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“What concerns me is...” Expression of emotion by advanced cancer patients during outpatient visits

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Abstract

Objective—Cancer patients have high levels of distress, yet oncologists often do not recognize patients' concerns. We sought to describe how patients with advanced cancer verbally express negative emotion to their oncologists.

Materials and methods—As part of the Studying Communication in Oncologist–Patient Encounters Trial, we audio-recorded 415 visits that 281 patients with advanced cancer made to their oncologists at three US cancer centers. Using qualitative methodology, we coded for verbal expressions of negative emotion, identified words patients used to express emotion, and categorized emotions by type and content.

Results—Patients verbally expressed negative emotion in 17% of the visits. The most commonly used words were: “concern,” “scared,” “worried,” “depressed,” and “nervous.” Types of emotion expressed were: anxiety (46%), fear (25%), depression (12%), anger (9%), and other (8%). Topics about which emotion was expressed were: symptoms and functional concerns (66%), medical diagnoses and treatments (54%), social issues (14%), and the health care system (9%). Although all patients had terminal cancer, they expressed negative emotion overtly related to death and dying only 2% of the time.

Conclusions—Patients infrequently expressed negative emotion to their oncologists. When they did, they typically expressed anxiety and fear, indicating concern about the future. When patients use emotionally expressive words such as those we described, oncologists should respond empathically, allowing patients to express their distress and concerns more fully.

Keywords

Patients; Cancer; Emotion; Distress; Communication

Introduction

Psychological distress, particularly in the form of anxiety and depression, is common in cancer patients, with a reported prevalence between 30 and 50% [13,24,27,53,54,60]. Psychological distress has been correlated with lower quality of life [3,4,54,58], a desire to hasten death [5], and caregiver distress [30,50,57], as well as increased health-care utilization [15,22,33] and shorter survival [19,35,52]. Cancer patients with unresolved concerns are more distressed than those whose concerns are resolved [7,18,26,38]. The way oncologists communicate impacts patients' disclosure of concerns and their distress associated with such concerns. When clinicians acknowledge patients' emotions and invite discussion, they give them the opportunity to convey their concerns. Patients whose physicians are empathic and invite discussion disclose more concerns [36] and, as a result, have lower levels of distress [20,45, 49].

Unfortunately, multiple studies document that oncologists, like other medical providers, usually do not respond empathically when patients express emotion [6,34,56]. For example, a cancer patient may state, “I’m *worried* about these headaches.” The oncologist can respond empathically by acknowledging the emotion: “I can understand how they would be difficult—can you tell me more?” Acknowledging the emotion allows the patient to talk further about the concern associated with the emotion: “I am *afraid* the cancer is coming back”. A bio-medically focused response ignores the emotion: “Do you feel nauseated with the headaches?”

While this response provides the clinician with medical information, it does not elicit information about the patient's concerns.

To respond empathically to patient distress, oncologists must first recognize it. However, oncologists' recognition of patient distress is often poor [16,21,37,39,51]. This may explain why oncologists do not offer empathic responses as often as may be desired. Patients express emotion in a variety of ways—through words, tone of voice, facial expressions, and body language [46]. Of these methods, direct verbal expression, where patients name the emotion they are experiencing, is not only the most overt and thus easiest to recognize, but also the most highly correlated with self-reported distress [12,48].

We sought to describe how oncology outpatients verbally express distress to their oncologists. In the Studying Communication in Oncologist–Patient Encounters Trial (SCOPE), we audio-recorded 415 visits between 59 oncologists and 281 patients with advanced cancer [28]. We identified all instances where patients verbally expressed negative emotion in these visits, recorded the words they used to express emotion, and classified these expressions by type and topic. We offer this analysis as a guide for clinicians to identify distress in their own patients.

Materials and methods

Participants

Outpatient visits between patients with advanced cancer and their oncologists were audio-recorded at three cancer centers in the USA: Duke University, the Durham Veterans Affairs Medical Center, and the University of Pittsburgh. Details about recruitment are described elsewhere [28]. Briefly, medical, gynecological, and radiation oncologists were recruited and enrolled into the study and then asked to identify patients who they “would not be surprised if they died or were admitted to an intensive-care unit within the next year.”

Measures

Digital recorders were placed unobtrusively in the clinic exam rooms before the oncologists entered. Each recorded visit was coded for the presence of verbal expression of negative emotion by the patient. We focused on negative, as opposed to positive or neutral, emotions because we were interested in describing the expression of distress. For each expression of emotion, we recorded the word the patient used to express the emotion and coded the type of emotion that was expressed and the topic about which the emotion was expressed. Sociodemographic information was collected from patients and oncologists at study enrollment.

Analysis

To reliably identify instances of negative emotional expression and code each by type and topic, we developed a standardized, explicit coding process [10,11]. Based on previous work [6,34,56], we defined negative emotional expression as any instance where a patient used words to describe a negative emotional state in the past, present, or future; for example, “I’m *anxious* about this test” or “I was feeling *depressed*.” We identified all instances of verbal expression of negative emotion using a web-based coding software (ENCOUNTER) that allowed direct coding on the audio files. To establish intercoder reliability for identification of expressions of emotion, two coders independently coded a random 20% of the recordings; Cohen’s kappa for agreement between coders was 0.65, indicating substantial agreement [9, 31].

We then transcribed all coded utterances, identified the specific word(s) that expressed the emotion, and described the topic about which the emotion was expressed. To verify the

reliability of this process, 20% of the sample was double-coded at this stage [40]. The two coders identified the same emotionally expressive word(s) in 22 (92%) instances, completely agreed on the topic of the emotion in 20 (83%) instances, and agreed at least partially for 22 (92%).

Our categories for type of emotion were based on the primary negative emotions as defined in the psychology literature: anxiety, fear, anger, and depression or sadness [47,55]. We grouped patients' emotional expressions into these categories using dictionary and thesaurus definitions to determine to which category the words related linguistically [1,2]. Emotions not related to one of the primary categories were classified as other. Codes were mutually exclusive, so each utterance could only be coded as one type of emotion.

To create categories that described the topics about which patients expressed emotion in a clinically relevant way, we used an iterative process [10,11]. First, two coders independently examined the transcribed utterances and topic descriptions of the expressions of emotion to identify common themes. A preliminary coding scheme was developed using these themes and informed by categorizations used in previous studies [6,14] and used by both coders to independently code all of the utterances. The two coders then met to review their coding, resolve disagreements, and further modify and refine the codebook. Often, the topic of emotional expression related to more than one category; thus, the topic codes were not mutually exclusive.

Finally, to provide a deeper understanding of patients' expressions of emotion, we conducted a thematic analysis of the transcribed utterances and topic descriptions using open- and axial-coding techniques [10,11]. During open coding, two coders independently identified attributes pertinent to the topic of emotional expression. Coders then compared attributes and achieved consensus by developing decision rules to reliably classify attributes. In axial coding, the attributes were grouped into overarching themes using decision rules, and the relationship between themes was described. A third coder reviewed the coding scheme and verified the accuracy of coding.

Results

Participants

We analyzed 415 visits of 281 patients with 59 oncologists (1–2 visits per patient, 1–9 visits per oncologist). Patient sociodemographic and clinical characteristics are listed in Table 1. The patients' mean age was 60 years (SD=13); 49% were men. Approximately 83% of the patients were white, 15% African American, and 1.4% Hispanic. Approximately 28% of the patients had been diagnosed with a hematological malignancy, 16% had lung cancer, 15% had breast cancer, 12% had a gastrointestinal malignancy, 10% had a brain malignancy, and 19% were classified as other, including gynecologic, prostate, and head and neck cancers. About 79% of patients had seen their oncologist for at least three previous visits.

Frequency of verbal expression of negative emotion

We identified 114 instances where patients verbally expressed negative emotion in 72 (17%) of the 415 recorded conversations. Approximately 64 (23%) of the 281 recorded patients expressed an emotion during at least one of the visits with their oncologist.

Words used to express emotion and types of negative emotions expressed

The most common words used to express emotion were “concern” and “scared” (17 instances each), followed by “worried” (16 instances), “depressed” (11 instances), and “nervous” (10 instances; Table 2 shows all the words used to express emotion and the frequency of their use).

The words patients used to express emotion most commonly related to the primary emotions of anxiety (46% of instances) and fear (25%), whereas depression (12%) and anger (9%) were less common (Table 2 shows how all the words were grouped into the emotion categories). Examples of each type of emotion are shown below:

Anxiety: “You see I had to wait so long—and that is just *nerve racking*.”

Fear: “It’s not bone cancer is it? You’re *scaring* me.”

Depression: “Because that’s so *depressing*” (Discussing her hair loss).

Anger: “It *aggravates* me—I used to do everything outside.”

Eight percent of emotions did not fit into one of these categories and were classified as other.

Topics about which patients expressed emotion

We defined five categories for the topic of emotion (Table 3). Patients most commonly expressed emotion about symptoms and functional issues (66% of instances), including physical symptoms, mental symptoms, and functional concerns, for example:

“I get like a *panic* attack.”

“I can’t walk at all...When she said are you *worried* about your health?—Yes, every time I come to a curb or a step.”

In most instances of emotional expression about symptoms, patients did not describe the reason for their concern. When patients did describe the cause of their concern, it was that the symptom indicated cancer progression. For example, one woman said about her pain, “When it aches, I get concerned...I worry that it’s the cancer.”

Medical diagnoses and treatments were also frequently a topic of emotion (54% of instances), including cancer and noncancer illness diagnoses and treatments, tests and test results, and medications and medication side effects.

“You mentioned the PET scan—and you *scared* me.

” “I’m sorta *scared* about that medicine for the bowel cancer.”

Social issues, including reference to family, finances, and the presence or lack of social support, were a topic of emotion in 14% of instances:

“So I’m kinda *concerned* about that” (If cannot start back at work, she may lose her job).

The health care system, including comments about communication and quality of care, was the topic of 9% of instances:

“I think it’s *stress*” (Stressed because patient was told over the phone that tumor markers were up).

Overt discussion of death and dying, where patients overtly discussed their mortality, was only found in 2% of the expressions of emotion. In expressions of emotion where patients did overtly discussed death and dying, they described dying from cancer progression. For example, one woman said she was depressed because she knew “the disease will get me in the end.”

Discussion

We analyzed 415 recorded visits between 281 patients with advanced cancer and their oncologists and found that patients verbally expressed an emotion in 17% of the visits. Anxiety and fear were the most common emotions expressed. The most common topics of emotion

were symptoms and function and medical issues. Social issues, the health care system (e.g., communication and quality of care), and death and dying were less frequently topics of emotion.

In our study, the rate of expression of emotion seems lower than in other studies of cancer, primary care, and surgical patients [6,34]. We feel this difference is due not to differential rates of emotional expression but to differences in methodology. First, in past studies of physician's responses to "cues" or "clues" that patients give during clinical visits, emotional as well as informational and social statements were included [6,34]. Thus, the rates of patient cues per visit were higher compared with our study, where we solely included emotional statements. Second, because we were interested in the expression of distress, we coded only the expression of negative emotions, whereas other studies coded both positive and negative emotions [6, 34,56]. Third, in our analysis, we only included "direct" expressions of emotion, when patients state a word that describes the emotion they are experiencing. Other studies have also included "indirect" expressions of emotion, where patients allude to the presence of an emotion but do not name it directly [6,34,56]. We did not include these expressions in our analysis because we could not reliably code the type of emotion being expressed indirectly.

Still, the fact that only 17% of visits in our study contained a direct expression of distress is concerning, given the high rates of reported distress in cancer patients [13,24,27,53,54,60]. Patients may not discuss emotional issues because they do not feel it is their oncologists' role to address them [48]. Physician behaviors also influence patients' disclosure of concerns and distress. When physicians focus on psychosocial aspects of care, use open-ended questions, listen actively, and make empathic statements, their patients are more likely to express distress and concerns [36,48]. An analysis of the oncologists' behaviors in the recordings used in this study is reported elsewhere; in that analysis, oncologists responded empathically to patients' expressions of emotion less than one third of the time [42]. Research shows that when clinicians repeatedly miss patients' expressions of emotion, patients eventually cease to express emotion [56]. As the majority of the patients in our recorded conversations knew their oncologist, it may be that the patients "learned" not to express emotion by the time they were recorded. This underscores the importance of recognizing and responding empathically to patient expressions of emotion.

The words patients used to express emotion, such as "concern," "scared," "worried," "depressed," and "nervous" are all commonly used in spoken English [32]. However, that these words contain an emotional content is not obvious unless the listener is primed to see them as emotionally charged. We hope that oncologists can use these words as flags marking opportunities to explore patients' concerns. Unlike nonverbal expressions of emotion, which can be hard for the untrained observer to recognize [12], verbal expressions of emotion are more straightforward and recognizable.

The types of emotion patients expressed and the topics about which they expressed emotion give us a sense of the concerns patients chose to discuss with their oncologists. In our study, the predominant emotions expressed were anxiety and fear, indicating that patients were concerned about the future and uncertainty (e.g., prognosis). Whereas the negative emotions anger and depression are related to a current, known negative event, anxiety and fear are related to the possibility or threat of a negative event [47,55]. Although the topic of emotion was most often symptoms, function, or medical issues, the root of patients' concern about these issues was often their meaning: "Does a headache mean the cancer is in my brain?" "Can we still control my cancer if they are taking my chemotherapy drug off the market?" These concerns indicate that oncologists providing information, when possible, will help to decrease uncertainty. Responding to emotion empathically is still important because the information

may be bad news. Even if the oncologist cannot solve the patients' concern with information, encouraging patients to discuss concerns can still decrease distress [20,45,49].

Another important finding was that certain topics were relatively infrequent topics of emotional expression. Specifically, patients infrequently expressed negative emotions about social issues, the health care system (e.g., communication and quality of care), and death and dying (14, 9, and 2% of instances, respectively). Our results could mean that patients were not concerned about these topics or that they were concerned but did not express that concern to their oncologist. Previous studies have documented that patients express different concerns to different types of doctors. For example, Levinson et al. [34] found that patients were more likely to express feelings about their biomedical condition in surgical outpatient visits and were more likely to express emotion about psychological or social concerns in primary-care visits. Thus, it may be that the patients in our study perceived their oncologist's role as relating more to their biomedical condition—symptoms and medical issues—than their social or psychological concerns.

The low frequency of expression of emotion about the health care system—issues of quality of care and communication—is interesting, given that these areas have been a focus of research [17,28]. Although objective studies of oncologists communication suggest that they often do not meet literature-recommended standards [6,34,56], satisfaction with care and communication is usually high [23,29]. This disconnect is worthy of further study.

The low frequency of emotional expression about end-of-life issues was surprising because all of the patients had terminal cancer. Other research has shown that most patients want their oncologists to be willing to talk about death and dying [25,59] and cite emotional support as an important physician skill to help them cope when discussing the future [8]. Unfortunately, factors such as disease stage do not predict whether patients want to talk about end-of-life issues [41], so there is no reliable way to predict whether a given patient has concerns about death and dying. By responding empathically to expressions of emotion, physicians can let patients know they are willing to talk about difficult topics without forcing the discussion. In our study, emotional expression about death and dying seemed related to concerns about cancer progression, which in turn related to concerns about symptoms. It is possible that concerns about death and dying were the underlying reason for concern in patients' frequent expressions of emotion about symptoms. Given the methodology of our study, we cannot know how many patients were concerned about death and dying. However, past studies indicate that patients who described their concerns about symptoms and medical issues narrowly might have given a fuller account if their oncologists had responded empathically to their expressions of emotion [36,42].

Our study has several limitations. First, we only coded the verbal expression of emotion. Although verbal expressions of emotion are the easiest to detect, they are less sensitive than tone of voice and nonverbal expressions, such as facial expressions and body language [12, 48]. Second, we only coded negative emotions. We elected to code only negative emotions because we were interested in the detection of distress. Describing the effect of patients' expression of and oncologists' responses to positive emotions will be important in future work. Third, patients may have expressed emotion less frequently because their visit was recorded, resulting in a Hawthorne effect [44]. Although the literature indicates that recording does not typically alter behavior [43], this is a concern in any study involving recorded medical exchanges. Fourth, because we recorded visits at US academic medical centers, we may not be able to generalize our findings to other settings.

In summary, the patients in our study infrequently expressed emotion to their oncologists. When they did, they typically expressed anxiety and fear about symptoms, indicating concern

about the future. Specific concerns about cancer progression and death and dying were left implicit by the patient and were not explored by the oncologists. We hope that oncologists can use the emotion words described in this paper as flags to identify expressions of emotion by their patients. Although oncologists cannot always solve the cause of patients' concerns, inviting patients to express them more fully can reduce associated distress.

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Table 1

Patient and oncologist demographics

	Patients ^a (n=281)	Oncologists ^b (n=59)
Age, mean years (SD)	60 (13)	45 (9)
Gender, Male (%)	49	75
Ethnicity, Hispanic (%)	1.6	7
Race (%)		
White	83	80
African American	15	2
Other	2	19
Married (%)	74	
Education (%)		
High school or less	33	
Some college	31	
Complete college	36	
Cancer type (%)		
Hematological	28	
Lung	16	
Breast	15	
Gastrointestinal	12	
Brain	10	
Other ^c	19	
Visits to this oncologist (%)		
0–2	21	
3–5	16	
6 or more	64	

^a Percentages are from the following numbers of patients: age and gender $n=281$, ethnicity and race $n=253$, education and marital status $n=254$, cancer type $n=276$, visits to this oncologist $n=252$.

^b Data on age was missing for one oncologist.

^c Including gynecologic, prostate, and head and neck

Table 2

Coding scheme for type of emotion, results of coding, and examples

Primary emotion	Count <i>n</i> =114 ^a (%)	Words used by patients (<i>n</i> =114) ^a	Quotation examples
Anxiety	52 (46)	Concern (17) Worried (16) Nervous (10) Anxiety (5) Stress (4)	My <i>concern</i> ... was that the tumor had gotten "larger." "I <i>worry</i> about that." (headaches) "I was a little <i>nervous</i> this past week with (my stomach) hurting more."
Fear	29 (25)	Scared (17) Afraid (4) Panic (4) Fear (3) Alarm	"I had a couple of chest pains that <i>scared</i> me a little." "I'm <i>afraid</i> of falling or something." "That's one thing I have as a big <i>fear</i> ." (that treatment will make her sick)
Depression	14 (12)	Depressed (11) Discouraged (2) Despondent	"I do that when I get <i>depressed</i> —I eat." "You can't go around to your family acting like you're super- <i>depressed</i> ..." "I'm quite <i>discouraged</i> ." (about losing weight)
Anger	10 (9)	Frustrating (3) Annoying (2) Mad (2) Aggravates Angry, Drives me nuts	"That was so <i>frustrating</i> to me." (feeling tired on chemotherapy) "This (leg swelling) is the most <i>annoying</i> part." "That makes me <i>mad</i> ." (spending all his money on treatments)
Other	9 (8)	Battle, Confused Disgusted, Embarrassing, Hate, Lonely, Miss, Numb, Upset	"And I'm just absolutely thoroughly <i>disgusted</i> ." (about not being able to do things she used to do) "It was <i>embarrassing</i> ." (not being able to finish a game of tennis) "I just feel kinda <i>numb</i> right now."

^a Emotion type categories were mutually exclusive so percents counts sum to 114.

Table 3

Coding scheme for topic of emotion, results of coding, and examples

Topic Category Subtopics Included	Count n=114 ^a (%)	Quotation Examples
Symptoms and function Physical symptoms Mental symptoms Functional concerns	75 (66)	<p>“When it aches, I get concerned....I worry that it’s the cancer.”</p> <p>Concerned that aching means there is cancer in her bones</p> <p>“It drives me nuts. It’s annoying.”</p> <p>Strange feeling of face from tumor and radiation</p> <p>“I’ve been having these little mini panic attacks.”</p> <p>Worried about chemotherapy drug being taken off the market</p> <p>“It’s still kinda scary.”</p> <p>Getting back to driving—using new hand controls on van</p>
Medical diagnoses and treatments Cancer Other illnesses Tests Medications	61 (54)	<p>“It’s very scary.”</p> <p>Feels treatment isn’t working—counts aren’t going down</p> <p>“I’m still concerned about this ulcer.”</p> <p>Acquired a decubitus ulcer during a recent ICU stay</p> <p>“I’m nervous.”</p> <p>Seeing doctor to discuss test results</p> <p>“I worry about having a stroke on that blood thinner.”</p> <p>Worried about having a stroke on Coumadin</p>
Social Issues Family Finances Supports	16 (14)	<p>“The most frustrating thing is the effect this has on (my wife).”</p> <p>Impact of his illness on his wife</p> <p>“What I worry about is if I lost my job...I lose my insurance.”</p> <p>Needs to take time off work, but worried will lose job</p> <p>“I had a very caring husband and I miss him terribly.”</p> <p>Husband died, missing him more now that she is sick</p>
Health care system Communication Quality of care	10 (9)	<p>“It’s frustrating.”</p> <p>Her fathers’ doctor did not tell him he was dying</p> <p>“I’m angry.”</p> <p>Was seeing a doctor regularly, feels cancer should have been found earlier</p>
Death and dying Overt discussion	3 (2)	<p>“I’m just depressed.”</p> <p>In a slump. Thinking about how disease will get her in the end</p>

^aThe topic of conversation about which emotion was expressed often required multiple topic categories to be accurately described, thus counts sum to greater than 114.