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Citation

Goldman, Roberta E., Amy Sullivan, Anthony L. Back, Stewart C. Alexander, Robin K. Matsuyama, and Stephanie J. Lee. 2009. "Patients' Reflections on Communication in the Second-Opinion Hematology–oncology Consultation." Patient Education and Counseling 76 (1) (July): 44–50. doi:10.1016/j.pec.2008.11.016.

Published Version

doi:10.1016/j.pec.2008.11.016

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Patient Educ Couns. Author manuscript; available in PMC 2010 July 1.

Published in final edited form as:

Patient Educ Couns. 2009 July ; 76(1): 44–50. doi:10.1016/j.pec.2008.11.016.

Patients' Reflections on Communication in the Second-Opinion Hematology-Oncology Consultation

Roberta E. Goldman,

Warren Alpert Medical School of Brown University, Department of Family Medicine, Providence, RI; and Harvard School of Public Health, Department of Society, Human Behavior and Health, Boston, MA, USA

Amy Sullivan,

Virginia Commonwealth University, Department of Social and Behavioral Health, Richmond, VA, USA

Anthony L. Back,

University of Washington, Department of Medicine, Seattle, WA, USA

Stewart C. Alexander,

Duke University Center for Palliative Care, Department of Medicine, Durham, NC, USA; and Durham VA Medical Centers, Durham, NC, USA

Robin K. Matsuyama, and

Virginia Commonwealth University, Department of Social and Behavioral Health, Richmond, VA, USA

Stephanie J. Lee

Fred Hutchinson Cancer Research Center, Division of Clinical Research, Seattle, WA, USA

Abstract

OBJECTIVE—The nature of communication between patients and their second-opinion hematology consultants may be very different in these one-time consultations than for those that are within long-term relationships. This study explored patients' perceptions of their second-opinion hematology oncology consultation to investigate physician-patient communication in malignant disease at a critical juncture in cancer patients' care and decision-making.

METHODS—In-depth telephone interviews with a subset of 20 patients from a larger study, following their subspecialty hematology consultations.

RESULTS—Most patients wanted to contribute to the consultation agenda, but were unable to do so. Patients sought expert and honest advice delivered with empathy, though most did not expect the consultant to directly address their emotions. They wanted the physician to apply his/her knowledge to the specifics of their individual cases, and were disappointed and distrustful when physicians cited only general prognostic statistics. In contrast, physicians' consideration of the unique elements of patients' cases, and demonstrations of empathy and respect made patients' feel positively about the encounter, regardless of the prognosis.

Corresponding author contact information: Roberta E. Goldman, PhD, Memorial Hospital of Rhode Island, Center for Primary Care and Prevention, 111 Brewster Street, Pawtucket, RI 02860, USA, Tel: 401-729-2924, Fax: 401-729-2494, roberta_goldman@mhri.org and roberta_goldman@dfci.harvard.edu.

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CONCLUSIONS—Patients provided concrete recommendations for physician and patient behaviors to enhance the consultation.

PRACTICE IMPLICATIONS—Consideration of these recommendations may result in more effective communication and increased patient satisfaction with medical visits.

Keywords

physician-patient cancer communication; oncology consultations; qualitative research; focus groups; patients' recommendations to patients; patients' recommendations to physicians

1. Introduction

Hematologic malignancies account for 9% of new cancer diagnoses annually in the United States.[1] The percentage of patients who seek hematology consultations for second opinions is unknown, but such encounters are common at tertiary care institutions. The quantity and content of what patients seek from their consultations change over time, even within the first few visits,[2–4] and communication may be very different for one-time consultations than for long-term patient-oncologist relationships.[5] When patients' desired levels of information have been met during a consultation, they are more satisfied and less distressed.[6] Gauging how much, and, possibly more importantly, *what kind* of information a patient is seeking during the visit is essential, though challenging to physicians who must consider multiple factors in their assessments, including patients' verbal and nonverbal behaviors, and demographic, contextual, and medical factors.[7–10] Asking patients to contribute to the visit agenda is a logical place to start,[11] though cancer consultation visits have been found to be predominantly physician-dominated.[3,7] Physicians have been found to have difficulty accurately assessing patients' anxiety, [12–14] and oncologists may be more reluctant to respond to patients' emotional cues than patients' information requests.[15,16]

Patient-centeredness is essential to quality cancer care, and employing communication styles that actively engage patients in their care is an increasingly recognized core clinical skill.[11, 17,18] A study in primary care settings emphasized that individual patient characteristics contribute greatly to patients' expectations for the visit and their assessment of patientcenteredness.[19] And studies of chronic disease care have shown that when parents' worries about their children's asthma are relieved and their concerns attended to, parents are more likely to feel that physicians listened to them and were interactive during the encounter.[20, 21] In contract to primary or chronic care, however, second-opinion hematology consultation visits may be the only time the cancer patient and the consulting physician meet, despite the profound nature of the discussions. Accurately assessing patient characteristics or providing relief from worries may present increased challenges. This creates a complex medical encounter where the physicians' need to convey expertise and provide information may eclipse patient-centered communication and the specific pressing needs of patients and their support people, though this may remain unacknowledged in the encounter.[11, 22] The second-opinion consultation therefore offers the opportunity to study physician-patient communication in malignant disease at a critical juncture in cancer patients' care and decision-making.

As part of a larger observational study of physician-patient communication in hematology consultations, a medical anthropologist (REG) conducted in-depth, qualitative interviews with a subset of the patients seeing hematology consultants. This paper reports the results of those interviews to elucidate the patient experience of communication involved in the second-opinion hematology consultation.

2. Methods

2.1 Data collection

Between January 2004 and November 2006, the lead author (REG), an anthropologist with extensive qualitative research experience, conducted in-depth qualitative interviews with 20 patients who had hematologic malignancies. Interviews were conducted by telephone two to four weeks following their subspecialty consultations at one of three tertiary care centers. Audio-taped telephone interviewing was chosen because patients were drawn from all over the United States.

The purposive sample for these in-depth qualitative interviews was selected from our larger study population by consideration of race, sex and estimated prognosis. The parent study entailed audio-taping patients' second-opinion hematology consultations, and administering a baseline survey and brief pre- and post-consultation interviews. Only the 20 patients selected for the subsample reported on in this paper received the additional in-depth interview.

In preparation for the two-hour, in-depth interview, the interviewer reviewed the brief pre- and post-consultation interview data that had been collected as part of the patient's participation in the parent study, listened to the consultation audio-tape, and read the consultation transcript. She identified content themes from each of these 20 consultations, including patients' and support people's questions and concerns; physicians' approaches and communication styles; social contextual factors; and topics raised by each party. This enabled the interviewer to supplement the core list of open-ended questions on the in-depth interview question guide with questions specific to each patient's previously-stated perspectives on his/her disease and treatment, and the actual consultation visit dialog. At the interviewer's discretion or the participant's request, the interviewer read sections of the consultation transcript aloud and the patient explained what he/she had been thinking during that portion of the consultation.

The study was approved by the institutional review boards of all participating hospitals. Patients signed written consents at entry into the parent study, and verbally confirmed their consent to participate in this additional in-depth interview for which they received \$50.

2.2 Data Analysis

Standard anthropological methods for qualitative data analysis were used, including the collaborative group analytic method of immersion/crystallization.[23] This entailed periodic meetings of authors for lengthy discussions of the consultations and the interview transcripts. In preparation for each analysis meeting, the authors individually listened to the consultation audio-tapes and/or read the consultation transcripts, and then read the qualitative interview transcripts to start the process of identifying emerging themes. As the in-depth interviews were tightly focused on all aspects of the patients' consultation visits, it was essential for the authors to become familiar with the content and verbal dynamics of the consultations prior to reading the texts of the in-depth interviews. This system aided the authors in more comprehensively understanding what the patients were referring to during their interviews. We then held periodic meetings of all of the authors for lengthy, joint discussions of the consultation and interview texts, to compare our individual analyses, explore alternate interpretations, and come to agreement upon a final interpretation of the data from the in-depth interview transcripts. Subsequently, we developed and tested a codebook for use with Weft ODA, an open-source qualitative data coding software package.[24] Two authors (REG and SJL) then subjected the in-depth interview texts to line-by-line coding, staying in communication throughout this process to modify the codebook as new codes emerged. The code reports were used to facilitate further analysis discussions, develop links between themes, finalize data interpretation, and identify supporting quotations. This paper reports our findings from the in-depth interviews,

the interpretations of which were informed by the transcripts from patients' consultation tapes. Analysis of the consultation tapes from the entire parent study will be reported elsewhere.

3. Results

Participants' demographic characteristics are shown in Table 1.

3.1 Desire for personalized treatment advice

Patients primarily sought information about treatment options. Many planned to return to the care of their local oncologists and had come to the consultation to have their diagnosis and treatment plan confirmed, modified, and/or to find out if there were new treatments to be considered. Most patients had expected the consultant to apply his/her expertise to their individual situations to arrive at tailored treatment recommendations and prognosis estimates based on their unique characteristics. They were highly disappointed when they received only statistics gleaned from published studies. Patients felt that personalized advice indicated the highest level of expertise as well as the greatest respect and empathy for their individual situations.

"So if the answer is 'well in your case, because you're thirty' ... you're definitely going to listen a little bit harder based on stats. And then getting into 'what would you do if it was your son?' I think those are both really, really effective ways of communicating. It just kind of takes the whole white-coat phenomenon out of it, where you're just trying to find out that he's talking to you in your best interest."

"Well I expected to walk in and have him say, 'Hey, I've reviewed your file, your history, and here's what we can do for you.' You know, 'based upon your file,' not just like an average of everybody and their mother."

The desire for personalized advice was particularly acute when the prognosis was not certain and when aggressive treatment was being considered.

3.2 Patient input into the consultation agenda

Regardless of what patients' expectations were for the consultation, only one particularly medically-sophisticated patient articulated her goals to the physician. No physicians asked patients what they were hoping to get from the consult, though some physicians announced their agendas at the outset and asked patients for their approval. All patients agreed to their physicians' stated plans, even if they would have preferred to focus the agenda differently. In the interview, participants noted that in the future they would be more assertive about their agenda.

"From now on I will go in armed. I will be very clear about what each of us thinks this consultation is about. What is your agenda? Now let me tell you mine."

"I think it's really important for the patient to formulate the purpose of the evaluation...and Dr. Smith should know the reason. And if Dr. Smith says, 'Gee, I can't do that,' then the consult shouldn't happen or there should be some sort of negotiation so at least there isn't a big disappointment."

3.3 Patient reactions to the physician's communication style

Most physicians began the consult with informal inquiries or comments (e.g., about the patient's trip to the hospital, a mutual interest in a sport). Patients did not have strong opinions about the content of what the doctor talked about, but noted the tone the physician set upon entering, and maintained throughout. Patients reacted positively when they felt that physicians

respected and cared about them, tried to interact at their level of understanding, spent a lot of time with them, or apologized for being late.

"She was not somebody who came in and looks at you as though you're ready for the casket. I mean she was somebody who was putting out information. And she was cheerful and alert and kind, and she just exuded a whole lot of confidence."

"The best doctor is one that is able to pick out what kind of patient they're talking to and talk to them where they are."

"I liked him a lot. He was just very personable. Even though he didn't get into the big emotional things that go along with this. I thought he was straightforward and kind and I just liked his whole demeanor. His face, his whole body, you know, carriage. He seemed like a sympathetic, nice man."

Patients reacted negatively when a physician appeared dismissive of their concerns, was not personable, had not reviewed their records prior to the consultation, or ignored factors that they felt were important to their unique cases. One patient asked the physician at the end of the consult how long he had been in practice because she "was trying to figure out why he's detached....Maybe they have to do that for protection. He's more scientific than he is warm and fuzzy."

"I just got the impression that they glanced at my folder. That kind of sets a tone - set my teeth on edge. My first thought was 'No one has read anything about me. They might have glanced at my information, but no one has done any paying attention to me.""

Patients had varied criteria for their assessments of physicians' communication styles. Some liked when the physician wrote on the whiteboard or on paper, while others felt that this made it more "like a lecture" and amounted to an impersonal distancing strategy. During the majority of consultations physicians engaged in extended monologues detailing the general history of the disease and treatment modalities, including disease sub-types and treatments that were not relevant to the patient in the room. No patient asked the physician to reduce the amount of detail on these subjects, and few claimed in the interview that they were annoyed by these monologues. Many stated that even though they were not able to understand or remember everything, the physician's behavior was appropriate either because it helped establish the physician's credentials, or it allowed the patient and support people to hear a comprehensive review of the disease and treatment.

"He's very professional, and he expected the same thing from his patient. He tended to want them to rise to his level. The information that I got [previously] was so partial, so having someone explain the whole thing to me was a big relief and a real light bulb going on in the process."

Patient: He covered a very broad base that day. Gave me a much better understanding of my disease, about how we were going to handle it. He went through the various treatment options -- and those I did take good notes on -- and told me the ones that simply didn't work.

Interviewer: Did that make sense to go through the treatment options that wouldn't work for you?

Patient: Yes, yes, because you read about them. And you need someone to take you through them and say, 'it's not going to work for you because...'"

Despite approving of the physicians' comprehensive, historical monologues, patients were ultimately dissatisfied if the history and statistics were not complemented by application of this knowledge to the specifics of their cases.

3.4 Trust in the physician

Trust in the physician was initially established based on information from other patients/family members/friends/local oncologists, or the national reputation of the physician or hospital. Many patients noted the role of good rapport in enhancing their trust. Trust was heightened when patients perceived the physician to have demonstrated his/her expertise through a detailed discussion of the disease and treatment options, a straightforward style, and good communication with their local physicians. Patients were reassured when the consultant acknowledged the expertise of their local hospital and recommended that part or all of the treatment could be obtained there.

Trust eroded when patients perceived physicians as relying on generic statistics rather than addressing their individual cases, when it appeared that they were trying to "sell" their institution to the patient for treatment or a clinical trial, or when they contradicted a trusted local doctor.

"I mean my words might have been 'Oh okay', but I'm thinking, '*Amway Amway'* -- they always try to sell you something."

[The doctor's] just too close to the statistics and not close enough to the humanness. ...I was just potentially another recruit, a number, a statistic. I was potentially another source of revenue. And that's infuriating."

"He's like, 'No, I'm just gonna call him and tell him to give you the full dose.' And I'm thinking, 'He ain't gonna tell my doctor nothin'. He's my doctor, you know.' So I'm kinda having a war of the people on my head the whole time -- I'm like I can't believe he's saying 'no no no' to my doctor."

3.5 Emotional support from physicians

While some patients stated that they did not care whether their consulting physician provided emotional support or not, most patients did feel strongly about the topic. Some had been looking for support from the physician, and specifically noted in the interview that the physician did or did not pick up cues about their emotional needs. Those who felt they received emotional support, however minimal it might have been, expressed satisfaction; those who felt that the physician ignored their emotional cues were highly disappointed. This was illustrated by a patient who felt that the consultation itself was a damaging experience that could affect the course of her disease; she explained how she reacted in the consultation room:

"I am generally a person who's very articulate, I'm an RN, but as an individual with a diagnosis, I walked into that session open and vulnerable. None of that was acknowledged and it's like I got to the beach, laid down my towel and as I was straightening it out in the sand, I got hit by a tsunami and I could never emotionally recover until he left the room. I looked at my friend and I cried."

More of the patients felt that providing explicit emotional support was not part of the consulting physician's role. That role, they believed, should be reserved for their primary oncologist who knows them better and in most cases would continue to see them through their treatment. And some patients went as far as expressing fear that providing emotional support would interfere with the physician's ability to address medical aspects of their cases.

"The best doctors in my experience are the ones who are so focused on their craft that they probably don't spend as much time handholding.... Yes it would be nice, but is it a requirement in hiring a doctor? No. But communicating fully and honestly is."

"I wanted to get the most information from the doctor because that's the strength of the doctors, they can give you the information, a better idea of the prognosis, a better

In a similar vein as emotional support, patients had opinions about whether their consultant viewed them as a whole person who needed to strategize how to live with the disease, prognosis, and treatment. Patients were pleased when the discussion included how the disease will affect the totality of their life. Most, however, stated that the physician did not do this well, though they also had not expected the consulting physician to address more than the specifics of the disease, treatment, and prognosis.

"I went for him to tell me how we were going to fix the broken mechanism of my body. And that was really what I was expecting of him, and that was what he delivered."

3.6 Preference for full disclosure, delivered with empathy

A strong theme that arose among the participating patients' stories of their consultation experiences was the distinction between a physician's explicit provision of emotional support, and the more implicit expression of empathy that could pervade the tone and phrasing of the physician's discussion of the patient's medical case. In the latter instance, patients described physicians who did not specifically address their emotional status, however the physicians talked to them about their disease in a caring, empathic manner. Many acknowledged that not all physicians are capable of engaging in this kind of communication, and some doubted that empathic communication could be adequately learned if it did not come naturally to the individual. Despite that most patients did not expect to have their emotional state addressed, many indicated that their ideal physician would indeed provide a full and honest assessment of their condition, while employing empathy to acknowledge them as individual human beings -- not just diagnoses.

"I didn't want no false hope or pretenses into this whole thing. I'd rather have someone that's going to be straight with me, tell me the truth and lay it out and say 'This is what I think we should do and what are your feelings about this?"

"I just wanted to be told the truth and not too bluntly, but the truth nonetheless. So that I could make a decision myself, be able to accept it, decide what I was going to do about it."

"Just kind of have a little empathy there. Like look them in the eyes. Sometimes you don't need to touch anybody but you could always just kind of sigh or something like, 'Look, I understand, but we're gonna work through this.' That's what I needed and I just felt like: 'Okay, hey, here's the facts.'"

While patients insisted that they did not want to hear falsehoods about their condition, some also noted the importance of getting information or comments from physicians that would help them to maintain hope.

"I think it's always good to plant hope into people when you're treating them because you never know which way it's going to go.... Your illness, it may not be something you can control, but what you can control is how you feel about it."

"The numbers are pretty damn low of being a success. On the other hand, both of them had said 'We think you have a chance of being on the winning side of the odds.' And when two doctors tell you that, that's got to make you feel better, and it did make me feel better."

Except for the patients who had wanted the physician to directly address their emotional needs, patients had a variety of ready explanations for why their physicians appeared to lack empathy.

Many reasoned that their consulting physicians' priority had to be to use the time allotted to impart their medical expertise. Other patients endeavored to understand what a physician would have to do to protect his/her psyche while speaking with seriously ill cancer patients all day long, day in and day out.

"You're either breathing or you're not. That's where their focus is. How you're breathing and how you're living doesn't seem to factor much in. They probably just can't deal with those kinds of things...they have so many people they're dealing with who have these kinds of illnesses, they can't go into that much detail if they themselves want to stay sane. And professionally, it's probably just not having enough time."

"He [talked about prognosis] in a business-like fashion. 'I've seen people recover and I've seen people die and these are the odds.' And it was like any other piece of information and I think that's probably how he has to do it if he's going to keep doing it. If you ask a man like that to keep getting emotionally attached then you're probably going to break him eventually."

When the prognosis was not good, patients often commented that they needed to recognize this fact, but they did not want to hear too much about it. Whether the physician had spoken with empathy or not, patients approved of their having kept the discussion of prognosis to a minimum.

3.7 Patients' recommendations for improving consultations

After considering their own consultation experiences, interview participants recommended that other patients: communicate their agendas to their physicians; read about the disease and treatment options before the consultation; prepare psychologically; bring someone to listen carefully and ask questions; bring paper and pen; and prior to the consultation personally ensure that all medical records have arrived at the consulting office. While most patients felt that they could ask questions, in many cases their unasked questions were answered naturally during the course of the consultation. Nevertheless, patients felt that preparing questions in advance was beneficial. Patients did not include in their recommendations that people audio-tape their consultations. Although some participants in the study had done this, none had listened to the tapes after the visit, nor had any of their support people.

Patients had a variety of logistical recommendations for physicians: review patient records beforehand; inquire about the patient's goals for the consultation; speak honestly and directly ("don't sugar-coat"); speak slowly enough; provide personally-meaningful information that specifically relates to the patient's situation; provide written information on the risks and benefits of treatment options; and show empathy through tone of voice and by checking with patients about how they are receiving and feeling about the information.

Some patients described not having been ready to hear particular details about their condition at the time of the consultation, but because of how their disease and diagnosis processes proceeded, they became ready for those details at a later time. These patients suggested that physicians make an effort to find out what and how much patients want to hear at the consultation to avoid overwhelming them, and provide a means for them to ask further questions later on.

4. Discussion and Conclusion

4.1 Discussion

Patients varied about whether they were primarily looking for the consulting physician to provide more information about their disease and potential treatment options, to confirm their cancer diagnosis and treatment plan, or to outline a new treatment. A point of confluence among

patients, as has been found elsewhere, [25] was their desire to seek expert advice, and most importantly, have the consulting physician apply his/her knowledge and experience to the specifics of their individual cases. When physicians appeared unable or unwilling to tailor their prognostic comments to the patients' unique characteristics, patients were uniformly disappointed. This reliance on generalized statistics can serve to erode the physician-patient relationship and reduce patients' sense of the statistics' personal relevance. [26,27] While most patients deemed the physician's communication style as acceptable for an initial visit, [3] and our patients had explanations for multiple aspects of their physicians' behaviors, patients offered no excuses for physicians' failure to provide personalized, individualized prognostic and treatment information.

Physicians serving as second-opinion consultants may seek to mitigate the tension posed by discussing emotionally-laden issues and presenting or confirming bad news for a patient with whom they have no previous relationship and may not see again. In the second-opinion hematology consultation it may therefore be more difficult--or seem to be less necessary--to convey empathy, and more critical to establish medical expertise. However, our results and those of other studies show that both are important to patients, along with a means to preserve hope [5,12,28–32] without unduly emphasizing the positive. [25,33–35] Most patients in our sample did not expect their consulting physicians to address their emotional concerns, but like participants in other studies,[31,32] they did expect physicians to demonstrate empathy while discussing treatment options and prognosis. In some cases patients felt that the nature of physicians' communication with them could directly affect them physically due to how it affected them emotionally.[36] Some believed that empathy cannot be taught, although recent research indicates that oncologists' communication skills may be improved through training. [29,37-40] An interesting finding from previous studies confirms the complex nature of physician-patient communication in that physicians' ostensibly facilitating behaviors, like asking direct questions, can work to both enhance or inhibit patients' verbal participation, particularly in regard to patients' expressions of concerns.[41,42] And a study in Holland found that physicians' inhibiting behaviors may not always serve to inhibit patient participation in specialist care.[41]

Limitations of the study include the small number of participants and non-random sample. However, as is appropriate for qualitative research design, the purposive stratified sample ensured inclusion of individuals with the range of characteristics relevant to this study. The extended length of each interview, and the interviewer's ability to refer back to the consultation tape and survey data allowed us to explore in depth participants' experiences with and perspectives on their consultations.

Most patients in this study assessed their physicians' communication styles as adequate overall despite having had specific points of critique. However, recall of the details of their cases was an issue, with many admitting in the interview that they were confused during or after the visit. Research has found that cancer patients who were sent a letter by their consulting physician did not recall more details of the clinical encounter, though patients highly appreciated receiving the letter.[43] It is unclear whether audio-taping consultations is beneficial; our participants who tape-recorded their consultation did not make use of the tape after the visit. In another study, patients who were provided with audio-recordings of their consultation felt they had been given more information, though it did not affect their satisfaction with the visit. [44]

4.2 Conclusion

Participants' advice for other patients focused on the importance of patients setting the agenda for the consultation. This is notable since only one of our participants had done this; the others simply went with the flow that the physician established, which was largely physician

dominated.[3] Some studies have found that patients want as much information about their condition as possible, [45,46] while other research shows that the physician's ability to gage the quantity of information desired by each patient is essential to patient satisfaction.[7,9] Many in our study were given information they were not ready to hear, while others did not receive information they were looking for. Participants had numerous recommendations, including that patients research their disease and prepare questions, which are actions that they themselves had taken. While most had their questions answered, this often occurred through the natural course of the long consultation, and not because the patients manage their communication with physicians,[47–49] but this strategy ignores the physicians' contribution to the course of the visit [22,50] and the impact of physician dominance on the encounter. [51] Patients' recommendations for consulting physicians focused on issues of patient-centered care, including the need to empathically provide individually-meaningful prognosis information rather than generalized statistics.

4.3 Practice Implications

Our results support other research showing that small signs during the consultation that the physician cares about and respects the patient make them feel positive about the encounter, regardless of the outcome.[29] Even those of our participants whose first concern was to get the best information from the most expert consultant noted that it is desirable, though often not possible, to have the consultant employ an empathic manner. While our patients may not all have desired attention to emotional issues,[3] as other found, they did not want physicians who are emotionally negative.[28] Consulting physicians may serve their patients well by asking at the outset of the visit for the patient's specific agenda items and questions.[52,53] Concomitantly, to enhance patient activation, it may benefit patients if a provider from their primary care or oncology office helps prepare them in advance for the second-opinion consultation by reminding patients to inform the consultant of the agenda items they want addressed, and to bring a written list of questions with them to the visit. We found that our participants' agendas could have fallen within the purview of the consultants' typical roles, yet because patients were not asked about their agendas, their particular priorities were often not the focus of the consultation. This became exacerbated when physicians quoted general prognosis statistics, and did not appear to consider patients' individual characteristics. This paper has focused on a particular form of one-time consultation, finding that attention to patient priorities in this critical, second-opinion consultation may result in more effective communication, efficient use of the consultation time, and greater patient benefit from the consultation experience.[31] These findings, while highly acute due to the limited exposure patients have to a consulting physician, may have broader implications for physician-patient communication, as the assessments patients made of their hematology consultations could well apply to other specialty consultations and to routine primary care visits.[18]

Acknowledgments

The authors wish to thank all the patients who participated in this study. We are grateful to Arnold Gonzales, Tarrah Kirkpatrick, Kate Chilson and M. Shannon Hill who assisted with study management. Funding was provided by the Samuel Rosenthal Foundation, the Dunkin Donuts Rising Stars Program, and NIH grant CA98486.

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Table 1

Participant characteristics

N	20
Male, N (%)	8 (40%)
Median age, years (range)	50 (32–73)
Disease, n (%)	
Acute leukemia	6 (30%)
Chronic leukemia	3 (15%)
Multiple myeloma	6 (30%)
Lymphoma	2 (10%)
Myelodysplastic syndrome	2 (10%)
Aplastic anemia	1 (5%)
Race, n (%)	
White	12 (60%)
Black	5 (25%)
Asian	1 (5%)
American Indian	1 (5%)
Multiple races	1 (5%)
Education, n (%)	
Less than college	2 (10%)
Some college/college degree	12 (60%)
Postgraduate degree	6 (30%)
Median length of visit with hematology-oncology consultant, minutes (range)	69 (25–132)