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# Assessment of patient symptom burden and information needs helps tailoring palliative care consultations: An observational study

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## 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.

KEYWORDS

advance care planning, information needs, palliative care, palliative medicine, question prompt list, symptom assessment

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Jenny T. van der Steen and Yvette M. van der Linden contributed equally.

# 1 | 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 (World Health Organization, n.d.). However, patients, their family, and clinicians often consider addressing such topics to be difficult (KNMG, 2015). Patients and family often do not know what palliative care entails, what they might need or what to discuss during palliative care consultations (Hebert et al., 2008; Taber et al., 2019). Most patients underreport their symptoms (Janssen et al., 2008; Rainbird et al., 2009). They often appreciate receiving information about symptoms, prognosis and about practical, psychosocial or spiritual issues. These information needs may change over time (Hebert et al., 2008; Kirk et al., 2004; Parker et al., 2007; van der Zwaard et al., 2003). Clinicians often feel unprepared to discuss end-of-life matters or do not know which topics to address (KNMG, 2015; Pieters et al., 2019; Wise, 2012). Research has shown that clinicians tend to underestimate and under-document the severity of symptoms compared to what patients report themselves (de Graaf et al., 2018; Pakhomov et al., 2008; Stromgren et al., 2001).

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 (Li et al., 2019; Stromgren et al., 2006). Before initiating symptom management, scores should therefore always be discussed with patients following a multidimensional approach (Brooks et al., 2020). 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 (Clayton et al., 2003).

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.

# 2 | METHODS

## 2.1 | 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 (van der Stap et al., 2021). 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) (van der Baan et al., 2020) 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 (Verhoef et al., 2022). 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.

## 2.2 | 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 and 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;

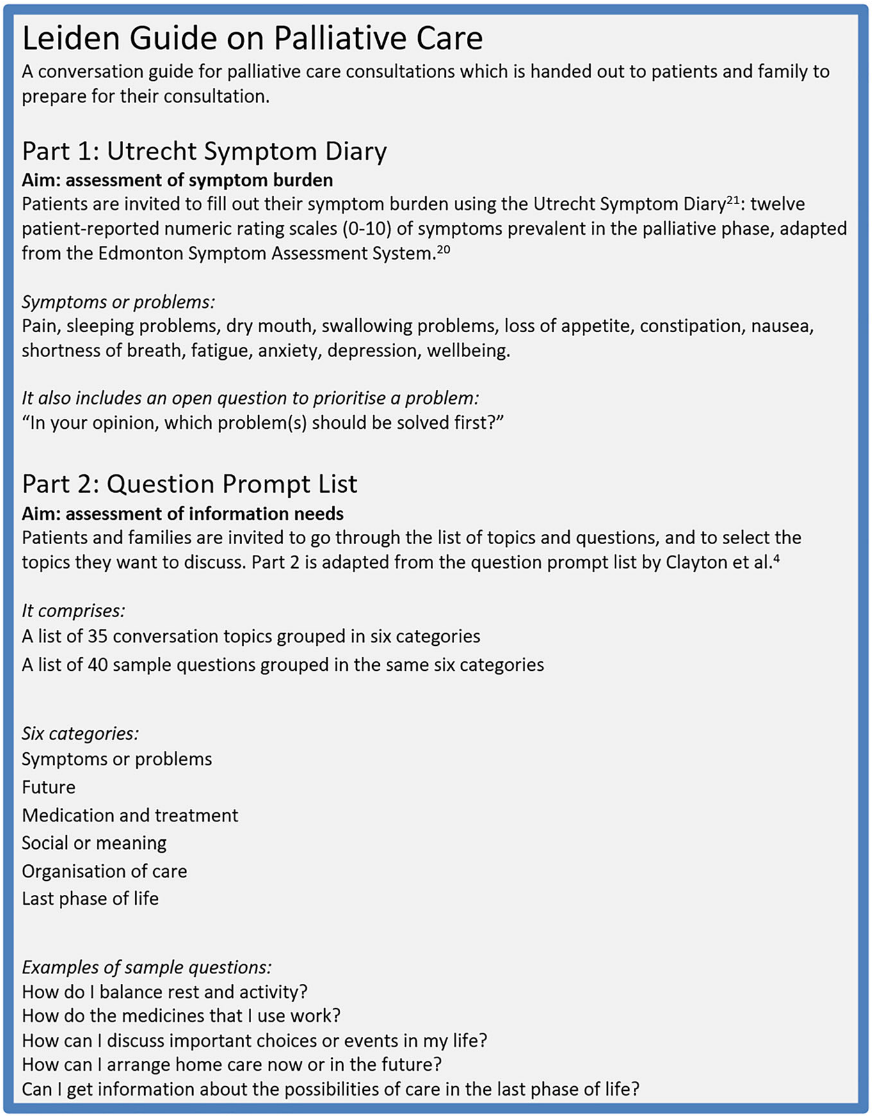
- Symptom-management phase, in which treatment is aimed at symptom relief or terminal care (Lynn & Adamson, 2003).

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

## 2.3 | 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 (Bruera et al., 1991; van der Baan et al., 2020). 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 (de Graaf et al., 2018).

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 Appendix S1) (Clayton et al., 2003; Verhoef et al., 2022). 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



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 System.[20]

*Symptoms or problems:*

Pain, sleeping problems, dry mouth, swallowing problems, loss of appetite, constipation, nausea, shortness of breath, fatigue, anxiety, depression, wellbeing.

*It also includes an open question to prioritise a problem:*

“In your opinion, which problem(s) should be solved first?”

Part 2: Question Prompt List

**Aim: assessment of information needs**

Patients and families are invited to go through the list of topics and questions, and to select the 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:*

Symptoms or problems
Future
Medication and treatment
Social or meaning
Organisation of care
Last phase of life

*Examples of sample questions:*

How do I balance rest and activity?
How do the medicines that I use work?
How can I discuss important choices or events in my life?
How can I arrange home care now or in the future?
Can I get information about the possibilities of care in the last phase of life?

**FIGURE 1** Outline of the conversation guide (Leiden Guide on Palliative Care) used for data collection collected the data on symptom burden and information needs that patients had reported via the conversation guide.

## 2.4 | 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) (Oldenmenger et al., 2013; Selby et al., 2010). 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 (Appendix S2). 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-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

**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[a] | 4 | (1.2) | 2 | (1.4) | 2 | (1.1) | |
| Neurological deterioration[b] | 3 | (0.9) | 0 | (0.0) | 3 | (1.7) | |
| Cardiovascular[c] | 1 | (0.3) | 0 | (0.0) | 1 | (0.5) | |
| Other[d] | 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 |

*Note*: 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 (Lynn & Adamson, 2003).

Abbreviation: IQ-range, interquartile range.

[a] Diagnoses: chronic obstructive pulmonary disease; lung fibrosis; combined restrictive/obstructive pulmonary disease due to bronchiectasis; interstitial lung disease.

[b] Diagnoses: amyotrophic lateral sclerosis; Parkinson's disease; post-anoxic encephalopathy.

[c] Diagnoses: right-sided heart failure; aortic dissection.

[d] Diagnosis: persistent ileus of the small intestine.

either were excluded. Associations between disease phase and topics included in the question prompt list that were <0.01 were regarded as statistically significant.

## 3 | 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).

### 3.1 | 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.

### 3.2 | 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*.

### 3.3 | 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

**TABLE 2** Patients-reported symptom burden assessed with the Utrecht Symptom Diary ($n = 321$)

| | Score | | Score ≥4[a] | | Score ≥7[a] | | Priority[b] | |
|---|---|---|---|---|---|---|---|---|
| **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[c] | 5 | (4–7) | 224 | (69.8) | 88 | (27.4) | 0 | |

Abbreviation: IQ-range, interquartile range.

[a] 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.

[b] One-hundred-six 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.

[c] A higher score indicates poorer well-being; “Well-being” is never prioritised by any patient.

**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[a] | 5 | (3–7) | 5 | (4–7) | 0.50 |

*Note*: 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. (Lynn & Adamson, 2003). Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.
Abbreviation: IQ-range, interquartile range.

[a] 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 $n = 118$ | Symptom-management phase $n = 148$ | |
|---|---|---|---|---|---|
| **Topic** | ***n*** | **%** | **%** | **%** | ***P* value[a]** |
| 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 |

**TABLE 4** (Continued)

| | Total population *n* = 266 | | Disease-modifying phase *n* = 118 | Symptom-management phase *n* = 148 | |
|---|---|---|---|---|---|
| **Topic** | ***n*** | **%** | **%** | **%** | ***P* value**[a] |
| 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 |
| 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 |

*Note*: 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 similarly to the question prompt list. See Appendix S2 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 (Lynn & Adamson, 2003).

[a] 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.

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*.

## 4 | 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.

### 4.1 | 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 in the last 6 months of life, and a systematic review among patients with incurable cancer (Seow et al., 2011; Teunissen et al., 2007). 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 (Jobbins et al., 1992). 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 (Li et al., 2019; Stromgren et al., 2006). 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

**TABLE 5** Relationship between symptom burden and information needs of patients in the palliative phase ($n = 266$)

| | Symptom burden <4 | | | Symptom burden ≥4[a] | | |
|---|---|---|---|---|---|---|
| Utrecht symptom diary item | Total <4 n | Information needs n | (% of 266) | Total ≥4 n | Information needs n | (% of 266) |
| Pain | 116 | 39 | (33.6) | 139 | 109 | (78.4) |
| Dry mouth | 100 | 4 | (4.0) | 156 | 71 | (45.5) |
| Loss of appetite | 74 | 25 | (33.8) | 173 | 113 | (65.3) |
| Constipation | 91 | 11 | (12.1) | 155 | 51 | (32.9) |
| Nausea | 194 | 24 | (12.4) | 65 | 40 | (61.5) |
| Shortness of breath | 169 | 17 | (10.1) | 87 | 51 | (58.6) |
| Fatigue | 57 | 25 | (43.9) | 201 | 149 | (74.1) |
| Anxiety | 156 | 21 | (13.5) | 99 | 68 | (68.7) |
| Depression | 134 | 18 | (13.4) | 114 | 64 | (56.1) |

*Notes*: 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.

[a] 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.

[b] One-hundred seventy-seven 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.

**TABLE 5** (Continued)

| | Symptom burden ≥7[a] | | | Prioritised symptom[b] | | |
|---|---|---|---|---|---|---|
| Utrecht symptom diary item | Total ≥7 n | Information needs n | (% of 266) | Total prioritised n | Information needs n | (%) |
| Pain | 55 | 45 | (81.5) | 70 | 61 | (87.1) |
| Dry mouth | 88 | 52 | (59.0) | 10 | 10 | (100) |
| Loss of appetite | 115 | 78 | (67.8) | 14 | 14 | (100) |
| Constipation | 75 | 36 | (48.0) | 10 | 7 | (70.0) |
| Nausea | 30 | 23 | (76.7) | 18 | 16 | (88.9) |
| Shortness of breath | 36 | 27 | (75.0) | 87 | 51 | (58.6) |
| Fatigue | 129 | 103 | (79.8) | 23 | 22 | (95.7) |
| Anxiety | 56 | 44 | (78.6) | 17 | 17 | (100) |
| Depression | 56 | 41 | (73.2) | 12 | 12 | (100) |

*Notes*: 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.

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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 (Li et al., 2019).

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. (2015), a difference in burden of ≥1 is clinically relevant. 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 (Stiefel & Razavi, 1994). Zweers et al. (2019) found that experienced anxiety may be associated with having accepted that disease-modifying treatment is not an option anymore.

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 (Brooks et al., 2020). 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 (Zweers et al., 2019). 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.

## 4.2 | 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 (Arora et al., 2007). 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 (Verhoef et al., 2022). 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 (de Vocht et al., 2011). 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 (Cathcart-Rake et al., 2020; Kelemen et al., 2019). 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 in the new version 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.

## 4.3 | 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 (Shirai et al., 2012; Verhoef et al., 2022). 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 (Brandes et al., 2015; J. M. Clayton et al., 2012; Epstein et al., 2017; Hebert et al., 2009; Verhoef et al., 2022).

## 4.4 | 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.

### 4.5 | 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.

## 5 | 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.

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### CONFLICT OF INTEREST

All authors declare no conflict of interest.

### DATA AVAILABILITY STATEMENT

Research data are not shared.

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