

Providers' Perceptions of Communication Breakdowns in Cancer Care

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BACKGROUND: Communication breakdowns in cancer care are common and represent a failure in patient-centered care. While multiple studies have elicited patients' perspectives on these breakdowns, little is known about cancer care providers' attitudes regarding the causes and potential solutions.

OBJECTIVE: To examine providers' (1) perceptions of the nature and causes of communication breakdowns with patients in cancer care and (2) suggestions for managing and preventing breakdowns.

DESIGN: Qualitative study of nine focus groups held at three sites (Massachusetts, Georgia and Washington).

PARTICIPANTS: Fifty-nine providers: 33 % primary care physicians, 14 % oncologists, 36 % nurses, and 17 % nurse practitioners, physician assistants, and others.

APPROACH: Directed content analysis of focus group transcripts.

KEY RESULTS: Providers' perceptions of the causes of communication breakdowns fell into three categories: causes related to patients, providers, or healthcare systems. Providers perceived that patients sometimes struggle to understand cancer and health-related information, have unrealistic expectations, experience emotional and psychological distress that interferes with information exchange; and may be reticent to share their confusion or concerns. Providers described their own and colleagues' contributions to these breakdowns as sharing inaccurate, conflicting, or uncoordinated information. Providers also described the difficulty in balancing hope with reality in discussions of prognosis. System issues named by providers included insufficient time with patients, payment systems, and changing protocols that inhibit communication and coordination of care. Potential solutions included greater patient engagement, team coordination, and systems that promote patient feedback.

CONCLUSIONS: Providers described multiple causes for communication breakdowns at the patient, provider, and system level. Multi-level interventions that coordinate care and encourage feedback may help to address or prevent communication breakdowns.

KEY WORDS: patient-centered care; medical errors; care management; cancer.

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INTRODUCTION

Cancer care is frequently complex, intense, and prolonged, all of which can precipitate communication problems for patients and providers. When communication breaks down in cancer care, it can lead to lower quality medical care,^{1–6} poor clinical outcomes,^{5,7,8} increased litigation⁹ and damage to the patient–provider relationship.^{3,4}

Considerable research has explored cancer patients' perspectives concerning communication, documenting shortcomings during the diagnostic period,¹⁰ after adverse events,¹¹ in advanced cancer,^{12–14} and across the cancer continuum.^{15–17} Recent data also suggest that patients often do not share their concerns about problems in their cancer care with providers or healthcare institutions.^{4,18,19}

Very little is known about cancer care providers' attitudes regarding communication breakdowns. While physicians generally support shared decision-making,²⁰ they may misunderstand patients' health beliefs, desires for information and decision-making,^{15,20,21} and wishes about the delivery of diagnostic and prognostic information.^{22,23} The number of different providers involved in cancer care increases the need for coordination and the potential for miscommunications.²⁴

Understanding providers' attitudes about communication breakdowns in cancer care could reduce these problems. Therefore, we conducted focus groups with primary care physicians, oncologists, and nurses to assess their attitudes and experiences with communication breakdowns involving patients, their families, and other providers, and their suggestions for solutions.

METHODS

This study was conducted in the Cancer Communication Research Center (CCRC) of the HMO Cancer Research

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Network (CRN). These National Cancer Institute-funded projects involve a consortium of research organizations affiliated with integrated healthcare delivery systems, working to improve cancer care through population-based research. The focus of the CCRC is on discovering and disseminating promising practice-based approaches to cancer communication and care coordination.

A focus group guide was developed by the research team (available upon request), informed by findings from 78 in-depth interviews with patients who perceived that there were problems with their cancer care.²⁵ The focus groups explored: examples of communication challenges in cancer care, including those associated with adverse events, the role of patient expectations in communication, aspects of cancer care that make communication challenging, and recommendations for individual and systems-focused improvements.

Participants were recruited by email invitation at three healthcare organizations in Massachusetts, Georgia, and Washington. Eligible providers included primary care providers; medical, surgical, and radiation oncologists; oncology nurses; and clinical pharmacy specialists; all of whom were in clinical practice for at least one-third of their time and involved in the screening, treatment, diagnosis or survivorship of breast or colorectal cancer.

Each focus group was conducted by one of two experienced facilitators: TG, a primary care physician-researcher moderated seven groups, and KM, a researcher with expertise in patient-centered cancer care moderated two groups. Each group lasted 60–90 min and was audio recorded. Participants received a variety of incentives (0 - \$150), as allowed by the site's Institutional Review Board (IRB), and provided written informed consent.

Recordings were transcribed verbatim, removing identifying information, and were reviewed by five team members (CP, KM, SG, CF, BR). Codes were developed from the focus group questions and the transcripts using directed content analysis techniques.²⁶ Three team members (CF, CL, CP) coded the transcripts. Code definitions were modified and new codes added as needed. All transcripts were double-coded, after which all three coders met to discuss and resolve coding differences. Themes, subthemes, and exemplary quotes were identified.

The IRB of each site approved the study protocol.

RESULTS

Participants

We conducted nine focus groups (three per site) between January and August, 2010. A total of 59 cancer care providers participated, including primary care providers; surgical, medical, and radiation oncologists; nurse practitioners; physician assistants; clinical pharmacy specialists; and oncology nurses representing both the inpatient and ambulatory perspective (Table 1). The mean number of participants per group was 6.5 (s.d.=3.8, range 2–13). Four groups had a mixture of physician

and non-physician cancer providers, two groups were physician-only, and three groups were nurse-only.

1. Providers' General Attitudes about Communication Breakdowns in Cancer Care

Cancer care providers considered communication breakdowns to be common, and potentially present at every phase of cancer care, from the suspicion of illness through diagnosis, treatment, palliation, and end of life. Providers attributed the frequency of communication breakdowns to the complicated nature of cancer care, the emotional burden and steep learning curve for patients with a cancer diagnosis, the physical and logistical challenges of treatment, and the multiple providers involved in care. Providers considered communication breakdowns in cancer care to have complex causes, and highlighted the roles that patients, providers, and the healthcare system potentially play in these events. Below we describe providers' attitudes and experiences. Illustrative quotes are provided in the text, with additional examples in Text Box 1.

1.1. Communication Breakdowns Attributed to Patients

When asked to describe communication breakdowns in cancer care, providers focused first on patient characteristics that make communication challenging.

1.1.a. Patients' Lack of Understanding may Interfere with Information Exchange

Providers expressed concern that patients' limited understanding of cancer diagnosis and treatment

Table 1. Demographics of Focus Group Participants

Providers	N	Valid %
Total	59	100
Sex (female)	41	69.5
Hispanic or Latino?		
Yes	1	1.7
No	58	98.3
Race/ethnicity		
White	39	66.1
Black or African American	11	18.6
Asian	9	15.3
Provider type		
Internal Medicine, Family Practice	19	32.2
Oncologist	8	13.6
Other physicians (2 surgeons, radiologist, OB/Gyn)	4	6.8
Registered Nurse	21	35.6
Nurse practitioner/Physician Assistant	5	8.5
Other (clinical pharmacist, genetic counselor)	2	3.4
Average years since licensure	17.9 (s.d.=10.4)*	

*Missing data for six providers

Text Box 1 Communication breakdowns associated with Patients, Providers, and Systems

Communication breakdowns associated with Patients	
Patients' lack of understanding may interfere with information exchange	<i>I think people assume that if there is a screen for one, there's a screen for every one. So if they've had their PAP smear they can't have ovarian cancer, or they can't have bowel cancer, because they were just here...I don't think there's an understanding of the art of medicine as opposed to the science, or how limited our science is.</i>
	<i>Patients have an unrealistic expectation that they could walk in to a doctor's office and have answers instantly because the technology is just so advanced, we obviously know everything that's going on with them. And people don't appreciate that, no, it's not that easy to see inside of people.</i>
Patients may have unrealistic or different expectations for their care	<i>I think a lot of people come in with preconceived notions that they see on TV... for example, they can get their IMRT tomorrow. Or they can get their PET scan or CAT scan done in a very short period of time. And I think it's important to let them know that logistically, there are some things that we just can't do at the drop of a hat.</i>
Patients' emotional responses to cancer can interfere with information exchange	<i>By the time [they] leave the doctor's office, they just are so overwhelmed they just don't know, or questions come up later.</i>
	<i>A lot of it is also that you have this conflict of patients and families wanting to be hopeful, and sort of ala carte choosing what they want to hear and perceiving how they want to hear.</i>
Patients sometimes share inaccurate or inconsistent information with providers	<i>There's also a part on the patient that they don't want to tell the physician because of the impact they have on their care, on their treatment...They gloss over grade three and grade four toxicities if they have it in their mind that they want to get treatment. And like fatigue, if they don't tell us, there's no way to know...They're probably spending the entire week, they get their chemotherapy in bed, and then come to the doctor's office with their makeup on and there is nothing for us to tell.</i>
	<i>There's a tendency among a lot of patients not to bring up symptoms. I mean you don't hear if the patient is in pain or the patient is having trouble with constipation or diarrhea, very often you don't find out unless you specifically ask those questions during the visit...even though you'd think that these symptoms that are bothering the patient, that they would just come out and tell you that.</i>
Patients avoid alienating their providers	<i>They may think the doctor will hold it against them... I can imagine many scenarios where people are like, this doctor is really in control of my fate here and if I go in and complain and piss him off, then they may blow me off.</i>
	<i>A lot of times when there's miscommunication, the patient does not communicate that problem to the health care provider.... If they have cancer, they might feel like they need this doctor to continue the care and I'm sure they have no motive in endangering that relationship, so I'm sure they're not as honest or straightforward as they would like in terms of communicating how they perceive things.</i>

made it difficult for patients to know what questions to ask, reduced the likelihood of them

asking questions at all, and interfered with information exchange between patients and providers.

Communication breakdowns associated with Providers

Providers may deliver inaccurate, insufficient, or incomplete information	<i>[An] inaccurate prognosis or an unwillingness or a discomfort in even discussing prognosis is a problem. So I'm often in the position of, "Tell me what your oncologist has told you about your diagnosis," only to find out that they've never talked about that.</i>
Providers find it challenging to balance hope and reality	<i>...it's a lot easier and more obvious to choose being nice, even if it means saying something that's not quite true. And that's... where we get on this real slippery slope of set up for dissatisfaction.</i>
	<i>I think this is the heart and soul of oncology is preserving hope but giving reality. I mean that's where the rubber meets the road. And so I think a lot of it is poor communication from physicians not being really willing or comfortable themselves giving really bad news.</i>
Poor information exchange amongst providers	<i>Sometimes when they go back to their primary care physician, the primary care physician doesn't have the input from the oncologist that says, "These are types of issues that you should look for, because the patient had this type of chemotherapy."</i>
	<i>To have different visits at different times is actually, I think more confusing for patients because they hear different things from different people. Even if they're saying the same thing, they come out differently, the patient hears different things. So then the patient ends up being confused and angry.</i>
	<i>There's so many layers of people that you [the patient] can reach or contact that might not ... you might talk to the person who isn't going to give you the best answer right off the bat. And yet, the question is answered and you're done with it.</i>

Communication breakdowns associated with Systems

Insufficient time with patients	<i>You cannot tell a patient in a ten-minute visit that, "By the way, you've got cancer and such-and-such is going to happen." It just can't be done. There's no patient that is going to walk out satisfied from that kind of meeting.</i>
Lack of clarity about treatment protocols and responsibilities amongst providers	<i>The movement from outpatient to inpatient and back to outpatient, because there's so many changes in providers when we move patients into an inpatient setting that that is an area that is always prone to breakdown because the communications between the various providers and getting all the providers on the same page is a major issue.</i>

They may not be knowing that they can ask, or they feel like they asked and they didn't get the answer they wanted, or they didn't understand the answer..., so they didn't press further for clarification.

1.1b. **Patients May Have Unrealistic or Different Expectations for Their Care**

Breakdowns in information exchange and knowledge gaps were seen as leading patients

to develop unrealistic expectations about screening, diagnosis, treatment and prognosis.

One of the things that I experience a lot...is, "Why did it take so long for this to be diagnosed? Why aren't you fixing me?" And I often have the impression that somebody is looking for a magic wand.

The media, family, friends, and advertisements from cancer institutions were also named as contributing to those expectations.

Some providers believed that patients and providers have fundamentally different expectations about the scope of the clinical encounter: providers are often concerned with impending treatment choices, while patients may be concerned about larger life issues.

But sometimes when... you just give them the diagnosis outright, ...the physician is thinking they've told everything they had to, but the patient is thinking, 'Oh I really have so many other questions', because the patient is taking it in the whole perspective of their life...and how they have to deal with it. But the physician...is only talking about the treatment plan.

1.1c. ***Patients' Emotional Responses to Cancer Can Interfere with Information Exchange***

A common topic of discussion was providers' perception that patients' emotional responses to their cancer diagnosis and treatment—including grief, fear, discomfort, and feeling overwhelmed—make it difficult for patients to receive information and to voice questions.

The first time we reveal the prognosis, really they are just struck by the number. They don't know what to ask, and what kind of questions will come to mind. All they are thinking is, 'Oh I have this amount of time to live'. And they cannot really hear whatever follows that discussion.

Providers saw the interface between patients' emotions and effective information exchange as complex, and noted wide variation in needs for emotional support and information among patients as well as for individual patients over the course of their illness.

1.1d. ***Patients Sometimes Share Inaccurate or Insufficient Information with Providers***

Patients were described as sometimes sharing inaccurate or insufficient information with providers, especially neglecting to report treatment-related symptoms, forcing the provider to "ferret out" information. Patients were described as wanting to focus on the "bigger picture", and "putting on a brave face", or even "being in denial".

I think sometimes the patients don't want to be necessarily honest with you; they want you to guess that they have something. And sometimes unless you ask a specific question, they're not going to tell you.

One nurse described patients withholding information to ensure they received their cancer treatment.

"Why didn't you tell the physician all this?" "Well I was afraid that I wouldn't get my chemotherapy today. I didn't want the physician to know."

1.1e. ***Patients Avoid Alienating Their Providers***

Providers believed that many patients are acutely aware of how they are being perceived by their cancer treatment team, and want to avoid alienating their providers. Some patients were seen as "managing" their relationship with the person who they perceive holds their life in their hands, and even trying to "impress their doctors with how much they know, not wanting to be perceived as stupid". Some patients were felt to be uncomfortable talking directly to their providers, didn't want to bother anyone, or were afraid that the provider would get mad at them. Providers perceived that such actions by patients contribute to communication breakdowns.

Providers also thought that patients often hesitated to voice negative opinions about their care, especially if the patient thought something had gone wrong. "What we hear is the tip of the iceberg." Providers believed that these patients did not want to criticize their providers, be perceived as annoying, or risk a 'negative reaction' from their provider, out of concern for how it could affect their care.

It may be their perception that something went wrong, [yet] they may not really want to say that because they don't want to put themselves in a position to be treated any differently.

Another provider agreed that some clinicians respond negatively if patients are too vocal about perceived problems in their care:

You're much better off not being perceived as a complainer if you're trying to get some situation rectified.

2. Communication Breakdowns Attributed To Providers

Providers also described the roles they and their colleagues play in communication breakdowns (Text Box 1).

2.1. Providers May Deliver Inaccurate, Insufficient, or Incomplete Information

Focus group participants described breakdowns that occur when providers deliver inaccurate or incomplete information to patients, concerning diagnosis, surgical/pathology result discrepancies, treatment, and in particular, prognosis.

From what some patients say, they weren't told the clear extent of their scan results. They didn't know they had some issues or metastasis to the lungs, liver; that wasn't told to them... Or a patient thinking that this is going to cure them and it's not going to cure them.

2.2. Providers Find it Challenging to Balance Hope and Reality

Deciding which information to present to patients, and how to present it, is challenging for providers, as they seek to balance hope and reality with patients. A variety of approaches were described, from "stop being Mr. Nice Guy" to "being a beacon...trying to hold out hope for the patient".

And we really have to be willing, as a group of providers, nurses, doctors, PAs to stop the crap.... You don't have to be mean or harsh, but I think it's a real disservice to be completely wedded to only delivering nice news. That's not fair to that person, their family.

Some providers saw their colleagues as tending to be unduly optimistic, more likely to be "the nice guy" and "overly rosy", rather than "being ready to scramble the eggs".

Some patients are never ready to hear it, or willing to ask. And you don't want to say, "Well, 50% of people die in six months." You say something like

that, and then they say, "Oh you just took all my hope away." You're dealing with cancer and you need to have the hope. You're damned if you do; damned if you don't...

2.3. Poor Information Exchange Amongst Providers

Information exchange—or a lack thereof—between providers was also felt to contribute to communication breakdowns. Involvement of multiple providers with diverse perspectives was thought to result in patients getting different, sometimes conflicting, information.

You have instances where the surgeon is saying one thing and...the medical oncologist is telling them something completely different...You have this, well which is it? And they're left to kind of figure it out on their own.

Additional examples included communication breakdowns resulting from giving information to patients without sufficient consultation with colleagues, not preparing patients for future appointments or treatment plans involving other providers, differing professional roles (medical vs. surgical, in-patient vs. out-patient), or not letting the patient know the information in a "bigger picture way, which makes the second provider's job more difficult".

3. Communication Issues Attributed To Systems

Beyond patient-derived or provider-derived communication breakdowns, providers described issues related to the healthcare systems as a cause of communication breakdowns (Text Box 1).

3.1. Insufficient Time with Patients

Insufficient time with patients was named as a common source of communication breakdowns, particularly given the inherently complex conversations in cancer care, making it difficult for providers to address the patient's concerns.

You're on a gerbil wheel and in order to make your salary you've got to see so many people. And have you given them enough time to ask the questions? ... And sometimes you walk out saying, "Oh wish I had a little bit more time." But you don't. And unfortunately it isn't a matter of greed. It's a matter of, how am I going to get through the day?

3.2. *Lack of Clarity About Treatment Protocols and Responsibilities Amongst Providers*

Unclear or changing protocols for treatment and for movement of patients through different services (inpatient to outpatient, surgery to medicine) were named as sources of communication breakdowns. Additionally, some system-related communication issues concerned unclear responsibilities of multiple providers, such as who should answer patients' questions when different providers order lab tests than those who are delivering the results.

One provider noted that payment systems do not encourage provider-provider communication and may discourage care coordination.

I think we're fragmented...we get compensated by seeing individual patients over and over again, not spending time talking to each other and coordinating services.

3.3. *Providers' Suggestions for Preventing and Addressing Communication Breakdowns*

Providers' suggestions for preventing and addressing communication issues are summarized in Text Box 2. Providers recommended asking patients for

their preferences and expectations around communication, encouraging cancer-care teams to coordinate effective communication, and creating systems that promote patient feedback, education, and time with providers. Specifically, providers supported systems that would facilitate patients reporting their concerns.

DISCUSSION

Effective communication is critically important to cancer patients' health care experiences, their emotional and physical health, and their decision-making. The literature on improving communication with cancer patients has provided relatively little information about how front-line providers view the causes and potential solutions of communication breakdowns. Our in-depth exploration of cancer care providers' attitudes and experiences found that these clinicians consider communication breakdowns with cancer patients to be common and complex. Multi-level interventions to enhance communication will be required to deliver truly patient-centered care.^{4,15,19,27}

Historically, efforts to improve communication with cancer patients have focused largely on skills training for providers. Our study highlights the limitations of this approach. Our findings

Text Box 2 Providers' suggestions for managing communication breakdowns

Focus of intervention	Suggested solutions
<i>Provider-Patient focused solutions</i>	<p><u>Individualize communication:</u></p> <ul style="list-style-type: none"> • Ask how patients would like to receive information (Mode: either over the phone or in person etc. and also in how much detail they prefer) • Assess patients' understanding of past and current communication • Ask what information is a priority for patients, • Explore patients' expectations <p><u>Facilitate communication:</u></p> <ul style="list-style-type: none"> • Encourage patients to be proactive • Give patient contact information • Prioritize what the patient needs to know • Encourage family members/friends to attend appointments • Manage patient's expectations: give reminders and reassurance (e.g., tell patient in advance about side effects; remind patient of prior discussion when side effects do occur)
<i>Team-focused solutions</i>	<ul style="list-style-type: none"> • Have a team approach to care, using support staff and nurses to check in and report problems. • Routine schedule follow-ups and communication after procedures, tests, biopsies, treatment. • Have an individual(s) to help navigate health care system • Have social worker intervene when there is a communication problem
<i>System-focused solutions</i>	<ul style="list-style-type: none"> • Allow for a forum for patient complaints with feedback to provider and patient • Allow more time for encounters, allow for compensation system to encourage more time with patients • Provide improved educational materials for patients

suggest that communication breakdowns in cancer care result from a complex interplay between patient, provider, and health system factors. Providers' identification of the difficulty of meeting both patients' informational and emotional needs largely echoes patients' reports of communication breakdowns they experience during cancer care. The similarity of providers' and patients' views about these challenges suggests that broad-based efforts to enhance communication in cancer care would be welcome by both patients and providers.

Our study also highlights the need to develop systems that encourage patients to share concerns about their cancer care. Prior studies have documented patients' reluctance to speak up about perceived care problems, in part out of fear of alienating their cancer care providers.^{3,28–30} These providers focused primarily on patient factors as the root cause of this problem. Cancer providers and institutions should be more aware of the critical role they play in creating an environment in which patients feel comfortable speaking up about care problems.

This study also highlights that effective communication with cancer patients requires system support. Providers found coordinating diagnostic and treatment planning, communication about patient navigation, and sharing views of prognoses particularly challenging. Providers described well-known time limitations, but also changing protocols, and payment structures that dissuade providers from coordination of care. Multi-modal interventions that seek to improve communication across the patient, provider, and health system axes will be required to reduce communication breakdowns with cancer patients.

Two areas are especially ripe for interventions to help providers and institutions reduce communication breakdowns in cancer care, and for research on their effectiveness. First, new approaches are needed to help providers with effective information transfer to patients, conveying both hope and reality.³¹ Skills training could help providers better elicit patients' understanding of their disease, prognosis, and treatment plan, allowing providers to empathically provide mid-course corrections to patients' beliefs as needed. Institutions can supplement this improved expectation setting by clinicians in the examination room, by providing patients with better access to cancer educational material that patients can readily understand. Expanding patient access to their electronic health record could further align patient and provider expectations about their cancer care.³² Second, providers should encourage patients to share any concerns they have about care, and work with institutions to ensure real-time response.

This study has limitations. These groups represent a modest sample of providers, all of whom work with insured patients; these factors may reduce the generalizability of our findings. Relatively few oncologists participated in the focus groups, though all focus group members were experienced cancer care providers. Focus groups risk encouraging socially desirable responses. In addition, professional hierarchies can inhibit contributions in inter-professional groups. Further, each focus group was comprised of providers from a single organization,

and participants may have sought to show loyalty to their organization. For these reasons, our findings may underestimate providers' actual concerns about communication breakdowns in cancer care.

Communication breakdowns in cancer care have profound effects on patients and their families. Refined measures of patients' experiences of care breakdowns could help healthcare providers and institutions enhance the quality of cancer care they deliver. Yet healthcare institutions should also recognize that their providers represent an important and largely untapped source of insights into where breakdowns occur in the care of cancer patients and how they can be minimized. Integrating the perspectives of both patients and providers, along with consideration of the healthcare system factors associated with care breakdowns, will be required for the delivery of truly patient-centered cancer care.

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