What is Your Understanding of Your Illness? A Communication Tool to Explore Patients' Perspectives of Living with Advanced Illness

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BACKGROUND: Provider communication courses and guidelines stress the use of open-ended questions, such as “what is your understanding of your illness?” to explore patients’ perceptions of their illness severity, yet descriptions of patients’ responses are largely absent from the current literature. These questions are most often used by clinicians as they deliver bad news to cancer patients or address code status at the end of life, but have not been well studied in other diseases or earlier in the disease course.

OBJECTIVES: To explore the responses of patients living with serious illness to the question “what is your understanding of your illness?” and to identify similarities and differences in themes and language used by cancer and non-cancer patients to discuss their illness.

DESIGN: We conducted a qualitative analysis of patients’ responses to “what is your understanding of your illness?”

PARTICIPANTS: Two hundred nine subjects, 69 with cancer, 70 CHF, and 70 COPD, who had an estimated 50 % 2-year survival. Mean age was 66 years.

APPROACH: Responses were recorded at the baseline interview of a larger, longitudinal study of patients with advanced life-limiting illness (cancer, CHF, or COPD). After thematic content analysis using open coding, investigators conducted pattern analysis to examine variation associated with diagnosis.

RESULTS: We identified five major themes: naming the diagnosis or describing the pathophysiology, illness history, prognosis, symptoms, and causality. Responses varied by diagnosis. Cancer patients’ responses more often included specific diagnostic details and prognosis, while non-cancer patients referenced symptoms and causality.

CONCLUSIONS: Patients’ responses to the open-ended question “what is your understanding of your illness?” can provide the clinician with important information and insight on how they view their illness in a non-acute setting. The identified themes can serve as a foundation for patient-centered communication strate-

gies as we strive to build a mutual understanding of illness with patients.

KEY WORDS: communication; qualitative research; advanced illness; patient-centered care; palliative care.

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INTRODUCTION

Clinicians find communicating with seriously ill patients challenging.¹ Physicians face uncertainty regarding not only their own understanding of prognosis, but also in discerning how and when to relay prognostic information to patients.¹⁻³ Communication guidelines suggest probing patients’ preferences for the amount and level of information desired. To begin such discussions, these guidelines recommend using open-ended questions, such as “what is your understanding of your illness?”⁴⁻⁶

Despite the common use of this question in palliative care, we know of no study offering empirical examination of how patients respond. Studies that inform communication guidelines are largely limited to areas of specialty training such as oncology and palliative care, and focus on specific physician communication tasks such as breaking bad news, establishing patients’ understanding of terminal prognoses, or determining the code status in acute care settings.⁴⁻¹³ The focus on communicating with cancer patients or those at the very end of life leaves a gap in our understanding of best practice among those living with other life-limiting illnesses. Ideally the use of open-ended questions allows patients with a variety of diseases to respond based on their disease knowledge and experiences.

The primary purpose of this study was to explore the responses of a diverse group of patients living with serious illness to the question, “what is your understanding of your illness?” Second, we explored whether patients’ response patterns varied by diagnostic group (cancer vs. non-cancer).

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Our findings provide an empirically based framework for facilitating patient-centered communication with seriously ill patients.

METHODS

We analyzed baseline data from a longitudinal cohort study of 210 patients living with advanced illness (cancer, CHF, or COPD) that sought to capture patient and caregiver experiences as they transition over the course of serious illness until the end of life.¹⁴ The baseline quantitative analysis and study description have been previously published.¹⁴ The Institutional Review Board of each participating hospital, Durham Veterans Affairs and Duke University Hospital, approved the study, and each participant (patient and caregiver) provided written informed consent.

Using hospital databases and tumor registries, we identified patients residing within 35 miles of the study site to allow for in-home interviews. We sought to identify patients with an estimated 50 % or less 2-year survival based on information available at the time of study design. By using these broad criteria, we hoped to better capture the experiences of patients as they transitioned from living with serious illness toward end of life. We therefore included patients with stage IV breast, colorectal, and prostate cancer, stage IIIb or stage IV lung cancer, NYHA stage III or IV CHF with LVEF < 40 %, and COPD with hypercapnea $p\text{CO}_2 > 46$ with hospitalization or an ED visit within that last year.¹⁴ Subjects were recruited based on a single life-limiting illness (cancer, CHF, or COPD), but could also have other comorbid conditions. For example, a subject could have both CHF and COPD; however, he/she would be categorized by the diagnosis that was thought to be life-limiting at the time of study enrollment based on the above criteria. The study was designed to recruit equal numbers of subjects in each diagnostic group (cancer, COPD, CHF) to describe the experiences of living with varying serious illness trajectories. Non-English speaking patients and those with impaired cognitive function limiting their ability to communicate were excluded.

Between 2004 and 2007, baseline interviews were conducted by experienced interviewers. Participants were asked open-ended qualitative questions allowing them to relay experiences in their own words. Interviews were scripted, and interviewers received training on how to record participants' responses using the patient's own words within the 250 character limit of the database, along with the qualitative measures that were part of the larger study. No clinical relationship existed between the interviewers and patients. Each subject was asked "What is your understanding of your illness?" and no additional prompting was provided. Only one patient refused to answer this

question. Data on the reason for refusal was not recorded. Responses were transcribed at the time of the interview. This included full responses in all but 19 cases. In addition to primary diagnosis, descriptive variables including demographics were also collected and have been previously described.¹⁴ All data were entered into Atlas.ti software.

ANALYSIS

We conducted a qualitative thematic content analysis using open coding and theme matrix techniques. Investigators (KS, NA, and DM) reviewed textual data of 30 subjects for common and recurrent themes, and developed an initial codebook. When possible, codes reflected subjects' own words. After refinement, codes were then applied to all transcripts. Upon completion of open coding, a randomly selected subset of subjects, 10 % from each diagnostic group, were examined by three investigators (DM, KJ, KS) to identify thematic patterns. Investigators constructed matrices of responses, associated codes, and subject characteristics such as demographics and disease severity (self-rated health and number of bed days). Patterns were confirmed across the entire sample of responses. Throughout the coding process, codes and themes were reviewed for agreement and disagreement, and discussed for consensus. While primarily a qualitative content analysis of textual data, we also include quantitative frequency of thematic responses across the full sample.

RESULTS

Sample Description

A total of 209 subjects completed baseline interviews, including 70 patients in each diagnostic group. Baseline characteristics of subjects have been previously described (Table 1).¹⁴ The mean age of the sample was 66 years, and 59 % of subjects were male. Whites made up 61 % of the sample, and African Americans were the largest minority group, making up 35 % of the sample. Subjects with CHF were more likely to be African American and male. Thirty-six patients (18 cancer, 13 COPD, and 5 CHF) died within 1 year of the initial interview. Overall, 103 patients died during the course of the larger longitudinal study with an average of 685 days from baseline interview to death.

Themes

We identified five major themes from subjects' responses to the question "what is your understanding of your illness?": *nam*ing the diagnosis or the pathophysiology description, *illness history*, *symptoms*, *causality*, and *prognosis* (Table 2). The presence of themes was not mutually

Table 1. Baseline Subject Characteristics

	Total (n=209)	Cancer (n=69)	CHF N(n=70)	COPD (n=70)
Mean age years (SD)	66.1 (12.3)	64.5 (13.2)	65.4 (13.4)	68.3 (9.9)
Age range years	29–90	35–89	45–90	29–87
Gender n (%)				
Male	123 (59 %)	36 (52 %)	51 (73 %)	36 (51 %)
Ethnicity n (%)				
African American	72 (34 %)	15 (22 %)	40 (57 %)	17 (24 %)
White	127 (61 %)	51 (74 %)	28 (40 %)	48 (69 %)
Other	10 (5 %)	3 (4 %)	2 (3 %)	5 (7 %)
Marital status n (%)				
Married	104 (50 %)	41 (59 %)	32 (46 %)	31 (44 %)
Education n (%)				
Less than high school	43 (21 %)	10 (14 %)	16 (23 %)	17 (24 %)

exclusive, with some responses containing multiple themes. While this is a qualitative study of textual responses, we offer some quantitative description of response theme frequency by diagnostic category (Table 3). No patterns in themes emerged when data were examined by ethnicity or disease severity.

Naming Diagnosis or Describing Pathophysiology. The first and most common thematic distinction apparent in the data was subjects' tendency either to name their diagnosis (cancer, CHF, COPD), or to describe the organ problems or pathophysiology. Only half of all respondents answered the open-ended question by specifically stating their diagnosis by name, and those with cancer were more likely to do so than those with non-cancer diagnoses (77 % cancer, 39 % CHF, 41 % COPD). Additionally, respondents giving

precise biomedical terms were more likely to have cancer than CHF or COPD.

Stage 4 breast cancer, metastatic in bones liver spleen, multiple lymph nodes. Uncertain mortality.
(Cancer subject)

In contrast to offering their diagnosis, those with non-cancer diagnoses often provided detailed statements relating the organ dysfunction and pathophysiology of their disease.

Blood vessels and veins are clogged up and caused me to have heart attacks and damaged my heart.
(CHF subject)

It's pretty comprehensive; I understand a lot. I know my lungs have taken a beating. Not functioning.
(COPD subject)

Finally, while the majority of patients provided either the diagnostic name or pathophysiological description, there were subjects who expressed little or no understanding of their illness or diagnosis. These respondents had less education than those naming their diagnosis and were always living with a non-cancer illness.

Tell truth don't know much about it. Knowing the Lord, things happen to us that we don't understand so got to hang in there and be strong about it. Sometimes it gets me down but I just keep going.
(CHF subject, some high school)

I don't know anything about it, I praise God and take medicine. (COPD subject, less than 8th grade)

Table 2. Major Themes and Exemplary Quotations

Theme	Subthemes	Quotations
Diagnosis naming or describing pathophysiology	Diagnosis name	Stage 4 breast cancer, metastatic in bones liver spleen, multiple lymph nodes. Uncertain mortality
	Not understanding/not knowing	I don't know anything about it, I praise God and take medicine
	Pathophysiology	From what I've been told, the valves in my heart are weak. They are not pumping off the right amount of blood
Illness history	Medical interventions	CHF, along with other problems, have had 7 bypasses and a defibrillator. It is a constant effort with medications and procedures
	Cycles of treatments	Lung cancer, stage 3B or 4, two different doctors have told him different stages. Cancer not big, but concentrated where it cannot be removed. Been through radiation 2 times, chemo 3 times. Went in remission and has come back before
	Comorbidities	They say I have CHF, I'm diabetic, SOB, colostomy. The erratic, heart doing 2/3rds of what it's should do, was 1/3 a year ago
Symptoms	Physical symptoms	I have both CHF and COPD, and I think it's mostly CHF. I don't know how it operates. SOB is principal symptom. Lack of energy, totally blah
	Limited function	It affects my life in some ways. Things I can't do that I used to do. Not a whole lot can be done for me, only medicine
Causality	Smoking	Come from my smoking—others tell me, chemical industry that sprayed on that tobacco, worked in wood working, run a sanding machine without a mask
Prognosis	Specific prognosis	I have non-small cell lung cancer, stage 3B–4, mets to mediastinal lymph nodes. Some pleural effusion, unilateral. Prognosis is 1–3 % survival after 5 years
	General prognosis	That it is life threatening from a medical standpoint

Table 3. Proportion of Respondents Describing Theme by Diagnostic Group

Themes	Cancer	CHF	COPD	Overall
Diagnosis naming or describing				
pathophysiology				
Named diagnosis	77 %	39 %	41 %	52 %
Described pathophysiology	0 %	19 %	7 %	9 %
Not knowing or not understanding	1 %	4 %	13 %	6 %
Illness history	55 %	43 %	33 %	44 %
Symptoms	4 %	30 %	26 %	20 %
Cause	1 %	7 %	23 %	11 %
Prognosis	27 %	5 %	7 %	13 %

Illness History

After naming the diagnosis or organ problem, subjects frequently discussed their personal *illness history* by recounting a complex timeline of medical events and interventions. For example, some cancer patients typically described cycles of treatments, chemotherapy, and radiation, while non-cancer patients referenced hospitalizations, surgeries, and implantable devices. These descriptions sometimes included an initial diagnostic naming followed and predominated by histories.

Lung cancer, stage 3B or 4, two different doctors have told him different stages. Cancer not big, but concentrated where it cannot be removed. Been through radiation 2 times, chemo 3 times. Went in remission and has come back before. (Cancer subject)
CHF, along with other problems, have had seven bypasses and a defibrillator. It is a constant effort with medications and procedures. (CHF subject)

For non-cancer patients, the life-limiting illness was only part of the complex histories that often referenced multiple comorbidities. At times the histories were a litany of treatments and events, separate from their primary diagnostic category.

COPD-emphysema. Then in 2004 x-ray found spots in my left lung, said it was cancer and I had to have part of it removed. Then found it was aspergillus, a fungus. Went to rehab. Use oxygen when I walk and sleep. Four heart attacks since 1985. Angioplasty. (COPD subject)

Swinging leg syndrome. Had part of my lung removed from pneumonia. Had throat cancer epiglottis removed in 1977. Had heart attack 1998 and stents in 98 and 2001. (CHF subject)

The composite of these medical events informed patients' current understanding of their illness. Because of multiple

interventions and complex medical histories often unrelated to a single illness, some subjects doubted their physicians' ability to appreciate the totality of the experience.

I have a greater understanding of my illness than my docs do. Very complicated history, docs focus on one thing instead of the whole, other things are minute or not addressed. (COPD subject)

Symptoms

Although many patients described intricate illness histories, other individuals discussed their *symptoms*.

Shortness of breath is principal symptom. Lack of energy, totally blah. (CHF subject)

I can't breathe. If I stay inside will be okay, if walk will be short of breath. (COPD subject)

While cancer subjects rarely mentioned symptoms (4 %), nearly one third of CHF and one-quarter of COPD subjects did. Others understood their illness in terms of the limitations in daily activities and described limited function. Patients offering such descriptors were non-cancer patients.

Use a nebulizer, can't walk like used to. Can only go a couple of blocks. Depressing. (COPD subject)

I can't do the things I used to do—they limit me. I wish I didn't have the problem. (CHF subject)

Causality

In some instances, patients described causality associated with their diagnosis. Such causal statements rarely were found among sample participants with cancer (1 %), while nearly ¼ of the sample of COPD participants (23 %) referenced causality, most often smoking.

I have COPD from years of smoking cigarettes and not using a face mask when doing painting jobs so I didn't inhale particles/chemicals. All of that has junked up my lungs. (COPD subject)

Have arterial disease, everything caused by smoking, stress has a lot to do with it, CHF, COPD, acid reflux. (CHF subject)

Prognosis

In answering the question "what is your understanding of illness?," our subjects rarely discussed *prognosis* (13 %

overall). The subset who did introduce the theme of prognosis was more likely to have cancer (27 %) than CHF (5 %) or COPD (7 %). Additionally, recitation of detailed prognostic estimates, while exceedingly rare in these data, came from individuals with higher levels of education.

I have non-small cell lung cancer, stage 3B-4, mets to mediastinal lymph nodes. Some pleural effusion, unilateral. Prognosis is 1–3 % survival after 5 years. (Cancer subject, graduate or professional degree)

Of those who mentioned mortality, most did so in more general terms.

I have lung cancer and brain cancer, and it's likely to recur. I don't have a long future. (Cancer subject)

Interestingly, even when referencing general mortality, patients with cancer and non-cancer diagnoses often emphasized living with rather than dying from incurable illness. Further, they sometimes acknowledged the unpredictability of the disease course and length of life remaining.

I can die at any time. But right now they say I'm doing pretty good with the medication I'm on. (Cancer subject)

I got an incurable heart condition that only a transplant can fix. They say the people can live adequate lives with this problem. I try to do what is necessary to live. I have a few more years but tomorrow is not promised to anyone. (CHF subject)

DISCUSSION

In this study of 209 patients with advanced serious illness (cancer, CHF, and COPD), we examined subjects' responses to the open-ended question "what is your understanding of your illness?" We identified five common themes: *naming the diagnosis or describing the pathophysiology, illness history, symptoms, causality, and prognosis*. Although not every patient with the same diagnosis responded to this question in the same way, distinct patterns did emerge by disease group. Individuals with non-cancer diagnoses more often discussed unique themes of symptoms and causality, while cancer patients more often referenced their specific disease and general prognosis. These findings suggest that the question "what is your understanding of your illness?" can provide clinicians with important information and insight on how patients with a variety of

life-limiting illnesses view their disease and may be used to facilitate communication with seriously ill patients in non-acute settings. As discussed below, careful attention to the prevalent theme(s) in a patient's response can help to establish a framework for patient-centered communication.

For example, the question may allow clinicians to assess whether patients can identify their overall disease or whether they view their experience as a collection of individual problems and symptoms unrelated to a larger disease process. Non-cancer patients were less likely to name their diagnosis, appearing to lack the clear illness identity seen among cancer patients. These differences are likely shaped in part by how health-care providers talk to patients about their disease, and patients' experiences living with advanced illness and multiple comorbidities.^{15–17} Moreover, our data suggest that patients who do not name their diagnosis or describe the pathophysiology in response to questions probing their illness understanding may not know or understand their diagnosis. Previous studies showed that patients with non-cancer diagnoses desire disease-specific education regarding their diagnosis and disease course.^{17,18} Patient responses to the question, "what is your understanding of your illness?" may give physicians the opportunity to determine if patients want additional information about their underlying diagnosis using queries like "Would you like me to tell you more about your illness?"

Relatedly, some patients described intricate histories of medical interventions, treatments, hospitalizations, and surgeries. Because these descriptions often included the very factors physicians use to consider prognosis and treatment decisions, physicians may assume that patients understand their illness severity.^{19–22} However, relating complex illness histories may not reflect patients' understanding of their current status or future course. The use of the open-ended question serves as an invitation to explore the clinical history and can provide patient-relevant context for discussing illness severity and transitions in care.²³ If patients respond to the question "what is your understanding of your illness?" by primarily recounting a medical history of their disease, a clinician may respond "You've shared a lot about what has happened in the past; can you tell me how these events have affected your life?"

Prior research on illness understanding has tended to focus on patient's ability to quantify their life expectancy or to categorize their illness as terminal or not.^{29,32} Similarly, clinicians often ask "what is your understanding of your illness?" to discern if patients know they are dying or not in attempts to determine code status or other preferences regarding the use of life-sustaining treatments.^{24,25} However, in this study we found that many patients with life-limiting illness do not discuss their illness in terms of prognosis.^{26–28} While they may acknowledge that time may

be limited, they prefer to focus on living with illness. Most patients who did reference prognosis had cancer and did so in general terms without emphasis on numeracy or statistics. Patients' responses may reflect physician uncertainty surrounding prognosis, especially for non-malignant diseases, and subsequent avoidance of discussions of prognosis.^{18,29,30} Since individuals rarely spontaneously offer estimates of their own mortality in response to "what is your understanding of your illness?," this open-ended question better serves as a communication tool to facilitate mutual understanding in which patient-centered decision-making can occur. For example, if patients do not mention prognosis, clinicians can follow with questions like "would you like more information about the likely course of your illness based on my experience caring for other patients with CHF (or other life-limiting illnesses)?" or "I'm wondering what are your thoughts about where this might lead in the future."

We also found differences among disease groups in discussions of symptoms and causality. Some subjects with COPD and CHF mentioned symptoms and functional limitations associated with their illness. Almost 1/4 of subjects with COPD referenced what they believed to be the cause of their illness, most commonly smoking. These findings are concerning as previous research shows that patients who smoke often struggle with issues of stigma and regret.³¹⁻³³ Physicians may note the reference to causality and use it as an opportunity to explore unmet emotional needs. Rather than pursue the logic of causality, clinicians may attend to underlying emotions with statements like "It sounds like you've been thinking about choices you've made."

This study has several limitations. First, responses were obtained in a research setting, most often in the patient's home, not by a physician in the clinical setting. However, the questions were posed by experienced clinical researchers as part of a larger baseline interview similar to a clinical history. Although it is unclear if the responses obtained reflect what subjects would convey to a physician, the repetition and frequency of themes give no reason to indicate preferential responses. Second, subjects' responses were limited to 250 characters because of database constraints of the larger study in which quantitative and qualitative measures were collected; only 19 patients talked beyond this limit. The presence or absence of specific themes (i.e., prognosis) may be due to limited character response or to the lack of prompting in this brief query. Third, our interpretations of these responses were not shared with the subjects for further exploration or elaboration. However, all themes were generated directly from our patients' responses. Our sample size and diversity allowed for varying voices and cross-case comparisons. Open-ended questions often employed in end-of-life discussions provide physicians with the opportunity to partner with patients earlier in the course of advanced medical illness, as they discuss and plan for the future.^{34,35} Our findings suggest

that the question, "what is your understanding of your illness?" can help to facilitate communication in non-acute settings between clinicians and patients with a variety of illnesses with uncertain prognoses. Although patients' responses may vary based on their diagnosis and life history, by listening and identifying prevalent themes, clinicians can center discussions on patients' specific illness experiences and individual information needs. Further research is needed to explore disease-specific differences and to identify special needs in patient-physician communication across the trajectory of advanced medical illness.^{15,17} The findings of this study should inform further research to develop communication interventions for patients living with advanced illness and the physicians who care for them.

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