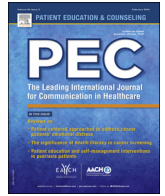




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# What is symptom meaning? A framework analysis of communication in palliative care consultations

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### ABSTRACT

**Objective:** There is a limited understanding of symptom meaning and its significance to clinical practice within symptom experience literature. This study aims to qualitatively explore the ways in which symptom meanings are discussed by patients and responded to by palliative care physicians during consultations.

**Methods:** Framework analysis was conducted with 40 palliative care consultation transcripts.

**Results:** 55% of consultations discussed symptom meaning. Six themes regarding patients' symptom meanings emerged while four themes conveyed physicians' responses to these utterances. Key symptom meanings included symptoms representing diminished function and uncertainty about symptom cause or future. Physicians usually gave scientific medical responses concerning symptom cause and treatment, versus reassurance or empathy.

**Conclusion:** This study has provided greater insight into the different symptom meanings that exist for palliative care patients. Physicians' responses highlight their reliance on medical information when patients are distressed. Future studies should explore the impact of different responses on patient outcomes, and health practitioners' views about optimal responses.

**Practice implications:** Physicians could explore symptom meanings with their patients, looking out for those identified here. Apart from information-giving and treatment, active listening to these concerns as they present in consultations may help improve the therapeutic relationship and better guide optimal care.

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## 1. Introduction

During end-of-life care, patients can endure symptoms such as pain, fatigue, diminished food and water intake, bowel problems and breathlessness (dyspnoea) [1,2]. However, the experience and degree of suffering for each symptom often differs between patients [3]. The Symptom Experience Model proposed by Armstrong maintains that patients perceive and therefore experience symptoms based on four key factors: frequency, intensity, distress and meaning [4]. Of these factors, symptom meaning is somewhat more complex and posits that regardless of symptom characteristics, the meaning given to a symptom largely influences

an individual's perception of that symptom's significance, and whether their symptom experience is positive or negative [4].

The literature has defined two types of symptom meaning: situational meaning, where the patient focuses on the struggle of daily living and their ability to cope with the symptom, and existential meaning, where symptoms act as reminders of death and mortality, their diagnosis, loss of purpose or patients' spiritual beliefs [4,5]. Patients appear to form symptom meanings based on their perception of severity, the symptom's threat to normalcy, its familiarity or its urgency for treatment [6]. Symptom meanings can also form based on what the symptoms may signal for the future, for example, pain could signify an agonising death, while fatigue might signify an inability to return to 'normal' living [7]. The Australian Cancer Council's guidelines for cancer pain management acknowledge the importance of symptom meaning, by highlighting the need to 'assess and record the meanings the person's pain has for them' [8].

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Advanced cancer and palliative care symptom experience studies provide insight into symptom meanings for seriously ill patients. For adults with malignant brain tumours, symptoms meant the loss of social, familial and intimate roles and relationships, employment, independence, spontaneity, dreams and future life plans, and sense of self [9]. Other symptom meanings include powerlessness, the nearness of death, disease progression or cancer recurrence, restriction and isolation [10–12]. Symptom meanings can thus depend heavily on whether symptoms are controlled enough for patients to perform usual activities, as this determines whether patients themselves or the disease has greater control over their lives [13].

Information alone about the meaning, cause and future of their symptoms can reduce symptom burden. For example, some patients claimed their burden of fatigue reduced after attributing meaning to it, usually that the cancer caused their tiredness [13,14]. Health professionals therefore play an important role in providing both treatment and information so that patients may understand and give meaning to their symptoms. Yet, a study of palliative care consultations has shown that 64% of physician utterances related to medical and technical issues about the patient's condition and treatment regime, whereas only 23% of utterances were dedicated to health-related quality of life issues such as counselling or asking questions about symptoms (15.7%), daily activities (2.7%) and emotional functioning (5%) [15]. In comparison, patients expressed more than double the amount of health-related quality of life utterances as physicians (48%) and when emotional issues were discussed, patients usually initiated them [15]. While typically physicians may want to convey scientific causes and cures to a patient, not acknowledging what symptoms mean or how they impact the patient can impair communication and clinical care [5]. Indeed, research suggests that health professionals can alleviate distress by listening to patients' experiences and discussing the patient's situation meaningfully and empathically, rather than information-giving alone [14].

Despite the importance of clinicians exploring symptom experience and meaning, research directly exploring the communication of symptom meaning between palliative care physicians and patients is yet to be conducted. Given this critical gap in symptom experience research, this study aimed to explore the range of ways in which symptom meanings are communicated by

patients and responded to by clinicians in palliative care consultations.

## 2. Methods

### 2.1. Design

As a relatively unexamined phenomenon, a qualitative approach is most suitable for exploring the communication about symptom meaning and to begin understanding the significance of symptom meaning to individual experience. Qualitative methodology aims to gain insight into individuals' beliefs and thoughts, and the unique ways they interpret and experience their social world [16].

### 2.2. Sample

Soft copies of 92 palliative care consultation transcripts were obtained from a previous study that evaluated the effectiveness of a question prompt list in meeting patients' information needs during palliative care consultations [17]. The parent study was approved by all ethics committees involved. Patients were eligible for the parent study if they were over the age of 18, were seeing a palliative care physician for the first, second or third time, could speak English and were not too ill to participate. Patients in the parent study were randomised to receive the question prompt list or not. For this study, only consultation transcripts where the prompt list was received were used since these were of longer duration and had richer symptom discussions. More in-depth exchanges were preferred to better understand the range of ways in which symptoms are discussed between physicians and patients. Consultations were selected randomly from the pool of eligible transcripts until saturation of themes was reached (that is, no new themes emerging from six consecutive transcripts). A total of 40 transcripts of palliative care consultations were analysed.

### 2.3. Data analysis and rigour

The consultations were analysed based on the seven stages of framework analysis [18]. With this method, key themes are identified inductively from the data to create an analytical coding framework, then the evidence for these themes is charted onto a

**Table 1**  
Seven stages of the consultation analysis following the framework method.

Stage	Method
<b>Stage 1: Transcription</b>	Verbatim transcripts of consultations were used. Since the content of the transcripts is most important in framework analysis, dialogue conventions such as pauses and um's were not examined in detail.
<b>Stage 2: Familiarisation</b>	The first twelve consultations were read and re-read to increase familiarisation with the data and understand the dynamics of palliative care consultations. Initial notes were made on the transcripts of first, how symptom meanings were discussed, and second, how these meanings were responded to by clinicians.
<b>Stage 3: Coding</b>	Paragraphs or phrases of interest were highlighted on the initial transcripts and assigned a potential code according to their content and meaning, as a form of open coding. The researcher's supervisor also independently read and commented on twelve different transcripts for a second perspective. In this way, C.E. and P.B. could both identify and explore the different ways symptom dialogue occurred during consultations.
<b>Stage 4: Developing a working analytical framework</b>	Patterns and potential codes that emerged from the initial consultation transcripts were discussed by the researcher and her supervisor in order to collaboratively form two preliminary analytical frameworks: one for patients' symptom meanings and one for clinicians' responses. These frameworks were agreed upon once all the ideas in the initial consultation data, relevant to the research questions, were captured. For the frameworks, similar codes were grouped into themes and categories that were clearly defined.
<b>Stage 5: Applying the analytical framework</b>	The preliminary frameworks were then used to code the initial and subsequent transcripts until data saturation was achieved (no new themes after six consecutive consultations). The frameworks were modified when any new themes emerged, or themes or codes appeared to overlap.
<b>Stage 6: Charting data into the framework matrix</b>	The themes and codes, using quotes and page numbers from each transcript, were then mapped onto separate Excel spreadsheets for symptom meanings and clinicians' responses, creating two framework matrices. This allowed the full set of data to be condensed and summarised into the relevant information for the study.
<b>Stage 7: Interpreting the data</b>	By analysing the data and examining the framework matrices, the researcher could identify patterns and make comparisons across the set of transcripts, note the frequency and prominence of themes, and map relationships between codes.

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