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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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% woman; 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 per cent 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) proactively 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.

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 centres, 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 centre 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,

> **Box 1 Overview of topics covered in the question prompt list**
>
> 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 online supplemental file 1.

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 (online supplemental file 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 general practitioners (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 email. 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] (online supplemental file 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 GPs and elderly care physicians.[19 27–30]

All items were rated on 1–5 point scales 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 V.23 (2018). 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. Interviewees were offered a gift card of €30. Semi-structured face-to-face interviews (seven) were held by SH—male master's student working in nursing homes, JTvdS—female PhD epidemiologist (double interview) and AK—female MD researcher who had not been involved in QPL development (one, and one with SH).

The interviews were guided by an interview guide (online supplemental file 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 general data protection regulation (GDPR). Interview data were managed and coded in Atlas.ti (V.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 on the coding (188 codes and 11 inter-related 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 (ie, 320 in total). Between June and December 2018, 66 (21%) were returned completed by 18 GPs including 2 general practice-based assistant practitioners and 46 elderly care physicians, 1 geriatrician and 1 geriatric nurse. The response rates of the Leiden (21%; 40/190) and Nijmegen centre (20%; 26/130) were similar.

The majority (73%) of the participants were woman, 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 SD (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; online supplemental file 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 recognising that for some questions, there is no, or no certain answer. Overall one-third (35%) of the

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 patients with dementia; 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 patients with dementia; 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 patients with dementia dying in the past year, %	
0	2
1–4	27
5–9	25
10–19	34
20 or more	13

Significant differences (p<0.05) between GPs and elderly care practitioners were not observed for sex, trainee or supervisor status (χ^2), age and experience (t-test). With the hierarchical gamma test there were differences between the last three items; elderly care physicians cared for patients with dementia more frequently (eg, daily 70% vs 22%), cared for patients in later stages (eg, advanced stage 70% vs 11%) and more patients with dementia died in their practice in the past year (eg, 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.
GP, general practitioner.

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 vs example questions, %	
Too much information	20
Too many example questions	9
Just right	70

No differences (p<0.05, t-test or χ^2 as appropriate) were observed between general practitioners (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 online supplemental file 2, table S1 and table S2 for individual items and item scores).
†Theoretical range score: 0–10.
‡Theoretical range score: 16–80 (see online supplemental file 2, table S3 for item scores).

participants 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 from July to November 2018. Of the physicians (seven female and 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) min.

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) proactively engaging in end-of-life discussions in practice; and (3) considering possible implementation of the QPL.

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:

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

Range of perceived barrier scores (means and SDs five items)*	2.4–2.9 (0.89–1.1)
Goals and anticipated benefits of use (means and SDs seven items)*	3.1–3.9 (0.79–0.94)
Do you think patients with dementia 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

*Items are shown in online supplemental file 2, table 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, χ^2 or t-test as appropriate) were observed between general practitioners (GPs) and elderly care practitioners 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.
QPL, question prompt list; MMSE, Mini-Mental State Examination.

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 (χ^2) were observed between general practitioners (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'

"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 on 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)

Proactively 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 proactive 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 educational 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)

Considering possible implementation of the QPL

The interviewees selected for being positive about the QPL would like to consider 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 hypothesised 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 with those who felt they could (46 vs 54; p=0.015), with a higher SD (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 vs 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 centre 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 this 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 centre, may not be generalisable 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 seven more questions and new, practical tips (online supplemental file 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 generalise 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 do not 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 recognised.[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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Data availability statement The de-identified survey participant data may be requested from the corresponding author upon reasonable request. Interview recordings and transcripts are not available as they might render physicians recognisable to insiders.

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