The Doctor–Patient Relationship and Information-Seeking Behavior: Four Orientations to Cancer Communication

Matthew Adamson, BA¹, Kelsey Choi, BA¹, Stephen Notaro, PhD¹, and Crina Cotoc, MD¹

Abstract

Background: In cancer communication, patients and physicians often understand a patient’s experience and situation differently. This can negatively impact health outcomes and the physician–patient relationship. Aim: To explore how cancer patients’ interpretations of the physician’s role as information giver affect the communication relationship with the physician and their information-seeking behavior regarding different aspects of their cancer care. Design: Participants completed a semistructured qualitative interview addressing their treatment experience and communication with their physician. Interviews were coded and analyzed using inductive thematic analysis. Setting/Participants: Ten patients with cancer treated at a regional cancer center in central Illinois participated in the study. Cancer stages I to IV and 4 cancer types were represented. Results: Participants’ orientations to the relationship with their physician (and their information-seeking behavior) were classified into 4 general categories: (1) “questioners” have a general mistrust toward their physicians and the information doctors are giving; (2) “the undecided” focuses on physician “fit,” often requiring time to step away in order to make decisions and process information; (3) “cross-checkers” are concerned with content of their treatment protocol, often double-checking the treatment plan; and (4) “the experience-oriented” feel a gap between their experience and their physician’s experience (and perspective), often seeking information from other survivors. All categories described a perceived lack of adequate exchange of information and the need to seek information outside of the physician–patient relationship to compensate. Conclusion: Participants exhibited different information-seeking behaviors based on how they interpreted the role of their physician as information giver. This affected what kind of information they sought and how they understood the information received, which in turn affected understanding of their broader experience and care.

Keywords
cancer care, communication, doctor–patient relationship, cancer, palliative care, health communication, information-seeking behavior

Introduction

Patient–physician communication in the context of cancer care has received significant attention because of its fundamental connection to respecting patient autonomy.¹,² Patients cannot make informed decisions without first acquiring and understanding relevant information about their disease and treatment management, including diagnosis and likely disease progression.³ Many studies focus on how communication about cancer occurs and how that communication affects treatment outcomes, including patient decision-making, satisfaction with care, and understanding of the goals of care.³⁻⁸ The communication of prognosis has received particular attention.²,⁹,¹⁰

In this article, we employ Clayton et al’s definition of prognosis presented in their clinical practice guidelines: “life expectancy, how the illness may progress, future symptoms and effect on function.”¹¹ While including the discussion of survival rates and time frames, this definition adds other important factors integral to the patient’s short- and long-term experience and decision-making process, including side effects that may occur during treatment, long-term side effects, future symptoms, and permanent impacts on functional ability resulting from treatment.¹¹ While our participants rarely discussed life expectancy, survival rates, and time frames with their physicians, their communication experience and concerns did incorporate aspects of how their illness and treatment would progress (including side effects of treatment), future symptoms they may experience or should prepare for, and long-term effects of treatment. The term “prognosis” in this article emphasizes the inclusion of these aspects of cancer patient experience into the understanding of what prognosis means.

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Cancer communication literature has consistently observed a discrepancy between how patients and their physicians understand various aspects of care. Specifically, misunderstanding has been observed regarding the consequences of treatment, likelihood of treatment success, patient preferences for care, probability of cure, status (progression) of illness, and likelihood of survival. This misapprehension can have drastic consequences, including patients seeking “futile” treatments or delaying end-of-life discussions and preparations until too late, as well as adversely affecting patient satisfaction, the patient–physician relationship, and compliance with treatment.

The literature focuses on patient preferences regarding types of information and communication style, what is actually communicated and how it is understood, and the effect of communication on patient satisfaction, participation, well-being, and the physician–patient relationship. Several theories have emerged from these efforts to explain this discrepancy, including incomplete disclosure, the use of euphemisms to communicate “bad” news, and compromised understanding due to the stress of receiving unexpected bad news. However, these theories cannot account for all instances of misunderstanding, including instances of incomplete disclosure.

Although many studies have sought to understand how communication contributes to misunderstanding and how to intervene, few have evaluated how the patient’s relationship with the physician and their perception of the physician’s role (and authority) regarding information giving affect the communication and reception of information. Previous research explores how communication builds an effective working relationship and how the physician–patient relationship affects decision-making, health outcomes, and meeting patient’s needs and goals. However, the impact that this relationship has on patient understanding has received less attention. Our study explores how the cancer patient’s interpretation of the physician’s role and authority as information giver affects their communication relationship and how this in turn affects their information-seeking behavior.

This analysis is part of a larger project designed to assess the extent to which individuals with cancer discussed aspects of their care (and in particular their prognosis) with individuals other than their physician. This idea arose from initial informal discussions with health-care providers and cancer survivors, as well as from attending a monthly cancer survivor group for a year. The project has 3 hypotheses: first, patients feel the need to discuss their care, concerns, and prognosis with individuals other than their physician/treatment team; second, these “outside” discussions inform their understanding and interpretation of various aspects of their cancer experience; and third, assimilating this additional information may contribute to discrepancies and divergent understandings of the cancer care process, treatment plan/goals, and prognosis between patient and physician. Although initially unexpected, it became clear that the current analysis is an important contributor to the dynamics we initially set out to explore.

### Table 1. Demographic Characteristics

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>No. of Patients</th>
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</thead>
<tbody>
<tr>
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<tr>
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<tr>
<td>Female</td>
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<tr>
<td>Primary cancer</td>
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<tr>
<td>Breast</td>
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<td>Prostate</td>
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<tr>
<td>Lymphoma</td>
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<tr>
<td>Stages of cancer</td>
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<tr>
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<td>III</td>
<td>3</td>
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<tr>
<td>IV</td>
<td>3</td>
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</tbody>
</table>

*Demographic information of the participants.

### Methods

All participants (n = 10; see Table 1 for demographic information) had completed treatment or were undergoing follow-up treatment at the Carle Cancer Center in East Central Illinois. Participants had cancer of varying types and stages, although stages I to IV were represented. Potential participants were referred from Carle Foundation Hospital. A research assistant with previous qualitative interviewing experience conducted an in-person semistructured interview with each participant. Interviews averaged 74 minutes in duration. We conducted all interviews one-on-one with individual participants. In some instances, follow-up communication through e-mail was used for clarification. Interviews broadly addressed patient experience with cancer treatment, focusing on the communication that they had with their physician and other individuals regarding what they should expect during their care (for details and interview guide, see Appendix A).

We used inductive thematic analysis to produce a codebook. To generate themes and codes, we followed the approach outlined by Braun and Clarke. First, 2 researchers audio recorded and transcribed interviews. Once familiarized with the interviews, initial codes were established which were then grouped into tentative common themes. The 2 researchers then independently coded transcripts and audio recordings using the codebook. The researchers met upon coding each interview to refine the codebook/thematic definitions and to ensure consistency of analysis. These themes were reviewed and refined throughout the coding and discussion process to generate more precise and clear definitions. Themes centered on understanding the different orientations that participants took toward their physician as information giver. Specifically, codes focused on information-seeking behavior, how that behavior related to participants’ feelings about their physician, and barriers to effective communication.

To ensure rigorous methodology, we engaged in member checking with our participants by providing them a draft of the results of the study and their personal ID number.
allowed them to see their quotes in context and give feedback about our interpretations. Five out of 10 participants responded and 3 gave feedback that resulted in changes to our discussion.

**Results**

Analysis yielded several different orientations that patients took toward seeking and applying information from their treating physicians. We organized these into 4 general but distinct groupings, which we then categorized as follows: “the questioner,” “the undecided,” “the cross-checker,” and “the experience-oriented.” All participants (save one) exhibited characteristics from at least 2 groupings, although some converged more toward one particular group (Table 2). Primary versus secondary orientations were determined based on frequency of reference to behaviors specific to a particular orientation and the emphasis the participant placed on those behaviors in the interviews. Five out of 10 participants verified their particular distinctions during member checking (see Methods section). For participants 3 and 4 who had 2 primary orientations, each explicitly emphasized the dual importance of behaviors particular to both orientations in their interviews.

**The Questioner**

The questioner’s orientation toward the physician is characterized by a degree of mistrust about the information the doctor is providing. This manifests in various ways, ranging from expressing concern about the physician’s willingness to listen to patient concerns, to actively trying to test the physician’s priorities or objectivity. Importantly, this sense of skepticism is not always outwardly expressed but manifests in other information-seeking behaviors outside of the physician–patient relationship (Figure 1).

Questioners also expressed feelings that physicians may not always provide objective information or recommendations but rather may seek to direct patients to undergo treatments that the physician specializes in. This can be understood as a sense that the physician has “skin in the game” and thus cannot provide unbiased recommendations.

The worry about bias does not necessarily prevent patients from seeking information from their physician but often involves taking that information at face value and measuring it against other perspectives, including other friends or family outlook, Internet sources, survivor forums, and so on. This concern can also translate into questioning the physician’s skill or ability to provide effective treatment, leading patients to seek out other physicians or treatment. For example:

One oncologist was sort of nonchalant about it and he recommended that I wait a year and get the MRI and I said I’m not comfortable with that...actually I chose a different oncologist to continue my...preventative treatment (Participant 1)

The feeling that the physician will not listen to or address patient concerns can undermine their authority regarding other aspects of care. This can become a barrier to further information seeking from the physician.

**The Undecided**

The undecided take a noncommittal, “need to think about it” approach. The hesitancy to commit to specific treatment plans stems more from a desire to process and consider information rather than a mistrust of the information they are receiving. Because of this, communication style and the relationship with the physician are more prominent concerns. This translates into an emphasis on the “fit” of their physician and a desire to have some sense of familiarity and an effective communication relationship (especially communication style).

Often these patients feel rushed or unable to fully comprehend their situation when information is given or decisions need to be made. Participant 5 described his initial discussion with his oncologist, where communication style, speed, and amount of information given caused him to feel the need to pull back and question the physician’s approach. Following this discussion, he sought out another physician with a new pace and communication style that seemed to work better (Figure 1). The desire to seek out other opinions or switch physicians was common among the undecided group.

The problem of having multiple treatment options (or too much information) figures as a prominent concern with this group. Participant 9 expressed that “the hardest part for me was...trying to figure out mastectomy, lumpectomy, and consequences out of that and I just didn’t like any of the options.” The issue of having multiple alternatives without one clear “best” option led her to seek out multiple physicians where she moreover experienced concerns with relationship/communication style.

I don’t remember when we raised the question about the surgeon...It was a temporary surgeon and I asked for a second consult and got someone I was very pleased with. Something happened on the radiation too; I ended up with a second person. I also saw...a plastic surgeon here and then a second plastic surgeon.

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**Table 2. Participant Orientations Toward Physician Information.**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Questioner</th>
<th>Undecided</th>
<th>Cross-Checker</th>
<th>Experience-Oriented</th>
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</thead>
<tbody>
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Abbreviations: F, female; M, male.

*aRespective patient orientations toward seeking information from their physician. Black represents primary orientations; gray represents secondary orientations. Some patients exhibited more than 1 primary or secondary orientation.*

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She also described seeking the right “fit” for each of her physicians and how that calculated into her decisions. Obtaining information from multiple sources and then stepping back to process that information before making a final decision was characteristic of this group.

**The Cross-Checker**

Cross-checkers generally trust their doctors but feel the need to double-check aspects of their experience with other sources of information. These individuals prioritize the content of their treatment protocol as opposed to the credibility of their physicians, often focusing on what they should expect and on the decision-making process.

Participant 3 mentioned how her sister was an important collaborator in making treatment decisions and said that in particular, “[she would ask] all the right questions and go to the computer to cross-check everything and make sure that everything was being done according to protocol.” Importantly, this patient and her sister used Internet-retrieved information to verify that the treatment and other actions were being carried out according to the decided course of action.
Cross-checking can be a tool for the patient to bring up discussions that the physician may not be initiating or can sometimes result in going against physician recommendations. Participant 6 (who worked as a nurse) discussed her experience with seeking a palliative care consult and the initial resistance from her physician. Her past experience working in the healthcare context led her to verify that her personal experience as a patient was unfolding in a way she understood to be best practice (Figure 1).

In some instances, cross-checkers feel this need because they are receiving divergent information or recommendations from different treating physicians:

[The tumor board] wanted to start me with chemo first. And my surgeon said he didn’t recommend that. The tumor was 6 cm, it’s very large, and he said, “If it were me, I would recommend this.” And he suggested surgery first and then chemotherapy, and then radiation. (Participant 2)

Her previous interactions with the various physicians and her own research had led her to believe this course of action was best, which was confirmed by the surgeon’s recommendations. One of our participants mentioned a physician who anticipated their cross-checking approach to treatment information and provided them a source for specific verification of their treatment plan (from the American Cancer Society). This aided in developing a relationship of trust with this patient going forward, making this patient much more comfortable in making treatment decisions with this physician.

The Experience-Oriented

For the experience-oriented, the patient feels a gap between their own experience and the physician’s experience. The primary concern is that the physician cannot relate to what they are going through simply because they have not experienced the ins-and-outs of cancer treatment themselves. Hence, provider support and perspective are limited and impersonal. This concern moves these patients to seek out additional medical information (eg, advantages/disadvantages of available treatment options, advice for dealing with side effects, physician and other resource referrals) and emotional support from other sources (particularly cancer survivors). This outreach may begin during treatment but can also occur before treatment has started (and even before treatment decisions have been made).

Participant 1 described her observation that although her physician was engaged in her care and concerns, they could not fully understand the daily effects of treatment on her life. Her solution to this was to seek out other cancer survivors and to lean on them for advice and support throughout her care process. She emphasized that these survivors provided her both medical and nonmedical information.

Additionally, the depth of concern about various aspects of care expressed by other survivors seemed more appropriate or helpful than the physician: “[My physician] was great in terms of knowing what chemo to give . . . but she did not understand the concern that cancer patients have . . . The concern that they get for . . . well what’s this symptom, what’s that symptom? . . . She was much more laid back . . .” (Participant 3). Several participants mentioned that the information that they received from other survivors had more depth, often addressing medical concerns in more detail and in ways that felt more relevant to everyday life.

The support group [is] where there’s been a lot of information. Because when we share in the support group, there’s a lot more depth and information that’s shared . . . there are people with a lot more . . . that preceded me and shared things about what I would be experiencing . . . (Participant 3)

In some instances, the experience-oriented turn to other survivors for medical advice even before discussions with their physician. Sometimes this is because of the time constraints placed on physician visits and the limited time that patients sometimes felt they had with their physicians. Participant 2 emphasized that the time with her physician was short (“my 15 minutes”) and so would take many of her more minor concerns to the support group: “[I] just need my 15 minutes with [my physician] . . . . I just need the big things.” Participant 2 started attending support group meetings specifically because of a minor concern (“fingernails falling off”) that she felt was too minor to discuss in the limited time she had with her physician.

In other cases, turning to other survivors is due to other factors such as trouble with physician communication or sensing a lack of empathy. Participant 1 described her feeling that physicians sometimes had trouble relating to what she was experiencing (see Figure 1): “I don’t think the doctors know just how, just from like a random off-the-cuff comment here or there . . . I don’t think they see what happens day in and day out after treatment to people. And it’s not a criticism of them because they just don’t . . . they’re not living with it.” Participant 9 sensed both time constraints and a lack of empathy from her physicians. She felt that her physicians did not or could not prioritize discussing the side effects she was experiencing, expressing that this can be difficult because it takes time: “[After finishing treatment], I made a list of about 10 side effects that are still happening. And the doctors aren’t interested in it because they’re not gonna make you die.” She emphasized the importance of being connected with other survivors and her willingness to provide a listening ear or advice to others now that she has completed treatment. In each instance, the experience-oriented mentioned the importance of the need to discuss these things with someone who could relate to their experience.

Discussion

We discussed the different orientations that patients with cancer take toward their physician as an informational resource, emphasizing 4 general orientations toward the patient–physician communication relationship: “the
questioner,” “the undecided,” “the cross-checker,” and “the experience-oriented.” Additionally, we discussed how these different orientations affect information-seeking behavior, including when patients seek out information from a treating physician and how they interpret it.

It is important to note that each of the participants manifested characteristics from multiple orientations. Although some of them may have been more pronounced in one particular group, no participant fell completely within one group alone (Table 2). The 4 groupings above are general categories that describe motivations for specific behaviors relative to information seeking and communication with the physician. Patients sometimes manifested behaviors from different groupings depending on various contextual factors, including the development of the patient-physician relationship, time from diagnosis, degree to which experiences felt unexpected, and availability of other informational resources.

As far as information seeking, the different orientations led patients to be more or less assertive about asking questions or eliciting physician input and in some instances caused patients to avoid these discussions entirely. Often, patients would do their own research, sometimes coming to their own conclusions and then returning to the physician to inform them of specific decisions. To varying degrees, the processing and interpretation of the specifics of a patient’s treatment and care may be happening outside of the physician-patient communication relationship. This can often include other sources of information and perspectives besides the treating physician, which directly impact how patients understand their experience.

There were different motivations for seeking out information about their cancer care and prognosis from other sources. These motivators stemmed in part from how patients were interpreting the role their physician was taking or should take in terms of being a source of information about their care. In instances where the patient felt their physician was not qualified or capable to address the broader aspects of their care, they sought information, advice, and help from other sources. Patients may seek out other information or have trouble with their physician simply because of a sense of their inability to empathize, give meaningful feedback/info, and so on, relative to their complete care experience.

In interpreting the amount of authority a physician’s perspective should take in decision-making, patients establish both informational boundaries for physician communication and informational needs to compensate for information they feel they lack. Different factors caused patients to explore other sources of information about their situation. This process always provided additional information that needed to be incorporated into their understanding and would sometimes undermine or contradict their physician’s perspective. Adding these new elements to a patient’s informational resources can change their understanding of different aspects of their experience from what was communicated to them by their physician.

This means that physicians and treatment teams should consider their patients’ processes of negotiating the meaning of their experience and information they receive. This entails situating their own authority and contribution (however expansive or limited) within a broader array of other sources available to their patients. These sources are attributed differing levels of authority regarding various aspects of a patient’s experience, understanding, and decision-making. This may also mean connecting patients with other trusted resources from which they can gain additional insight and support. We also suggest being more generally attentive to the dynamic nature of what medical information “means” to individual patients. Being attentive to the processes and people that patients go through to understand and make sense of their experience can help to monitor how patients are understanding their experience and information they receive and how that understanding may be changing over time. This should be considered as discussions of treatment options and plans, treatment success/failure, survival, and decision-making are taking place. This can include checking in with patients at various points (and perhaps more frequently) throughout treatment to reengage relevant aspects of prognosis and treatment, reevaluate patient understanding of these aspects, and recommunicate the physician’s perspective.

Future Research

In terms of next steps, we are currently in the process of analyzing this initial data to establish a preliminary list of specific individuals or sources of information that participants utilized to inform their decision-making regarding their treatment and prognosis. Additionally, we plan to find a larger and more diverse sample to represent a wider range of ages and types of cancer to allow for more detailed analysis of particular aspects of this phenomenon. For example, generational communication differences may impact information-seeking behavior and patient interpretations of the role of their physician in this regard. Additionally, available information and established support networks also differ for different types of cancers, which may also affect this process. There may also be other variables that influence this process, including especially race, gender, and socioeconomic status, which we were unable to adequately assess with our sample. These variables may impact access to care, trust in the physician-patient relationship, and access to informational resources.

Limitations

We had a relatively small sample size with breast cancer being significantly overrepresented. It was clear that although there were similarities in experiences, the different types of cancers often came with unique concerns relative to treatment and prognosis. We were not able to capture this diversity with our sample. The cancer center from which we drew participants has a breast cancer focus, and those individuals with breast cancer often had different experiences in terms of interactions with hospital staff and communication.

Communication was discussed in retrospect, and so there may be some recall bias. Although most of the participants...
(7) had finished treatment within the past year, 3 participants had finished cancer treatment over 3 years in the past. This certainly could have affected their recollection of the particulars of their experience with physician communication. Additionally, most of our participants were middle-aged adults or older adults. We had 2 participants who were under the age of 40 (see Table 2). Our sample was too small to be able to assess how generational differences may have influenced communication preferences and behaviors, as well as expectations regarding physician communication and the role of the physician.

Conclusion
Our study sought to explore how a patient’s orientation to the role of the physician as a provider of information might affect their communication relationship and information-seeking behavior. We found 4 general orientations that our participants took toward the communication relationship with their physician: “the questioner,” “the undecided,” “the cross-checker,” and “the experience-oriented.” These orientations affected how assertive participants were in seeking out information from or having discussion with their physicians, the types of boundaries they placed on the authority of the information received from their physicians, and how readily they sought out and utilized information from other sources. Patient understanding of various aspects of their diagnosis, prognosis, and care may be influenced by the way they approach the physician as a source of information. These orientations may also affect patient information-seeking behavior.

Appendix A

The Interviews
Two research assistants conducted interviews, 1 graduate student (RA-1) and 1 undergraduate student (RA-2). RA-1 has past experience conducting qualitative interviews for 2 separate projects dealing with social psychology and disability and health related to neurodegenerative disorders. Eight of 10 interviews were conducted one-on-one, in person, with 1 research assistant. RA-1 conducted 6 interviews; RA-2 conducted 2 interviews. The other 2 interviews were conducted with both assistants. Interviews on average were 74 minutes long and were conducted at Carle Foundation Hospital.

Interviews began with prompting the participant for a detailed description of their experience, starting from what prompted them to first go see their doctor. As participants told the story of their experience, relevant questions from the interview guide (as well as clarifying or probing questions) were inserted to gather more detail or focus on particular aspects of the narrative. The interview guide below was utilized in a semistructured way, with each question being addressed but not necessarily in the specific order laid out here. This allowed the participants to guide the interview process. Additionally, during interviews, any questions dealing with prognosis were clarified by defining prognosis as “what to expect.”

Interview Questions

1. Timing and information
   a. How many visits did you meet with your physician to discuss your initial diagnosis, treatment options, and “time frame?”
   b. How did you feel about the amount of information conveyed during each visit? Was it too much, too little, or adequate?
   c. How did the time frame information the physician gave you affect you? Your decisions? Which aspects of that felt more open, flexible, and uncertain, and which felt more closed or certain?
   d. Did your physician express any uncertainty regarding your illness or its course? If so, in what areas? In what ways did he/she express this?
   e. How did you cope with the day-to-day changes or aspects of your cancer? How did you cope with the larger concerns regarding your cancer?

2. Communicating and interpreting information
   a. What questions came up later that you wished you would have known to ask when you initially were told you had cancer?
   b. Since you have been diagnosed, which aspects of your experience have caused uncertainty? How have you dealt with that uncertainty?
   c. Where did you get information about your cancer? What were some of the sources of information that you found most valuable?
   d. How would you describe your present health and quality of life? What are your present concerns? How have those concerns changed since your initial diagnosis?

3. Uses of information
   a. What type of “time frame” information did your physician give you regarding your cancer?
   b. How did you use the information the doctor gave you? How did it affect your decisions (both health related and otherwise), your outlook?

4. Important individuals for establishing what prognosis means
   a. Who was important as you sorted through your experiences? Why were they important?
   b. Who would you consider to be your “support group?” How do/did those individuals support you (ie, what type of support)?
   c. How did communicating with others affect your understanding of your prognosis? Who else besides your physician was important in understanding this information?
   d. How did you come to understand what your prognosis meant as it related to other aspects of your life?
e. Besides the medical aspects of your cancer, what other concerns did you have about your diagnosis? How did you work through those concerns?

f. How did your diagnosis affect your relationships with others?

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References


