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Patients' and Family Members' Views on Patient-Centered Communication During Cancer Care

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Abstract

Objectives—To explore patients' and family members' views on communication during cancer care, and to identify those aspects of clinician-patient communication which were most important to patients and family members.

Methods—We conducted a secondary data analysis of qualitative data from 137 patients with cancer and family members of patients with cancer. We used a modified version of the constant comparative method and coding paradigm of grounded theory.

Results—Patients want sensitive, caring clinicians who provide information that they need, when they need it, in a way that they can understand; who listen and respond to questions and concerns, and who attempt to understand the patient's experience. Effective information exchange and a positive interpersonal relationship with the clinician were of fundamental importance to patients and family members. These were interrelated; for instance, failure to provide information a patient needed could damage the relationship, while excellent listening could foster the relationship. Information exchange and relationship were also integral to decision making, managing uncertainty, responding to emotions, and self-management. Clinicians who were responsive to patients' needs beyond the immediate medical encounter were valued.

Conclusions—The complexity of cancer care today suggest that efforts to improve communication must be multi-level, acknowledging and addressing patient, clinician, organizational and policy barriers and facilitators. Measurement tools are needed to assess cancer patients' and family members' experiences with communication over the course of cancer care in order to provide meaningful, actionable feedback to those seeking to optimize their effectiveness in communicating with patients with cancer.

Introduction

Patient-centered communication (PCC) is an essential component of patient-centered care,[1–2] and the cornerstone of comprehensive cancer care[3]. Communication during cancer care is particularly complex due to the involvement of multiple clinicians over an extended period of time, the emotional and psychological impact of the disease, the use of complex and potentially toxic treatments, and the uncertainties associated with the progression of disease and impact of treatment[4].

In an effort to advance patient-centered communication in the context of cancer care delivery the National Cancer Institute supported an extensive review of the literature on communication in cancer care.[5] One product of that review was a conceptual framework which posited six key functions of effective PCC processes in cancer care: (1) fostering clinician-patient relationships; (2) exchanging information; (3) responding to patients' emotions; (4) managing uncertainty; (5) making decisions; and (6) enabling patient self-management. These functions are considered inter-related rather than discrete[5–6].

The purpose of the present study was to explore patients' and family members' views on communication during cancer care. Using the functions named above as an organizing framework, we sought to identify those aspects of clinician-patient communication which were most relevant, meaningful, and salient to patients and family members.

Methods

Study Design and Sample

This study was conducted in the context of the HMORN Cancer Research Network (CRN) and the CNR Cancer Communication Research Center (CCRC). The CRN and the CCRC are National Cancer Institute-funded projects involving a consortium of research organizations affiliated with integrated healthcare delivery systems. This study entailed a secondary data analysis of qualitative data. Data were drawn from four prior studies using similar but not identical methods to interview patients with cancer and/or their family members. Each interview guide explored participants' perspectives on communication during cancer care, but the specific questions and primary focus varied across studies. In one study a small number of patients also documented and commented on their communication experiences during cancer care in online "communication logs". These studies are further described in Table 1. The interview transcripts generated from each of the studies and the communication logs were reviewed using qualitative content analysis. We searched patients' and family members' comments to understand how the functions aligned with respondents' values and experiences, reactions to those experiences, and communication that respondents viewed as important but were not included in the organizing framework.

The studies were approved by the Institutional Review Boards of the participating sites.

Interviews—All interviews were conducted in-person or via telephone by one of seven experienced interviewers using a detailed interview guide. All interview guides focused on some aspect of the interviewee's experiences with and views on communication during cancer care, and all interviewers were encouraged to seek elaboration as needed. The specific interview questions varied across studies and the interviewee's role (i.e., patient or family member). Each interviewer confirmed informed consent prior to the interview. All interviews were audio-recorded, all but 10 were professionally transcribed (for these 10 the interviewer took detailed notes). Additional details on the interview methodology for the interviews are provided elsewhere.[7–8]

Communication Logs—Patients participating in the study which included communication logs (Table 1) were asked to make an entry for each encounter with their cancer care team over the course of the study. Communication logs were completed online via a secure website, and included questions about communication content, what was helpful and unhelpful, who was present, and whether communication occurred in-person, via telephone, or email. Patients also provided global ratings of communication during the encounter.

Qualitative Analysis

An initial team of coders reviewed the narrative data to identify potentially relevant portions of transcribed interviews (i.e., portions that referred to patients' and family members' experiences with and views on communication during cancer care); a sample of complete interview transcripts was also analyzed for reliability and to check that additional themes were not apparent in the unselected portions. The analysis then proceeded using an iterative process between two authors (RB, KM). The selected textual data were reviewed collaboratively by these two authors. All data were analyzed using a modified version of the constant comparative method and coding paradigm of grounded theory[9–10]. Since this method aims to generate overarching themes, line-by-line coding was performed to identify core categories in the data. Initial "open-coding" was performed on all narrative data, followed by targeted reading for the six functions specified in the National Cancer Institute framework proposed by Epstein and Street[5]. A comprehensive code book was assembled and data were (re)read until "saturation" occurred (i.e., all data fit into existing codes). This paper reports on the themes that related to patients' and family members' perceptions of communication in cancer care, and how these perceptions relate to the six function framework proposed by Epstein and Street[5]. To avoid influencing the results, Street was not involved in any aspect of the data analysis.

Results

A total of 120 patients with cancer and 17 family members of patients with cancer (including parents of children with cancer) participated in interviews used in this analysis. In addition, 4 patients completed a total of 30 log entries about their communication experiences during care. The majority of the participants (88%) were female; interviewees' ages ranged from 37 to 81; ages of pediatric cancer patients (children of the participating parents) ranged from 6 to 19 years. Collectively, patients had 21 different types of cancer, with breast and colorectal cancers being the most common. Patients and family members were drawn from five states in four regions of the United States: northeast, southeast, midwest, and west.

Qualitative Findings

While our analysis reaffirms Epstein and Street's six functions of communication, these patients and family members were most aware of and sensitive to two overarching and highly interrelated functions: information exchange and fostering the relationship. Given this prominence, we begin by presenting findings related to patients' and family members' views on these two functions. We then present additional findings related to uncertainty, decision-making, managing emotions, and enabling patient self-management. All of the substantive themes identified in this study related to communication during cancer care fit within one of these six headings.

Information Exchange

Patients' and family members' responses highlight that information exchange is a critical communication function throughout the course of cancer care, and that it is important to consider both the flow of information from clinicians to the patient and family, and from the patient or family members to the healthcare team.

With regard to the flow of information from clinicians to patients, we identified five domains as salient to patients and family members: Content, Timing, Sufficiency, Clarity, and Accuracy. These are described briefly below.

Under Content several categories of information needs were identified (Table 2). Insufficient information in one or more of these content areas often contributed to uncertainty, which in turn led to patient stress or distress. This comment from a woman with breast cancer is an example of how this affected patients: "There was no sit down and talk to the doctor and I did kind of feel a little…insignificant." In contrast, sufficient or ample information about the process of care, preparation, and the future/prognosis were perceived as very helpful and reassuring: "I like to be told the truth. I'd rather know the truth than somebody kind of beating around the bush and knowing half of it."

Many patients and family members noted how important it was that clinicians simultaneously convey hope and optimism about the prognosis and treatment outcomes. Some patients referred to conversations where the clinician explicitly made optimistic statements, others referred to devastating (and in at least one case, highly inaccurate) predictions of death in the near future. Patients also referred to clinicians being "upbeat", positive, and reassuring, and valued those attributes.

The second aspect of information exchange identified was timing. Patients experienced fear, anxiety and other negative emotions while awaiting important information such as test results or surgery outcomes. Delays in information provision extended patients' uncertainty, and contributed to patients' and family members' emotional distress. Timing also affected patients' experiences of their disease and treatment, as timely information could help to mitigate or at least anticipate treatment side effects. Patients who felt that clinicians helped them prepare and anticipate problems were appreciative; those who felt that their clinicians *could have, but did not* provide information that would have helped them prepare saw this as a serious and sometimes harmful omission.

With respect to the sufficiency of information provided, for these patients' the perception of having received too little information was more common than the perception of too much information. Perceptions of the sufficiency of the information appear to be influenced both by individual preferences, and ability to take in the information; the latter is also influenced by timing. Some patients referred to difficulty absorbing information immediately after diagnosis, while others expressed frustration that the person who told them of their diagnosis was unable or unwilling to answer questions, especially questions about next steps.

With respect to clarity, patients reacted negatively to clinicians' use of jargon and "rattling things off"; and valued explanations that they could understand. The use of jargon or convoluted explanations led to uncertainty, lack of comfort in or satisfaction with the interactions, and sometimes increased anxiety.

With respect to accuracy, most patients assumed that their clinicians would provide accurate information. However, some patients later questioned the validity of the information they had received, for instance when subsequent information proved an early conclusion to be false, a second opinion contradicted an earlier opinion, or a patient's own research called into question some aspect of what he or she had been told. Patients had strong negative reactions when they perceived they had been given inaccurate information.

The findings discussed to this point refer to information flowing from clinicians to patients; how clinicians respond to patients seeking information was also important. Whether clinicians listened to patients and responded to questions and concerns appropriately was critical. Patients expressed a variety of concerns to clinicians. Some concerns were directly related to the disease or treatment, such as problems with side effects, or worries about recurrence, others related to the impact of their treatment on work, family, or self-image. Virtually all patients had questions about their diagnosis, cancer, treatment, and other things. They appreciated clinicians who encouraged questions and answered them fully and clearly. Patients viewed various clinician behaviors as encouraging questions, including asking for questions, and appearing unhurried. In addition, patients who had access to someone to answer questions which arose outside of appointments or regular office hours valued this and found it reassuring.

Patients also told clinicians about their needs and preferences, such as a desire for help in navigating the healthcare system, accessing care in a timely manner, or for family members to be present. Patients' comments about clinicians' responses suggest patients are sensitive to both whether clinicians are responsive *within* the encounter (for instance, providing information on how to manage side effects), and whether they take action *beyond* the encounter (for instance, directly contacting a colleague to facilitate a referral).

Each aspect of information exchange had the potential to affect the relationship. Patients who felt they did not get sufficient information from their physician, or who believed they had been given inaccurate information sometimes changed physicians. In this sample, we did not identify any instances where delays in providing information or poor clarity on the part of the clinician caused a patient to change physicians, but such experiences did appear to weaken the relationship. Clinicians who conveyed hope and optimism fostered the relationship. Clinicians who listened to patients, who encouraged and answered questions, and who were responsive to patients' concerns and preferences fostered the relationship; clinicians who did not listen or were unresponsive did not.

Fostering the Relationship

We found strong evidence for the importance of the relationship between the patient and the clinician. We identified four dimensions which characterized patients' responses relating to perceptions of whether the clinician fostered the relationship. Results relating to Information Exchange were discussed in the prior section. The three additional dimensions identified were interpersonal manner, patient commitment, and knowing the patient.

The clinician's interpersonal manner strongly influenced patients' perceptions of the relationship. Patients frequently used the words and phrases in Table 3 to describe clinicians with whom they felt they had a positive relationship. In some instances, patients referred to specific behaviors (such as smiling), but more often patients recalled a feeling rather than specific actions or words. Patients also described clinicians who displayed qualities at the opposite end of the spectrum, and the negative effects of these. When respondents' comments were predominantly, or exclusively negative or positive, we present quotes only from that perspective. When our data suggest both positive and negative representations of a dimension, we provide examples of both; negative representations are italicized.

The second dimension within fostering the relationship is patient commitment. Under this dimension we include a variety of clinician behaviors, including some which occur outside of the encounter, and which go beyond communication as typically defined. The first behavior is being prepared for the encounter, including being familiar with the patient's case. This behavior was noteworthy and harmful by its absence. Other behaviors in this category included assisting the patient in accessing care (for instance, in providing a referral), and offering procedures, visits or calls at times that met the patient's needs. One patient noted how a physician had called with good news about a test result even as the physician was leaving for vacation. Patients also appreciated clinicians who were available outside of regularly scheduled visits, as noted above.

The third dimension relating to fostering relationships was knowing the patient. This ranged from negative feelings of "The same thing isn't right for every person" to the comfort that came from feeling that clinicians knew them for who they really were. For example: "He [my doctor] recognized that [I am tough], so he didn't spend time saying, 'And how are you doing?'" or "My feeling was, let me first try my holistic manner that I've lived my whole life, as I've been raised [first]." Our respondents clearly had an impression of whether their healthcare team knew them, and that view was essential to their perception of the quality of the relationship.

Additional themes

While comments related to the two primary themes of information exchange and fostering the relationship predominated, we also identified comments related to uncertainty, decision-making, responding to emotions and enabling self-management.

Uncertainty

Our analysis suggests that for patients and family members, the experience and management of uncertainty is strongly connected to information. Most references to uncertainty related to how care would progress, what the patient should expect, or to delays in being given information or instructions (i.e., sufficiency and timing of information). For those who experienced this, the perceived lack of information or not being "kept in the loop" was particularly problematic as it exacerbated an already stressful emotional period for them and their families. We did identify instances where patients referred to uncertainty about whether their cancer would return or how long they would live, but these references were few in this data set.

Decision Making

Most comments related to decision making referred to whether the patient felt included in the decision. Patients who felt included talked about physicians sharing their rationale for favoring a particular course of action; patients who were clearly dissatisfied with decision making told of physicians who presented options without additional information, or simply told the patient what the physician would do, without offering an alternative or a rationale. As one patient said, “When somebody can give me good, crisp answers, I don’t feel like I’m being taken advantage of or I’m being railroaded into anything.” Few patients in this study referred to a clinician talking through the pros and cons of various options.

Responding to Patients’ Emotions

In this study, effective information exchange helped to reduce patients’ anxiety and distress; patients who were prepared and knew what to expect had less distress; those who weren’t prepared, or felt that they were unable to get their questions answered were distressed months and sometimes years later. Reassurance and optimism also helped to reduce fear and anxiety. No patients in this study expected clinicians to delve into their emotions; rather they wanted their clinicians to recognize, appreciate and take into account the emotional and psychological impact of the diagnosis and treatment. For example, one patient spoke highly of a physician who recognized that she was “flipping out” and “needed a little more time” before surgery. Others simply appreciated having some, but not too much time to let the diagnosis “sink in” before decisions were made or treatments began.

Enabling Patient Self-Management

Patients’ and family members’ comments relating to self-management referred primarily to information exchange as described above, and clinician assistance in navigating the healthcare system itself. Patients appreciated assistance with referrals, help coordinating schedules and appointments, and clinicians encouraging independence in managing their own care when possible. Clinicians and other staff who helped patients with these aspects of care were appreciated.

DISCUSSION

Effective information exchange and a good clinician-patient relationship are critical to patients with cancer. The prominence of these two key functions, sometimes referred to as instrumental and relational communication, has been noted previously[11–14]. Our findings confirm that these functions are indeed vitally important and are highly interrelated. In addition, the perspectives of these patients and families provide novel insights regarding how clinicians and healthcare systems can improve communication in cancer care.

The clinician’s interpersonal manner clearly influences the patient’s perception of care. The words these patients used to characterize their clinicians highlight the importance of gestures and actions which clinicians can consciously consider and modify. Almost inseparable from perceptions of manner were patients’ beliefs about whether the physician treated them as a person. Thorne and colleagues have also stressed patients’ need to feel a connection with their physician, their desire to feel known, and the importance of being treated like a person[15]. Yet most current patient satisfaction surveys do not assess these often subtle communication behaviors, leaving physicians unaware of patient perceptions, and at a loss for how to improve. Instruments that accurately capture patients’ communication experiences and perceptions are needed to fill this gap.

We found that clinician behaviors outside of the exam room, and especially their availability and responsiveness, can have important effects on the clinician-patient relationship, an observation that has received limited attention in the literature to date. Clinicians' willingness to respond to questions, to be flexible in scheduling and to assist in referrals, can all contribute to perceptions of caring and commitment, consistent with earlier findings suggesting that physicians' efforts to arrange care beyond the encounter were construed as evidence of caring[16]. When the patient leaves the exam room, the clinician turns his or her attention to the next patient or task, while the patient may continue to struggle to digest information, make decisions, see another clinician, or to coordinate their own care. Many patients experience cancer care as fragmented and uncoordinated[17], so it is not surprising that help beyond the encounter is needed and valued by patients. The potential for e-communication and for patients to view their electronic health record [18] is likely to increase patients' expectations for ongoing access to their care team, and to challenge clinicians' and healthcare systems' ability to respond.

While patients and family members in this study focused primarily on the individual clinicians who provided care, efforts to facilitate patient-centered communication during cancer care must consider organizational and environmental factors as well. Clinicians facing organizational pressures to increase efficiency may sacrifice communication[19]; and financial incentives reward technical procedures such as infusion, not provision of information or emotional support[20]. While increased awareness and training efforts are important, as Beckman and Frankel have noted, "synchronicity between expectations and the practice environment" is needed for clinicians to provide patient-centered communication[21]. Thus efforts to improve communication must be multi-level, acknowledging and addressing patient, clinician, organizational and policy barriers and facilitators. As Levinson and colleagues have suggested, policy makers and stakeholders can leverage training grants, incentive programs, certification requirements and other approaches to encourage and reward effective communication[2].

An important limitation of this study is our inability to explore the extent to which patients' communication experiences and needs varied according to clinician characteristics (e.g., training and specialty), disease characteristics (e.g., type of cancer or stage of cancer) or treatment intensity or complexity. These factors are likely to have important effects on patients' communication needs, preferences and perceptions, as well as on clinicians' communication behaviors. Some patients in this study noted that their views were strongly affected by their diagnosis and treatment trajectory. Unfortunately, because this was a secondary analysis, we were not able to investigate *how* such factors affected patients' communication experiences. Thus, while the findings reported here represent themes that we believe are generally applicable across a range of patient experiences, additional research is needed to further explore how patients' needs and experiences vary in different contexts.

In our analysis, information exchange and fostering the relationship emerged as most salient to respondents. Our subjective sense is that these were most important to patients in this study, but an alternative explanation is that the interview questions or the interviewer inadvertently focused respondents' attention on these functions. Further, other patients, interviewed at different stages in their care might identify the other functions are more important.

Because this was a secondary analysis of existing data, we were unable to modify the interview questions or to revisit issues that arose during analysis. In addition, the original studies utilized different recruitment criteria, different interview guides, and focused on diverse aspects of communication. Many of the patients (n=78) were originally recruited because they believed that something had gone wrong over the course of their cancer care, which may have influenced our findings. However, our use of multiple data sources, and the consistency of the themes which emerged provides some support for the generalizability of our results. These interviews and communication logs investigated communication from the perspective of patients and family members; communication is by definition an interactive process; the perspective of the clinician is necessary for a complete understanding. The results and discussion presented here focus primarily on what patients and family members want from clinicians; we do not focus on patients' communication behaviors, which are obviously also of central importance in the communication process. Finally, our decision to focus the analysis on themes related to patient-centered communication means that other significant topics of interest, such as the phenomenological experience of cancer were beyond the scope of this paper.

In conclusion, information exchange and patient-provider relationship are critical dimensions of cancer care communication, are interrelated, and integral to other communication functions. Patients want sensitive, caring clinicians who provide information that they need, when they need it, in a way that they can understand; who listen and respond to questions and concerns, and who attempt to understand their experience. They also appreciate clinicians who are responsive to their needs beyond the immediate medical encounter. The accumulation of concordant research results in this area highlights patient and family expectations and current gaps. Providing truly patient-centered cancer care will require that healthcare providers and institutions redouble their efforts to enhance communication. Measurement tools are needed to assess cancer patients' and family members' experiences with communication in order to provide meaningful, actionable feedback to clinicians seeking to optimize their effectiveness in communicating with patients with cancer.

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Table 1

Description of Data Sources

Interview focus	Sites	Timeframe of data collection	Recruitment Methods	N, type of participants	Patient status at recruitment	Data collection
Patients' experiences of communication around patient-perceived adverse events and errors in cancer care.[7] [Funded as a core project of the HMO CRN CCRC P20CA137219]	Massachusetts, Georgia, Washington	May 2009 to November 2009	Letter of invitation; telephone follow up to determine interest and eligibility	78 patients with cancer	6–18 months post treatment	1 time telephone Interview, ~ 1 h
Patients' and family members' views on assessing communication experiences during cancer care[8] [Funded by a supplement to the HMO CRN CCR P20CA137219]	Massachusetts, Colorado	January 2011 to March 2011	Letter of invitation, telephone follow up to determine interest and eligibility	37 Patients 9 family members of adult patients with cancer	~6 months post diagnosis	1 time telephone or in person Interview, ~ 1 h
Parents' views on assessing their communication experiences during their child's cancer care[8] [Funded by CTSA funds KL2 RR031981].	Massachusetts	March 2011 to May 2011	Oncology staff identified potential interviewees; study staff approached in person	8 parents of pediatric patients with cancer	1 undergoing treatment 7 Post-treatment	1 time telephone or in person Interview, ~ 1 h
Patients' communication experiences over the course of cancer, and views on helpful and unhelpful interactions with clinicians. [Funded by pilot funding to the HMO CRN U19 CA79689]	Massachusetts, Michigan, Georgia	March 2011 to April 2011	Letter of invitation, identification by oncology staff, or participation in previous study; telephone follow up to determine interest and eligibility	9 patients with cancer*	5 undergoing treatment 4 post-treatment,	Single retrospective interview ~1 h (N= 9) Second retrospective interview (N=4)Communication log (N= 4 participants, 30 log entries total)

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*4 patients had also participated in the "Patients' and family members' views on assessing communication experiences during cancer care" study.

Table 2

Information Content: Patients' Information Needs

Area	**Information Needed**	**Quote**
Process of care	What will happen, when	[The doctors] explained not only what should happen, but they were also telling me that there were things that could happen that they weren't expecting.
	Test results and procedures, including interpretation and meaning for patient	I felt like the doctor just explained to me everything that they had done and what they had found and that they had put a marker in there so that they would be able to pinpoint it if they needed to again. [The doctor] explained to me that what they would hope for is that they could have found something on the ultrasound because that would probably mean that it was a cyst, but the fact that it wasn't found doesn't necessarily mean that it's cancerous, but it's not as good as if they had found something.
	Rationale for treatment recommendation	[The doctor] had explained to me the difference between invasive and … I had invasive ductile carcinoma. And he explained what that meant, and what the difference was between it being invasive and being the other one where it's all within itself. And he explained that because it was invasive that they would want to do chemotherapy and explained what it does, that it looks for those rogue cells.
Preparation	How the test or treatment will affect the patient; what the patient should expect in terms of the experience	My MD told me exactly what was going to happen next. He told me the information that I needed to know and then he told me what was going to happen next, so I was prepared. They just went down and gave me my options and the whole smear, what goes along with it. They were very thorough in what to expect and so on, and they didn't leave any stones unturned.
	What actions the patient should take to prepare for treatment, manage symptoms, or mitigate side effects	A radiation oncologist came in and spoke to us, and explained to us what they expect to have happen and talked to me about side effects.
Future /Prognosis	What outcomes the patient should expect; prognosis; follow up care	We were lucky because he was so upfront about it…he had seen worse cases than [patient's name], but there's really no treatment for it. And then he sat down and explained that what I have to do is, I still have to get my regular mammogram once a year, but going forward I will see him every six months until he feels that we don't have to. So he will go in and exam … he explained he will do an exam that is not … it will be more of an evaluative exam than a mammogram would be because I've had cancer.

Table 3

Interpersonal Manner

Attribute	**Illustrative quotes**
Accessible; available	When I spoke to the breast care coordinator, I mean she was always accessible, she gave me her card, it has a direct phone number to her, you don't have to sit there and get put on hold to go to somebody else, to leave a voice mail for her to call you back, I mean she picks up her phone and answered it. They were extremely accessible and receptive to any questions or any issues that I had. …she [care coordinator] said to me "Whatever you need, here is my phone number. If you're having any problems with this or that or the other thing, call me at my desk and I will fix it for you." *She [surgeon] said, "Here are two options; I'd like you to decide." And she was speeding up the process because she was going on vacation.*
Calm	The doctor was very polite and calm [when he told me the diagnosis]. He answered any questions that I had and he was very understanding and I was very calm. It was like he had all the time in the world.
Caring, kind, warm	And they're very responsive to people who are in…I think they understand the trauma that you're under psychologically. The nurses at the hospital are so personal. They are very caring. They [the clinical team] were kind, caring, they were just wonderful. And we talked about books….it wasn't that they [the women who did my radiation] knew about my care particularly, it's just that they were warm and connected. *[This site] is driven by their studies, the protocols…and as a scientist I really appreciate that [but]…it de-emphasizes on the personal relationship. And I think that the relationship has a capacity to be supportive and healing in its own right."*
Committed	I just thought it was wonderful. He was on vacation and he took the time to call me at home.
Compassionate	He [MD] said, "Because you have to be mentally and physically prepared for surgery. And you are not prepared." And I thought that was really nice, because he had realized that I was just flipping out. So he sent me to the breast cancer clinic. And I thought that was really nice. He understood that I was going through some things, and I needed a little more time. And once I get a little more time I'll get ahold of myself and we'll get this situated.
Engaged; present	*The first oncologist I had, it seemed to me when he was talking he was talking more through the computer than looking directly at me. And it seemed like sort of a distracting way to communicate with somebody that's going through cancer treatment.* *As I say, [doctors should] maintain eye contact instead of being … punching away on a stupid computer when they're trying to talk to these people. I mean there has to be more personal … make it a little bit more personal.* *They're typing into their computers, they're looking at the computer screen, they aren't facing you, they're collecting data. The nurse is collecting data, the doctor is collecting data, they're meeting their job's obligations. But something is lost in that. They're gathering good information, but something is lost in terms of the human connection.* *He [MD] was just …it was like he'd rather be somewhere else.* *I saw a medical oncologist and he could barely give me the time of day. He was just very lackadaisical…He just didn't want to be there.*
Hopeful, optimistic	"The doctor said, "[The tumor's] slow growing and it's the best kind you can get"…She [the doctor] was fantastic and positive, uplifting. *I guess I felt it could have been said in a little more positive tone, a little more like there were some options out there, it wasn't just a dead end deal, which is what I felt.*
Interested	I think the biggest thing with my son was that she [MD] was very interested in the details of what I was saying. *He would just talk and talk and talk and he didn't care what I had to say.*
Polite	She [RN] went over all the questions and she was very polite and easy to talk to and everything was good.

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Reassuring	I felt that she [nurse coordinator] went above and beyond. I was very anxious and she was there to answer my questions. He [doctor] basically told me that I was going to be taken care of. I felt everything was going to be taken care of.
Respectful	[Clinicians] should be respectful of who they're taking care of and that we're all different, and that they should handle [us] in different ways. It's really important to me that the doctor respect me and respect my opinion…because.. I want an even relationship…because you're giving somebody an awful lot of control over your life.
Sensitive	[The nurse] just came in and she put her hands on me…she just touched my arm and she goes, "How are you tonight?" I mean in such a loving way. *I don't need to tell you what I was going through, and a nurse came in one night and she said, "Oh, it must suck to be you." You don't say that to a patient who's in bed, like in the pits of despair because their intestines are leaking their contents all over the floor.* *They wheeled me down there and everybody's like so cold when I get there. I'm obviously totally screwed up. But they uncover me and [the doctor] comes in and she looks, she goes, 'Oh, I'm not touching that [breast filled with fluid]'*
Treated the patient like a person	I think the thing that's really important is that doctors be able to kind of get a feel for what's important to each individual person. That's what's really important. *Did she get to know me as an individual person? No. Did she treat me like a person and not just another patient? No.* *I just felt like I was a number or a statistic in a line of a bunch of people, which in a way, I am. But you take it more personally than just being someone that is there doing this.* *[Doctors should] clarify and then communicate, communicate and clarify again. And don't treat me like a number.* *[Go] back to the basics of, you treat the patient, not the lab work. You treat the patient, not the X-ray results. And empowering me to believe in what my body's telling me and…just those things you kind of lose sight of when you're in the vortex of panic and uncertainty.* *Her [doctor] solution wasn't anything except kind of more procedural…So just…it was lock, step, following a procedure manual as opposed to responding to me, the unique individual at the end of the line who is in a significant degree of distress*
Understanding of the patient's experience	[My doctor] knew I was scared. And I think that he was very…he encouraged me, he definitely made me feel like this is not the end of the world. Just hope for the best. And he took me from every step until I had my surgery. And he totally understood how I felt. And I thought he was wonderful. But I thought he was very considerate, wanting to get me in so that I wouldn't have to have a longer session when I can back.
Unhurried	Everything was covered with smiles. They acted as if each one of them had all the time in the world for me.
Upbeat	The people were so nice and pleasant and just upbeat…I just picture all the people I had to deal with, and they made me feel good about everything. They are very, very upbeat and that really makes a difference.

Table note: Italics indicate reference to negative perspectives or experiences.