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Cancer Patients' Understanding of Prognostic Information

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Abstract

Prognostic information is necessary for cancer patients to be fully informed about the likely course of their disease. This information is needed for practical planning and treatment decisions. This study sought to examine how cancer patients understand the prognosis information available to them. The setting is an urban safety net hospital. Six focus groups with cancer patients ($N=39$) were digitally recorded and transcribed verbatim then analyzed using phases of content analysis. Participants in all groups discussed the prognosis almost exclusively in terms of mortality and reported that their physicians and nurses mostly provided prognostic information in terms of months or years for survival. This finding held across all cancer types and stages. Patients tend to think of prognosis information as being only estimated limited survival and find the idea upsetting. Due to this view on prognosis, patients need further explanation regarding where the prognosis information comes from and what prognostic information can tell them in order to make use of it.

Keywords

Cancer; Prognosis; Patient communication; Cancer education

Background

Conversations about prognosis are necessary for patients to be fully informed about the likely course of their disease. A positive prognosis could alleviate patients' anxiety regarding a cancer diagnosis while a poor prognosis may prompt patients to establish advance directives, have necessary end of life conversations with loved ones, and settle any end of life concerns [1, 2].

A patient's prognosis also informs treatment decisions. Patients with good prognoses may choose aggressive treatments with the goal of remission. Conversely, patients with poor prognoses may opt for palliative treatment that will alleviate side effects and improve quality of life [1, 2]. In addition, prognosis is not static and may change as a result of treatments received or disease progression [2–4]. Thus, sharing of prognostic information needs to be thought of as a process to be revised and updated over time in order for patients to make informed treatment choices [5].

Although much exists in the literature documenting patients' struggles to understand health information and medical consultations [6–8], fewer studies have been done in the USA to examine how patients understand the prognostic information available to them. Despite limited understanding of prognostic information, patients reported high levels of confidence in understanding, and those who did not understand prognostic terms were not significantly less confident than those that did understand the terms. Importantly, having personal experience with cancer or experience in a caregiver role to a cancer patient was not associated with higher levels of comprehension [8].

Studies examining communicating prognosis to patients have shown that the needs of patients are highly individualized, and the informational needs and desires of a group of patients can be quite diverse [9–14]. Although preferences for the amount and timing of prognostic information varies greatly among patients and health-care providers, the literature does indicate that both groups believe it is important information that patients need for planning and decision making despite it being unreliably conveyed in practice [9, 11, 15].

Research also finds more agreement from patients in regard to how this information is conveyed. Patients emphasize the importance of realistic information, the ability to ask questions, and a confident and supportive health-care professional [10, 11, 15]. Research recommends asking patients what, if any, prognostic information they desire before initiating prognostic conversations [14, 16, 17]. Although this addresses the issue of respecting patients' information wishes, health-care professionals also need to be cognizant of how patients understand prognosis as a larger concept. Back suggests health-care professionals should frequently ask patients not only if they understand the information but also if the information is meeting their needs and expectations [16].

The aim of this study was to examine how cancer patients understand and discuss prognostic information. Despite being potentially uncomfortable for both physicians and patients, prognostic information can be useful to patients and can aid them in making treatment decisions when there are multiple options. How an individual frames prognosis could preclude productive conversations or lead to misunderstandings, so it is important for health-care professionals to consider what perceptions patients bring in to discussions of prognosis.

Methods

Study Design

As part of an ongoing National Institute of Health study (1R01CA140151-01), six focus groups were conducted by an experienced moderator for the purpose of identifying group norms and perceptions surrounding the experience of being a cancer patient [18]. The larger goal of the parent study was to develop a measure of cancer health literacy. As part of the parent study, the focus groups were conducted to inform the development of items for a new measure of cancer health literacy. As such, the moderator's guide was developed to elicit information related to participants' experiences as cancer patients regarding such topics as understanding treatments, decision making, skills needed for cancer patients, and shared myths and confusions. During the analysis of focus group transcripts for item development, themes related to prognosis emerged resulting in this secondary analysis.

Participants

Individuals eligible to participate in this study were cancer patients, 18 years and older, and fluent in English.

Recruitment Procedures

Patients were recruited by study staff in person and through distribution of flyers posted in an urban safety net cancer clinic waiting room. Oncologists were asked for permission before contacting their patients. Of the 83 eligible patients contacted, 68 (82 %) agreed to participate and 15 (18 %) refused. Nonparticipants did not significantly differ from participants in terms of race/ethnicity and gender.

Forty-three patients were scheduled to participate in a focus group and the remaining 25 patients were placed on a waiting list for future participation in the parent study. Four patients scheduled for a focus group became too ill to attend. The groups were balanced with respect to race and gender and divided by education level. Three focus groups consisted of participants with a high school degree or equivalency or less (<HS) and three with those individuals who had completed education beyond high school diploma. Dividing the groups by education level was done to examine how education may contribute to some of the topics listed in the moderator's guide.

Signed informed consent was obtained when participants arrived for their scheduled groups. A moderator's guide was designed to explore patients' understanding of their cancers and their experiences as cancer patients. Each focus group lasted approximately 90 min. Participants were compensated \$50 for their participation. This study was approved by the Virginia Commonwealth University IRB.

Analysis

All six focus group sessions were digitally recorded and transcribed verbatim by professional transcribers. Each transcript was verified for accuracy by research assistants who compared the transcripts with the digital recordings. While saturation (where no new themes emerge) was achieved for this analysis by the third focus group, the investigators conducted the other three scheduled groups to capture all relevant themes for the parent study and to have a balanced sample with respect to education level [18].

Content analysis, an established qualitative methodology for analyzing qualitative data collected directly from study participants [18], was used. Analysis of the verbatim transcripts was conducted in several phases as a part of the parent study. After a preliminary review of the transcripts, prognosis, diagnosis, and staging emerged as themes. The coding team was comprised of the four coauthors. The analysis presented here included identification of all discussions pertaining to diagnosis, staging, or prognosis, which were charted as direct quotes in a data matrix. After repeated readings of the transcripts to ensure all mentions of diagnosis, staging, or prognosis had been charted, the data were clustered by topic. These clusters of quotes were then used to populate three individual matrices, one each for diagnosis, staging, and prognosis. In cases where a patient's quote could be coded over multiple categories of diagnosis, staging, and prognosis, the quote was represented in

each of the matrices. The three matrices were analyzed separately and further reduced as topics and themes were identified. This study was designed to examine specifically themes surrounding prognosis.

To ensure reliability, the primary author (LC) met regularly with coinvestigators of the study to review data interpretation. Discussions were held to examine identified themes, differences in coding, and interpretations. Interpretations were largely concordant, and the use of coding matrices and such meetings addressed intra- and inter-rater reliability concerns. Analyses reported here are also highly concordant with analyses conducted separately by the study's coinvestigators and a coding team (unpublished data) as part of the parent study.

Results

Participants ($N=39$) included 23 (59.0 %) African-American, 15 (38.5 %) non-Hispanic White, and 1 (3.5 %) Native American cancer patients received treatment at the Massey Cancer Center, Richmond, VA. The mean age was 52.3 (SD 9.2) with 53.8 % female and 46.2 % male. Less than half (46.2 %) had completed education above high school, 35.9 % had a high school diploma or general education diploma (GED), and 17.9 % had less than a high school diploma. Forty-four percent of participants reported having income less than \$30,000 per year with 17.9 % having \$10,000 or less per year. Nearly half of the sample reported being either unemployed (28.2 %) or on disability (20.5 %) and 51.2 % had either Medicaid or the hospital's insurance available to low-income patients. Cancer types included breast (38.5 %), hematologic (28.2 %), colorectal (12.8 %), lung (10.3 %), and other cancer (10.3 %). Stages of cancer included I (15.4 %), II (20.5 %), III (28.2 %), IV (25.6 %), and unknown (10.3 %) (Table 1).

Despite a wide range of experiences, diagnoses, and stages, how participants discussed prognosis was the same across groups. No differences were seen with regard to education level, gender, and cancer diagnosis or cancer stage. This was a surprising result, as we expected that those with more extensive disease would have a more emotional or anxious response to prognostic information. Instead, we found that how participants discussed prognosis was a shared experience regardless of disease status. Results outline themes that emerged and use illustrative quotes that best represent these themes.

Understanding Prognosis

Participants in all groups discussed prognosis almost exclusively in terms of mortality and reported that their physicians and nurses mostly provided prognostic information in terms of months or years for survival. A participant shared his story of receiving his prognosis:

What she [nurse] did was after she told me that I had cancer...my wife said okay, what is the outcome of all of this? What she said was on average 3 to 5 years [survival]. That's a little bit—to give an average just it didn't cut it with me. I've never been average.

Eight participants discussed their prognosis in terms of a "rate" and used several terms. For example, one participant shared the following, "That is what they told me; my survival rate

was better if I removed the cancer first and then start treating it.” However, another participant used the term “percentage rate” during a discussion of treatment success saying, “My percent rate was very small. I thought I was gone by March or April of last year to be honest with you. Percent rates catch you.” It was unclear if these rates were being understood as intended by physicians due to the ambiguous way participants spoke of rates. In context, it was frequently unclear if rates discussed were survival rates, treatment success rates, or prognostic information.

Only one participant was able to clearly explain the statistics that were provided to him. He knew his cancer was incurable and stated:

They were giving me a success rate there of 20 % of decreasing size and another 20 % of the size staying the same which was 40 %, which are pretty good odds compared to what I was looking at.

Another participant stated that he never received any prognostic information, “I don’t have a percentage rate. I just came in and they took care of it and I didn’t get that.” In response, another participant commented, “Neither did I.”

Only two participants seemed to indicate that they used prognostic information to make treatment and lifestyle choices. One participant took into account prognostic information and the impact of side effects when choosing treatment saying:

My lifestyle is very important to me because I live a certain way and I don’t want anything to change too much of my lifestyle... I changed chemo treatment because of the fact that it took too much of my lifestyle up. It kept me in bed, it kept me sick and that is not my person. I asked those kind of questions...because I want to be comfortable with the choice that I made and whatever came down the pipe with the choice I made, I needed to make sure that my body could handle that choice.

The other participant, knowing he had an incurable cancer and a poor prognosis, was mostly concerned with side effects and quality of life. His focus was on a peaceful end of life experience explaining:

No, I don’t want a whole lot of pain, and I don’t want to be lingering on for no long time. If I’ve got to go, I could go right now. You ain’t got to give me nothing to stretch this thing out. If I’ve got to suffer—I don’t want to suffer for 5 or 10 years. I’d rather go now.

Communicating Prognosis

The negative perception of prognosis as meaning limited life expectancy greatly impacted discussions regarding how or if this information should be presented to patients by physicians. This held true regardless of participants’ cancer stages. For example, when discussing provision of prognostic information by physicians, a participant stated, “I think that is wrong to put an expiration date on your life. Nobody has the right to put that expiration date on you.” Participants also indicated that by providing this information, physicians were not being compassionate and failed to be champions for their patients. The entire group agreed with the participant who said:

I feel like you got to fight, and also the doctor got to fight for you too. You don't need a doctor come in your room, hospital bed, and say, "Oh this is it. Ain't nothing I can do for you. You just going to die." You don't know that. You don't know if I'm going to die or not.

Participants consistently stated that physicians could not truly know a patient's potentially poor outcome and indicated that providing such information could be needlessly upsetting. A participant commented, "I don't think that's right. I don't think that's right for a doctor to tell you how many months you have. He doesn't know. I mean, he's guessing like everybody else. Nobody knows how long anybody got," to which another person in the group vocally agreed.

Several participants indicated that they believed that they were not given prognostic information by their physicians intentionally. They seemed to believe that by withholding the severity of their condition, their physicians were keeping them from giving in to the disease. One participant believed he was not told of his prognosis because, "if they would have told me too much at first I would have given up. You know, realizing how sick I was going to get, and all this stuff. I probably would have gave up you know right at the start."

These conversations led four participants to indicate that they thought physicians should provide prognostic information gradually to patients and other participants agreed.

Exceeding Prognosis

Participants demonstrated a certain pride when noting that they had outlived their initial prognosis. One participant shared, "Mine was supposed to be done... She said she's never heard of anybody surviving it for more than a year. And that's been 3 years for me."

Only one participant indicated that he was provided with updated prognostic information from his physicians following treatments, scans, or exams. He discussed how getting a new treatment changed his prognosis stating, "The percent rate was not good for me. What changed my percentage rate was the treatment I got which was something that was pretty much new."

Attitude Impacts Prognosis

Participants put an emphasis on their personal roles with regard to their prognoses. Ten participants made statements regarding their beliefs that their own personal attitudes, strength, and stamina to fight cancer carried great weight in determining the outcome of their disease. These comments were met with agreement from the other participants in their groups with the exception of one participant, who did not seem to believe that individual will would affect outcomes stating:

I can look at the statistics and see for myself what the success rate is and stuff like that, so if 90-something percent of the people die with this, what would make me think that I'm going to be the miracle?

One participant seemed to take an inordinate amount of responsibility for the outcome of his cancer stating, "You [cancer center and physicians] can only do so much. As an individual

you have to fight. It is your fight. You can tell me how to fight but I have to be the one to fight.” Another participant read many books and did his own research regarding cancer and his own prognosis and shared with the group that, “...the main thing is something, one thing I learned is if you want to live that’s a big factor in if you’re going to make it or not.”

Discussion

Information surrounding the prognosis of cancer is complex. Health-care providers intend this information to be used by patients to make informed treatment decisions, set realistic goals, experience higher quality of life, and assist with planning. However, participant discussions of prognosis in this study indicated that it was not being understood or used as intended by health-care providers. Participants were confident in their understanding even when misusing terms to explain their prognosis, and prognostic information was primarily discussed in terms of mortality. With such a pervasive negative connotation, it is difficult to interpret participants’ thoughts on a comprehensive definition of prognosis. Study participants did not appear to see and share any positive reasons for receiving prognostic information.

Although we understand that patients can have positive prognoses, physicians primarily discuss it when the prognosis is poor and it is frequently coupled with end of life discussions. Gordon and Daugherty found that oncologists reported disclosing prognostic information when (a) treatment decisions needed to be made, (b) therapy fails, (c) patients are sick or in pain, and (d) transitioning patients into a palliative care program [19]. Except for patients who actively seek the information, prognostic information often is disclosed when disease progresses or a patient declines, as opposed to explaining it in the context of treatment decision making. It is therefore not surprising that patients are troubled by the notion of prognostic information and are resistant to discussing it. This negative connotation may lead to further delays in discussions of prognosis and may be a barrier to understanding it for patients.

Only two participants reported using prognostic information as guidelines to inform decisions. The remainder perceived that prognosis only predicts the end of their lives, which they felt took away hope. It is possible that the timing of prognostic information discussions could be feeding this perception. If prognostic information has not been presented to patients previously, a first introduction to the concept during a decline may contribute to the notion that prognosis only is related to imminent death. Patients may feel more comfortable with the notion of prognostic information if it is shared as an ongoing process of keeping them informed through the entire diagnosis and treatment process. This study adds to the literature that encourages health-care providers to ask patients what information they would like and, importantly, to keep checking with patients to make sure the information is still desired and understood as intended [16, 17]. In one study, 35.9 % of cancer patients who wanted quantitative prognostic information did not ask for it [13]. Of those who wanted qualitative prognostic information, 14.5 % did not ask for it. Waiting for patients to request prognostic information can leave many without the information they desire when they need it.

Physicians may need to explain the concept of prognosis in order to have productive discussions with patients about individual prognoses. Patients will tend to frame prognostic information in terms of time before death, which may make them too emotionally overwhelmed to use this information or even be willing to hear it. The teach-back method has been proven to be effective in assessing how well health-care providers explain a concept in a way that does not shame or embarrass patients [20, 21]. The teach-back method puts the burden of clear communication on the physician instead of expecting patients to speak up when they are unsure or confused. This method should be used with all patients, not just those who appear confused to the health-care provider [21]. Patients may confidently state that they understand the information being presented, but it is not always clear if it is being understood as intended [22]. Utilizing the teach-back method can also bring to the surface some misconceptions patients may have about what personal factors impact their disease progression or prognosis.

Furthermore, the ease with which patients can use medical terminology should be something physicians and health-care workers keep in mind, as it may mask underlying confusion regarding their prognosis [22]. Physicians should likely anticipate needing to repeat information over time, as the cancer diagnosis and treatment process is emotionally and physically taxing for patients [23]. Using the teach-back method can assist with this by creating opportunities to confirm patient understanding before moving on or adding additional information [20, 21].

Participants in this study also discussed prognosis as though it was a reflection on their spirits or individual strengths. Health-care providers should be sensitive to the fact that not only are they potentially discussing end of life concerns when explaining prognostic information but also the patient may feel that they are discussing their character and sense of self. This framing of prognosis makes it clear why outliving an initial prognostic estimate was seen as a point of pride for participants. By exceeding expectations, they felt they were stronger than initially perceived.

The inherent emotional impact of these discussions may mediate a patient's ability to understand the information and use it to make informed decisions. By addressing the emotional and social impact of prognostic information, health-care providers can remove a potentially large barrier to decision making and planning.

This study has several limitations. First, although the focus groups were well attended, the sample size is small. However, saturation was met by the third group, and three more groups were conducted to ensure that all relevant themes were captured for the parent study, thereby ensuring that the data collected from the groups is likely representative of a broader patient population. Second, participants were recruited from a designated cancer center clinic, where primarily low-income individuals receive healthcare, which may limit generalizability. Third, all information collected was self-report, and data were not collected from the participants' physicians regarding prognostic information they had shared with their patients or on the patients' actual prognoses. This study was exploratory in nature and its goal was to examine how patients discuss prognosis. Future studies are needed to assess concordance between patient understanding and physician communication and examining

the timing and frequency of prognostic discussions. However, perceptions and experiences described by the participants in this study are how they view prognosis regardless of actual information they may have received.

Cancer patients are involved in treatment decisions and require information on prognosis to make informed decisions. Patients desire information but are often apprehensive about receiving prognostic information, need assistance in understanding the complicated details, and contextualizing the information provided to them. Patients tend to think of prognosis information as being only estimated limited survival and find the idea upsetting. Due to this view on prognosis, patients need further explanation regarding where prognosis information comes from and what prognostic information can tell them in order to make use of it. With past research showing that patients frequently misunderstand their prognosis, further work should be done to address the communication barriers regarding prognosis [22, 24]. Additional research is needed to identify how to convey prognostic information in ways that support patients and makes the information accessible and useable. Simplifying prognostic information, training health-care providers in conveying the information, and using the teach-back method in prognostic discussions could help patients process this complex and potentially emotional information.

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Table 1

Sociodemographic characteristics

<i>N=39</i>	<i>N (%)</i>
Gender	
Male	18 (46.2)
Female	21 (53.8)
Race/ethnicity	
African-American	23 (59.0)
White	15 (38.5)
Native American	1 (2.5)
Cancer type	
Breast	15 (38.5)
Hematologic	11 (28.2)
Colorectal	5 (12.7)
Lung	4 (10.3)
Other	4 (10.3)
Cancer stage	
Stage I	6 (15.4)
Stage II	8 (20.5)
Stage III	11 (28.2)
Stage IV	10 (25.6)
Unknown	4 (10.3)
Employment status	
Full-time paid	5 (12.8)
Part-time paid	2 (5.1)
On disability	8 (20.5)
Retired	3 (7.7)
Not working	11 (28.2)
Unknown/missing	10 (25.6)
Insurance	
Private	7 (17.9)
Medicaid	10 (25.6)
Medicare	10 (25.6)
Hospital provided insurance	10 (25.6)
Unknown	2 (5.1)
Marital status	
Married	14 (35.9)
Not married	25 (64.1)
Education level	
<High school/GED	7 (17.9)
HS degree/GED	14 (35.9)
Some college/college degree	15 (38.4)

<i>N</i> =39	<i>N</i> (%)
Post-graduate degree	3 (7.7)
Income	
Mean	33,506.75
Median	17,500
Mode	12,000
Minimum	\$0
Maximum	\$200,000
	Mean (range)
Age	52.3 (35–73)