Opportunities to improve palliative care: towards a more patient-centred and proactive approach

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CHAPTER 7

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.

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?

- 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.
- 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.

INTRODUCTION

Palliative care aims to address needs and preferences of patients in the last phase of 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 healthcare system (see Supplement 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 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%.

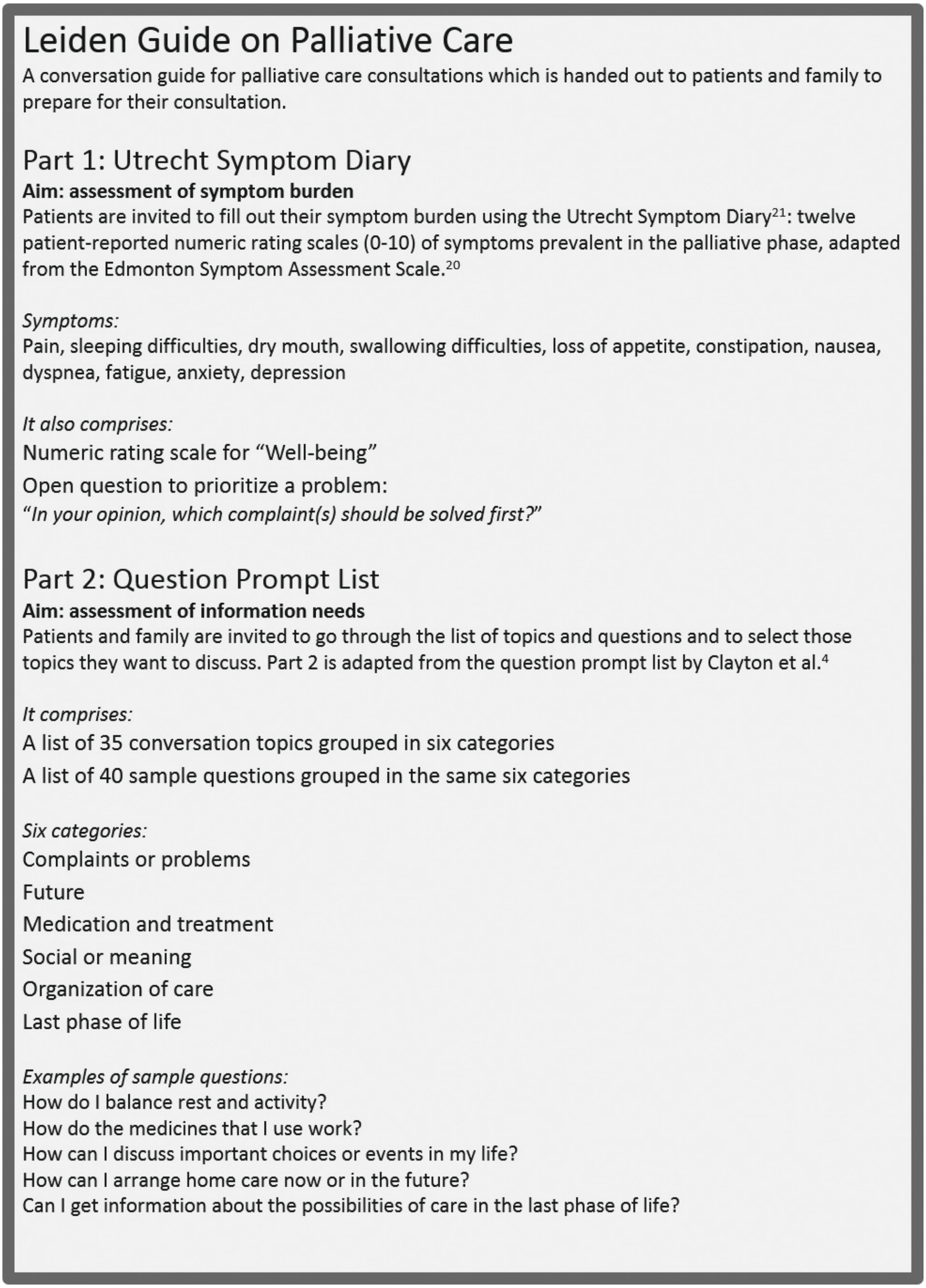
Study design

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 (for the topic list, see Supplement 2). 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 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



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 Diary[21]: 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?

Fig. 1. Outline of the Leiden Guide on Palliative Care

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 categorized 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, Supplement 1). Frequencies are reported using descriptive statistics.

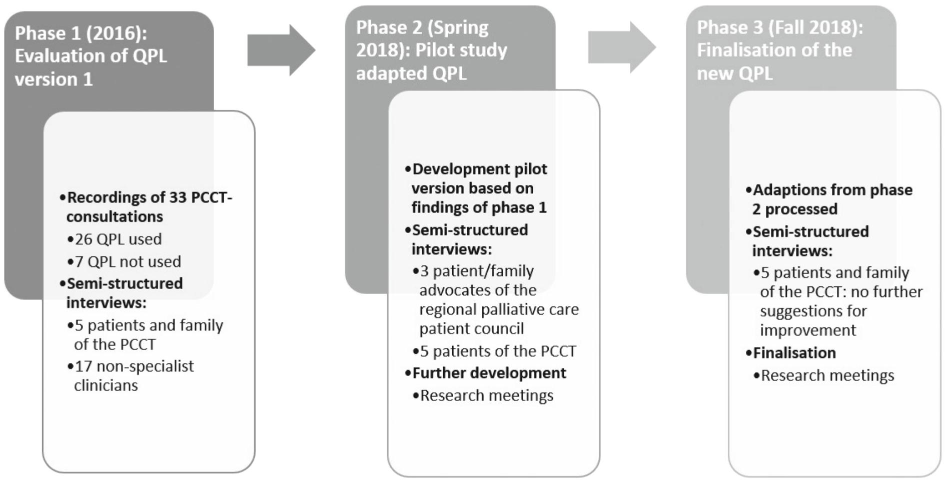


Figure 2. Schematic view of the evaluation and further development of a question prompt list (QPL) in palliative care

The hospital Palliative Care Consultation Team (PCCT) of our regional Center of Expertise in Palliative Care developed the first version of the QPL in 2013. In 2016, this study was initiated, aimed at evaluating and further developing the QPL using input of the triad of patients, family and clinicians. Version 1 was used until a new version was developed for the pilot study in 2018. The third and last version was finalised in December 2018.

The evaluation part (phase 1) of this study focused on how the QPL was used and its use during consultation was experienced. During phase 2 and 3 additional interviews were held to further develop the QPL.

The further development part of phase 2 also included the adaptation of the QPL using the input of the previous phase and was executed during research meetings with three palliative care physicians (two general practitioners, and one elderly care physician), two clinical nurse specialists in palliative care two specialized nurses in palliative care, and three researchers.

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

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 Supplement 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 (Supplement 4 and 5).

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 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)

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

Interviews		
Patients, family, and patient/family advocates: n=18		
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[a], 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)
Clinicians: n=17		
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)
Orthopaedics	1	(6)
Psychiatry	1	(6)
Surgery	1	(6)
Paediatrics	1	(6)
>1 specialty	2	(12)

Table 1. Characteristics of interviewees and of patients whose consultations were audiotaped (continued)

Audiotaped consultations		
Patients who used a QPL: n=25[b]		
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 minutes (range: 4-39; the shortest interview was stopped because the patient was called for diagnostic imaging). Median duration of interviews with clinicians was 30 minutes (range: 18-57). Median duration of 25 consultations was 53 minutes (range 38-78).

[a] The primary disease diagnosis of one patient was missing

[b] In total, 32 consultations were recorded; 7 patients had not used the QPL. The median duration of 32 consultations was 53 minutes (range 35-78).

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

	Selected in the QPL		**Addressed during the consultation**		**Selected and addressed**		**Initiator of topic**			
							Patient or family		*Palliative care consultant*	
Topic	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**
Category: Complaints or problems	**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
Category: Future	**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
Category: Medication and treatment	**76**	**19**	**96**	**24**	**95**	**19**	**63**	**15**	**96**	**23**

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

	Selected in the QPL		**Addressed during the consultation**		**Selected and addressed**		**Initiator of topic**			
							Patient or family		*Palliative care consultant*	
Topic	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**
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
Category: Social or meaning	**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
Category: Organization of care	**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
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.

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

Table 3. Barriers to use, value of the question prompt list, and recommendations for clinicians

Barriers to use and value	Recommendation for clinicians
Patient-related barriers	
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 • Not enough space, time, and energy to think over and fill out • Decreased cognitive ability, unable to comprehend	Family can fill out the QPL if the patient is not able to use it
	Hand out the QPL at least several days before the consultation takes place
Clinician-related barriers	
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

List of abbreviations: QPL, question prompt list 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 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.

Table 4. Input for improvement of question prompt list by patients, family and clinicians, transcribed consultations and Arthur et al.'s[22] consensus list of prompt questions

Content added to question prompt list[a]	
Source	*Subject*
18 interviews with patients and family	• 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	• Relationships and family • (limitations on) hospitalizations • Contact persons in specific situations • Future scenarios
33 transcribed consultations	• Independence • Psychological care
Comparison with consensus list of prompt questions[22,b]	• Questions about informal caregivers • Questions for informal caregivers
Adjusted lay-out and wording of the question prompt list	
Source	*Subject*
Interviews, consultations, and grey literature	• Shape of the document was changed from 5 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*"[23] • Cover page with instructions for patients and family was made more clear • Supplemental leaflet with advice for use and to overcome barriers for clinicians

[a] Patients, family, patient/family advocates and clinicians preferred no adaptations to the content of the question prompt list.
[b] Arthur et al.[22] 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.

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).

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 (Supplements 6 and 7). 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 (i.e., respecting the patient's autonomy at all times), or in the passenger seat (i.e., 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 3). 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] Fliedner 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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Contributors

AHP, EDN and YvdL provided the conceptual framework for this study. M-JV, EDN, BS and DW-V contributed to data collection. M-JV, BS and DW-V analysed the data. NH was involved in analysis of quantitative data. M-JV wrote the manuscript and all authors contributed by providing critical comments on the manuscript. M-JV is the guarantor of the content.

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Competing interests

None declared.

Patient consent for publication

Not applicable.

Ethics approval

The Medical Ethical Committee of Leiden University Medical Center approved this study (on 14 July 2016, reference number P16.112). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data availability statement

Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. All relevant data is shown in the manuscript; the authors may provide additional data upon reasonable request.

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SUPPLEMENTARY MATERIALS

Supplement 1

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care.

Topic prompt list	Question prompt list	
Category: Complaints or problems		
N/A	1	If I have symptoms, what can be done to improve them?[a]
	2	What can I do myself to reduce my symptoms?[b]
	2b	What are the different options available for controlling my symptoms?[c]
	3	How do I achieve the highest possible quality of life with my symptoms?[d]
	7	How can I still do the things that are important to me?[e]
	13	Where can I find reliable information, websites or flyers?[f]
Pain	10	How can I reduce pain?[g]
	10a	Can you help me reduce my pain?[g]
	10b	What else can I do myself to reduce the pain?[h]
Constipation	*N/A*	-
Shortness of breath	*N/A*	-
Nausea	*N/A*	-
Less appetite	8	What kind of food should I eat?
	9	What can I do to get more appetite for food?[i]
Fatigue	4	I am very tired, how do I deal with this?[j]
	5	How much activity or exercise is too much and how much is too little?
	4_5	I am very tired; how do I deal with rest and activities?[k]
	6	What can I do to stay in shape?[l]
Anxiety	12	Who can help me with depression and anxiety?[m]
	12	Who can help me with depression and anxiety?[m]
Dry mouth	*N/A*	-
Nutrition	*N/A*	-
Sexuality and intimacy	11	I don't feel like having sex or cuddling, how do I deal with this?[n]
Future		
Complaints expected for the future	14	What symptoms may occur in the future and what should I do if they arise?
	15	Will I be in pain?
Possibilities for managing complaints in the future	16	Will my pain and other symptoms be controlled in the future?

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care. (continued)

Topic prompt list	**Question prompt list**	
Medication and treatment		
N/A	27	Are there other painkillers or alternatives available?
	28	What are all my tablets for?
Side effects of medication	29	What side effects do the medicines I use have?[o]
	30	What is the chance that I will get side effects?[o]
	31	What can be done about side effects?
Medication intake times	32	How and when should I take my medication?
Next steps medication	*N/A*	-
Medication for when I suddenly get more complaints	*N/A*	-
Types of morphine-like medication	33	If I use morphine (or a morphine-like medicine), can I:[p] − become addicted, so it no longer works, or I need more and more? − stop taking it if my pain goes away? − get sleepy or confused? − drive? − get nauseous or constipated (difficulty or unable to defecate)?*
Choice of whether or not to treat the disease	35	What can be done if I choose not to treat the disease anymore (for example if I stop taking chemotherapy)?[q]
Choice between treatment and quality of life	34	What does the treatment of the disease do to my quality of life?[z]
Social or meaning		
N/A	20	How can I discuss important choices / events in my life?[r]
	21	How do I find a way of saying goodbye that suits me?[z]
Help or information for my children	17	Where can I find good help / guidance for my children?[s]
	18	Are there good websites for (young) children?[z]
Help or information for the people around me	19	Which websites / organizations can help my family and friends (caregivers)?[s]
Meaning or philosophy of life	22	My view of the meaning of life and about life after death is changing. How do I deal with this?[z]

Organization of care		
Home care	23	How can I arrange home care or household care now or in the future?[t]
	23a	How can I arrange home care now or in the future?[t]
Household care	23	How can I arrange home care or household care now or in the future?[t]
	23b	How can I arrange household care now or in the future?[t]
Hospice care	*N/A*	-
Volunteers	24	Are there any volunteers available to help me? (e.g. to take me to an appointment or to do the shopping)
Point of contact for symptoms	25	Who do I call in case of symptoms?[u]
Role of the general practitioner	*N/A*	-
Possibilities of care	26	Can I get help with an activity, travel or trip?[v]
Last phase of life		
Palliative sedation	37	Can I get information about palliative sedation or euthanasia?[w]
Euthanasia	37	Can I get information about palliative sedation or euthanasia?[w]
Fluids and nutrition	38	How do I deal with fluid and nutrition in the event of illness or the end of life?[z]
Practical matters of the end of life	39	Can I get information about the possibilities of care in the last phase of life?
	40	What are the costs of care (for example home care / hospice)?[x]
Course of the last phase of life	36	Can I get information about the last weeks of life?*[y]

List of abbreviations: N/A: not applicable.
Legends: Because the topic prompt list and question prompt list were separately presented in the Leiden Guide on Palliative Care, the above depicted classification was made to report how often categories and topics were indicated. Some questions did not belong to one specific topic. Topics could be grouped with more than one question and to zero questions. a-z: adaptations made to the question prompt list (see below)

Construction of the question prompt list
The Center of Expertise Palliative Care of Leiden University Medical Center constructed a Dutch version of Clayton et al.'s question prompt list (QPL) on palliative care in 2013. In team meetings with the palliative care consultants, it was concluded that the QPL needed practical, cultural and organizational adaptations. The QPL consisted of 35 topics and 40 questions in 6 categories. The QPL became part of a conversation guide, the Leiden Guide on Palliative Care, which also included the Utrecht Symptom Diary for assessing symptom burden on symptom assessment scales.

1. Practical:

a. Palliative care consultants estimated that many of their patients would lack energy and time to view all questions in Clayton et al.'s QPL. Therefore, they selected the most important questions and formulated a topic prompt list consisting of all relevant topics, which preceded the list with questions. Questions on "Spiritual and Cultural support" were left out.
b. Questions about symptoms were specified for each symptom, because these would support the symptom assessment scales that the palliative care consultants also used as part of their consultations.
c. Patients often asked questions about the truths and falsehoods about morphine and morphine-like medication, thus questions about this topic were made more specific.

d. Questions for family were excluded in this first version, because palliative care consultants focused primarily on the patient.
e. The palliative care consultation team already used a folder containing information sources (flyers, leaflets and websites), which they could hand out to patients and family during consultations.
f. Contact details of the palliative care consultation team were not a part of the QPL because they had their own business card to hand out.

2. Cultural:
a. Some questions were formulated more directly, which many Dutch people are used to.
b. Personal autonomy is a highly respected principle in the Netherlands; some questions were therefore formulated in such way that patients can maintain self-control.

3. Organizational:
a. In the Netherlands, palliative care consultants are often consulted to get their advice, and do not have the role of co-practitioners. They therefore do not actively participate in decisions about the treatment of the patient's disease.
b. The aim of a palliative care consultation is to empower patients and family and to improve self-management. The formulation of some questions in Clayton et al.'s QPL was changed into a more active form, so that the patient can ask what he or she can do or organize care.
c. Palliative care is covered by Dutch insurance companies, so questions about financial support were omitted.

Adaptations made to the question prompt list

a The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g. pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". The Center of Expertise Palliative Care experienced that patients would rather have the question divided into one question for each symptom.
b The original questions in Clayton et al. are: "Can you help to control my pain?" and "Can you help to control my other symptoms?". See 2a: this question was formulated more directly.
c The original questions in Clayton et al. are: "Can you help me to control my other symptoms?" and "What are the different options available for controlling my pain?" See 2a: this question was formulated more directly.
d The original question in Clayton et al. is: "How can I make the most of my life?" See 1b: the relation to symptoms was added to the formulation of the question.
e The original question in Clayton et al. is: "What can I expect to be able to do?"
f The original questions in Clayton et al. are: "What information is available about palliative care and my illness?" and "Are books, videos or pamphlets available?" See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
g The original question in Clayton et al. is: "Can you help to control my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.
h The original question in Clayton et al. is: "What are the different options available for controlling my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.
i The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of decreased appetite during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
j The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of fatigue during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
k This question occurred in an older version of this QPL combining questions 4 and 5.
l This question was added based on experience from palliative care consultants. Dutch patients often wish to stay independent and autonomous as long as possible, and often express this in questions about their physical fitness.
m The original questions in Clayton et al. are: "How can I deal with depression if this occurs?" and "Is there someone I can talk to about my fears and concerns?" See 1a: these questions were combined into one question.
n The original question in Clayton et al. is: "How can I remain close and intimate with my partner (physically and/or emotionally)?" See 2a: this question was formulated more directly.

o The original question in Clayton et al. is: “Please tell me the side effects of any new medication you prescribe. How likely are they to occur?”. Because patients often ask these questions, this question was split into two questions.

p The questions about morphine are all based on the questions in the section “Morphine” in the original QPL by Clayton et al. In their QPL, the question “Is it OK for me to drive?” was placed in the section Lifestyle & Quality of Life, but this question was added in this QPL as a question about morphine-like medication. In addition, nausea as a side effect of morphine was added as a question.

q The original question in Clayton et al. is: “Can you give me advice about treatment decisions that I am discussing with other doctors? For example, whether to stop or start chemotherapy or other treatments”. See 3a: this question was re-formulated, as the palliative care consultants do not make treatment decisions, but can explain the future scenarios related to treatment.

r The original question in Clayton et al. is: “Can someone help me to communicate with other members of my family about what is happening to me?” See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.

s The original question in Clayton et al. is: “What support is available for other people in the family, such as my carer or my children?” The aspect about children was formulated into a new question.

t Questions on how to manage care at home (home care and household care) were added to empower the patient and family to self-manage their care.

u In the Netherlands, the general practitioner or medical specialist remains the coordinator of care; the palliative care consultant is not a co-practitioner (see 3a). Therefore, no specific questions about who to contact in which situation were provided, only the open question.

v This question replaced the original question in Clayton et al.: “Is there a program of activities available through the palliative care service? (e.g., physiotherapy, massage, spa, breathlessness clinic, day centre)”, because palliative care is a consultation-based service and may give advice about certain activities (see 3a).

w Because palliative sedation and especially euthanasia are part of end-of-life care in the Netherlands, this question was added.

x The original question in Clayton et al. is: “What costs will I have during my illness (e.g. for any equipment required or medications)?” See 3c: palliative and terminal care are covered by Dutch insurance companies; only questions about the costs of hospice care arose during consultation.

y In the original question prompt list by Clayton et al., the category “End of life issues” comprises several questions about the end of life. This question attempted to summarize these questions into one.

z These questions were added to the question prompt list, because these were questions that were often asked during consultations with palliative care consultants of our Center of Expertise Palliative Care.

Supplement 2

Topic list for interviews

Interview guide for the interviews with patient and family and patient/family advocates

About the question prompt list in general

- What do you think about the question prompt list?
- What do you like about the question prompt list?
- What do you dislike about the question prompt list?
- Is the question prompt list clear to you?
- Have you read all the topics and questions?
  - What was the reason that you did not read everything?
  - Did you read through one time or several times?
  - Did you go through the conversation guide on your own or with someone else?
- What did you think of the length of the question prompt list?
- Were there any parts of the question prompt list that you found unclear?
  - What did you find unclear?
- When did you go through the question prompt list?
  - (Did you go through the question prompt list before and/or after the conversation with the palliative care consultant? How much time before your conversation with your palliative care consultant?)
- Did the question prompt list facilitate talking about a difficult topic?

Overview of possible discussion topics and questions

- Do you feel that all conversation topics are clearly formulated?
- Are there discussion topics in the question prompt list that you find relevant and that you had not thought of yourself to discuss with the palliative care consultant?
- Did you find some topics unsettling to think about?
  - If yes, which subjects?
  - After ticking these topics, did you talk to your loved ones about these topics?
- Did you find some subjects too personal to discuss during the consultation?
- What did you think of the sample questions?
- Did you yourself have any questions?
- Did you think of new questions thanks to the example questions?
- Did they help you ask more questions during the consultation?
- What did you think of the number of sample questions? (too many / too few)

- What did you think of the overlap between the topics of discussion and the overview of the questions? (this question was added when the overlap was raised several times during interviews)

Consultation
- Did the question prompt list help you get an idea of what would be discussed during the consultation?
- Did the question prompt list help you to ask the right questions in the conversation with the palliative care consultant?

After consultation
- Has the question prompt list helped you better identify the questions you have about your future?

Per topic
- Which subjects do you think can be left out?
- Which topics need to be added?
- Which example questions do you think can be left out?
- Do example questions need to be added?

Interview guide for the interviews with clinicians

Structured part of the interview
- Sex
- Age
- Working in which department
- Working as
- How many years have you been active as a care provider (including training years)?
- How many palliative patients do you see per month?
- How often per month do you have a bad news conversation with a patient?
- How many times a month do you have conversations with patients in which end-of-life issues are addressed?
- Do you find it difficult to start bad news conversations with patients?

Helpfulness of topics
- Do you consider the topics of the category Complaints helpful?
- Do you consider the topics of the category Future helpful? Do you consider the topics of the category Medicine and treatment helpful?
- Do you consider the topics of the category Social and meaning helpful?

- Do you consider the topics of the category Organization of care helpful?
- Do you consider the topics of the category Last phase of life helpful?
- Do you consider the example questions helpful? (going through all questions)
- What do you think of the order of the topics?
- Should any topics be added?
- Should any topics be left out?
- What is your opinion about the question prompt list?
- Do you think the question prompt list comprises unsettling topics?
- Hypothetical use of question prompt list (how would you use the question prompt list?)
- Other remarks

Supplement 3

Table. Characteristics of the n=32 patients whose consultation was audiotaped

Patient characteristics[a]		
Age, median (range)	65	(46-80)
Sex, male, n (%)	17	(53)
Patient primary disease diagnosis, n (%)		
Oncological	31	(97)
Kidney failure	1	(3)
Median survival, months (IQ-range)	6	(3-51)

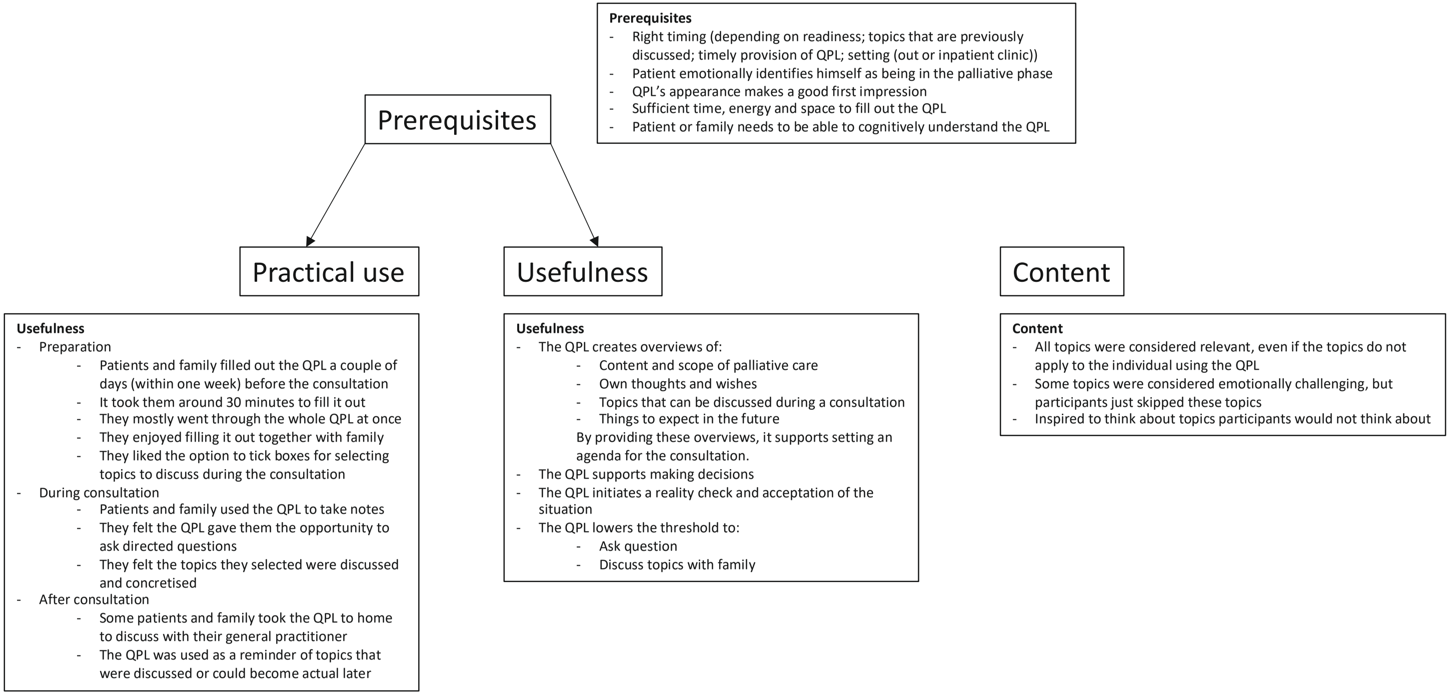
[a] *25 patients had used the question prompt list; 7 had not.*

Supplement 4

Leiden Guide on Palliative Care 2018

To improve comprehensibility, the wording of the Leiden Guide on Palliative Care was simplified and the lay-out was adapted according to participants' suggestions (Table 4). Questions were added and placed next to a topic so that each topic is accompanied by at least one question. The final version comprised nine categories with 43 topics and 133 questions (Supplement 6). In addition, we wrote an instruction leaflet for healthcare providers to facilitate the use of the QPL and to optimize palliative care consultations (Supplement 7).

Supplement 5



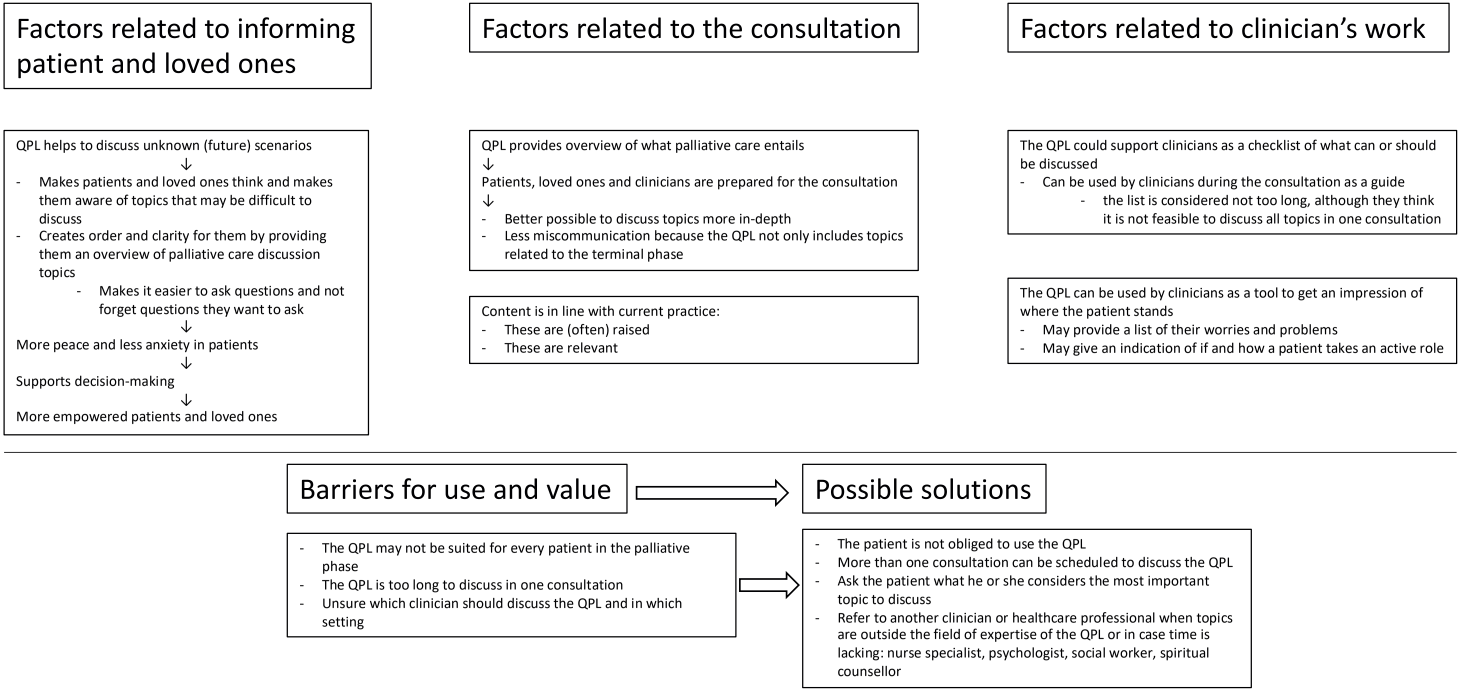
Prerequisites
- Right timing (depending on readiness; topics that are previously discussed; timely provision of QPL; setting (out or inpatient clinic))
- Patient emotionally identifies himself as being in the palliative phase
- QPL's appearance makes a good first impression
- Sufficient time, energy and space to fill out the QPL
- Patient or family needs to be able to cognitively understand the QPL

Usefulness
- Preparation
    - Patients and family filled out the QPL a couple of days (within one week) before the consultation
    - It took them around 30 minutes to fill it out
    - They mostly went through the whole QPL at once
    - They enjoyed filling it out together with family
    - They liked the option to tick boxes for selecting topics to discuss during the consultation
- During consultation
    - Patients and family used the QPL to take notes
    - They felt the QPL gave them the opportunity to ask directed questions
    - They felt the topics they selected were discussed and concretised
- After consultation
    - Some patients and family took the QPL to home to discuss with their general practitioner
    - The QPL was used as a reminder of topics that were discussed or could become actual later

Usefulness
- The QPL creates overviews of:
    - Content and scope of palliative care
    - Own thoughts and wishes
    - Topics that can be discussed during a consultation
    - Things to expect in the future

    By providing these overviews, it supports setting an agenda for the consultation.
- The QPL supports making decisions
- The QPL initiates a reality check and acceptation of the situation
- The QPL lowers the threshold to:
    - Ask question
    - Discuss topics with family

Content
- All topics were considered relevant, even if the topics do not apply to the individual using the QPL
- Some topics were considered emotionally challenging, but participants just skipped these topics
- Inspired to think about topics participants would not think about



Factors related to informing patient and loved ones

QPL helps to discuss unknown (future) scenarios

↓

- Makes patients and loved ones think and makes them aware of topics that may be difficult to discuss
- Creates order and clarity for them by providing them an overview of palliative care discussion topics
    - Makes it easier to ask questions and not forget questions they want to ask

↓

More peace and less anxiety in patients

↓

Supports decision-making

↓

More empowered patients and loved ones

Factors related to the consultation

QPL provides overview of what palliative care entails

↓

Patients, loved ones and clinicians are prepared for the consultation

↓

- Better possible to discuss topics more in-depth
- Less miscommunication because the QPL not only includes topics related to the terminal phase

Content is in line with current practice:

- These are (often) raised
- These are relevant

Factors related to clinician's work

The QPL could support clinicians as a checklist of what can or should be discussed

- Can be used by clinicians during the consultation as a guide
    - the list is considered not too long, although they think it is not feasible to discuss all topics in one consultation

The QPL can be used by clinicians as a tool to get an impression of where the patient stands

- May provide a list of their worries and problems
- May give an indication of if and how a patient takes an active role

Barriers for use and value

- The QPL may not be suited for every patient in the palliative phase
- The QPL is too long to discuss in one consultation
- Unsure which clinician should discuss the QPL and in which setting

Possible solutions

- The patient is not obliged to use the QPL
- More than one consultation can be scheduled to discuss the QPL
- Ask the patient what he or she considers the most important topic to discuss
- Refer to another clinician or healthcare professional when topics are outside the field of expertise of the QPL or in case time is lacking: nurse specialist, psychologist, social worker, spiritual counsellor

Supplement 6

Leiden Guide on Palliative Care 2018

LUMC Expertisecentrum Palliatieve Zorg

LEIDSE GESPREKSHULP PALLIATIEVE ZORG[1]

De Leidse Gesprekshulp Palliatieve Zorg (LGP) geeft een overzicht van mogelijke klachten, problemen, gespreksonderwerpen en vragen van patiënten die ongeneeslijk ziek zijn. De gespreksonderwerpen en vragen zijn samen met patiënten en naasten gekozen.

De LGP kan u helpen belangrijke onderwerpen voor uw gesprek met de consulent van het Palliatief Advies Team te benoemen. We vragen u daarom ter voorbereiding op uw gesprek de LGP in te vullen. Als u vindt dat sommige vragen niet op u van toepassing zijn, kunt u deze vragen overslaan.

Het invullen van de LGP kost ongeveer 20 minuten. Ook als u weinig tijd hebt of erg moe bent, vragen we u in ieder geval deel 1 in te vullen.

Tot ziens bij uw gesprek.

Uw gegevens:

Naam	__________________
Geboortedatum	___ - ___ - ___
Datum	___ - ___ - ___

---

[1] Versie 3.0 2018

DEEL 1: MOGELIJKE KLACHTEN EN PROBLEMEN

Utrecht Symptoom Dagboek 4-Dimensioneel (USD-4D[2])

Onderstaande vragen gaan over lichamelijke en emotionele klachten en problemen. Met een cijfer van 0 tot 10 kunt u aangeven hoeveel last u heeft. 0 = afwezig 10 = ergst denkbaar.

Ik heb op dit moment:												
geen pijn	0	1	2	3	4	5	6	7	8	9	10	erg veel pijn
geen	0	1	2	3	4	5	6	7	8	9	10	erg veel slaapproblemen slaapproblemen
geen droge mond	0	1	2	3	4	5	6	7	8	9	10	erge droge mond
geen slikklachten	0	1	2	3	4	5	6	7	8	9	10	erg veel slikklachten
goede eetlust	0	1	2	3	4	5	6	7	8	9	10	geen eetlust
goede ontlasting	0	1	2	3	4	5	6	7	8	9	10	geen ontlasting

Ik voel me op dit moment:												
niet misselijk	0	1	2	3	4	5	6	7	8	9	10	erg misselijk
niet benauwd	0	1	2	3	4	5	6	7	8	9	10	erg benauwd
niet moe	0	1	2	3	4	5	6	7	8	9	10	erg moe
niet angstig	0	1	2	3	4	5	6	7	8	9	10	erg angstig
niet somber	0	1	2	3	4	5	6	7	8	9	10	erg somber

Welke klacht(en) moet(en) wat u betreft als eerste worden opgelost?

Onderstaande vragen gaan over uw draagkracht en uw gedachten over het levenseinde. Als u vindt dat de vragen niet op u van toepassing zijn, kunt u deze vragen overslaan.

Ik voel me op dit moment:												
goed	0	1	2	3	4	5	6	7	8	9	10	slecht
Het leven heeft voor mij op dit moment:												
veel waarde	0	1	2	3	4	5	6	7	8	9	10	geen waarde
Ik kom toe aan mijzelf												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet
Ik kan wat me overkomt dragen												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet
Ik voel mij in balans over mijn leven												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet

Verder wil ik nog graag laten weten dat……

1. ……
2. ……

---

[2] © juli 2015 USD4D EPZ Utrecht & AHzN & VGVZ;

DEEL 2: MOGELIJKE GESPREKSONDERWERPEN EN VRAGEN

Lichamelijke klachten	***Mogelijke vragen***
Pijn	o Hoe kan ik minder pijn krijgen? o Kan ik pijn voorkomen? o Zijn er (andere) pijnstillers voor mij?
Benauwdheid	o Hoe kan het dat ik zo benauwd ben? o Wat kan ik tegen benauwdheid doen?
Klachten van de mond	o Wat kan ik doen als ik last heb van een droge mond? o Wat kan ik doen als ik moeilijk kan slikken? o Wat kan ik doen als ik pijn heb in mijn mond?
Eetlust	o Waardoor heb ik minder trek in eten? o Wat kan ik doen om meer zin in eten te krijgen? o Hoe voorkom ik dat ik afval? o Wat kan ik het beste eten? o Kan een diëtiste mij helpen?
Misselijkheid en braken	o Waardoor wordt mijn misselijkheid veroorzaakt? o Zijn er medicijnen tegen misselijkheid?
Problemen met de ontlasting	o Wat kan ik doen aan te harde of te zachte ontlasting? o Waardoor wordt mijn ontlastingspatroon beïnvloed? o Hoe gebruik ik de medicijnen voor de ontlasting?
Vermoeidheid	o Ik ben erg moe, hoe ga ik hier mee om? o Hoe verdeel ik rust en activiteit? o Wat kan ik doen om in conditie te blijven?
Slaapproblemen	o Ik slaap slecht. Wat kan ik hier aan doen? o Zijn er medicijnen om beter te slapen?
Jeuk	o Wat kan er aan jeuk gedaan worden?
Uw eigen vragen	o …….

Medicijnen	***Mogelijke vragen***
Aanspreekpunt	o Bij wie moet ik zijn met vragen over mijn medicatie? o Wie is er verantwoordelijk voor mijn medicatie?
Bijwerkingen	o Welke bijwerkingen hebben mijn medicijnen? o Hoe groot is de kans dat ik bijwerkingen krijg? o Ik heb last van bijwerkingen. Wat kan ik hier aan doen?
Innemen van medicijnen	o Op welke tijden kan ik mijn medicijnen innemen? o Hoe kan ik mijn medicijnen het beste innemen? o Welke medicijnen heb ik niet meer nodig? o Zijn er andere mogelijkheden als ik mijn medicijnen niet meer kan slikken?

Medicijnen	***Mogelijke vragen***
Morfine-achtige medicijnen	o Wat zijn de bijwerkingen van morfine? o Mag ik autorijden met morfine? o Kan ik stoppen met morfine als mijn pijn over is?
Uw eigen vragen	o …….

Behandelingen	***Mogelijke vragen***
Kwaliteit van leven	o Wat is de invloed van de behandeling op mijn kwaliteit van leven? o Hoe kan ik zorgen dat mijn klachten zo min mogelijk invloed hebben op mijn leven?
Keuzes over de huidige behandeling	o Waar vind ik betrouwbare informatie over behandeling? o Wat kan er gedaan worden als ik ervoor kies om de ziekte niet meer te laten behandelen? o Wie kan mij helpen bij beslissingen over de behandeling van mijn ziekte?
Uw eigen vragen	o …….

Persoonlijke aspecten	***Mogelijke vragen***
Omgaan met ziekte	o Hoe combineer ik ziek zijn met werk, school of hobby's? o Met wie kan ik praten als ik moeite heb met omgaan met ziek zijn? o Hoe kan ik omgaan met lichamelijke of geestelijke veranderingen door de ziekte? o Wie kan mij helpen met mijn zorgen? o Waar kan ik ervaringen delen met andere patiënten?
Angst	o Wie kan mij helpen als ik bang ben? o Wat kan ik doen om minder angstig te zijn?
Somberheid	o Wie kan mij helpen als ik somber ben? o Wat kan ik doen om minder somber te zijn?
Zin van het leven	o Hoe kan ik de dingen blijven doen die belangrijk voor mij zijn? o Mijn kijk op het leven en over het leven na de dood verandert. Hoe ga ik hier mee om? o Met wie kan ik praten over de zin van het leven? o Met wie kan ik praten over religieuze vragen?
Zelfstandigheid	o Hoe kan ik regie houden tijdens mijn ziekteproces? o Ik word meer afhankelijk van anderen. Hoe kan ik hier mee omgaan? o Hoe kan ik mensen om mijn heen om hulp vragen? o Hoe kan ik zo zelfstandig mogelijk blijven? o Kan ik hulp krijgen als ik ergens naar toe moet? o Kan ik hulp krijgen bij een reis of dagje-uit? o Kan een fysiotherapeut of ergotherapeut mij helpen?
Intimiteit	o Hoe zorg ik dat ik het contact met mijn partner houd? o Ik heb minder zin in knuffelen of vrijen, hoe ga ik hier mee om?
Uw eigen vragen	o …….

Toekomst	***Mogelijke vragen***
Verwachtingen	o Wat staat mij te wachten? o Welke klachten kan ik in de toekomst krijgen? Zal ik pijn krijgen? o Wat kan er gedaan worden aan klachten die ik in de toekomst krijg? o Wat kan er gezegd worden over mijn levensverwachting?

Toekomst	***Mogelijke vragen***
Keuzes in de toekomst	o Kan ik bespreken welke zorg ik in de toekomst wil, als ik dat zelf niet meer kan zeggen? Met wie bespreek ik dit? o Welke keuzes over behandeling kan ik in de toekomst maken? o Hoe leg ik vast wat ik wel of niet meer wil, zoals niet meer naar het ziekenhuis gaan?
Uw eigen vragen	o …….

Sociale aspecten	***Mogelijke vragen***
Hulp voor mijn familie of vrienden	o Waar vind ik hulp voor mijn familie, vrienden of (klein)kinderen? o Bestaan er websites voor (jonge) kinderen? o Welke websites of organisaties zijn er om mijn familie en vrienden te helpen? o Hoe leg ik kinderen uit dat ik ernstig ziek ben? o Hoe bespreek ik keuzes of gebeurtenissen die voor mij belangrijk zijn met mijn naasten?
Uw eigen vragen	o …….

Organisatie van zorg	***Mogelijke vragen***
Aanspreekpunt bij lichamelijke klachten of andere problemen	o Wie bel ik bij lichamelijke klachten? o Wie bel ik bij problemen buiten kantoortijden? o Wie bel ik als ik behoefte heb om over mijn ziekte te praten?
Huisarts	o Wat kan de huisarts voor mij doen? o Waar kan ik de huisarts voor bellen?
Ziekenhuis	o Wat kan het ziekenhuis voor mij doen? o Waar kan ik het ziekenhuis voor bellen? o Is het nog nodig om naar het ziekenhuis te gaan?
Hulpmiddelen	o Welke hulpmiddelen kan ik thuis krijgen? o Hoe kan ik hulpmiddelen voor thuis regelen? o Wie kan mij helpen met hulpmiddelen of aanpassingen in huis?
Huishoudelijke zorg	o Hoe kan ik huishoudelijke hulp regelen?
Thuiszorg	o Kan ik in de toekomst thuis zorg krijgen? o Hoe kan ik thuis zorg regelen?
Vrijwilligers	o Wat kunnen vrijwilligers voor mij doen? o Waar vind ik informatie over zorg door vrijwilligers?
Hospice zorg	o Wat is een hospice? o Welke zorg kan een hospice geven? o Wat zijn de kosten van een hospice?
Palliatief Advies Team	o Wat kan het Palliatief Advies Team voor mij doen? o Kan het Palliatief Advies Team mij helpen met het vinden van betrouwbare informatie, websites of folders?
Psychische ondersteuning	o Hoe kan psychische ondersteuning mij helpen? o Hoe kom ik in contact met psychische ondersteuning? o Kan ik ook psychische hulp aan huis krijgen?
Uw eigen vragen	o …….

Laatste levensfase	***Mogelijke vragen***
Praktische zaken rondom het levenseinde	o Wat moet ik bespreken met mijn naasten? o Hoe vind ik een manier van afscheid nemen die bij mij past? o Wie kan mij helpen een wilsverklaring op te stellen? o Hoe regel ik mijn zaken en stel ik een testament op? o Met wie kan ik praten over mijn financiële situatie? o Hoe moet ik mijn uitvaart regelen?
Verloop van de laatste fase	o Kan ik informatie krijgen over hoe de laatste weken van het leven er uitzien? o Welke zorg kan ik krijgen in de laatste periode van het leven?
Plaats van overlijden	o Kan ik zelf kiezen waar ik wil overlijden? o Welke plaats kan ik kiezen om te overlijden?
Vocht en voeding	o Wat moet ik doen als ik meer moeite krijg met eten en drinken in de laatste periode van leven? o Hoe kunnen mijn naasten mij helpen als ik meer moeite krijg met eten en drinken in de laatste periode van leven? o Is het erg als ik bijna niet eet of drink als het overlijden dichtbij is?
Palliatieve sedatie	o Wat is palliatieve sedatie? o Wanneer kom ik in aanmerking voor palliatieve sedatie? o Kan ik mijn arts vragen om palliatieve sedatie?
Euthanasie	o Wat is euthanasie? o Wanneer kom ik in aanmerking voor euthanasie? o Wie moet ik mijn euthanasiewens vertellen? o Kan ik informatie krijgen over het regelen van euthanasie?
Uw eigen vragen	o …….

Vragen van naasten of mantelzorgers	***Mogelijke vragen***
Zorg verlenen	o Hoe kan ik het beste voor mijn dierbare zorgen? Wat moet ik hiervoor kunnen? Waar kan ik hulp bij krijgen? o Wat moet ik doen als hij/zij weinig wil eten of drinken? o Zal hij/zij door minder te eten of drinken korter leven? o Kan het helpen voor de zorg als ik meer vertel over de persoonlijkheid en cultuur van mijn dierbare?
Ondersteuning	o Hoe houd ik het als mantelzorger vol? o Waar kan ik hulp vragen als de zorg te veel voor mij wordt? Wat zijn de mogelijkheden? o Waar vraag ik hulp als ik het emotioneel moeilijk heb? o Bij wie geef ik aan dat er meer zorg nodig is? o Wie stel ik vragen over de zorg die mijn dierbare krijgt? o Waar kan ik aan zien of het moment van overlijden dichterbij komt?
Nazorg	o Hoe ga ik straks om met het verlies van mijn dierbare? o Kan ik hulp krijgen als mijn dierbare er niet meer is? o Waar kan ik hulp krijgen bij het verwerken van mijn verlies? o Is een nagesprek met de zorgverlener mogelijk?
Uw eigen vragen	o …….

Eigen onderwerpen en vragen

……

……

……

……

Heeft u nog vragen?
Neem contact op met het Palliatief Advies Team:

Telefoon	071 52 61916 (tijdens kantooruren)
E-mail	palliatievezorg@lumc.nl

Supplement 7

LEIDEN GUIDE ON PALLIATIVE CARE:

Guide for clinicians

Instrument can be requested by e-mailing with palliatievezorg@lumc.nl

What is the Leiden Palliative Care Conversation Tool?

The Leiden Guide on Palliative Care (LGP) is a list of possible topics and questions that can support patients and/or their loved ones in preparing for a conversation about palliative care and end-of-life decisions. It can help them formulate the questions they want to discuss. The topics and questions of the LGP were chosen together with patients and their loved ones.

The LGP consists of:

1. An Utrecht Symptom Diary 4-Dimensional (USD-4D) to indicate symptom burden and quality of life;
2. A list of topics and questions on themes within palliative care about:

a. Physical complaints
b. Medications
c. Treatments
d. Personal aspects
e. Social aspects
f. Future
g. Organization of care
h. Last stage of life
i. Questions from loved ones or informal caregivers

Space has also been left open for patients and family to add their own questions.

Who is the target population for the LGP?

- The LGP is intended for any patient in the palliative phase and his/her loved ones.
- If the LGP cannot be completed by the patient and loved ones together (e.g., because the patient is too tired, has cognitive problems, or is low-literate), a loved one can complete the LGP.

When do I introduce the LGP?

- The LGP can be used at any time within the palliative phase, from the time a person is diagnosed with an incurable disease.
- The LGP is used to prepare for conversations of physicians and nurses (both 1st and 2nd line) with patients in the palliative phase. For example, conversations about symptoms (what bothers them based on the results of the USD), about end-of-life decisions or other expected problems/questions about the course of the illness based on the subject list. The earlier these discussions are held in the course of the disease, the more useful they can be for the patient.

What use is the LGP to me as a clinician?

- It provides an overview of possible topics to discuss in the palliative phase.
- It lowers the threshold to bring up topics that are difficult to discuss.
- How the patient has filled out the LGP can provide insight into
  - Dealing with the disease,
  - The ease with which the patient can talk about the illness and its consequences,
  - Whether the patient needs little or a lot of information,
  - Whether the patient prefers not to discuss specific themes. For example, there are patients who say ‘not applicable’ when asked about the dying phase.

How do I introduce the LGP to my patient and his/her loved ones?

- The LGP can be emotionally challenging for patients and loved ones. Therefore, when handing over the LGP, it is wise to give a brief verbal explanation. For patients who have a lot of difficulty talking about the end of life, it may be more appropriate to only introduce the USD and leave the topic list for now. Give the patient enough time to complete the LGP by giving it to them well in advance of the consultation.

Important points to tell patients when introducing the LGP are:

- Palliative care is more than care in the dying phase and focuses primarily on quality of life.
- The LGP is a list of common discussion topics and possible questions from patients in the palliative phase and their loved ones.
- The LGP is a tool that allows the patient to gain insight into his/her questions and issues that may become important in the coming period.
- There are questions in the LGP that are not (yet) applicable. Ask the patient to tick only those questions that are appropriate for him/her.
- The LGP is used as a guide for the discussion with the clinician. In this way, the patient controls which topics he does or does not want to discuss.

- Completing the LGP takes approximately 20 minutes. For many patients it is pleasant to do this together with a loved one. In this way, it can also enhance the conversation between patient and loved ones.

How do I use the LGP during my consultation?

- Time is needed to discuss the LGP with patients and loved ones, usually at least 1 hour. If necessary, the topics can also be discussed in several sessions.
- Start the discussion by asking what the patient considers the most important topic to be discussed. Then the other topics can be discussed point by point.
- Patients often want to obtain a future view of their disease, their symptoms, their prognosis and their end of life. Therefore, it is advisable to discuss possible so-called "future scenarios" from each complaint and possibly record them in a so-called roadmap.
- If themes or questions do not fall within your area of expertise, it may be useful to refer the patient and his relatives, for example, to a spiritual counselor or the palliative care team.