Universiteit
Leiden
The Netherlands

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

Verhoef, M.J.

Citation
Verhoef, M. J. (2022, November 23). *Opportunities to improve palliative care: towards a more patient-centred and proactive approach*. Retrieved from https://hdl.handle.net/1887/3486999

Version:	Publisher's Version
License:	Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden
Downloaded from:	https://hdl.handle.net/1887/3486999

Note: To cite this publication please use the final published version (if applicable).

CHAPTER 6

Assessment of symptom burden and information needs helps tailoring of palliative care consultations: an observational study

Verhoef M, Sweep B, de Nijs EJM, Valkenburg AC, Horeweg N, Pieterse AH, van der Steen JT, van der Linden YM

The authors JT van der Steen and YM van der Linden contributed equally to the manuscript.

European Journal of Cancer Care, e13708. https://doi.org/10.1111/ecc.13708. Online ahead of print.

ABSTRACT

Objective

The objective of this study is to study (1) the relationship between patient-reported symptom burden and information needs in hospital-based palliative care and (2) differences in patient-reported needs during the disease trajectory.

Methods

Observational study: patient-reported symptom burden and information needs were collected via a conversation guide comprising assessment scales for 12 symptoms (0–10), the question which symptom has priority to be solved and a question prompt list on 75 palliative care-related items (35 topics, 40 questions). Non-parametric tests assessed associations.

Results

Conversation guides were used by 266 patients. Median age was 65 years (IQ-range, 57–72), 49% were male and 96% had cancer. Patients reported highest burden for *Fatigue* (median = 7) and *Loss of appetite* (median = 6) and prioritised *Pain* (26%), *Fatigue* (9%) and *Shortness of breath* (9%). Patients wanted information about 1–38 (median = 14) items, mostly *Fatigue* (68%), *Possibilities to manage future symptoms* (68%) and *Possible future symptoms* (67%). Patients also wanted information about symptoms for which they reported low burden. Patients in the symptom-directed phase needed more information about hospice care.

Conclusion

Symptom burden and information needs are related. Patients often also want information about non-prioritised symptoms and other palliative care domains. Tailored information-provision includes inviting patients to also discuss topics they did not consider themselves.

INTRODUCTION

Effective communication between patients, their families and clinicians during the palliative phase of disease is essential to adequately assess and meet physical, psychosocial and spiritual needs, and to set goals of care.[1] However, patients, their family, and clinicians often consider addressing such topics to be difficult.[2] Patients and family often do not know what palliative care entails, what they might need or what to discuss during palliative care consultations.[3, 4] Most patients underreport their symptoms.[5, 6] They often appreciate receiving information about symptoms, prognosis, and about practical, psychosocial, or spiritual issues. These information needs may change over time.[4, 7-9] Clinicians often feel unprepared to discuss end-of-life matters or do not know which topics to address.[2, 10, 11] Research has shown that clinicians tend to underestimate and under-document the severity of symptoms compared to what patients report themselves.[12-14]

Core elements of palliative care consultations are a comprehensive assessment of needs of patients and family, and informing them about (future) symptoms and social, psychological, and existential dimensions of their palliative disease phase. However, palliative care consultations may take up time and patient-reported burden and information needs may change during the disease trajectory, requiring regular assessments. Insight into patient-reported symptom burden and information needs may inform clinicians about how they can tailor palliative care consultations to the needs of patients and family.

Patients can report symptom burden and wellbeing by completing patient-reported outcome measures (PROMs). It is known that individual patients can score symptom burden differently because they experience their problems in many ways, and because symptoms may also have social, psychological or existential aspects.[15, 16] Before initiating symptom management, scores should therefore always be discussed with patients following a multidimensional approach.[17] Another tool that supports palliative care consultations is a question prompt list, i.e., a structured list of sample questions that can help patients and family formulate questions for their consultation.[18]

The primary objective of this study was to determine whether patient-reported symptom burden and prioritised symptoms are related to patients' information needs, using a PROM and a question prompt list. The second objective was to study whether there are any differences in patient-reported symptom burden and information needs between the disease-modifying phase versus symptom-management phase.

METHODS

Setting

This observational study took place at a Dutch academic hospital that includes a Center of Expertise in Palliative Care since 2011 and hosts a palliative care consultation team.[19] This team is available for consultation to all clinical departments that care for adult patients. To support consultations, the team has developed the Leiden Guide on Palliative Care, hereinafter referred to as the *conversation guide*, which encompasses a PROM (the Utrecht Symptom Diary)[20] and a question prompt list to help patients, their families, and clinicians to prepare for consultations. The development of the conversation guide is published elsewhere.[21] The conversation guide is distributed to patients and family before consultations to empower them to ask their questions and collaboratively set the agenda for the consultation. Patients and family are instructed by the palliative care consultant on how to use the conversation guide. Patients could use it alone, or with family. Before providing the conversation guide, the consultants of the palliative care consultation team estimate whether patients and family have sufficient time and energy to use it. They do not give it to patients who are already in the dying phase. Patients and family may refuse to use (parts of) the conversation guide. In 20-25% of all palliative care consultations, the conversation guide is used. Written consent from patients was not required according to Dutch (WGBO, article 458) and European (General Data Protection Regulation) Law. The study was approved by the Medical Ethical Committee of Leiden University Medical Center on 26 April 2019.

Participants and procedures

Patients were included if they had had a consultation with a palliative care consultant, had used a conversation guide between December 2013 and November 2018, and were at least 18 years old. If patients had used a conversation guide multiple times, only the first conversation guide was used for data collection. Two trained research assistants collected data from the conversation guides. Patient characteristics (age, sex, primary diagnosis) and survival in weeks from consultation to death or study closure were taken from electronic patient records. Survival data were updated until 21 January 2021. For all primary diseases, the palliative disease phase (disease-modifying phase or symptom-management phase) was categorised retrospectively from electronic patient records by a palliative care consultant (EJMdN) and a researcher (MV). They used Lynn and Adamson's classification:

- Disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management;
- Symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

They had consensus meetings about codes that were unclear during data collection.

Data collection using the conversation guide: the Leiden Guide on Palliative care

The conversation guide comprises two parts (Figure 1). Part 1 consists of the Utrecht Symptom Diary (USD, an adapted and translated version of the Edmonton Symptom Assessment System, ESAS) and includes twelve 0-10 numeric rating scales (0 = *no symptom burden*; 10 = *worst symptom burden imaginable*) to assess pain, sleeping problems, dry mouth, swallowing problems, loss of appetite, constipation, nausea, shortness of breath, fatigue, anxiety, depression and wellbeing.[20, 23] Patients can prioritise symptoms and problems with the item "*In your opinion, which problem(s) should be solved first?*". The USD is used to monitor burden over time and to assess treatment effects on often-experienced symptoms in the palliative phase. Using the USD, patients can score experienced wellbeing and severity of their symptoms.[12]

Part 2 consists of a question prompt list about palliative care to assess the information needs of the patient and family. The question prompt list was translated from Clayton et al. and adapted, and now consists of 35 conversation topics and 40 sample questions (75 items in total) grouped in six categories (Figure 1 and Supplement 1).[18, 21] Patients are instructed to tick the boxes of the topics and/or questions in the conversation guide they would like to discuss during consultations. The Center of Expertise in Palliative Care keeps duplicates of all conversation guides that patients have used, for purposes of care evaluation. In this study, we collected the data on symptom burden and information needs that patients had reported via the conversation guide.

Analyses

Descriptive statistics were used to describe patient characteristics, patient-reported symptom burden, prioritised symptom(s) and the topics and questions that patients and families selected in the question prompt list. Survival from consultation to death or study closure was calculated using Kaplan-Meier's methodology. We used a log-rank test to compare survival between patients in the disease-modifying phase versus symptom-management phase and rounded up to whole weeks. Symptom burden ratings were analysed both as continuous and as categorial outcomes; for the latter, ratings were classified as mild (rating <4), clinically relevant (burden requiring more comprehensive assessment, rating ≥4), or serious (rating ≥7).[24, 25] Patients could fill in more than one symptom to prioritise; for purposes of analysis, the first four symptoms reported as priorities were included. Also for purposes of analysis we clustered questions from the question prompt list by topic and category (Supplement 2). We assessed the associations between patient-reported symptom burden, prioritised symptom(s), and information needs about symptoms with Chi-square tests, Fisher's exact tests, or and Mann–Whitney U tests (for not-normally distributed continuous variables) as appropriate; these tests were also used to compare patients in the disease-modifying versus symptom-

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 conversation guide (Leiden Guide on Palliative care) used for data collection.

management phase by characteristics, symptom burden, prioritised symptom(s), and information needs. For analyses using data from both the USD and the question prompt list, patients who had not used either were excluded. Associations between disease phase and topics included in the question prompt list that were <0.01 were regarded as statistically significant.

RESULTS

From December 2013 to October 2018, 1,485 patients were referred to the palliative care consultation team. Table 1 lists the characteristics of all 321 patients who filled in the conversation guide were included; 266 (83%) patients filled in both parts. The median age was 65 years (IQ-range, 57-72), 49% were male and most patients had cancer (96%). Median survival from consultation was 7 weeks (IQ-range: 2-26).

Reported symptom burden and prioritised symptom(s)

Patient-reported symptom burden is presented in Table 2. Patients reported the highest median burden for *Fatigue*, *Loss of appetite*, *Dry mouth,* and *Constipation*. Patients reported a median of six symptoms (IQ-range: 4-8) with clinically relevant burden, and a median of three symptoms (IQ-range 1-5) with serious burden, most often *Fatigue*, *Loss of appetite* and *Dry mouth*. Seventy per cent of the patients reported clinically relevant burden related to *Well-being*. Patients in the symptom-management phase versus disease-modifying phase reported higher burden for *Loss of appetite* (median=7 vs. 5, p=0.010) and lower burden for *Anxiety* (median=2 vs. 3, p=0.030; Table 3). Overall, patients most often prioritised *Pain*, *Fatigue* and *Shortness of breath*. Regardless of the particular symptom, the higher the patient-reported symptom burden, the more often patients indicated that the symptom in question should be prioritised.

Information needs

Table 4 lists the topics patients selected in the question prompt list. Patients selected a median of five out of six categories (range 1-6) and of 14 out of 75 items (range 1-38) to discuss. The category *Symptoms/problems* was selected most often and *Social/meaning* least often. The top five selected topics were *Fatigue*, *Treatment options for future symptoms*, *Expected future symptoms*, *Pain* and *Home care*. The five least selected topics were *Sexuality and intimacy*, *Volunteers*, *Medication intake times*, *Meaning/philosophy of life* and *Next steps regarding medication*. Patients in the symptom-management phase versus disease-modifying phase more often selected *Hospice care* and less often selected *Sexuality and intimacy*.

Table 1. Characteristics of 321 patients who filled out the Utrecht Symptom Diary in the Leiden Guide on Palliative Care.

	Total population		Disease-modifying phase		Symptom-management phase		
Patient characteristics	**n**	**(% of 321)**	**n**	**(% of 140)**	**n**	**(% of 181)**	**P-value**
Male gender	158	(49.2)	63	(45.0)	95	(52.5)	0.18
Age in years, median (IQ-range)	65	(57-72)	63	(52-70)	68	(60-73)	<0.0001
Diagnosis							
Cancer (per anatomic region)	*307*	*(95.6)*	*136*	*(97.1)*	*171*	*(94.5)*	*0.24*
Gastro-intestinal	100	(31.2)	39	(78.1)	61	(33.7)	
Gynaecological	42	(13.1)	18	(12.9)	24	(13.3)	
Respiratory	41	(12.8)	20	(14.3)	21	(11.6)	
Soft tissue	31	(9.7)	15	(10.7)	16	(8.8)	
Urological	22	(6.9)	8	(5.7)	14	(7.7)	
Head-neck	19	(5.9)	6	(4.3)	13	(7.2)	
Melanoma	17	(5.3)	13	(9.3)	4	(2.2)	
Haematological	13	(4.0)	6	(4.3)	7	(3.9)	
Breast	11	(3.4)	5	(3.6)	6	(3.3)	
Unknown primary	3	(0.9)	1	(0.7)	2	(1.1)	
Neurological	2	(0.6)	2	(1.4)	0	(0.0)	
Other	6	(1.9)	3	(2.1)	3	(1.7)	
Non-cancer	*14*	*(4.4)*	*4*	*(2.9)*	*10*	*(5.5)*	*0.24*
End-stage renal failure	4	(1.2)	2	(1.4)	2	(1.1)	
Pulmonal failure†	4	(1.2)	2	(1.4)	2	(1.1)	
Neurological deterioration‡	3	(0.9)	0	(0.0)	3	(1.7)	
Cardiovascular§	1	(0.3)	0	(0.0)	1	(0.5)	
Other¶	1	(0.3)	0	(0.0)	1	(0.5)	
Survival in weeks, median (IQ-range)	7	(2-26)	12	(5-54)	5.0	(-13)	<0.0001

Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

† *Diagnoses: chronic obstructive pulmonary disease; lung fibrosis; combined restrictive/obstructive pulmonary disease due to bronchiectasis; interstitial lung disease*

‡ *Diagnoses: amyotrophic lateral sclerosis; Parkinson's disease; post-anoxic encephalopathy*

§ *Diagnoses: right-sided heart failure; aortic dissection*

¶ *Diagnosis: persistent ileus of the small intestine*

List of abbreviations: IQ-range: interquartile range

Table 2. Patients-reported symptom burden assessed with the Utrecht Symptom Diary (n=321).

	Score		Score ≥4†		Score ≥7†		Priority‡	
Utrecht Symptom Diary item	**Median**	**(IQ-range)**	**n**	**(% of 321)**	**n**	**(% of 321)**	**n**	**(% of 321)**
Pain	4	(1-6)	159	(49.5)	65	(20.2)	82	(25.5)
Sleeping problems	4	(1-7)	165	(51.4)	95	(29.6)	15	(4.7)
Dry mouth	5	(2-8)	198	(61.7)	113	(35.2)	12	(3.7)
Swallowing problems	1	(0-4)	90	(28.0)	49	(15.3)	9	(2.8)
Loss of appetite	6	(3-9)	209	(65.1)	139	(43.3)	15	(4.7)
Constipation	5	(2-7)	182	(56.7)	90	(28.0)	12	(3.7)
Nausea	0	(0-3)	73	(22.7)	35	(10.9)	21	(6.5)
Shortness of breath	1	(0-5)	110	(34.3)	48	(15.0)	28	(8.7)
Fatigue	7	(4-8)	242	(75.4)	157	(48.9)	29	(9.0)
Anxiety	2	(0-5)	115	(35.8)	62	(19.3)	17	(5.3)
Depression	3	(0-6)	133	(41.4)	63	(19.6)	12	(3.7)
Well-being§	5	(4-7)	224	(69.8)	88	(27.4)	0	

† *Patient-reported symptom burden scores of ≥4 are considered as clinically relevant burden; ≥7 as serious burden. In this table, both percentages are reported per symptom. Totals of rows may therefore exceed 100%. Results of scores <4 are not presented in this table.*
‡ *106 patients did not indicate which symptom they want to be solved first. Patients could fill in more than one symptom; for purposes of analysis, the first four symptoms reported as priority were included in the analyses. Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.*
§ *A higher score indicates poorer well-being; "Well-being" is never prioritised by any patient.*
List of abbreviations: IQ-range: interquartile range

Table 3. Differences in patient-reported symptom burden in 140 patients in the disease-modifying phase versus 181 patients in the symptom-management phase.

	Disease-modifying phase (n=140)		Symptom-management phase (n=181)		
Utrecht Symptom Diary item	**Median**	**(IQ-range)**	**Median**	**(IQ-range)**	**P-value**
Pain	3	(1-6)	4	(2-6)	0.13
Sleeping problems	4	(1-6)	5	(1-7)	0.15
Dry mouth	5	(1-7)	5	(2-8)	0.12
Swallowing problems	1	(0-3)	1	(0-5)	0.47
Loss of appetite	5	(1-8)	7	(4-9)	0.010
Constipation	5	(1-7)	5	(3-7)	0.24
Nausea	0	(0-4)	1	(0-3)	0.13
Shortness of breath	1	(0-4)	2	(0-5)	0.07
Fatigue	6	(4-8)	7	(4-9)	0.12
Anxiety	3	(0-6)	2	(2-5)	0.030
Depression	3	(1-6)	2	(0-6)	0.70
Well-being†	5	(3-7)	5	(4-7)	0.50

Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]
Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.
List of abbreviations: IQ-range: interquartile range
† *A higher score indicates poorer well-being; "Well-being" is never prioritised by any patient.*

Table 4. Topics patients (n=266) selected to discuss during consultations with help of a question prompt list.

	Total population n=266		Disease-modifying phase	Symptom-management phase	
Topic	**n**	**%**	**% (n=118)**	**% (n=148)**	**P-value†**
Category 1: Symptoms/problems	**250**	**94.0**	**94.1**	**93.9**	**0.96**
Pain	159	59.8	51.7	66.2	0.017
Dry mouth	78	29.3	24.6	32.9	0.13
Loss of appetite	147	55.3	55.1	55.4	0.96
Constipation	69	25.9	23.7	27.7	0.46
Nausea	66	24.8	18.6	29.7	0.039
Shortness of breath	74	27.8	20.3	33.8	0.016
Fatigue	181	68.0	68.6	67.6	0.85
Anxiety	96	36.1	39.0	33.8	0.38
Depression	88	33.1	37.3	29.7	0.19
Nutrition	82	30.8	33.1	29.1	0.48
Sexuality and intimacy	13	4.9	10.2	0.7	0.007
Category 2: Future	**188**	**70.7**	**73.7**	**68.2**	**0.77**
Expected future symptoms	179	67.3	70.3	64.9	0.35
Treatment options for future symptoms	181	68.0	70.3	66.2	0.47
Category 3: Medication and treatment	**215**	**80.8**	**81.4**	**80.4**	**0.85**
Side effects of medication	80	30.1	29.7	30.4	0.90
Medication intake times	46	17.3	19.5	15.5	0.40
Next steps regarding medication	51	19.2	13.6	23.6	0.040
Medication for when I suddenly have more symptoms	99	37.2	33.1	40.1	0.21
Types of morphine-like medication	120	45.1	38.1	50.7	0.042
Choice between treatment/no treatment of the disease	105	39.5	42.4	37.2	0.39
Choice between treatment and quality of life	138	51.9	60.2	45.3	0.016
Category 4: Social/meaning	**138**	**51.9**	**58.5**	**46.6**	**0.06**
Support or information for my children	73	27.4	31.4	24.3	0.20
Support or information for the people around me	100	37.6	39.0	36.5	0.68
Meaning/philosophy of life	47	17.7	18.6	16.9	0.71
Category 5: Organisation of care	**210**	**78.9**	**73.7**	**83.1**	**0.06**
Home care	151	56.8	50.0	62.2	0.047
Domestic care	103	38.7	36.4	40.5	0.50
Hospice care	64	24.1	14.4	31.8	0.001
Volunteers	37	13.9	10.2	16.9	0.12
Point of contact for symptoms	122	45.9	44.1	47.3	0.60
Role of the general practitioner	129	48.5	48.3	48.6	0.96
Possibilities of care	125	47.0	47.5	46.6	0.89

Table 4. *(continued)*	**Total population**		**Disease-modifying phase**	**Symptom-management phase**	
Category 6: Last phase of life	**197**	**74.1**	**69.5**	**77.7**	**0.13**
Palliative sedation	147	55.3	54.2	56.1	0.76
Euthanasia	147	55.3	55.1	55.4	0.96
Foods and fluids	82	30.8	28.8	32.4	0.53
Practical matters relating to the end of life	149	56.0	50.8	60.1	0.13
Course of last phase of life	114	42.9	40.7	44.6	0.52

This table shows how often patients selected the topics for discussion with the help of a question prompt list. The categories and topics are ordered similar to the question prompt list. See Supplement 2 for the code book that was used to group topics and questions of the question prompt list. Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

† *This p-value represents the statistical differences in information needs between disease-modifying phase versus symptom-management phase. P-values of <0.01 were considered statistically significant.*

Relationship between symptom burden and prioritised symptom(s) with information needs

Patients had more information needs regarding symptoms they reported as conferring a serious or clinically relevant burden or had prioritised (Table 5). *Pain* and *Fatigue* were symptoms on which patients scored ≥4 and most often wanted information about. Mild symptoms (score <4) about which patients most frequently wanted information were *Fatigue* and *Loss of appetite*.

DISCUSSION

This study aimed to describe the relationship between patients' symptom burden and information needs and to assess the relationship between those. Patients wanted information about the symptoms for which they reported clinically relevant burden but also about symptoms for which they reported mild burden. In general, patients had information needs about a wide range of topics; these mostly concerned current and future symptoms and symptom management. The need for information about sexuality and intimacy came last on the list of patients and families, especially when the disease was in the symptom-management phase. In that phase, patients often needed information about hospice care.

Symptom burden and prioritised symptom(s)

Patients in our study reported the highest symptom burden for *Fatigue* and *Loss of appetite*, which corresponds with the findings in a study on patients with advanced cancer

Table 5. Relationship between symptom burden and information needs of patients in the palliative phase (n=266)

	Symptom burden <4			Symptom burden ≥4†			Symptom burden ≥7†			Prioritised symptom‡		
Utrecht Symptom Diary item	**Total <4 n**	**Information needs n**	**(% of 266)**	**Total ≥4 n**	**Information needs n**	**(% of 266)**	**Total ≥7 n**	**Information needs n**	**(% of 266)**	**Total prioritised n**	**Information needs n**	**(%)**
Pain	116	39	(33.6)	139	109	(78.4)	55	45	(81.5)	70	61	(87.1)
Dry mouth	100	4	(4.0)	156	71	(45.5)	88	52	(59.0)	10	10	(100)
Loss of appetite	74	25	(33.8)	173	113	(65.3)	115	78	(67.8)	14	14	(100)
Constipation	91	11	(12.1)	155	51	(32.9)	75	36	(48.0)	10	7	(70.0)
Nausea	194	24	(12.4)	65	40	(61.5)	30	23	(76.7)	18	16	(88.9)
Shortness of breath	169	17	(10.1)	87	51	(58.6)	36	27	(75.0)	87	51	(58.6)
Fatigue	57	25	(43.9)	201	149	(74.1)	129	103	(79.8)	23	22	(95.7)
Anxiety	156	21	(13.5)	99	68	(68.7)	56	44	(78.6)	17	17	(100)
Depression	134	18	(13.4)	114	64	(56.1)	56	41	(73.2)	12	12	(100)

This table depicts the proportion of patients having information needs about the symptom with a score of <4; ≥4 or ≥7 respectively, and symptoms the patient prioritised. Total patients included 266; 45 patients were excluded because they did not fill out the question prompt list. Not all patients completed the assessment scales for all symptoms. Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.

"Sleeping problems", "Swallowing problems" and "General wellbeing" are part of the Utrecht Symptom Diary, but do not have a corresponding item in the question prompt list and are therefore not part of this table.

† Symptom burden and prioritised symptoms were statistically significantly associated with more information needs. P-values of <0.05 were considered statistically significant. Symptom burden ≥4 also includes the patients who reported symptom burden ≥7.

‡ 177 patients (66.5%) reported symptoms they wanted to prioritise and had used the question prompt list; there was room to report more than one symptom. For purposes of analysis, the first four prioritised symptoms were included in this analysis.

in the last six months of life, and a systematic review among patients with incurable cancer.[26, 27] The high percentage of patients in the palliative phase with clinically relevant burden from having a dry mouth was also reported in study among UK hospice patients.[28] Our patients most often prioritised *Pain*, *Fatigue* and *Shortness of breath*, even though these did not always cause the highest burden. This is in line with previous studies on how patients prioritise symptoms and suggests that patient-reported symptom burden does not fully reflect symptom experience.[15, 16] Also, in hospital care, there may be more focus on physical symptom burden compared to symptom burden in other dimensions (psychological, social, and existential), influencing the symptoms patients may worry about. Moreover, patients may not be aware that some symptoms, such as a dry mouth, are treatable or occur frequently in the palliative phase. Additionally, pain, fatigue, and shortness of breath significantly impact daily life, and patients and family may fear the occurrence of these symptoms, which might explain why they prioritised them.[15]

Anxiety was reported to be more severe among patients in the disease-modifying phase than those in the symptom-management phase. The difference may be small, but according to Hui et al. a difference in burden of ≥1 is clinically relevant.[30] This difference may be due to a difference in situational anxiety: patients in the disease-modifying phase may experience more anxiety caused by uncertainties associated with life-prolonging treatment and what the future will look like, whereas patients in the symptom-management phase have had more time to deal with their situation, and have more certainty about their prognosis. Additionally, there may be a difference in organic anxiety, which entails somatic causes of anxiety such as side effects of treatment.[31] Zweers et al. found that experienced anxiety may be associated with having accepted that disease-modifying treatment is not an option anymore.[32]

Since Utrecht Symptom Diary symptoms are often multidimensional problems, discussion about these symptoms should extend to psychological distress, social impact and existential aspects to foster optimal care. We hypothesise that patients and families may also worry about symptoms that they associate with death approaching, such as pain and shortness of breath. Clinicians should therefore discuss not only symptom scores, but also possible future symptoms to tailor information-provision.[17] A study in hospice patients demonstrated that although patients scored "0" on the anxiety scale using the Utrecht Symptom Diary, they still may experience tension, or worries.[32] Using a question prompt list in addition to symptom assessment may support a more comprehensive symptom assessment by adding information about the symptoms patients and family worry about. Having a comprehensive insight into symptoms, information needs, and wishes helps to support them better.

Information needs

Patients most often reported information needs related to *Symptoms/problems*, *Medication and treatment* and *Organisation of care*. Least needs for information concern topics about *Social/Meaning*. Patients and families are known to expect clinicians to provide information about their illness, symptoms, care, and future. They expect to discuss social or spiritual support among themselves or with a social worker or spiritual carer.[33] Few patients reported information needs regarding *Sexuality and intimacy*. In a previous study, it was shown that neither patients nor clinicians initiated this topic during consultations.[21] This may be because of time limitations, other priorities, or considering the topic taboo. Additionally, patients find that healthcare professionals generally focus on medical treatment and checking physical symptoms.[34] Yet, in a study on the impact of disease on sexuality and intimacy in patients receiving palliative care, almost half of the patients reported that their intimacy was impacted by their illness, and over 75% of the patients thought discussing intimacy can be helpful.[35, 36] It is likely that, even if the question prompt list explicitly gives them this option, patients do not want or expect to discuss the topic during a palliative care consultation. They may need a more encouraging invitation than a question prompt list to start this particular conversation. In the used version of the question prompt list, the word "sexuality" was placed before "intimacy". We have reversed it to make it more inviting to discuss non-sexual physical contact with loved ones.

We found that information needs of patients depend on the palliative disease phase. Patients in the symptom-management phase had more information needs about *Hospice care* than patients in the disease-modifying phase. A possible explanation is that the former have fewer treatments or contacts in the hospital and need to organise care in a hospice.

Relationship between symptom burden, prioritised symptom(s), and information needs

We found that patient-reported symptom burden and prioritised symptoms were positively associated with information needs. In addition, patients who reported mild symptom burden often reported information needs on these symptoms. This suggests that symptom scores alone are not fully indicative of patients' information needs regarding symptoms. For example, concerns about future symptoms or experience with symptoms in others may prompt a wish for information. Using a question prompt list to support patients and families to prepare for palliative care consultations can close the gap between concerns and actual symptom burden, because it encourages patients and families to ask more questions during consultations, and improves understanding of treatment plans and recall of information.[21, 37] Additionally, clinicians of patients who used a question prompt list expressed more engagement with the patient, explained more about prognoses and treatment, responded more to emotions, and were reminded to pay more attention to topics patients wanted to discuss.[21, 38-41]

Strengths and weaknesses

To our knowledge, this is the first study to explore the relationship between symptom burden and information needs, and the differences between patients in the disease-modifying phase versus symptom-management phase, referred to a hospital-based palliative care team. The results of this study may not apply to all patient populations referred to hospital-based palliative care, because it was conducted in an academic medical centre and almost all patients had cancer. The palliative care consultant assesses whether a patient is fit enough to go through the conversation guide, excluding patients in the dying phase. Therefore, this study does not report on symptom burden and information needs of these patients and their families. Patients reported their symptom burden and information needs at the same time. The fact that symptom burden was assessed first in the conversation guide, followed by information needs, may have influenced reported information needs about symptoms; these information needs may have been less had the order been reversed. Since patients and families received only one conversation guide before the consultation, it was not possible to distinguish patient from family needs. However, the information needs of both are relevant in palliative care consultations. The data, although collected some years ago, are still relevant because information provision by clinicians has not changed substantially.

Further research

Our study was conducted among patients of a specialist palliative care team at an academic hospital. In future research, symptom burden and information needs should be assessed in other settings and among patients with a non-cancer diagnosis. Ways to address intimacy and sexuality in palliative care could be further explored. We did not study if patient-reported symptom burden and information needs altered over time, which would be an interesting topic for further research. Future research could study the effect of using a symptom assessment scale combined with a question prompt list on quality of life and person-centred care. This study was conducted using an observational study design in patients who have used the conversation guide. More precise insight into the symptom burden and information needs of patients in palliative care in several care settings can be provided by using a prospective follow-up design in a cohort of patients who have all received the conversation guide. Additionally, reasons for (not) using the conversation guide can be tracked. Also, the use of the conversation guide in the dying phase in identifying the needs of family of patients can be studied.

CONCLUSION

Symptom burden and information needs in the palliative phase are related. However, patients often also have information needs in other domains of palliative care. The use of a conversation guide comprising a symptom assessment scale and a question prompt list can identify patient concerns about current and future symptoms and thus support tailoring of consultations and appropriate care.

Acknowledgements
The authors would like to thank their colleagues at the Center of Expertise in Palliative Care for their help in data collection.

Conflict of interest
All authors declare no conflict of interest.

Data availability statement
Research data are not shared.

REFERENCES

1. World Health Organisation (2018) WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/. Accessed 05-10-2018.
2. *Just because we can, doesn't mean we should. Appropriate end-of-life care*. 2015. Utrecht, the Netherlands: Royal Dutch Medical Association.
3. Taber JM, Ellis EM, Reblin M, et al. Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample. *PLoS One* 2019; 14: e0219074. 2019/08/16. DOI: 10.1371/journal.pone.0219074.
4. Hebert RS, Schulz R, Copeland V, et al. What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *J Palliat Med* 2008; 11: 476-483. 2008/03/28. DOI: 10.1089/jpm.2007.0165.
5. Janssen DJ, Spruit MA, Wouters EF, et al. Daily symptom burden in end-stage chronic organ failure: a systematic review. *Palliat Med* 2008; 22: 938-948. 2008/09/20. DOI: 10.1177/0269216308096906.
6. Rainbird K, Perkins J, Sanson-Fisher R, et al. The needs of patients with advanced, incurable cancer. *Br J Cancer* 2009; 101: 759-764. 2009/08/06. DOI: 10.1038/sj.bjc.6605235.
7. Kirk P, Kirk I and Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 2004; 328: 1343. 2004/05/21. DOI: 10.1136/bmj.38103.423576.55.
8. Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage* 2007; 34: 81-93. 2007/05/29. DOI: 10.1016/j.jpainsymman.2006.09.035.
9. van der Zwaard J, Francke A and Gamel C. Informatiebehoeften van patiënten die palliatieve zorg ontvangen en hun naasten: Een literatuurstudie. *Verpleegkunde* 2003; 18: 8-20.
10. Wise J. Dying remains a taboo subject for patients and GPs, finds survey. *BMJ (Clinical research ed)* 2012; 344: e3356.
11. Pieters J, Dolmans D, Verstegen DML, et al. Palliative care education in the undergraduate medical curricula: students' views on the importance of, their confidence in, and knowledge of palliative care. *BMC Palliat Care* 2019; 18: 72. 2019/08/29. DOI: 10.1186/s12904-019-0458-x.
12. de Graaf E, Zweers D, de Graeff A, et al. Symptom Intensity of Hospice Patients: A Longitudinal Analysis of Concordance Between Patients' and Nurses' Outcomes. *J Pain Symptom Manage* 2018; 55: 272-281. 2017/09/20. DOI: 10.1016/j.jpainsymman.2017.09.005.
13. Pakhomov SV, Jacobsen SJ, Chute CG, et al. Agreement between patient-reported symptoms and their documentation in the medical record. *Am J Manag Care* 2008; 14: 530-539. 2008/08/12.
14. Stromgren AS, Groenvold M, Pedersen L, et al. Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. *J Pain Symptom Manage* 2001; 21: 189-196. 2001/03/10. DOI: 10.1016/s0885-3924(01)00264-0.
15. Li B, Mah K, Swami N, et al. Symptom Assessment in Patients with Advanced Cancer: Are the Most Severe Symptoms the Most Bothersome? *J Palliat Med* 2019; 22: 1252-1259. 2019/05/08. DOI: 10.1089/jpm.2018.0622.
16. Stromgren AS, Sjogren P, Goldschmidt D, et al. Symptom priority and course of symptomatology in specialized palliative care. *J Pain Symptom Manage* 2006; 31: 199-206. 2006/03/28. DOI: 10.1016/j.jpainsymman.2005.07.007.

17. Brooks JV, Poague C, Formagini T, et al. The Role of a Symptom Assessment Tool in Shaping Patient-Physician Communication in Palliative Care. *J Pain Symptom Manage* 2020; 59: 30-38. 2019/09/09. DOI: 10.1016/j.jpainsymman.2019.08.024.
18. Clayton J, Butow P, Tattersall M, et al. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer* 2003; 89: 2069-2077. 2003/12/04. DOI: 10.1038/sj.bjc.6601380.
19. van der Stap L, de Nijs EJM, Oomes M, et al. The self-perceived palliative care barriers and educational needs of clinicians working in hospital primary care teams and referral patterns: lessons learned from a single-center survey and cohort study. *Ann Palliat Med* 2021; 10: 2620-2637. 2021/01/22. DOI: 10.21037/apm-20-1706.
20. van der Baan FH, Koldenhof JJ, de Nijs EJ, et al. Validation of the Dutch version of the Edmonton Symptom Assessment System. *Cancer Med* 2020 2020/07/10. DOI: 10.1002/cam4.3253.
21. Verhoef MJ, de Nijs E, Sweep B, et al. Non-specialist palliative care - question prompt list preparation: patient, family and clinician experiences. *BMJ Support Palliat Care* 2022 2022/02/12. DOI: 10.1136/bmjspcare-2021-003035.
22. Lynn J and Adamson DM. Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. *RAND Health*. Santa Monica, United States of America2003, p. 18.
23. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7: 6-9. 1991/01/01.
24. Selby D, Cascella A, Gardiner K, et al. A single set of numerical cutpoints to define moderate and severe symptoms for the Edmonton Symptom Assessment System. *J Pain Symptom Manage* 2010; 39: 241-249. 2009/12/08. DOI: 10.1016/j.jpainsymman.2009.06.010.
25. Oldenmenger WH, de Raaf PJ, de Klerk C, et al. Cut points on 0-10 numeric rating scales for symptoms included in the Edmonton Symptom Assessment Scale in cancer patients: a systematic review. *J Pain Symptom Manage* 2013; 45: 1083-1093. 2012/09/29. DOI: 10.1016/j.jpainsymman.2012.06.007.
26. Seow H, Barbera L, Sutradhar R, et al. Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncol* 2011; 29: 1151-1158. 2011/02/09. DOI: 10.1200/JCO.2010.30.7173.
27. Teunissen SC, Wesker W, Kruitwagen C, et al. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 2007; 34: 94-104. 2007/05/19. DOI: 10.1016/j.jpainsymman.2006.10.015.
28. Jobbins J, Bagg J, Finlay IG, et al. Oral and dental disease in terminally ill cancer patients. *BMJ* 1992; 304: 1612. 1992/06/20. DOI: 10.1136/bmj.304.6842.1612.
29. Hui D, Shamieh O, Paiva CE, et al. Minimal clinically important differences in the Edmonton Symptom Assessment Scale in cancer patients: A prospective, multicenter study. *Cancer* 2015; 121: 3027-3035. 2015/06/11. DOI: 10.1002/cncr.29437.
30. Stiefel F and Razavi D. Common psychiatric disorders in cancer patients. II. Anxiety and acute confusional states. *Support Care Cancer* 1994; 2: 233-237. 1994/07/01. DOI: 10.1007/BF00365727.
31. Zweers D, de Graeff A, Duijn J, et al. Patients' Needs Regarding Anxiety Management in Palliative Cancer Care: A Qualitative Study in a Hospice Setting. *Am J Hosp Palliat Care* 2019; 36: 947-954. 2019/05/11. DOI: 10.1177/1049909119846844.
32. Arora NK, Finney Rutten LJ, Gustafson DH, et al. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psychooncology* 2007; 16: 474-486. 2006/09/21. DOI: 10.1002/pon.1084.

33. de Vocht H, Hordern A, Notter J, et al. Stepped Skills: A team approach towards communication about sexuality and intimacy in cancer and palliative care. *Australas Med J* 2011; 4: 610-619. 2011/01/01. DOI: 10.4066/AMJ.20111047.

34. Cathcart-Rake E, O'Connor JM, Ridgeway JL, et al. Querying Patients With Cancer About Sexual Health and Sexual and Gender Minority Status: A Qualitative Study of Health-Care Providers. *Am J Hosp Palliat Care* 2019: 1049909119879129. 2019/10/12. DOI: 10.1177/1049909119879129.

35. Kelemen A, Cagle J, Chung J, et al. Assessing the Impact of Serious Illness on Patient Intimacy and Sexuality in Palliative Care. *J Pain Symptom Manage* 2019; 58: 282-288. 2019/04/26. DOI: 10.1016/j.jpainsymman.2019.04.015.

36. Shirai Y, Fujimori M, Ogawa A, et al. Patients' perception of the usefulness of a question prompt sheet for advanced cancer patients when deciding the initial treatment: a randomized, controlled trial. *Psychooncology* 2012; 21: 706-713. 2011/03/23. DOI: 10.1002/pon.1955.

37. Clayton JM, Natalia C, Butow PN, et al. Physician endorsement alone may not enhance question-asking by advanced cancer patients during consultations about palliative care. *Support Care Cancer* 2012; 20: 1457-1464. 2011/07/27. DOI: 10.1007/s00520-011-1229-2.

38. Epstein RM, Duberstein PR, Fenton JJ, et al. Effect of a Patient-Centered Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilization in Advanced Cancer: The VOICE Randomized Clinical Trial. *JAMA Oncol* 2017; 3: 92-100. 2016/09/10. DOI: 10.1001/jamaoncol.2016.4373.

39. Hebert RS, Schulz R, Copeland VC, et al. Pilot testing of a question prompt sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues. *Am J Hosp Palliat Care* 2009; 26: 24-32. 2008/10/10. DOI: 10.1177/1049909108324360.

40. Brandes K, Linn AJ, Butow PN, et al. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psychooncology* 2015; 24: 245-252. 2014/08/02. DOI: 10.1002/pon.3637.

SUPPLEMENTARY MATERIALS

Supplement 1

Question prompt list of the Leiden Guide on Palliative Care 2015.

OVERVIEW OF
POSSIBLE CONVERSATION TOPICS
AND QUESTIONS

Center of Expertise in Palliative Care

During the consultation I want to talk about:

Symptoms /problems
- ☐ Pain
- ☐ Constipation (problems with bowel movement)
- ☐ Shortness of breath
- ☐ Nausea
- ☐ Loss of appetite
- ☐ Fatigue
- ☐ Dry mouth
- ☐ Nutrition
- ☐ Anxiety
- ☐ Depression
- ☐ Sexuality and intimacy

Future
- ☐ Expected future symptoms
- ☐ Treatment options for future symptoms

Medication and treatment
- ☐ Side effects of medication
- ☐ Medication intake times
- ☐ Next steps regarding medication
- ☐ Medication for when I suddenly have more symptoms
- ☐ Types of morphine-like medication
- ☐ Choice between treatment/no treatment of the disease
- ☐ Choice between treatment and quality of life

Social/ Meaning
- ☐ Support or information for my children
- ☐ Support or information for the people around me (informal caregivers)
- ☐ Meaning of life / philosophy of life

Organisation of care
- ☐ Home care
- ☐ Domestic care
- ☐ Hospice care
- ☐ Volunteers
- ☐ Point of contact for symptoms (who do I call for what)
- ☐ Role of the GP
- ☐ Possibilities of care

Last phase of life
- ☐ Palliative sedation
- ☐ Euthanasia
- ☐ Food and fluids
- ☐ Practical matters relating to end of life
- ☐ Course of last phase of life

My personal questions
- ☐ .....
- ☐ .....
- ☐ .....

Example questions:

Symptoms/problems

□ When I have symptoms, what can be done to reduce them?
□ What can I do myself to reduce my symptoms?
□ How can I achieve the best possible quality of life with my symptoms?
□ I am very tired, how do I deal with this?
□ How do I balance rest and activity?
□ What can I do to stay fit?
□ How can I continue to do the things that are important to me?
□ What is the best food for me to eat?
□ What can I do to increase my appetite for food?
□ How can I reduce my pain?
□ I feel less like having sex or cuddling, how do I deal with this?
□ Who can help me with feelings of depression and anxiety?
□ Where do I find reliable information, websites or information leaflets?

Future

□ What symptoms can I expect in the future and what can I do about them?
□ Will I have pain?
□ Will my pain and other symptoms also be treatable in the future?

Social/ Meaning

□ Where can I find good support/counselling for my children?
□ Are there any good websites for (young) children?
□ Which sites/organisations can help my family and friends (family caregivers)?
□ How can I discuss important choices/events in my life?
□ How do I find a way of saying goodbye that is right for me?
□ My views on the meaning of life and on life after death are changing. How do I deal with this?

Organisation of care

□ How can I arrange home care or domestic help now or in the future?
□ What can volunteers do for me?
□ Who do I call for what symptom?
□ Can I get help with an activity, travel or outing?

Medication and treatment

□ Are there any other painkillers for me?
□ How do the medications that I am taking work?
□ What are the side effects of the medications I am taking?
□ What are the chances that I will experience side effects?
□ What can be done about side effects?
□ How and when should I take my medication?
□ If I am taking morphine (or a morphine-like medication), can I:
  o become addicted, so it doesn't work anymore or I need more and more of it?
  o stop taking it when my pain is gone?
  o get sleepy or confused?
  o drive a car?
  o become nauseous or constipated (difficult or no bowel movement)?
□ What does treatment of the disease do to my quality of life?
□ What are the options if I decide against further treatment of the disease (for example, if I stop chemotherapy)?

Last phase of life

□ Can I get information about the last weeks of life?
□ Can I get information about palliative sedation or euthanasia?
□ How do I manage food and fluids during illness or end of life?
□ Can I get information about the care options in the last phase of life?
□ What are the costs of care (for example, home care/hospice)?

Personal questions:

□ .....
□ .....
□ .....
□ .....
□ .....
□ .....
□ .....

Supplement 2

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]

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	
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 atient 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.