Assessing Patient-Centered Communication in Cancer Care: Measures for Surveillance of Communication Outcomes

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Although conceptualized in various ways, patient-centered communication (PCC) typically involves directing patients to the care they need when they need it, respecting the patient as a person, providing timely information that is understandable and relevant, supporting patient and family (as appropriate) involvement in decision making, and making decisions based on the evidence and consistent with patients values.¹⁻³ Not only is PCC an indicator of quality health care in and of itself,⁴ it also contributes directly or indirectly to improved clinical outcomes and health-related quality of life.^{5,6}

Unfortunately, the goals of PCC in cancer care often are not achieved.⁷ Poor communication between clinicians and patients and their families can have significant negative consequences, including less patient or family satisfaction with cancer care,^{8,9} less trust in physicians,¹⁰ fear of being abandoned,^{11,12} poorer pain control,¹³ feelings of hopelessness,¹⁴ caregiver burden,^{15,16} less commitment to treatment decisions,¹⁷ lower rates of cancer screening,¹⁸ and disparities in cancer care.^{19,20} Given the importance of PCC in improving cancer care quality and outcomes, there is a need for systematic assessment of patients' communication experiences when receiving cancer-related health care. Moreover, measures are needed covering issues salient to patients and their families that can be tailored to different phases of cancer care, impose minimal burden on patients, and

assess whether, from the perspectives of the patient and his or her family, key communication goals were achieved.²¹

Hence, the purpose of this editorial is to advocate for a set of measures that assess key outcomes of the communication experiences of patients with cancer when receiving care and that can be used efficiently and effectively for surveillance and quality improvement purposes across a variety of cancer care settings.

Measures for Surveillance of PCC in Cancer Care

Building on previous work funded by the National Cancer Institute,^{2,22} we present a set of recently published²³ survey items for PCC surveillance that focus on communication outcomes (ie, whether key communication goals were achieved; [Table 1](#)). The survey items are conceptually grounded in a functional model of PCC in cancer care.²² A functional approach focuses on important outcomes of communication with respect to the work communication must do well to achieve patient-centered cancer care. Six functions of PCC are particularly important in that they tap into the quality of cancer care a patient receives across the cancer control continuum: fostering healing relationships, effectively exchanging information, responding to emotions, making quality decisions, managing uncertainty, and enabling patient self-care.

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Table 1. PCC Assessment Items

Item	Function
I was treated with sensitivity and respect.	Relationship building
I felt known as a person.	Relationship building
I felt listened to.	Relationship building
I felt comfortable asking questions and voicing my concerns.	Information exchange
I felt that everyone worked together as a team in taking care of me.	Relationship building
My wishes were respected.	Decision making
I got the information I needed, when I needed it.	Information exchange
I got clear, understandable information.	Information exchange
I knew whom to contact if I had a question or concern.	Enabling self-management
I felt comfortable bringing up anything that was on my mind.	Information exchange
I got consistent information from all my physicians and nurses; everyone was on the same page.	Information exchange
My cancer care team helped me cope with any uncertainty or unknowns.	Managing uncertainty
My cancer care team helped me cope with difficult feelings, like fear, anxiety, and feeling down.	Responding to emotions
I felt optimism and hope from my physicians and nurses.	Responding to emotions
I was involved in making decisions as much as I wanted.	Decision making
I knew whom in the health care system I could reach out to if I was worried that something had gone wrong with my care.	Enabling self-management

Abbreviation: PCC, patient-centered communication.

These 16 core items were selected based on a literature review that identified domains of the functions of PCC² and on patient reports on cancer care experiences related to each function.²⁴ Although no single measure can feasibly assess all domains of PCC, these items tap into specific elements of experience that have been linked to quality of care and health outcomes. For each function, there are two to five assessment

items that offer a number of advantages for PCC assessment and surveillance (Table 1).

How the Proposed Measures Complement Existing Measures

Although cancer care providers routinely acknowledge the importance of effective clinician–patient communication, there is little evidence of systematic assessment, let alone surveillance of their patients’ communication experiences when receiving cancer care. Patients’ self-reports of their satisfaction with care are not always informative, because the scores tend to be highly skewed, with most distributed at the positive end of the scale,²⁵ and do not identify what aspects of the interaction between patient and health care provider accounted for the evaluation. Surveys that include some communication items, such as the Agency for Healthcare Research and Quality Consumer Assessment of Healthcare Providers and Systems survey, are improvements over those that include only global satisfaction items; however, such surveys ask respondents for a general assessment of clinician performance (eg, how well did the physician “explain things” or “listen carefully”)²⁶ and also are highly skewed, with roughly 90% of patients answering the Consumer Assessment of Healthcare Providers and Systems surveys marking the most positive response.²⁷ Finally, national surveys generally provide cross-sectional data or snapshots of some aspects of communication experiences for a sample of patients with cancer, but these surveys are not designed for longitudinal, ongoing assessments of PCC quality.

The PCC assessment items listed in Table 1 add value to existing measures in several respects. First, the PCC functions assessed have been linked to a number of quality cancer care indicators and health outcomes. For example, patients’ outcomes and experiences have been improved (or diminished) when their communication with cancer care clinicians is more (or less) effective in maintaining healing relationships,^{11,12,28} providing and understanding information and preferences,²⁹⁻³¹ responding to emotional distress,^{32,33} achieving informed and shared decision making,³⁴⁻³⁶ managing uncertainty,^{37,38} and fostering patient self-care (in person as well as through Web-based resources [ie, educational materials, support groups, decision aids]).^{39,40} Second, the proposed items focus less on a patient’s perception of what an individual clinician did in his or her communication and more on what the patient and clinician accomplished communicatively (eg, “I got the information I needed when I needed it,” “I felt listened to”;

Table 1). This is consistent with the so-called equifinality nature of communication—multiple patterns of communication can accomplish the same goal.⁴¹ For example, a patient may actively participate in decision making because the clinician explicitly encouraged his or her involvement, or because the patient was activated at the outset. Thus, an item such as “I was involved in making decisions as much as I wanted” provides more information on whether that communication goal was achieved than does an item like “The clinician encouraged me to participate in making decisions.” This communication outcome approach is also consistent with the notion that patient centeredness is not solely an attribute of clinicians; it is the responsibility of all participants and achieved through collective interactions among patients, their families, and health care systems.^{22,42}

Third, the multidimensional nature of the functional approach to PCC measurement provides opportunities for drilling down into specific yet important communication outcomes related to patients’ experiences in cancer care. Such specificity increases the likelihood respondents will make more discriminating responses when pondering specific aspects of the care received. For example, in a recent study, Mazor et al²³ pilot tested the PCC items listed in Table 1 with a panel of cancer survivors who were asked to evaluate their communication with cancer care providers over the course of their care (from suspicion of cancer to post-treatment). The percentage of patients answering less than “always” to the items listed in Table 1 ranged from 21% to 38%. Respondents’ ratings were highest for items such as “being treated with respect” and “involved in decision making as much as I wanted to be,” whereas the lowest scores were for items related to “helped me cope with difficult feelings,” “I knew who to reach out to,” and “got consistent information from the team.” Similarly, the 2012 HINTS survey, which included one item for each of the PCC functions (eg, “How often did your providers involve you in decisions about your health care as much as you wanted?”, “How often did your providers give the attention you needed to your feelings and emotions?”) found that 11% to 26% of respondents chose the lowest two response options (“never” or “sometimes” as opposed to “often” or “always”).⁴³ These two studies demonstrate that assessing different functions of PCC may elicit more discrimination in evaluation compared with existing measures.

Fourth, wording items to focus measurement on communication outcomes and not on the person doing the communicating offers considerable flexibility when choosing targets

of assessment. Table 2 demonstrates how several of the items in Table 1 can be used to measure patients’ communication experiences, ranging from an individual encounter to interactions over time with an entire health care system. In Table 2, two items are used in all four examples, with an additional two items selected specifically for each target of assessment.

From PCC Surveillance to Quality Improvement

Routine and ongoing surveillance of patients’ PCC experiences could inform quality improvement initiatives aimed not only at enhancing patients’ experiences with care but also at improving health outcomes. Although 16 self-report items do not represent an unreasonable burden on respondents, we expect health care organizations will be interested in some items more than others. Because each item is standalone in tapping into a particular domain of PCC, health care providers could select specific measures of interest to their organizations, patient populations, or phases of cancer care (examples listed in Table 2). Moreover, users also could create compatible, supplemental items that could be administered simultaneously. For example, a reviewer of this editorial recommended including the following item to assess patients’ perceptions of nonabandonment: “I felt my cancer care team would be there for me no matter what happened.”

In a hypothetical case study, Singh et al⁴⁴ laid out an argument for using a subset of three items from the PCC measures—“I was involved in making decisions as much as I wanted,” “I got the information I needed, when I needed it,” and “I was treated with sensitivity and respect”—and added a fourth—“The doctors and nurses worked together as a team in taking care of me”—to assess important communication outcomes for the US Veterans Administration efforts to provide veteran-centered, safe health care coordinated through their Patient Aligned Care Teams. Not only would ongoing surveillance of patients’ reports on communication experiences provide indicators of the quality of care provided by the Patient Aligned Care Teams, it could also illuminate sources of communication problems that have been linked to appointment no shows or failures to follow up with care that in turn contribute to medical errors and delays in diagnoses, including cancer.⁴⁵ Another advantage of PCC surveillance would be to examine the effectiveness of interventions aimed at enhancing the communication experiences of patients with cancer. For example, Davies et al⁴⁶ described a program where eight different health plans in Minnesota surveyed a sample of their patients monthly over the course of a year to

Table 2. Examples of Different Targets of Assessment Using PCC Items

Target of Assessment	PCC Item
Based on your last visit with the oncologist, how much do you agree or disagree with the following statements?	<p>I felt comfortable asking questions and voicing my concerns.</p> <p>My oncologist helped me cope with difficult feelings, like fear, anxiety, and feeling down</p> <p>I felt listened to.</p> <p>I got the information I needed, when I needed it.</p>
Considering your experiences when receiving chemotherapy treatment from our clinic, how much do you agree or disagree with the following statements?	<p>I knew whom in the health care system I could reach out to if I was worried that something had gone wrong with my care.</p> <p>I felt listened to.</p> <p>My physicians and nurses were optimistic and hopeful.</p> <p>I got the information I needed, when I needed it.</p>
Based on your experiences with our clinical team both before and after surgery, how much do you agree or disagree with the following statements?	<p>I felt that everyone worked together as a team in taking care of me.</p> <p>I felt listened to.</p> <p>I was involved in making decisions as much as I wanted.</p> <p>I got the information I needed, when I needed it.</p>
Based on your experiences with the physicians and staff at Jones Cancer Center, how much do you agree or disagree with the following statements?	<p>I knew whom in the health care system I could reach out to if I was worried that something had gone wrong with my care.</p> <p>I got the information I needed, when I needed it.</p> <p>I felt that everyone worked together as a team in taking care of me.</p> <p>I felt listened to.</p>

Abbreviation: PCC, patient-centered communication.

assess patients' perceptions of the quality of their communication with clinicians and whether ratings improved after quality improvement initiatives. The proposed measures listed in Table 1 could serve similar purposes in cancer care.

In conclusion, as with most quality improvement initiatives, implementation of a PCC surveillance and improvement program that relies on patient surveys may face a number of challenges, including lack of support from organizational leadership, problems with data capture, inadequate data analytic tools for timely analyses and reports, noninteroperable databases, inertia associated with behavioral routines, and lack

of quality improvement infrastructure.⁴⁷ Although addressing these barriers is beyond the scope of this editorial, it is important to state the obvious—organizations providing cancer care vary greatly in terms of size, organizational structure, funding model, clientele, and services offered. To be successful, quality improvement initiatives must be tailored to the particular characteristics and resources of the cancer care organization. Although there is no one-size-fits-all solution, the measures described here provide an important complement to existing measures in that they assess the key outcomes of PCC, can elicit more discriminating patient reports of PCC quality, and have the flexibility to apply to cancer care providers of all sizes and at multiple levels of assessment within a particular system (eg, individual clinician, treatment centers, phases of care, types of cancer). **JOP**

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