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Non-specialist palliative care - question prompt list preparation: patient, family and clinician experiences

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ABSTRACT

Objectives Question prompt lists (QPLs) support patients and family to ask questions they consider important during conversations with clinicians. We aimed to evaluate how a QPL developed for specialist palliative care is used during consultations and is perceived by patients and family, and how non-specialist clinicians would use the QPL. We further developed the QPL using these perspectives.

Methods The QPL is part of a conversation guide on palliative care. Patients and family were asked to select topics and questions before consultation with a palliative care consultant. This qualitative study (2016–2018) included 18 interviews with patients and family who had used the QPL, 17 interviews with non-specialist clinicians and 32 audiotaped consultations with palliative care consultants. The data were analysed thematically and iteratively to adjust the QPL accordingly.

Results All participants considered the QPL elaborate, but recommended keeping all content. Patients and family found that it helps to structure thoughts, ask questions and regain a sense of control. They also felt the QPL could support them in gathering information. Although it could evoke strong emotions, their real challenge was being in the palliative phase. Clinicians considered the QPL especially helpful as an overview of possible discussion topics. During audiotaped consultations, topics other than those selected were also addressed.

Conclusion By using the QPL, patients and family felt empowered to express their information needs. Its use may not be as unsettling as clinicians assume. Nevertheless, clinicians who hand out the QPL should introduce the QPL properly to optimise its use.

INTRODUCTION

Palliative care aims to address needs and preferences of patients in the last phase of

Key messages

What was already known?

- It is important that patients and family are able to express their care needs and questions in order to tailor and offer appropriate palliative care.
- The use of the question prompt list (QPL) developed by Clayton *et al* enabled patients and family to ask more questions about prognosis and end of life during palliative care consultations.

What are the new findings?

- Patients and family as well as clinicians found the QPL comprehensive and not too extensive; because of its relevance they would not shorten the QPL.
- Clinicians considered the QPL both as a reminder for themselves to have an overview of what topics can be discussed, and as a helpful tool for patients and family to prepare their consultation; patients and family also used the QPL to discuss topics among themselves.

What is their significance?

Research

- The use of the QPL enabled patients and family to regain a sense of control over their life and future, which helps to make informed and personalised decisions about the end of life.

Clinical

- Prerequisites for optimal use are that patients and family are already familiar with the concept of palliative care, that patients identify themselves as being in the palliative phase and, that patients and family have enough time, energy and inner space to use the QPL.

life, and their family.¹ Effective communication is essential in determining their palliative care needs and values.^{2–4} Studies have shown that patients and family have information needs regarding palliative

care, what their future will look like, prognosis and the dying phase.^{5–8} Specifically, they often do not know what to expect from palliative care consultations, which questions they may ask or what palliative care entails.^{9,10} Lack of knowledge decreases feelings of self-efficacy and results in perceived loss of control.^{11,12} Providing information can stimulate self-management, help patients and family cope with their current situation and prepare for the future.⁵ However, clinicians without formal palliative care training (non-specialists) often do not ask patients about palliative care needs sufficiently, especially when it concerns non-physical domains.^{13,14}

Question prompt lists (QPLs) are structured lists of sample questions. These lists aim to support patients and family in formulating questions to obtain the information they need, in identifying their concerns, improving their communication with clinicians and, if possible, in fully participating in consultations and decision-making by expressing their wishes.^{15,16} Clayton *et al* developed a QPL for patients with palliative care needs.⁴ Patients who had used this QPL asked more questions, especially about prognosis and the future, compared with patients who had not used a QPL, and did not experience more anxiety than those who had not.^{6,17,18} Patients and family who had used QPLs in oncology memorised information better, and consultations were more tailored, while they did not take more time.¹⁹

In this study, we examined how a palliative care QPL is used and valued for hospital-based palliative care consultations from the viewpoint of patients and family and non-specialist clinicians. Using their perspectives, we further developed the QPL iteratively.

METHODS

Leiden Guide on Palliative Care

The QPL under study is part of the Leiden Guide on Palliative Care. This conversation guide was developed in 2013 by our Center of Expertise in Palliative Care to assess symptom burden and to empower patients and family in identifying and formulating their questions and information needs regarding palliative care. The conversation guide includes the Utrecht Symptom Diary (a Dutch adaptation of the Edmonton Symptom Assessment Scale)^{20,21} for symptom assessment and a Dutch adaptation of Clayton *et al*'s QPL on palliative care, to identify information needs (figure 1).⁴ Topics and questions were added to fit the Dutch health-care system (online supplemental file 1). The 2013 version of the QPL was used until the next iteration in October 2018. As part of their routine, the palliative care consultants provided the conversation guide to patients and family a few days before the consultation so that they could select topics to discuss. Patients and family were free to use (parts of) the conversation guide or not. Patients who did not have enough time to prepare for the consultation were either in an acute

Leiden Guide on Palliative Care

A conversation guide for palliative care consultations which is handed out to patients and family to prepare for their consultation.

Part 1: Utrecht Symptom Diary

Aim: assessment of symptom burden

Patients are invited to fill out their symptom burden using the Utrecht Symptom Diary²¹: twelve patient-reported numeric rating scales (0–10) of symptoms prevalent in the palliative phase, adapted from the Edmonton Symptom Assessment Scale.²⁰

Symptoms:

Pain, sleeping difficulties, dry mouth, swallowing difficulties, loss of appetite, constipation, nausea, dyspnea, fatigue, anxiety, depression

It also comprises:

Numeric rating scale for "Well-being"

Open question to prioritize a problem:

"In your opinion, which complaint(s) should be solved first?"

Part 2: Question Prompt List

Aim: assessment of information needs

Patients and family are invited to go through the list of topics and questions and to select those topics they want to discuss. Part 2 is adapted from the question prompt list by Clayton *et al*.⁴

It comprises:

A list of 35 conversation topics grouped in six categories

A list of 40 sample questions grouped in the same six categories

Six categories:

Complaints or problems

Future

Medication and treatment

Social or meaning

Organization of care

Last phase of life

Examples of sample questions:

How do I balance rest and activity?

How do the medicines that I use work?

How can I discuss important choices or events in my life?

How can I arrange home care now or in the future?

Can I get information about the possibilities of care in the last phase of life?

Figure 1 Outline of the Leiden Guide on Palliative Care.

situation, physically too unfit or dying. Consultations in these situations are mostly aimed at managing a palliative care crisis or the dying phase. Therefore, these patients were not provided with the QPL. We estimate, from our clinical records, that patients and family used the QPL prior to the consultations in 22%.

Study design

This study evaluated the use of the QPL-part of the Leiden Guide on Palliative Care with a triangulation of qualitative research methods: thematic analysis of semi-structured interviews and audiotaped consultations. This study took place between August 2016 and December 2018.

Participants and procedures

Consultants of the hospital palliative care team sampled patients and family purposively (regarding diagnosis, age and gender) to acquire a diverse sample for interviews about their experiences with the QPL (online supplemental file 2: Topic list). It was estimated beforehand that 15 interviews were needed to achieve data saturation. Patients were ineligible if they had not used the QPL, were not clinically fit to be interviewed or if the palliative care consultant estimated their life expectancy <3 months. After obtaining informed consent, a researcher (M-JV, BS or DW-V) interviewed the patients after the consultation. Family were invited

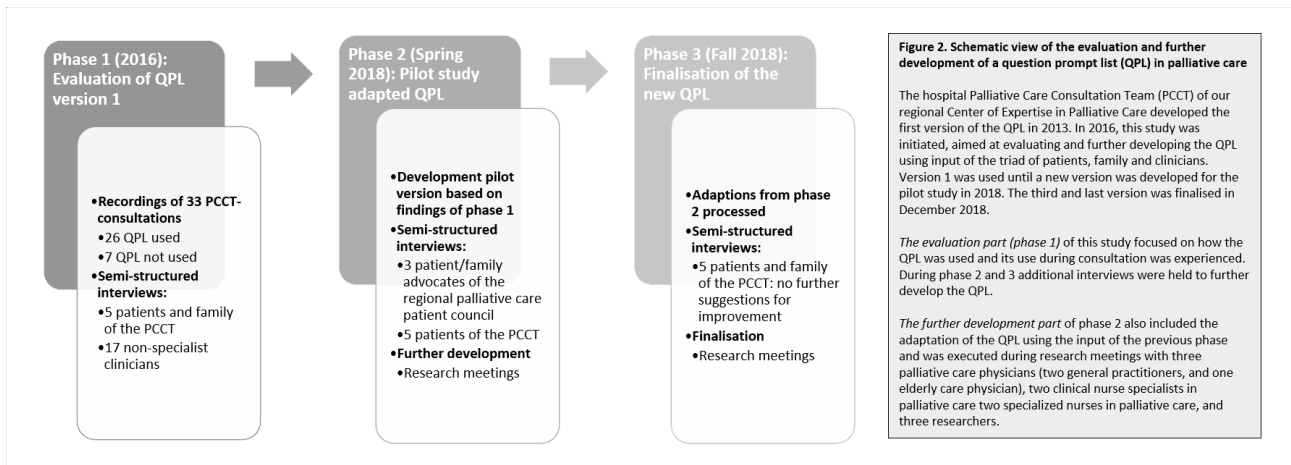


Figure 2 Schematic view of the evaluation and further development of a question prompt list (QPL) in palliative care.

to take part in the interview or to be interviewed instead of the patient if the patient preferred so. Although we aimed at purposive sampling, we found that some patients and family were too exhausted to discuss the full QPL or did not remember in detail how they had used it. In these cases, we had to resort to convenience sampling regarding prognosis or physical functioning; additionally, we further gathered input from the patient and family's perspective through patient and public involvement by interviewing three patient/family advocates from our regional palliative care consortium. These advocates had not used the QPL before and reviewed it before and during the interview.

Clinicians were included for an interview if they had no formal palliative care training,²² but worked in a medical specialty providing care for patients in the palliative phase on a regular basis. To explore whether these non-specialist palliative care clinicians would support the use of a palliative care QPL and how they would use it, we included clinicians who had not used the QPL before (figure 2). Clinicians were purposively sampled via the Center of Expertise in Palliative Care's network until a diverse sample was reached regarding profession, medical specialty, years of working experience and working in or outside the hospital. A researcher (BS) interviewed the clinicians; 15 interviews were planned to achieve data saturation.

Consultants of the hospital palliative care team selected consenting patients and family to audiotape their consultations with a palliative care consultant to explore which topics were addressed. Both patients who had used a QPL and patients who had not used it were included. To evaluate how the QPL was used during consultations, only consultations of patients who had used the QPL were included. To evaluate what topics had been addressed during consultations but are not listed in the QPL, also consultations in which patients had not used the QPL were included.

Further development of the QPL

The QPL was iteratively adapted based on suggestions made by the interviewees, findings from the audiotaped consultations and grey literature (figure 2). The first revision was done after analysing all consultations, interviews with clinicians and five interviews with patients and family. We aimed to revise the QPL iteratively after each set of five interviews with patients and family, until no additional suggestions emerged from the interviews. Adaptations were made in consecutive research meetings with three palliative care physicians (two general practitioners, and one elderly care physician), two clinical nurse specialists in palliative care, two specialised nurses in palliative care and three researchers.

Data analysis

A trained research assistant transcribed the interviews and consultations verbatim and de-identified all data. Two independent researchers coded the transcripts of the interviews inductively (BS and M-JV: interviews with clinicians; DW-V and M-JV: interviews with patients and family), adhering to Braun and Clarke's method for thematic analysis.²¹ Interviews were analysed thematically to explore user experience and usefulness of the QPL during the consultations, and to assess whether topics were missing in the QPL and what should be changed about the QPL. Themes were finalised in consensus meetings and were categorised using a code tree.

For content analysis of the audiotaped consultations (BS and M-JV), a coding scheme was developed (AHP and BS) to code: (1) which topics from the QPL were addressed during consultations; and (2) the person who initiated the discussion of a topic (patient, family or clinician). A category was considered to have been selected, addressed or initiated if one of the underlying topics had (figure 1, online supplemental file 2). Frequencies are reported using descriptive statistics.

RESULTS

Thematic saturation on the use of the QPL and suggestions for improvement of the QPL was reached after 18 interviews with patients and family (including the three patient/family advocates), and 17 interviews with clinicians (table 1). Of the 33 audiotaped consultations, one recording was excluded from analysis because of poor quality (table 2; for patient characteristics, see online supplemental file 3). Three iterations of the QPL were made based on the data; after the third round of interviews with patients and family, no new suggestions to improve the QPL emerged (online supplemental file 4).

Use of the QPL among patients and family

Patients and family described the QPL as helpful: its content raised awareness about what palliative care and a palliative trajectory entail. It structured their thoughts about their situation, problems and questions. "It is a very good summary of what might be coming your way. (...) It provides an overview." (patient 13) They appreciated that the QPL presented topics that they had not thought about before, supported their thinking about what questions they may have, and that it invited them to talk about it. "About hospice care, for example, I have never talked about that before, or even thought about it." (patient 1) "I found it illuminating to have a list of topics that can be discussed. And presenting the different topics also makes you think about the questions you may have." (daughter of patient 4) "I think that this could clearly contribute to an improved relationship between patient and clinician. (...) Because the patient and next of kin often experience a threshold towards a clinician. Um, like: can and am I allowed to ask this." (patient 12) It could also inspire patients and family to think about topics specific to their situation, even if they were not mentioned in the QPL. The QPL could further evoke discussions between patients and family members: "(...) that on the basis of this, by reading about the subjects, you actually start thinking about them, you start talking about them more, like 'what do you think?'" (daughter of patient 4) Two participants said that the QPL helped patients to think about and to report their end-of-life wishes, and it is important not to leave this to their family.

Patients and family felt that the QPL enhanced a sense of control by informing them, structuring their thoughts and questions, lowering thresholds to discuss matters and supporting reporting end-of-life wishes. They often had experienced loss of control because they regarded themselves as knowing nothing about palliative care and palliative care consultations. "(...) for us, it was actually the very first time we thought about palliative care and we really had no idea what to make of it." (patient 4) Additionally, their minds were often occupied with many questions, their palliative diagnosis and the elusiveness of their future: "I

Table 1 Characteristics of interviewees and of patients whose consultations were audiotaped

Interviews		
<i>Patients, family and patient/family advocates: N=18</i>		
Patient age, median (range)	69	(46-83)
Patient sex, male, n (%)	11	(61)
Role of interviewee, n (%)		
Patient	10	(56)
Family	5	(28)
Patient advocate	3	(17)
Patient primary disease diagnosis*, n (%)		
Oncological	14	(78)
Dementia/frailty	1	(6)
Complex regional pain syndrome	1	(6)
Haematological malignancy	1	(6)
Others present during interview, n (%)		
Partner	1	(6)
Children	2	(11)
Patient	1	(6)
Other	1	(6)
None	13	(72)
<i>Clinicians: N=17</i>		
Age, median (range)	36	(30-59)
Sex, male, n (%)	2	(12)
Occupation, n (%)		
Medical specialist	8	(47)
Nurse	6	(35)
Resident	3	(18)
Medical specialty, n (%)		
Medical oncology	4	(24)
General practice	3	(18)
Radiation oncology	3	(18)
Elderly care	1	(6)
Orthopaedics	1	(6)
Psychiatry	1	(6)
Surgery	1	(6)
Paediatrics	1	(6)
>1 specialty	2	(12)
Audiotaped consultations		
<i>Patients who used a QPL: N=25†</i>		
Age, median (range)	67	(46-80)
Sex, male, n (%)	15	(60)
Patient primary disease diagnosis, n (%)		
Oncological	24	(96)
Kidney failure	1	(4)
Median survival, months (IQ-range)	6	(3-51)

Median duration of interviews with patients, family and patient/family advocates was 17 min (range: 4–39; the shortest interview was stopped because the patient was called for diagnostic imaging). Median duration of interviews with clinicians was 30 min (range: 18–57). Median duration of 25 consultations was 53 min (range 38–78).

*The primary disease diagnosis of one patient was missing.

†In total, 32 consultations were recorded; 7 patients had not used the QPL. The median duration of 32 consultations was 53 min (range 35–78).

QPL, question prompt list.

Table 2 Topics from the question prompt list (QPL) that patients (N=25) selected and that were addressed during their consultation with palliative care consultants

Topic	Selected in the QPL		Addressed during the consultation		Selected and addressed		Initiator of topic			
	%	N	%	N	%	N	Patient or family		Palliative care consultant	
							%	N	%	N
<i>Category: Complaints or problems</i>	92	23	100	25	100	23	88	22	100	25
Pain	64	16	92	23	100	16	30	7	70	16
Constipation	20	5	76	19	100	5	16	3	84	16
Shortness of breath	28	7	44	11	86	7	27	3	73	8
Nausea	24	6	56	14	83	6	50	7	50	7
Less appetite	40	10	76	19	90	10	37	7	63	12
Fatigue	48	12	88	22	83	12	36	8	64	14
Dry mouth	24	6	60	15	100	6	13	2	87	13
Nutrition	20	5	76	19	100	5	63	12	37	7
Anxiety	28	7	68	17	86	7	35	6	65	11
Depression	28	7	56	14	100	7	29	4	71	10
Sexuality and intimacy	0	0	0	0	N/A	N/A	N/A	N/A	N/A	N/A
<i>Category: Future</i>	64	16	68	17	81	16	29	5	77	13
Complaints expected for the future	56	14	60	15	79	14	33	5	67	10
Possibilities for managing future complaints	52	13	32	8	39	13	13	1	88	7
<i>Category: Medication and treatment</i>	76	19	96	24	95	19	63	15	96	23
Side effects of medication	24	6	56	14	100	6	43	6	57	8
Medication intake times	20	5	48	12	100	5	17	2	83	10
Next steps medication	32	8	60	15	75	8	13	2	87	13
Medication for worsening complaints	44	11	48	12	64	11	8	1	92	11
Types of morphine-like medication	32	8	60	15	100	8	33	5	67	10
Choice of whether or not to treat the disease	44	11	48	12	64	11	50	6	50	6
Choice between treatment and quality of life	64	16	52	13	75	16	39	5	62	8
<i>Category: Social or meaning</i>	40	10	68	17	100	10	53	9	53	9
Help or information for children	28	7	44	11	100	7	27	3	73	8
Help or information for relatives	32	8	32	8	88	8	25	2	75	6
Meaning of life	4	1	20	5	0	1	80	4	20	1
<i>Category: Organisation of care</i>	68	17	100	25	100	17	68	17	96	24
Home care	44	11	80	20	91	11	30	6	70	14
Household care	8	2	20	5	100	2	0	0	100	5
Hospice care	44	11	52	13	91	11	46	6	54	7
Volunteers	8	2	20	5	100	2	40	2	60	3
Point of contact for complaints	44	11	60	15	82	11	33	5	67	10
Role of the general practitioner	40	10	100	25	100	10	24	6	76	19

Continued

Table 2 Continued

Topic	Selected in the QPL		Addressed during the consultation		Selected and addressed		Initiator of topic			
							Patient or family		Palliative care consultant	
	%	N	%	N	%	N	%	N	%	N
Possibilities of care	44	11	36	9	36	11	22	2	78	7
Category: Last phase of life	56	14	88	22	99	14	91	20	77	17
Palliative sedation	24	6	48	12	67	6	8	1	92	11
Euthanasia	40	10	68	17	100	10	47	8	53	9
Fluids and nutrition	16	4	24	6	50	4	50	3	50	3
Practical matters of the end of life	24	6	40	10	67	6	90	9	10	1
Course of the last phase of life	36	9	48	12	44	9	75	9	25	3

Patients and family were asked to select the topics they wanted to discuss during their consultation with a palliative care consultant. Their selections of topics were compared with the topics that were addressed during their actual consultation and who initiated the topic during the consultation.

The totals of topics may exceed the total of addressed categories, since a category was considered selected, addressed or initiated if one of the underlying topics was.

wasn't lying there for the fun of it. There was a lot of stuff going through my mind." (patient 8) Asking their questions helped them to gather concrete solutions for current and future problems: "Yes, and with the answers I now have a better idea of what I am in for. (...) you know what to expect, and what you can do, and what you need help with and how that works." (patient 17) "Maybe later, yes, then this can, you have something to hold on to [indicating the QPL]." (patient 14)

Patients and family considered the possibility to indicate which topic or question to discuss, before, during and after the consultation, convenient. "I also indicated that by ticking the boxes. I like that." (patient 5) They said that the QPL supported asking specific questions during the consultation. During consultations, the QPL was used to gather practical information about specific topics and to make notes. After the consultation, patients sometimes used the QPL as a reminder to discuss some topics later, or re-used it in consultations with other clinicians involved, such as the general practitioner or medical oncologist.

Usefulness of the QPL among non-specialist clinicians

Clinicians hypothesised that the QPL could be useful for them as an overview of information needs patients and family may have, and as a manual with topics relevant to palliative care conversations. They thought that it would help them focus more on patients' and families' needs. "It [the QPL] requires more depth, but I think that is something the clinician has to look for. (...) I really see this as a helpful tool to support the conversation." (clinician 14) They thought that the QPL could be used to check whether all relevant topics had been covered. "I think it is a fantastic reminder, but actually even more for the physician than for the patient." (clinician 5) Especially topics regarding

the future were considered important: "I think especially the future, indeed [is a topic that often emerges in conversations about palliative care]. (...) I think that that is something patients primarily want clarity about." (clinician 3) Some clinicians indicated that the QPL could be supportive as it listed topics they used to explain 'future scenarios' to patients and family: "We always try to list every possible scenario. Apart from the symptoms. (...) And then we try to go through them, and we try to make a plan." (clinician 15)

Barriers to QPL use

Patients, family and clinicians identified several barriers to using the QPL (table 3). Some patients and family indicated that they had not been properly informed yet about their disease phase or the concept of palliative care, or that they had not thought about it; this made them unprepared for some topics presented in the QPL. Other reported barriers were not being able to use the QPL because of lack of space, time and energy to go through the QPL and not having a trusting relationship with their clinician to discuss delicate topics. Three patients were unable to emotionally relate to the palliative care topics; they found them too challenging and skipped the sections they thought did not apply to them. Nonetheless, they understood these topics would become important at some point, or may already be relevant to others and they felt it was right that the topics were part of the QPL. Optimal use of the QPL was further thought to be impeded when patients and family had just received bad news, or when they were busy arranging medical visits and care. Some patients and family indicated that patients with cognitive problems would be unable to understand the QPL.

Most clinicians regarded the QPL as too extensive for discussion in a single consultation of 10–15 min. They indicated they would only discuss the topics

Table 3 Barriers to use and value of the QPL, and recommendations for clinicians

Barriers to use and value	Recommendation for clinicians
<i>Patient-related barriers</i>	
Patient cannot identify himself as being palliative	Introduce concept of palliative care to patient and family
	Explain what the QPL is: it is a tool providing insight into symptom burden and information needs that can be discussed during a consultation about palliative care
	Explain how the QPL can be used: irrelevant or unsettling parts can be skipped
Patient is not able to use the QPL	Family can fill out the QPL if the patient is not able to use it
▶ Not enough space, time and energy to think over and fill out	
▶ Decreased cognitive ability, unable to comprehend	Hand out the QPL at least several days before the consultation takes place
Patient does not trust the consulting clinician and therefore is not ready to discuss sensitive topics	Ask the patient whether he or she is ready to discuss palliative care; make clear to the patient that the QPL can be used at any time in the palliative phase, with any clinician
<i>Clinician-related barriers</i>	
Not sure if the QPL can be handed out to every patient in the palliative phase	The QPL can be used for all patients in the palliative phase and their family
Going through the QPL may take too much time	More than one consultation can be scheduled to discuss the QPL
	Ask the patient at the beginning of the consultation what he or she considers the most important topic to discuss
Not sure which clinician should discuss the QPL	Refer to another clinician or healthcare professional when topics are outside the field of expertise of the clinician or in case time is lacking: nurse specialist, psychologist, social worker, spiritual counsellor

QPL, question prompt list.

within their expertise and refer to other clinicians for the remaining, plan a second consultation or delegate the consultation to a (specialised) nurse.

Topics selected and addressed during consultations

The QPL was used in 25 audiotaped consultations (table 2). A median of 18 topics were addressed during consultations (range: 11–28). Overall, more topics were addressed than patients had selected. Thirteen topics and the categories *Complaints or problems*, *Social or meaning* and *Organisation of care* were always addressed if these were selected. *Sexuality and intimacy* was never selected, nor discussed during the consultations. *Role of the general practitioner* was addressed during all consultations, despite it not often having been selected. Overall, palliative care consultants initiated topics more often than patients and families did, except for topics about the *Last phase of life*. Patients and family most often initiated the topics *Meaning of life*, *Practical matters of the end of life* and *Course of the last phase of life*. The palliative care consultant most often initiated the topics *Household care*, *Medication for when I suddenly get more complaints* and *Palliative sedation*.

Suggestions to improve the content of the QPL

Overall, the QPL's content was considered to be comprehensive and relevant. Table 4 displays suggestions for additional topics and questions that patients, family and clinicians mentioned. They all wanted to add content, but had different ideas about which content should be added. The interviewees noted that all topics in the QPL can be relevant to patients in the

palliative phase and their family: “Oh, you don’t want to know everything we’re thinking about now. That is basically everything that is also in there [indicating the conversation guide].” (patient 11) “Everything [in the QPL] is relevant. It is a very good list. Not too much, not too little.” (clinician 12) Patients and family recommended keeping all topics and questions: topics irrelevant to themselves might be relevant to others; and clinicians agreed. Patients, family and clinicians commented that they would not initiate discussing *Sex and intimacy* during a consultation: “Well, I would be hesitant to discuss sexuality and intimacy, for example, with these ladies.” (patient 1); however, no-one wanted to exclude the topic. We changed *Sexuality and intimacy* into *Intimacy and sexuality* to make the topic easier to discuss.

Emotional challenge of using the QPL

Some clinicians indicated topics that might be emotionally challenging and should not be presented too early in the disease trajectory, meaning not to patients with advanced cancer who still undergo curative treatments. Most patients and family did not feel that using the QPL was more emotionally challenging than being confronted with the knowledge of having a potentially incurable disease. They mentioned that discussing the palliative phase was part of the disease trajectory; they therefore considered all items in the QPL to be relevant: “These are not nice topics, of course not, (...) but I personally find these kinds of subjects challenging. Like, well yes, the time will come, so you should be as prepared as possible.” (patient 2).

Table 4 Input for improvement of question prompt list by patients, family and clinicians, transcribed consultations and Arthur *et al*'s²³ consensus list of prompt questions

Source	Subject
Content added to question prompt list*	
18 interviews with patients and family	<ul style="list-style-type: none"> ▶ Wishes for the last phase of life ▶ Religion and view on life ▶ Spiritual and psychological help ▶ Treatment possibilities ▶ Contact details for acute situations ▶ Self-care for informal caregivers
17 interviews with clinicians	<ul style="list-style-type: none"> ▶ Relationships and family ▶ (Limitations on) hospitalisations ▶ Contact persons in specific situations ▶ Future scenarios
33 transcribed consultations	<ul style="list-style-type: none"> ▶ Independence ▶ Psychological care
Comparison with consensus list of prompt questions†	<ul style="list-style-type: none"> ▶ Questions about informal caregivers ▶ Questions for informal caregivers
Adjusted lay-out and wording of the question prompt list	
Interviews, consultations and grey literature	<ul style="list-style-type: none"> ▶ Shape of the document was changed from five A4 sheets to a 11-page printable booklet (A5) ▶ Lay-out and order of topics and questions were revised ▶ Wording was checked and improved according to Dutch level B1 according to the European Council: "Can understand the main points of clear standard input on familiar matters regularly encountered in work, school, leisure" ▶ Cover page with instructions for patients and family was made more clear ▶ Supplemental leaflet with advice for use and to overcome barriers for clinicians

*Patients, family, patient/family advocates and clinicians preferred no adaptations to the content of the question prompt list.

†Arthur *et al*²³ published a study in clinicians to list the most important prompt questions, which was used by our research group to compare if content should be added to our question prompt list.

DISCUSSION

Main findings

This study evaluated the use of a QPL as part of a conversation guide on palliative care, by means of interviews with patients, family, patient/family advocates and clinicians without formal palliative care training (non-specialists), and by audiotaping consultations with palliative care consultants. Patients and family indicated that the QPL had supported them in thinking about their care preferences and sharing their needs during consultations. Some content could evoke strong emotions in them, but their real challenge was being in the palliative phase. The clinicians indicated that the QPL could help remind them to address relevant palliative care issues. The QPL was improved according to the perspectives of patients, family and clinicians (online supplemental files 5; 6). Barriers to optimal use reported by interviewees included insufficient introduction of patients and family to palliative care and the QPL, lack of time and energy to go through the QPL and patients not seeing themselves as being in need of palliative care.

All interviewees considered the content of the QPL to be relevant, clear and comprehensive, and useful to prepare for palliative care consultations. Arthur *et al* shortened the original QPL on which the present

one was based using a Delphi study among clinicians, because of evidence suggesting that clinicians would prefer a brief QPL.^{4 23} The patients, family and clinicians in our study, similar to Clayton's study,⁴ considered the QPL to be extensive, but they would not shorten it, preferring a broader scope of topics. One topic, *Sexuality and intimacy*, was never selected or discussed. Interviewees doubted they would initiate this topic. Cathcart-Rake *et al* reported clinicians would not discuss sexuality and intimacy in palliative care because they prioritise a holistic view, have time constraints, are not used to talking about sexuality and intimacy or experience it as a taboo.²⁴ At the same time, many palliative care patients have unmet intimacy needs: 48% reported their illness impacted their intimacy; and >75% thought discussing intimacy was helpful both for patients who died within 3 months and patients who lived longer than 3 months.²⁵ We therefore recommend clinicians to bring up this topic during palliative care consultations and so invite patients and family to indicate whether they need information about intimacy and sexuality.

Patients and family reported that the QPL's content helped them to think about, formulate and discuss their questions and wishes and helped them gain an overview

of what the future could hold for them, which corresponds with existing literature.^{4 17 26} In general, information helps patients to regain a sense of control over self-management.⁵ Patients felt further supported by the QPL because it educated them about palliative care and their possible needs in this regard. Our patients and family described loss of control when referred to the palliative care consultant, comparable with Rolland's 'crisis phase'.²⁷ During this crisis phase, patients and family need to adapt to the situation with the new (incurable or palliative) diagnosis and only then, they can move on to adapting a more practical understanding about the illness and the new healthcare setting.

Non-specialist clinicians considered the QPL helpful for patients and family to ask specific questions, corresponding with previous studies.^{4 28} Rogg *et al* found that clinicians find discussing prognosis and future difficult for several reasons and might avoid these discussions.²⁹ In our study, the clinicians mentioned that the QPL provided them with an overview of future scenarios to discuss with patients and family. Literature shows that the future is often an information need in patients and family.^{6 30} However, our findings from the analysis of the actual consultations demonstrate that patients more often selected items about *Complaints or problems* and *Organisation of care*.

Discussions are facilitated when patients, family and clinicians explicitly agree on and allow each other to discuss difficult topics.³¹ In our study, patients and family felt that the QPL gave them permission to ask questions. By empowering patients and family, the QPL aids clinicians to formulate recommendations that are tailored to end-of-life preferences. This corresponds with Galekop *et al*'s results on patient-clinician collaboration: palliative care specialists and volunteers viewed patient-centred care as the patient being either in the driver's seat (ie, respecting the patient's autonomy at all times), or in the passenger seat (ie, collaborating with the patient and other clinicians and stepping in when the patient cannot decide for themselves; when he is too tired or insufficiently informed).³² Remarkably, items about the last phase of life were the only items that were initiated more frequently by patients and family than by the consultant. Perhaps patients and family perceive a consultation on palliative care as an opportunity to talk about the end of life, or consultants considered these to be delicate topics and adopted more of a 'wait-and-see' attitude.

Patients, family and patient/family advocates indicated that a proper introduction to palliative care and the QPL is key: both should be explained to patients and family before handing out the QPL. Additionally, they must have enough inner space, time and energy to use it (table 4). Effective communication about palliative care has been shown to depend on the context, disease stage, a good patient-clinician relationship, mutual understanding between patients and clinicians and 'readiness' of patients and family.^{31 33} This was confirmed by our findings: in order for the QPL to

be effective, several barriers have to be overcome in clinical practice. Clinicians participating in our study provided suggestions for dealing with these barriers, which we used to develop an instruction leaflet for clinicians. In our study, a minority of patients were not yet able to identify themselves as palliative care patients, but they found the QPL no more unsettling than their current situation, which is in line with other findings.¹⁶ Flidner *et al* demonstrated that although patients with advanced cancer found early palliative care consultations emotionally challenging, a QPL allowed them to plan for the future without considering use of the QPL itself burdensome.³⁴ Gatekeeping by clinicians may even disempower patients and family in expressing their needs. Therefore, clinicians should not hesitate to offer patients and family a QPL to prepare their consultation; patients and family can decide for themselves whether or not to use it. To date the QPL has only been used in the setting of specialised palliative care, but the diverse group of non-specialist clinicians who participated in our study indicated that the QPL could also be used by non-specialist clinicians. They indicated that they would refer to the appropriate palliative care clinician if patients and loved ones have complex questions or problems. This corresponds with the palliative care model described by Henderson *et al*: most palliative care is provided by non-specialist clinicians, and palliative care specialists have the responsibility to educate and support their non-specialist colleagues.³⁵ This model of palliative care allows a more integrated approach with current care and early discussion of the wishes, needs and values of patients and their family. To make the QPL more suitable for use by patients of non-specialist clinicians, we used their input to adapt the QPL accordingly.

Strengths and weaknesses

This qualitative study evaluating the use of a palliative care QPL included a triangulation of 35 semi-structured interviews with patients, family and clinicians and 32 audiotaped consultations. Including only patients who used the QPL for individual interviews may have resulted in an overly optimistic view of the QPL. We had decided to include patients with a life expectancy of at least 3 months; earlier experiences with including patients for who had a shorter life expectancy, showed them to be often too tired to participate in a qualitative interview, which makes including them unethical. This may have led to an over-representation of perspectives of patients and family in relatively good health, and to the inclusion of relatively more patients with a diagnosis of cancer compared with other life-limiting diagnoses. However, by asking patient advocates who had a loved one who had died and who had not used the QPL before, we believe we overcame these gaps introduced by selection bias through interviewing those who used the QPL and through a life expectancy of at least 3 months.

Further research

Our study included mostly patients with cancer, similar to most studies on QPLs in palliative care.^{15 36} Before implementing the QPL for use by non-specialist palliative care clinicians, qualitative research is needed on how they experience use of the QPL in clinical practice: the effect of using the QPL, facilitators and barriers to using the QPL effectively and how much training is required for them to use the QPL appropriately. Next, a study with cluster-randomised design in non-specialist clinicians can indicate its effect on patient outcomes. We also recommend further research on whether the interviewees' suggestions are sufficient in improving person-centred communication and patient empowerment. We studied the use of a QPL as a strategy to improve consultations with individual patients and family. Wider and systemic implementation should be preceded by clinical trials evaluating its effect in other patient populations and healthcare settings, such as in general practice and nursing homes. Future research aims include examining the effect of combining a symptom assessment scale and a QPL on perceived quality of care, and the effect of QPLs on patient autonomy and quality of life.

CONCLUSION

Patients and family considered the QPL to be relevant, clear and comprehensive. The QPL was thought to support patients and family in structuring their thoughts and in formulating and asking their questions. They felt better prepared for their current situation and the future. Clinicians can use the QPL as an overview of topics relevant in palliative care and to tailor consultations to the needs of patients and family. Although the QPL could evoke negative emotions, patients and family understood the necessity and usefulness of discussing these topics. Reported barriers to optimal use were insufficient introduction of patients and family to palliative care and to the QPL, patient lack of time and energy to use it, and patients not relating the topics integral to palliative care to themselves.

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