, % confirmed	35
Training on subject / content	19
Training in conversation techniques	5
Training on subject / content and conversation techniques	11

Differences (Chi-square) were observed between GPs and elderly care practitioners (first item, p=0.015, unable to answer, elderly care physicians 22% vs. GPs 56%; second item, p=0.001, any training elderly care physicians 20% vs. GPs 72%).

[*] The item included this explanation: “this does not mean that you have a ready-made answer to all questions, but that you think you can respond adequately to all questions”

Supplement 1. Question prompt list "Talking about the later stages of life in dementia" sample questions, tips and "things to think about"

- Translated from Dutch to English by a professional bi-lingual translator. The Dutch question prompt list additionally presents brief information on each of the topics.
- The pilot version used in the evaluation study with practitioners in 2018 was improved in 2019 based on the evaluation, and again with input from family caregivers and professional caregivers in 2020. Where versions differ, the 2018 text is presented in the lightest grey shade, 2019 in dark grey and 2020 text and unchanged text is presented in black [explanation added after the first questions].
- Changes are indicated with grey mark. The 2018 version included 76 questions. The 2020 and 2019 versions comprise 83 similar questions. After the evaluated 2018 version, various tips and nine questions were added (highlighted blue), one question was deleted, and two were combined in a single question (both highlighted green).
- The 2020 version also offers the sample questions as a separate list to facilitate preparing for a conversation with a health care provider.
- The 2020 question prompt list and separate list are available in Dutch from: https://www.lumc.nl/org/unc-zh/onderzoek/Palliatievezorgbijdementie/Ontwikkelengesprekshulpdementie/
- Reference: van der Steen JT, Juffermans CCM, Gilissen F, van der Linden YM, Koopmans RTCM. 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 relatives]. 2nd Edition. Leiden, The Netherlands: LUMC, 2020.

Talking about the later stages of life in dementia:

information and example questions
for people with dementia and their relatives
timely information and example questions
for people with dementia and their relatives
timely information and example questions for people with dementia and their relatives

Part 1 About illness and care
Part 1 About illness and care in general
Part 1 About illness and care in general
  1. Dementia and changes in health
  2. Care goals, palliative care and end-of-life decisions
Part 2 About treatments and choices
Part 2 About treatments and choices regarding health issues
Part 2 About treatments and choices regarding health issues
  3. Decisions about treatments and agreements [advance care planning]
  4. Treatment and care for common problems
  5. Choice of location of care and change of living environment
  5. Choice of location of care and change of living environment
  6. Choice of location of care and change of living environment
  6. End-of-life decisions regarding prolonging or shortening life
  6. Resuscitation and euthanasia
  5. Resuscitation and euthanasia

Part 3 About and for the relative
Part 3 The relative
Part 3 The relative
  7. Care for you as a relative
  8. The dying phase and after death
  8. The dying phase and the period after death
  8. The dying phase and the period after death

Tips

✓ There are many questions you could put to your health care professional.
If you have difficulty choosing a question at this point, you could start off with this one:
In your opinion, what is important for us to know about care now and in the future?

✓ There are many questions you could put to your health care professional.
If you have difficulty choosing a question at this point, you could start off with this one:
In your opinion, what is important for us to know about care now and in the future?

✓ People who have experience with dementia often say that it is important to start thinking in advance about decisions and support that will be needed in the future. This is in part so you can call in assistance from health care providers on time.

✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.

✓ Never hesitate to put any questions you may have to your care provider. Asking questions will prevent you worrying unnecessarily.

✓ Please don't hesitate to ask your care provider questions. Asking questions or expressing concerns may provide reassurance or clarification [of uncertainties].

1. Dementia and changes in health

- *Can you tell me more about the type of dementia I have? [unchanged, same in 3 versions]*

- *What changes can I expect, and in particular: what changes in behaviour? [2018 version]*
- *What changes can be expected, and in particular: what changes in behaviour? [change in 2019]*
- *What changes can be expected, and in particular: what changes in behaviour? [2020 = 2019]*

- *How long does it take before the symptoms clearly become worse?*
- *How long does it usually take before the symptoms clearly become worse?*
- *How long does it usually take before the symptoms clearly become worse?*

- *Can you explain how I can recognize the final stage of life?*
- *How can I make sure I can do the things I enjoy for as long as possible?*
- *How can I make sure I can do the things I enjoy for as long as possible?*

- *How long do I have?*
- *Can you tell me how much time I have left?*
- *Can you tell me how much time I have left?*

2. Care goals, palliative care and end-of-life decisions

Things to think about

What is important to me in terms of the care?
What is important to me in terms of the care?
What is important to me when I am in need of care?

What should the care focus on (i.e. which 'care goal' am I looking for?)

- *Can you tell me what palliative care in dementia is?*
- *Can you tell me more about palliative care in dementia?*
- *Can you tell me more about palliative care in dementia?*

- *Which palliative care is available in my situation?*

- *Who can help me formulate care goals? [newly introduced in 2019 version]*
- *Who can help me formulate care goals? [same in 2020 version, etc.]*

- *Who can I contact about care and care goals in which type of situation, and how?*

- *What care, matching my care goal, is available for me?*

Tips

✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it. So do not let the term palliative care put you off when you are thinking about future care.

✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. And to prepare you for it.

✓ Palliative care clearly entails much more than just care in the stage of dying: the focus of care is on a good quality of life now and later on. You can start preparing for ‘later’ now.

✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.

✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. Knowing preferences and wishes can bring peace later on.

✓ It may be difficult to think about the future and to talk about the future, but it is still good to do so. If you and others know what the preferences and wishes are, this can bring peace now and later.

✓ Start talking about what is important for the present. This is often easy to start with.

✓ Start talking about what is important for the present. This is often easy to start with.

✓ Start talking about what is important for the present. This is often easier to start with.

✓ When the end of life is in sight, the importance of supporting and being there for each other, of feeling connected increases.

3. Decisions about treatments and agreements [advance care planning]

Things to think about

The most important question is: ‘Which type of care best suits me or my loved one in this stage of life?’

- *I would like to talk about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*
- *I would like to talk about how I experience dementia and about my wishes and hopes for the future. When can I discuss this and with whom?*

- *What do you want to know about me, so you can provide quality care that suits me, now and later on?*

- *Is it possible to record my wishes regarding end-of-life care now, and if so: how?*

- *Which documents or plans are significant for me and what do I need to know about them?*

- *How confidential is the information about me? For example: who is allowed to know about my medical problems or behaviour problems?*

- *What is my role in the decision-making? And what is the role of my relatives?*

- *Who makes the decisions for me when I am no longer able to?*

- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that?*
- *How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*
- *Who decides that I am no longer able to make my own decisions? And how does the person in question decide that? How can I appoint a representative?*

- *What should I or my relative do in case we disagree with each other about a decision, or when we disagree with the doctor?*

- *Will I be able to change previously arranged agreements? And can my relatives do this when I am no longer able to?*

Tips

✓ It is important to make arrangements regarding finances, care and wellbeing at an early stage

✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.

✓ You and your relatives may have different principles and needs. It helps to identify these differences and talk about them.

✓ You and your relatives may have different principles and needs. It helps to identify these differences and discuss them together.

✓ What should always be central is the wish of the person with dementia even if it is an earlier wish. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.

✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia, i.e. determine what is the best course of action at that particular point in time, taking into consideration the previously expressed wishes.

✓ What should always be central is the wish of the person with dementia. Including any earlier wishes. Others must be able to later determine the intentions of the person with dementia. In other words: ultimately determine the most suitable course of action at that particular point in time, taking into consideration the previously expressed wishes.

✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.

✓ It is good to discuss at an early stage who can represent you when you are no longer able to make your wishes known.

4. Treatment and care for common problems

Things to think about

Which are treatments I definitely do NOT want to undergo?

What (action) do I want (taken) when I am in serious pain?
What do I want when I am in serious pain?
What do I want when I am in serious pain?

When there is no solution for burdensome symptoms, do I want the doctor to lower my level of consciousness (‘*palliative sedation’*), so I am less aware of them?
When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of ‘*palliative sedation’*), so I am less aware of them?
When there is no solution for very unpleasant symptoms, do I want the doctor to lower my level of consciousness (put me to sleep by means of ‘*palliative sedation’*), so I am less aware of them?

Do I also want to record these things, for example with the general practitioner?

What can help me accept that I am no longer able to do things, or know things (with experiencing losses)?
What can help me accept that I am no longer able to do things, or know things (cope with loss)?
What can help me accept that I am no longer able to do things, or know things (cope with loss)?

Questions about restlessness and challenging behaviour / behaviour problems

- *Where does the behaviour come from, for example refusing care?*

- *How can the problem behaviour be reduced?*

- *What might help in case of unsafe behaviour?*
- *What might help in case of unsafe behaviour?*

- *Are medications necessary or can we try something else first?*

- *Which potentially helpful medications are available?*

- *What side effects can these medications have?*

- *Can the use of medications be stopped when the problem behaviour is gone?*

Questions about incontinence
Questions about incontinence

- *What can help in case of incontinence?*
- *What can help in case of incontinence?*

- *How do we ensure incontinence does not affect dignity?*
- *How do we ensure incontinence does not affect dignity?*

Questions about feelings of depression, anxiety and lack of initiative

- *How can you diminish my depression or alleviate my anxiety?*
- *How can you diminish depression or alleviate anxiety?*
- *How can you diminish depression or alleviate anxiety?*

- *Which psychosocial interventions are available?*

- *How can my need for contact be met when I am no longer able to make contact?*

Questions about feelings of loss and existential questions

- *How can I and my relatives adequately cope with experiences of loss?*
- *How do we cope adequately with experiences of loss?*
- *How do we cope adequately with experiences of loss?*

- *Which type of spiritual care (based on world view, spiritual beliefs, religion), is available that is suitable for me?*

- *How do we ensure that every day brings positive and meaningful experiences?*

Questions about eating and drinking problems [order of paragraphs revised after 2019 version, which until then started with this paragraph; the paragraph title includes swallowing problems]

- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do for me to help my eating, drinking, or swallowing problems?*
- *What can you do about my eating, drinking, or swallowing problems?*

- *How can I reduce the risk of choking on food and drink?* [bullet 1 and 2 reversed order after 2018 version]

- *Would soft or pureed food, or thickened liquids help?*

- *Would a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*
- *Would a feeding tube or a drip be helpful in my case?*

Questions about infections [the paragraph title is Pneumonia and other infections]

- *Can I prevent pneumonia? What would help reduce the risk of developing pneumonia?*

- *What can you do in case of pneumonia or bladder infection?*

- *Are antibiotics a good option in my case?*
- *Are antibiotics suitable in my case?*
- *Are antibiotics suitable in my case?*

- *What about going to the hospital?*
- *What about going to the hospital?*

- *What are the options to alleviate symptoms, to make me more comfortable?*
- *Can you alleviate symptoms and provide some comfort?*
- *Can you alleviate symptoms and provide some comfort?*

Questions about shortness of breath

- *What can you do for me when I am short of breath?*
- *What can you do in case of shortness of breath?*
- *What can you do in case of shortness of breath?*

- *Could I suffocate?*
- *Could I suffocate?*

- *Can morphine make me die sooner?*
- *Will morphine make me die sooner?*
- *Will morphine make me die sooner?*

Questions about pain and feeling uncomfortable

- *How will you determine whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*
- *How will you determine (later) whether I am in pain? And is a relative able to see it too?*

- *What is the cause of the pain or discomfort?*
- *What is the cause of the pain or feeling uncomfortable?*
- *What is the cause of the pain or feeling uncomfortable?*

- *How can you alleviate the pain?*

- *Can I get addicted to morphine?*

Questions about other illnesses and what these may require

- *Which medications or medical checks will remain necessary for me?*

- *Do the different medications that I need work well together?*

- *How do the other illnesses affect the care in later stages or at the end of life?*

Tips

✓ Stay focused on the *care goal*, for example comfort or prolonging life

✓ Stay focused on the *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.

✓ Stay focused on the jointly determined *care goal*, for example providing comfort, or prolonging or not prolonging a person's life.

✓ You can raise existential with your health care professional to find support, even if you are not religious.

✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.

✓ You can raise existential questions like 'Why is this happening to me?' and 'How can I cope with being ill?' with your health care professional to find support, even if you are not religious.

5. Choice of location of care and change of living environment

Things to think about

How important is remaining at home for me when I compare it, for example, to my safety and the care that my relatives will then have to provide?
How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?
How important is remaining at home for me when I compare it to my safety and the care that my relatives will then have to provide?

Are there any situations in which I would not want to be taken to hospital?
Are there any situations in which I would not want to be taken to hospital?

How do we look at the end of life, for example: where and who will be present?

Questions about choosing the care location and living environment

- *Do you think I will be able to stay at home, and what does this depend on?*

- *Which help is available so I can stay at home for as long as possible?*
- *Which help is available so I can stay at home for as long as possible?*

- *When is hospitalisation necessary?*
- *When could hospitalisation be necessary and when is it not a good idea?*
- *When could hospitalisation be necessary and when is it not a good idea?*

- *Can I be admitted to a hospice, or a nursing home or residential home?*
- *Can I be admitted to a hospice, or a nursing home?*
- *Can I be admitted to a hospice, or a nursing home?*

- *Which (other) options are there when staying at home is no longer possible?*

Questions for you when you change living environment and health care provider

- *How can I make sure that a change goes as smoothly as possible?*

- *What will be done to secure my safety in the new environment?*

- *Who works in the new environment and which health care professional does what?*

- *How often will I see the doctor here?*

- *How do I make sure that the health care professional gets to know me, my background and my preferences?*

Tips

✓ Accept help such as home help when necessary. Do not hesitate and please don’t wait too long.

✓ Accept help such as home help when necessary. Do not hesitate and please don’t wait too long.

✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.

✓ Health care providers can give you care tips, for example about special beds or incontinence materials. And also about care at a later stage, like moving and legislation [such as the Social Support Act (Wmo), Long-term Care Act (Wlz) [locally relevant legislation], and health insurance.

✓ Ask your GP or acquaintances about good nursing homes. For example, not all small-scale nursing homes are equipped to provide good quality care.

✓ Ask your GP or acquaintances about good nursing homes. For example, not all small-scale nursing homes are equipped to provide good quality care.

✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.

✓ Day care or day treatment in a nursing home is a good way to become familiar with the home while you still live at home.

✓ To check whether a care facility like a nursing home or residential home is suitable for you, you could visit several to take in the atmosphere.

✓ To check whether a care facility like a nursing home is suitable for you, you could visit several to take in the atmosphere.

✓ To check whether a care facility like a nursing home is suitable for you, you could visit several to take in the atmosphere.

✓ Investing in good contact with the new health care professionals, who need to get to know you and your relatives, is helpful.

✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.

✓ Invest in good contacts with new health care professionals who want to get to know you and your relatives. Volunteer information about what is going on and what your wishes are.

✓ If you want to share it, a life book, for example [www.sprekenoververgeten.nl, [locally relevant example] can also help health care professionals get to know you.

✓ If you want to share it, a life book, for example [www.sprekenoververgeten.nl, [locally relevant example] can also help health care professionals get to know you.

✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

✓ A hospital is generally not a ‘dementia-friendly environment’. If hospitalisation is necessary, then it is good [used other Dutch term, closer to nice] idea to have someone there who has the time and patience to reassure you. For example a health care professional, volunteer, or a relative.

6. Resuscitation and euthanasia [order of topics in 2020 version; in the 2018 and 2019 versions, this topic was placed before topic 5]

Things to think about

How do I feel about prolonging or shortening life?
How do I feel about prolonging or shortening my life?
How do I feel about prolonging or shortening my life?

Questions about resuscitation

- *What are advantages and disadvantages of resuscitation in my case?*

- *How can I document that I do not want to be resuscitated, or do not want resuscitation under certain circumstances?*

Questions about euthanasia

- *Is euthanasia an option in my situation?*

- *Is euthanasia an option at a later stage when I am no longer able to say that that is what I want?*

- *Can my relative or the doctor decide about euthanasia?*
- *Can my relative or the doctor decide about euthanasia?*

- *What possibilities are there to not prolong life in a more natural way?*
- *What possibilities are there to not prolong life in a more natural way?*

7. Care for you as a relative

Things to think about

How do I as the relative prepare for the deterioration of my loved one with dementia?

What takes most of my energy, and what can I do to improve that?

- *How can I best support my loved one who has dementia?*

- *What emotions am I likely to experience?*

- *Which support am I entitled to, and where can I get it?*

- *What can I do to prevent becoming overburdened?*

- *How do I recognise that I am overburdened?*

Tips

- ✓ Make sure that you as the relative always get enough rest. This benefits everyone.
- ✓ In addition to your GP, also inform your employer that you are a family caregiver, because this is something that needs to be taken into account.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ Check what support the municipality provides for family caregivers.
- ✓ The Alzheimer's telephone helpline lends a sympathetic ear and offers advice on coping with dementia. The Alzheimer's telephone helpline can be reached via the free phone number 0800 5088, 7 days a week from 9:00 am to 11:00 pm.

8. The dying phase and the period after death

Things to think about

What do we want the final moments to be like?

- *Can you warn me, as the relative, when death is near?*
- *Who can help me sit up with my dying loved one?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*
- *Who can help me sit up with my dying loved one? Are there volunteers we can call in?*
- *What if my loved one dies when I am not there?*
- *What spiritual or religious care is available?*
- *What spiritual or religious care is available to us?*
- *What spiritual or religious care is available to us?*
- *How does a person feel when he does not eat or drink anything?*
- *What can you do about the loud breathing due to mucous build-up?*
- *What should or can I, the relative, do at the moment of death and afterwards?*
- *Do I, as the relative, get an opportunity to speak to the doctor again?*
- *What aftercare is available to me?*

Tips

- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor how necessary it is, despite the emotions that may be present.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary, despite the emotions you may be experiencing. Remember that doctors are generally in ‘treatment-mode’.
- ✓ If a stressful treatment or operation is suggested while your loved one is already in a poor condition: ask the doctor whether the treatment is really necessary and what will happen if it is decided to discontinue treatment. Despite the emotions you may be experiencing. Remember that doctors are generally in ‘treatment-mode’.

- ✓ Many nursing homes provide relatives the opportunity to spend the night there during the final days. If this is what you want, ask about it on time.

Supplement 2. Acceptability and all scale item scores: Tables with individual items and item scores

S1. Acceptability scale adaptations (track changes) compared to acceptability scale for evaluation of a family booklet[12-14]

Use of the question prompt list in practice

This section is about your expectations when using the question prompt list in your practice. Could you please indicate the extent to which you agree or disagree with each statement? (*circle the number that applies*)

	strongly DISagree		→		**strongly agree**
a. This question prompt list~~booklet~~ will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	1	2	3	4	5
b. This question prompt list~~booklet~~ will result in them~~my patients' families~~ making more informed decisions	1	2	3	4	5
c. This question prompt list~~booklet~~ is suitable for helping ~~patients' familie~~to~~s~~ make value laden choices	1	2	3	4	5
d. Th~~e~~is question prompt list~~booklet~~ will positively affect my relationships with the person with dementia and the families	1	2	3	4	5
e. This~~e~~ question prompt list~~booklet~~ will improve the quality of discussions with ~~families~~ them	1	2	3	4	5
f. This question prompt list~~e booklet~~ will increase ~~family~~ satisfaction of the person with dementia and the family with my care	1	2	3	4	5
g. This question prompt list~~booklet~~ will increase shared understanding of ~~patient's~~ preferences of the person with dementia	1	2	3	4	5
h. This question prompt list~~booklet~~ will increase ~~family~~ consensus on decision making between the person with dementia and family, and within families	1	2	3	4	5
i. This question prompt list~~booklet~~ complements my usual approach	1	2	3	4	5
j. This question prompt list~~booklet~~ will be easy for me to use	1	2	3	4	5
k. I would decide to adopt this question prompt list ~~it~~ even before experimenting with it	1	2	3	4	5
l. Using this question prompt list~~booklet~~ will save me time.	1	2	3	4	5

m. This question prompt list~~booklet~~ is likely to be used by most of my colleagues	1	2	3	4	5
n. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for physicians*	1	2	3	4	5
o. This question prompt list~~booklet~~ should be used as a teaching aid in training or continued medical education for nurses*	1	2	3	4	5

~~* Includes training before and after certification~~

S2. Acceptability of the question prompt list item scores (n=66 respondents)[*]

	mean	**SD**
a. This question prompt list will help families and a (capable) person with dementia better understand the natural course and possible complications of dementia	3.7	0.93
b. This question prompt list will result in them making more informed decisions	**4.0**	0.72
c. This question prompt list is suitable for helping to make value laden choices	3.6	0.89
d. This question prompt list will positively affect my relationships with the person with dementia and the families	3.4	0.92
e. This question prompt list will improve the quality of discussions with them	3.7	0.86
f. This question prompt list will increase satisfaction of the person with dementia and the family with my care	3.3	0.89
g. This question prompt list will increase shared understanding of preferences of the person with dementia	3.7	0.89
h. This question prompt list will increase consensus on decision making between the person with dementia and family, and within families	3.5	0.87
i. This question prompt list complements my usual approach	3.5	**1.2**
j. This question prompt list will be easy for me to use	3.0	**1.0**
k. I would decide to adopt this question prompt list even before experimenting with it	**2.5**	**1.1**
l. Using this question prompt list will save me time.	**2.7**	0.99
m. This question prompt list is likely to be used by most of my colleagues	**2.9**	0.94
n. This question prompt list should be used as a teaching aid in training or continued medical education for physicians	3.8	0.96
o. This question prompt list should be used as a teaching aid in training or continued medical education for nurses	3.8	0.89

Interpretation: summed scores range 15-75 with ≥45 meaning "acceptable." This equates to item scores ≥3. Summed scores of ≥60 mean "highly acceptable" and this equates to item scores ≥4. Cronbach's alpha 0.94. Bold indicates either not acceptable (red) or highly acceptable (green), and large variation (red, > 1 SD). No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs, except for the items f (mean 3.2 SD 0.88 for elderly care physicians vs. 3.7 SD 0.84 for GPs) and j (mean 3.2 SD 0.93 for elderly care physicians vs. 2.6 SD 1.1 for GPs).

[*] Number of missing values of 66, per item: 2 (because 2 respondents did not complete the scale), except for item c (a total of 3 missing values) and item m (a total of 4 missing values).

S3. Quality of the content of the question prompt list

	mean	**SD**	**N***
Part 1: About illness and care			
Dementia and changes in health			
information	3.7	0.84	65
questions	3.5	**1.0**	65
Care goals, palliative care and end-of-life decisions			
information	3.8	0.99	65
questions	3.7	0.80	63
Part 2: About treatment and choices with health problems			
Decisions about treatments and agreements (advance care planning)			
information	4.0	0.85	64
questions	4.0	0.84	65
Treatment and care for common problems			
information	4.0	0.82	64
questions	3.9	0.81	64
Resuscitation and euthanasia			
information	**4.0**	0.91	63
questions	**4.0**	0.87	62
Choice of location of care and change of living environment			
information	**4.1**	0.72	64
questions	**4.0**	0.73	64
Part 3: Relatives			
Care for you as a relative			
information	**4.3**	0.67	64
questions	**4.2**	0.61	64
The dying phase and the period after death			
information	**4.2**	0.77	63
questions	**4.1**	0.74	62

Bold indicates either close to poor (red, mean rating 1 to 2; did not occur) or close to excellent (green, mean rating 4-5), and large variation (red, > 1 SD).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs.
*One missing value (n=65) was due to a respondent who did not rate any quality item–but did complete the acceptability scale as the primary outcome.

S4. Perceived barriers to implementation of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
The hectic pace of practice will prevent me from using the question prompt list	2.8	**1.1**	64
This question prompt list will cause the person living dementia or the family to be anxious	2.9	**1.1**	64
I don't expect people living with dementia and family will want to use the question prompt list	2.5	0.93	64
Going through the question prompt list gives me enough inspiration for conversations: it is not necessary to hand it out to people living with dementia and family	2.4	**1.1**	64
The advantages of working with the conversation aid will not outweigh the time and effort invested	2.6	0.89	64

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs, except for the item "The hectic pace of practice will prevent me from using the question prompt list" (mean 2.5 SD 1.0 for elderly care physicians vs. 3.6 SD 0.98 for GPs).

S5. Goals achieved and anticipated benefits of the question prompt list (agreement scaled as in Table S1, acceptability)

	mean	SD	n
Question prompt list goals achieved			
This question prompt list will help the (capable) person living with dementia and the family organise their thoughts about the later stage of life	3.8	0.84	64
This question prompt list will help them formulate important questions about dementia and end-of-life care, making it easier to ask the health care professional questions	3.9	0.81	64
This question prompt list will help them to have conversations with healthcare professionals and also conversations with each other	3.8	0.79	64
This question prompt list will make choices about care and treatment easier for them	3.2	0.91	64
Other possible benefits of the question prompt list			
This question prompt list will help them to get information that is important to them in a timely manner	3.7	0.82	63
This question prompt list will make a person living with dementia or family feel supported and understood as to what they go through, and they will be better prepared for the future	3.6	0.94	63
Thanks to this question prompt list they can get the best possible personalized care.	3.1	0.88	62

Bold indicates either close to strongly disagree (red, mean 1 to 2; did not occur) or close to strongly agree (green, mean rating 4-5; did not occur), and large variation (red, > 1 SD; did not occur).
No differences ($p<0.05$, t-test) were observed between elderly care physicians and GPs.

Supplement 3. Interview guide

Interview guide for evaluation of the question prompt list ”Talking about the later stages in life in dementia” Translated from Dutch by a professional translator.

INTRODUCTION

First of all, thank you for your willingness to participate in this interview, after you have already assessed the question prompt list in a questionnaire. The purpose of this interview is to elaborate on what you think of the question prompt list and how it might be applied. It would be helpful to refer to the question prompt list you received from us during the interview. Of course we can provide a copy if you don’t have it with you. We will also ask you about your views on openly discussing end-of-life care and palliative care in dementia in general.

The interviews will be recorded. Your information will be treated confidentially and analyzed in the secure environment of LUMC. The data used for any publication will not be traceable to your personal data. If you agree, please sign the informed consent form.

Do you have any questions before we begin?

THE QUESTION PROMPT LIST

1. What do you think of the question prompt list in its current form?
   Possible follow-up question: Which themes are missing?
2. What do you like about the question prompt list?
3. What don’t you like about the question prompt list?
   Possible follow-up questions: Do you have tips on how to improve these points? If so, what are they?
4. Are there parts or factors in this question prompt list that could impede the conversation between you and the patient and (loved one) (family)?
   a. **If yes**: Which?
   b. **If no**: Do you feel that the question prompt list as a whole facilitates conversations?
      Possible follow-up question: How can these impeding factors be reduced or resolved?

For interviewer, to the participant:
Explain that the subject of the questions will now shift from the question prompt list to discussing sensitive subjects with persons living with dementia and family/loved ones. Also indicate that there will be more questions about the question prompt list later.

DISCUSSING SENSITIVE SUBJECTS

1. How difficult (or easy) do you find talking about the course of dementia and end of life (care) with patients and family/loved ones?
    a. *(**if little experience**): Which subjects seem most difficult to discuss? What do you think is the easiest way to make them discussible? Do you think this will become easier over the years (experience)?*
    b. *(**if very experienced**): Is it easier for you now than at the beginning of your career? What factors played a role? **If yes**: How do you deal with difficult subjects now and how is that different from the beginning of your career?*
2. Do you think the subjects highlighted in the question prompt list are easy to discuss in general?
3. Are there any subjects you find difficult to discuss with patient and family?
    a. **If yes**: Which subjects?
    b. **If no:** Are all subjects easy to discuss for you?
    Possible follow-up questions: Does this have to do with your experience regarding these conversations? (if not yet discussed under 1., and then elaborate in same manner) Does the question prompt list (also) contain certain example questions that you find difficult to answer?
    Possible follow-up question: What would you need to be able to answer these questions?
    Possible follow-up question: How to act when resistance is sensed from patient/family?
4. Have you (personally) found ways to make certain subjects easier to discuss in these types of conversations?
    a. ***If yes**: How do you go about it?*
    b. ***If no**: What do you need to change/improve your approach?*
5. Will the question prompt list contribute to initiating/starting the conversation with the patient and family/loved ones? And will it influence the moment of initiation?

IMPLEMENTATION IN PRACTICE

1. When a final version is available, would you want to apply this question prompt list? Why/Why not? ***If yes**: How would you want to apply the question prompt list?*
2. Are there any particular preconditions that must be met in order to be able to use this question prompt list?
3. Could this question prompt list also be applied by other healthcare professionals? ***If yes**: By whom, and would you recommend it?*
4. Do you think that question prompt lists should be used more frequently in the future in other fields or for other diseases, when available? ***If yes**: What fields/diseases?*

QUESTIONS BASED ON QUESTIONNAIRE RESPONSES

Explanation of goal:
In the final part of the interview, we would like to hear the physician's opinion, based on certain answers he/she provided in the questionnaire. As the answers to the questionnaires will vary from person to person, our goal is to record a few specific questions based on the answers to make sure all of the physician's perspectives and opinions are heard. This allows us to highlight as many different perspectives as possible.

Questions will partly have the same structure (but may deviate):

- In the questionnaire your answer to question [?] was [?]. We would really like to know what reasoning led to this answer. Can you please elaborate on your answer?
- **When physician is positive**: How do you think [?] can influence the conversations between physicians and persons with dementia and family/loved ones?
- **When physician is negative**: What should be changed in your opinion? What do you feel is necessary to do this?

1. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Topic	**Item No.**	**Guide Questions/Description**	**Reporting (reported in section, para)** **Note, page numbers refer to PDF MERGE PAGE NUMBERS**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	Interviews were conducted by JTS, SH, and physician AK named in the Acknowledgement section (Methods, before last para; page 6, line 3-7)
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	SH-Master student working in nursing homes a JTS-PhD epidemiologist AK-MD researcher who had not been involved in QPL development (Methods, before last para; page 6, line 3-7)
Occupation	3	What was their occupation at the time of the study?	See item 2
Gender	4	Was the researcher male or female?	JTS and AK are females, SH male (Methods, before last para; page 6, line 3-7)
Experience and training	5	What experience or training did the researcher have?	JTS has experience with qualitative research. SH and AK are novice qualitative researchers with no PhD title (yet), supervised by JTS. We did not include these details in the reporting of the mixed-methods study to leave room to reporting of the survey as well.
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No, we selected interviewees based on survey ratings linked to IDs without immediately seeing any names, and none of the interviewees happened to be known to the interviewers. We did not include this detail in the text but we reported selection of interviewees "based on a particularly high or a low acceptability score." (Methods, before last para; page 5, line 56-58)
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The participants knew we wanted to evaluate the question prompt list they read and evaluated by completing the survey before the interview. (The Methods section is structured around the survey performed first and interviews afterwards; page 5)
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons	No other characteristics than those under no 1-7.

		and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis was used with no specific methodological orientation (page 6, line 16)
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling (Methods, before last para; page 5 line 58)
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	If willing to be interviewed, the participants left contact details on the last page of the survey (telephone number or email or both according to their preference, but we did not specify contact details as we judged the choice offered for a preferred way of contacting practitioners not the most relevant detail). (Methods, before last para; page 5, line 54-55)
Sample size	12	How many participants were in the study?	10 interviewees (Results, para Interviewees; page 7, line 44-45)
Non-participation	13	How many people refused to participate or dropped out? Reasons?	None (Results, para Interviewees; page 7, line 44-45)
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	We traveled to the physician's workplace. (Results, para Interviewees; page 7, line 46)
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No-one else was present; we mentioned the interviewers with item 1.
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	We describe gender, profession, trainee / supervisor status (Results, para Interviewees; page 7, line 46-50)
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The interview topic guide was translated to English and provided as a Supplemental file (referred to page 6, line 8). It was not pilot tested but some late adaptations were based on interesting findings in the survey as this is a mixed-methods study.
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No, we felt this was not necessary for individual or dyadic interviews with practitioners on defined topics.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	The interviews were all audio recorded (Methods, last para; page 6, line 13)

Field notes	20	Were field notes made during and/or after the interview or focus group?	Limited field notes were made. We did not include this detail in the manuscript to leave room to report the Methods of the survey.
Duration	21	What was the duration of the interviews or focus group?	Interviews were held with a median duration of 46 minutes (SD 15) (Results, para Interviewees; page 7, line 50)
Data saturation	22	Was data saturation discussed?	The last three interviews contributed little to the findings. (Results, Interview themes, first para; page 7, line 53)
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	Transcripts were not returned to busy physicians.
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	The three interviewers coded the first interviews together, and other interviews were coded by SH. (Methods, last para; page 6, line 17-20)
Description of the coding tree	25	Did authors provide a description of the coding tree?	188 codes and 11 subthemes are available upon request - available in Dutch only (mentioned in the Methods, last para; page 6, line 20-21)
Derivation of themes	26	Were themes identified in advance or derived from the data?	We inductively identified themes (Methods, last para; page 6, line 15)
Software	27	What software, if applicable, was used to manage the data?	We used Atlas.ti version 7.5.18, 2012 (Methods, last para; page 6, line 15)
Participant checking	28	Did participants provide feedback on the findings?	No, the interview was a one-time effort for busy physicians. However, physicians who choose to develop an implementation plan for an accreditation point, received feedback on the plan. (Methods, fourth para; page 5, line 31-33)
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Quotes indicated with letters are included in the text of the Results section, each with a participant number, profession, and trainee or supervisor status (text in italics pages 8-10)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	We selected exemplary quotes (reference for standard / good research practice in Methods; page 6, line 21)
Clarity of major themes	31	Were major themes clearly presented in the findings?	We presented three major themes (page 7, line 53-56)
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Subthemes are included under the main themes in narrative format (pages 8-10). Purposive sampling of physicians with particular positive and negative acceptability

			scores (page 5, line 56-58) helped to identify and understand divergent approaches to discuss end of life and different perceptions on usefulness and implementation. We did not comment on this strength in the Discussion, to leave room to discuss survey results integrated with interview results.

2. Survey reporting checklist

https://www.equator-network.org/reporting-guidelines/good-practice-in-the-conduct-and-reporting-of-survey-research/

Kelley et al. 2003

Practitioners' perceptions of acceptability of a question prompt list about palliative care for advance care planning with people living with dementia and their family caregivers: A mixed-methods evaluation study

Reporting

When reporting survey research, it is essential that a number of key points are covered (though the length and depth of reporting will be dependent upon journal style). These key points are presented as a 'checklist' below:

1. Explain the purpose or aim of the research, with the explicit identification of the research question.

   Aim (abstract; page 3 line 8-10): To evaluate practitioners' perceptions of acceptability and possible use of a QPL [question prompt list] about palliative and end-of-life care in dementia.

   Question (last sentence of introduction; page 4 line 31-33): what are perceptions on acceptability and possible use of the QPL among physicians involved with advance care planning in dementia care?

2. Explain why the research was necessary and place the study in context, drawing upon previous work in relevant fields (the literature review).

   In brief (Introduction, page 4):

-in practice there are numerous barriers to early ACP initiation (references to systematic reviews)

-available booklets provide sensitive information but may not engage patient with dementia and family enough

-QPL can empower people to ask their physician questions and research has shown benefits for patients in oncology (reference to systematic review) and palliative care (reference to Clayton et al.; see also second of two bullet points "What is already known on the topic")

3. Describe in (proportionate) detail how the research was done.

a. State the chosen research method or methods, and justify why this method was chosen.

First paragraph of Methods (page 5, line 6-10): We performed a mixed-methods evaluation study of a QPL among practitioners because … We used validated quantitative instruments followed by interviews to understand perceptions around how the QPL would or would not fit practice.

b. Describe the research tool. If an existing tool is used, briefly state its psychometric properties and provide references to the original development work. If a new tool is used, you should include an entire section describing the steps undertaken to develop and test the tool, including results of psychometric testing.

For the primary outcome, acceptability of the QPL, we referred to an available scale that in turn was developed based on generic decision aid evaluation methodology. We included the full scale in a Supplementary file (referred to page 5, line 38), showing how we rephrased to refer to a QPL instead of a booklet. The Supplementary file also shows any missing values of items (2 to 4), also as an indicator of feasibility. Properties of the acceptability scale are described in the articles on booklet evaluation we refer to, and we added Cronbach's alpha (0.94) for the current study as a Footnote to Table 2 (page 19, line 36) and to the Table in the Supplement. Regarding the usefulness and quality of the contents as secondary outcomes, we referred to a list of barriers developed based on previous work (references included; page 5, line 41-44) and we used a simple 0-10 usefulness scale. For the quality of the contents, we used the same items based on

booklet and generic decision aid methodology (with references; page 5, line 39-40).

c. Describe how the sample was selected and how data were collected, including:

   i. How were potential subjects identified?

      Methods: "The academic medical training centres of universities in Leiden and Nijmegen, the Netherlands granted access to residents and supervisors in elderly care medicine and general practice." (page 5, line 21-23)

   ii. How many and what type of attempts were made to contact subjects?

      Methods: there was "one general reminder via e-mail" (page 5, line 31)

   iii. Who approached potential subjects?

      The academic medical center granted access to the research team to send the survey. (page 5, line 21-23)

   iv. Where were potential subjects approached?

      General practitioners and elderly care physicians. (page 5, line 21-23)

   v. How was informed consent obtained?

      Methods: "Completing and returning the survey on the QPL served as informed consent for this study" (page 5, line 30-31)

   vi. How many agreed to participate?

      Results: 66 of (160 * 2) copies of the surveys were returned. (page 7, line 7-9)

   vii. How did those who agreed differ from those who did not agree?

      Because of privacy regulation, we could not perform a non-response analysis. The response rate did not differ between the two academic centers (21% and 20%). We choose to not include this detail to leave room for reporting on the qualitative interviews.

   viii. What was the response rate?

      21% (66/160*2) (page 7, line 7-9)

4. Describe and justify the methods and tests used for data analysis.

   Methods: we used descriptive statistics to present the results and compared subgroups with appropriate tests (page 5, line 52-53). Footnotes to the Table specify we used the hierarchical gamma test, Chi-square, and t-tests to compare

characteristics between GPs and elderly care physicians, and adjusted for physician characteristics for continuous outcomes with linear regression.

5. Present the results of the research. The results section should be clear, factual, and concise.

   We used two headings for the survey results: “Survey participants,” and “Survey-acceptability and use” (page 7). Similarly, we used two heading for the interview results: “Interviewees” and “Interview themes” (page 7). The final Results paragraph for the mixed-methods study is called “Integration of survey and interview results” (page 10).

6. Interpret and discuss the findings. This ‘discussion’ section should not simply reiterate results; it should provide the author’s critical reflection upon both the results and the processes of data collection. The discussion should assess how well the study met the research question, should describe the problems encountered in the research, and should honestly judge the limitations of the work.

   To comply with this requirement, we used the structured Discussion with headings “Main findings and interpretation,” “Strengths and limitations of the study,” and “What this study adds: implications and conclusions” (page 12). The study showed practitioners’ perceptions on acceptability and possible use of the QPL.

7. Present conclusions and recommendations.

   In brief, the practitioners generally found the QPL acceptable and rated the contents as good, yet they had many concerns on how to use it in practice, and some were concerned they could not answer the questions that patient and family may select and ask them. To move forward, practitioners need training and patient and family should be able to access the question prompt list themselves to circumvent possible gatekeeping.

The researcher needs to tailor the research report to meet:

- The expectations of the specific audience for whom the work is being written.

  We assumed a basic understanding of palliative care and advance care planning.

- The conventions that operate at a general level with respect to the production of reports on research in the social sciences.

  We report for a health care audience, policy makers and researchers interested in palliative care in dementia, advance care planning, and promoting conversations about death and dying.