



Communicating Quality in Oncology

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Executive Summary

Oncology accounts for between 5 percent and 11 percent of all healthcare spending today. Thus, it is on the forefront of the transformative changes occurring in healthcare, particularly since demand for cancer care is increasing exponentially with an aging population.¹ Cost increases in the field are also driving calls for change, with costs rising faster than any other specialty. In 2010, the U.S. spent approximately \$125 billion in direct medical costs for cancer. By 2020, that figure is expected to top \$158 billion, an increase driven, in part, by exceedingly expensive new medications and other therapies.¹

As the U.S. healthcare system transitions from a volume-based to a value-based model, with emphasis on providing patient-centered care, reform efforts are focusing on reining in costs while continuing to seek to improve quality and outcomes. Efforts to define and measure quality in cancer care are ongoing.

As the oncology community participates in quality measures and reporting, and as the number of quality metrics, assessments, and accreditations grow, a number of questions arise: What do quality and value mean in cancer care? How should cancer programs define and integrate quality into their practices? And how do oncology professionals communicate quality and value to their stakeholders, including primary care clinicians, payers, and, most importantly, patients?

On June 26, 2014, the Association of Community Cancer Centers (ACCC) Institute for the Future of Oncology held its second annual forum in Chicago to explore two topics: Communicating Quality and Organizational Leadership. More than 20 participants including physicians, nurses, administrators, pharmacists, social workers, and patient advocates from cancer programs and practices around the country provided their insight and perspectives to help cancer programs better meet the challenges of a changing healthcare system.

This white paper is derived from the discussion on Communicating Quality and provides perspectives on how quality is currently being defined and communicated in community oncology programs.

The forum participants agreed that:

- Defining quality in cancer care is challenging
- Each stakeholder group—practitioners, payers, patients—has its own definition of quality

- Given the growing number of accrediting/quality improvement organizations/standards and reporting requirements, some streamlining or consolidating of these programs would be beneficial
- Patients often define quality by non-clinical parameters, such as environment of care and communication with providers
- The current reimbursement climate does not incentivize many of the approaches that improve quality
- Cost and quality must be considered in tandem when determining value.

I. Defining and Communicating Quality in Oncology

A recent article in the *Journal of Oncology Practice* concluded that measuring the quality of cancer care is “not easy.” Current efforts focus too much on process instead of outcome measures; do not capture patient preferences and comorbidities; and do not consider clinical decision-making “nuances” in determining benchmarks, the authors wrote.²

ACCC Institute forum participants agreed that it is very difficult to define quality in oncology. “Do we define it by outcomes or do we do what we’re doing now, which is using process as a proxy for outcome?” asked a physician who directs the oncology service line for a mid-Atlantic health system. After all, he noted, each cancer is unique and each patient is different.

Unlike discrete procedures such as hip replacements in which a successful outcome means the patient is pain free, is ambulatory, and can return to work and normal activities, forum participants noted that the parameters for quality outcomes in oncology are vast. On the clinical side, these could include freedom from adverse events and toxicities, progression-free survival, disease-free survival, 5-year survival, and 10-year survival, among others. Patients have completely different concepts of quality, as do referring physicians. “Defining outcome is so nebulous in oncology... it varies so much by disease, by stakeholder, by everything,” commented one administrator participant.

To primary care physicians, for instance, quality often means being able to schedule a patient quickly for an appointment, knowing the patient will have a good experience, and ensuring that the patient returns for non-cancer-related care. To payers, quality centers on process, metrics, outcome measures, value and comprehensive costs. And to patients, quality can mean everything from their relationship with the nursing staff to the soothing art on the wall in the infusion room and other patient-centered amenities. In other words, the message regarding quality differs based on the stakeholder.

“I think you can define quality in the clinical, financial, and operational domains of your practice,” said the executive director of a cancer center in the Northeast. “Not only do you have quality indicators around the clinical aspects, but there’s the financial piece. . . what are the financial quality indicators that a practice and an institution can put forth, along with the operational efficiencies?”

Forum participants also noted that quality must be determined on a scientific outcomes-based basis: Did the patient survive a survivable cancer? What side effects, both physical and emotional, did the patient experience? What are the long-term sequelae of the care provided? “Tier 1 [surviving a survivable cancer] is the most important,” one participant said. “But the others matter a lot.”

In defining quality care, forum participants concluded that the oncology community needs to engage different stakeholders, including payers, academic institutions, providers, patients, and professional societies, in the conversation about what quality in cancer care means.

II. Measuring Quality: Too Many Certification Options?

“It would be nice if we had a consolidated quality benchmarking agency. You expend a lot of resources, and the more certifications you get, the more resources you expend. So it would be nice if there were some streamlined way to do this.”—Medical director participant from cancer program in the Northwest

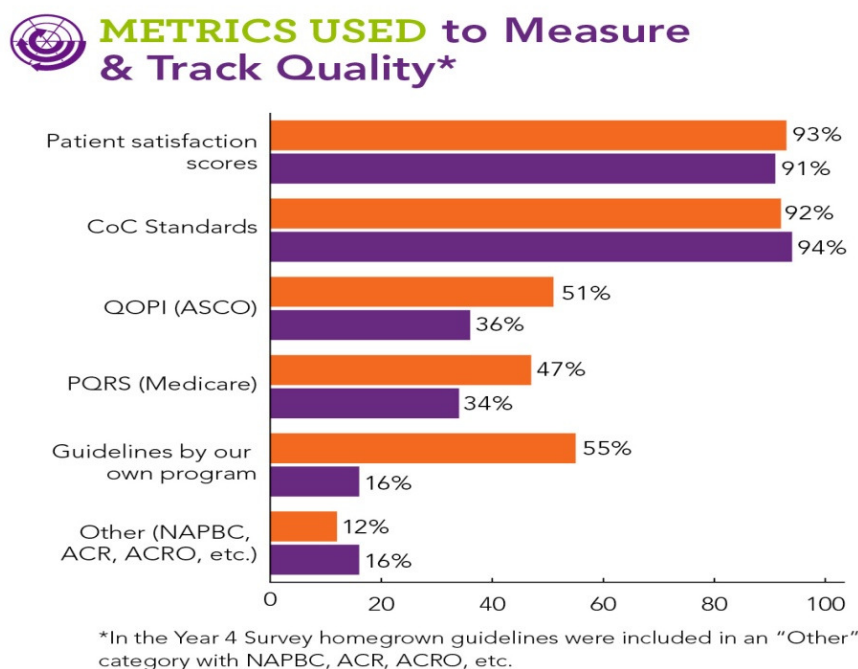
One of the biggest challenges programs face, said an oncology administrator who is also a nurse, is with data quality and the metrics. “You’re a nurse who gives really good care out there on the inpatient unit, how do you measure it?”

Today, those quality measures usually depend on external organizations such as the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI), which has certified more than 850 oncology practices.³ QOPI allows cancer programs to assess the quality of care they provide their patients, test their performance against a variety of process measures, and compare their results with national benchmarks.⁴

However, ASCO recently conceded that “simply creating a certification program is not enough to guarantee quality. . . It was naïve to imagine that simply sharing the results of process measures with QOPI participants would result in sustained improvement in practice performance.”⁴ Thus, ASCO recently announced the creation of its Quality Training Program (QTP), designed “to teach oncology providers to engage in successful quality improvement activities in their practice settings and to train oncologists to assume quality leadership positions and champion quality initiatives.”⁴

Other organizations involved in quality initiatives include the Accreditation Council for Graduate Medical Education (ACGME), the American Board of Internal Medicine, the Centers for Medicare & Medicaid Services, the Commission on Cancer (CoC), the National Quality Forum (NQF), and The Joint Commission (JCAHO).^{3,4} Figure 1 from ACCC’s 2014 Trends in Cancer Programs survey depicts the methods that ACCC member cancer programs report using to measure and track quality care, comparing Year 4 Survey results (in purple) with Year 5 results (in orange).⁵

Figure. 1⁵



Results from ACCC's 2014 Trends in Cancer Programs survey found that while only 28 percent of respondents reported that their payers currently require quality measures and metrics, most believe that payers will be requiring this information in the future.⁵ According to the survey, Blue Cross Blue Shield and CMS are the first to require these data. Realizing that more payers are likely to adopt similar requirements, survey respondents reported that they share the following information with payers:⁵

- CoC accreditation 84%
- JCAHO accreditation 60%
- Press Ganey survey results 51%
- NAPBC accreditation 34%
- Quality improvement initiatives 34%
- Patient outcomes benchmarked against other programs 33%
- ACR accreditation 14%

Forum participants questioned the utility of so many accreditation and quality standards, particularly since few focus on the patient perspective. "There are so many accreditations out there," said one. "How far do you go and when do you stop?" Instead, a peer network might be more appropriate; 91 percent of respondents to ACCC's 2013 Trends in Community Cancer Centers survey said they would be interested in participating in such a network that would measure the quality of cancer care delivery in hospitals and shares best practices.⁶

Participants also expressed frustration with the “top-down” approach of existing accreditation programs that rarely involves community clinicians. “You feel very disconnected from the people who are telling you what the quality measures are,” one participant said, and question how in touch they may be with those on the front lines of oncology care. Another frustration is the delay between reporting the data and receiving benchmarking information. “How meaningful is it to get data that’s two years old?” asked one participant. “We need more real-time data and we’re just not getting that.”

Some participants, however, cited benefits of the certifications. “I think the best part is it helps improve your processes within your clinic,” said one. “I do think it has helped us in communications with referring physicians. We always utilize it when we’re talking with the insurance companies.”

But participants agreed that achieving accreditation is both resource and time intensive. A participant whose organization was just QOPI-recertified said it took more than 200 hours of staff work to complete the paperwork, taking valuable time away from patient care.

And the use of such designations for marketing purposes was of concern to some participants. The potential for blurring of the lines between branding, marketing, and communicating quality to different stakeholders is worrisome, they said. One participant commented, “You can manipulate the data to your advantage and that’s a very slippery slope we have to be careful about as we go down this quality road.”

Recognizing the challenges and benefits of multiple accreditation standards and processes participants agreed that consolidating and streamlining of accreditations would be beneficial to cancer programs.

III. Communicating Quality: The Patient Perspective

“Currently, how we measure quality is a drop in the bucket, very isolated, it’s not at all comprehensive and it doesn’t get back to the core person—the patient.”—Medical oncologist participant from the Midwest

A participant who is a patient advocate helped frame the discussion of quality from the patient’s perspective. “It’s all about the experience....we’re all patients, we all see doctors....” he said. Patients want to be treated like human beings, he said, and “you want to feel like you’re being listened to, you don’t want to be condescended towards....If the fundamental nature of the human condition is we just want to feel like we matter, then that’s a good place to start to think about quality.”

Feeling as if “we matter” is often how patients determine quality, rather than by a program or practice’s certifications and accreditations. Said one participant, “I rarely ever see where a patient mentions in their comments how great we are because of our accreditation.” “I can’t say that I’ve ever heard of someone saying that they came to us because they saw that we were QOPI certified,” said another.

Institute forum participants agreed that the patient experience is often based on perception of quality, rather than objective measures of it. “The patients may think that the doctor is the best doctor in the world because that’s all they know,” one said. “So how do we start to educate them on some of the other factors that are important so they can actually make informed decisions about the quality [of care]?”

Patient satisfaction surveys are often used to gauge patients’ perceptions of quality care, but participants held differing views on the utility of information gleaned from these surveys.

“If the perception of the patient is ‘I don’t like to be here, I am here because I am forced to be here,’ [then] we are not doing our job,” said a medical oncologist from the Southwest. His practice surveys new patients within 24 hours of the first visit, asking how they chose the practice, how satisfied they were with the first consultation, and other experiential questions. “That gives us a tremendous amount of insight of how we work,” he said. “Although this could look like a trivial issue, it’s fundamental for the initial step of the care of the patient.”

Another participant agreed that surveying patients the day after an initial consultation is important, but he asked, “Is that something that has demonstrated better outcomes or better communication throughout the course of that patient’s treatment?”

Yes, responded the oncologist from the Southwest who conducts the surveys. It enables his practice to tailor treatment to the individual patient’s goals, which is the true definition of patient-centered care (see “Patient-Centered Care” on page 8).

The participants noted that it is often surprising what’s important to patients. For instance, the director of a mid-Atlantic cancer program said patients repeatedly praise the integrative medicine department within the oncology unit at his hospital “even though it has nothing to do with the outcome of their disease.”

Not surprisingly, patients also cite follow-up calls from a nurse after the first treatment and educational visits with nurse practitioners as important components in their experience. Another participant said that patients view his center’s nurse navigators as representing quality because they ease the patient’s journey through a complex system of care.

Meeting patients' psychosocial needs is recognized as an important component of quality cancer care. The Institute of Medicine (IOM) and other medical organizations highlight the management of psychosocial issues in patients with cancer as an indicator of quality, particularly as many cancers are increasingly becoming chronic illnesses.¹ Yet patients with cancer still report poor communication with physicians, lack of knowledge about their illness and its management, and financial and environmental barriers to care. Such psychosocial problems can significantly affect medical outcomes.⁷

Addressing patients' psychosocial needs includes addressing the cost of treatment and financial barriers to care. "For the patient, cost has to be a part of the quality equation because we talk about financial toxicity," said a medical director participant. "There are many, many costs patients have to bear." Indeed, medical costs are the leading cause of personal bankruptcy among Americans, and cancer is the leading diagnosis in these cases. In fact, people living with cancer are more than twice as likely to declare bankruptcy than those who are not, a rate that is even higher in younger cancer patients without Medicare.⁸

A recent study from Duke Cancer Institute, presented at the June 2013 ASCO Annual Meeting reported that although most cancer patients would like to talk about the cost of care with their doctors, often they do not.⁹ Patients' reasons included feeling embarrassed, assuming that it was not something that the doctor could help with, and fearing that cost of care discussions might compromise the quality of their treatment. The study findings come from a survey of 300 insured patients treated at Duke and affiliated clinics in rural North Carolina. Fifty-seven percent of the participants in the survey said they wanted to talk about treatment costs with their doctors, but only 19 percent actually had that conversation.⁹ While 61 percent of patients with the highest degree of financial distress reported that they wanted to discuss treatment costs with their doctors, only 25 percent had done so.

Patient-Centered Care

A large body of evidence points to better outcomes when clinicians deliver patient-centered care versus traditional paternalistic care.^{10,11} Such an approach lies at the heart of any quality initiatives and outcomes in oncology.¹ The IOM defines patient-centered care as providing care that is respectful of and responsive to individual preferences, needs, and values, and ensuring that patient values guide all clinical decisions.¹² In cancer care, patient-centered care includes fostering good communication between patients and their cancer care team; developing and disseminating evidence-based information to inform patients, caregivers, and the cancer care team about treatment options; and practicing shared decision making.¹

As the 2013 IOM report on quality in cancer care notes, today's cancer care system is far from patient centered, with clinicians asking patients about their preferences for medical care only about half of the time.^{13,14}

IV. Communicating Quality: Participants' Experiences

Instead of turning to certifications to communicate quality to patients, a participant from a small, rural Northeast cancer center says her program uses National Comprehensive Cancer Network (NCCN) guidelines as a way to talk about quality care. Since these patients would have to travel far to receive care from larger cancer centers, being able to show that her program follows NCCN guidelines—the same guidelines followed by larger programs—helps assure patients that they are receiving the same cancer treatment they would get at a larger program. “As far as communicating quality, I think that NCCN guidelines are something [concrete] that patients can understand and that to them is more important than QOPI or the CoC accreditation,” she said.

“With quality, I think we have to go to the very basics,” said a medical oncologist from an academic medical center. “I’m in favor of the concept of expansion of patient-reported outcomes. This gets to what is essential for comprehensive cancer care for the individual patient, where we should routinely be surveying patients not just about their side effects, but about what component of their experience was essential and made their lives better. Is it the financial counselor? Is it the psychologist? Is it the social worker? The pharmacist?” Identifying those components is also important, he said, so programs can gather data to support their use and to support advocacy efforts for reimbursement for these services because they improve the patient’s experience.

Several participants reported taking proactive steps to improve the patient experience, such as creating advisory councils and surveying patients in an effort to better define and communicate quality. In one participant’s mid-Atlantic cancer program, a patient advisory council reviews any issues that arise and identifies opportunities to improve processes. When mistakes occur or patients are unhappy, “We don’t say ‘You’re a bad doctor, or a bad nurse.’ We say, ‘This is a learning opportunity, let’s fix it.’” His program closes once a year just to communicate on quality to its staff; while another participant closes his practice for half a day, three times a year for the same purpose.

Such approaches, forum participants agreed, require an environment that emphasizes improvement, not punishment. “You need a culture of quality where people can communicate about issues, where the employees feel valued and that the work they’re doing is valuable,” said one. “Culture beats strategy every time. If you get that culture, the quality will come.”

Participants identified different individuals within their organizations as responsible for communicating quality. “One of the people who has a big role in that is our clinical director, who is our lead nurse,” said one participant. Others noted that the majority of quality concerns are clinical in nature and, therefore, do require a doctor or nurse to manage. “People want to make

sure that we're providing the best quality care. If there are issues that can't be resolved," said one administrator, "they call me."

Other participants, however, said that no single person within their organizations communicates quality. "I don't think it is one person's job," said one. "I think it's everybody's job," Indeed, said another, "At our institution, there are different layers of quality [measurements]. We have our clinical manager who is an RN who is in charge of keeping our dashboard and all of the data. But the group that helps define and control quality is our cancer committee."

The challenge in communicating quality to patients, participants said, comes with first defining "value" for them. Value, said one participant, is quality divided by cost. "At the end of the day, the goal of a high-value system is to improve value for the patient," he said. That can be done by improving quality and keeping costs constant, or keeping quality the same and reducing costs, or some variation thereof, he said. But "the value equation requires a conversation about both."

Using Social Media to Communicate Quality

Forum participants touched on the role of social media in communicating quality, particularly as it affects a practice or program's reputation. They noted that many patients today check sites like Health Grades to see how their doctors are rated. While some programs blog and maintain Facebook pages, most participants said they are not very active in using social media at present. "While social media is going to be increasingly important, I think we're just at the very beginning of that curve as to how important it is [in communicating quality]," one said.

While clinicians may not be using social media to *communicate* quality, they appear to be using it to improve quality. A survey of 485 oncologists and primary care physicians found that 85% use social media at least once a week or once a day to read or explore health information, and 60% said social media "improves the care they deliver."¹⁵ The use of health-related social media also helps patients make better treatment decisions, manage their symptoms, and perceive control over their condition—all components of patient-centered care.¹⁶

ACCC's 2013 Trends in Community Cancer Centers survey found that a third of respondent programs were on Facebook; while a third were also on YouTube and Twitter. More than half (57%) reported success in using social media to build an online community, and 80% said they plan to continue to use social media in the next one to two years.⁶

V. Quality and Cost

No discussion of quality today can occur without a concurrent consideration of cost and reimbursement. Yet, as forum participants noted, the current fee-for-service system (under which about 80 percent of cancer programs practice³) does not financially support many of the ingredients of quality cancer care, including multidisciplinary care, patient-centered care, and a focus on psychosocial issues.¹

For instance, the 2013 IOM report on Delivering High-Quality Cancer Care calls for a system of interprofessional cancer care teams aligned with patients' needs, values, and preferences which, studies find, significantly improve healthcare quality and outcomes.¹⁷⁻¹⁹ "There is a cost to [such teams]," one participant noted, "but, on the flip side, there are potentially tremendous savings if you really know a patient and can handle their needs." Reimbursement for such models, however, is often lacking.¹

One participant described efforts to maintain a primary nursing model in his program. "It helped in driving quality care with the patients," he said, "but the hospital saw it as an expensive model." Without quantitative data to demonstrate its financial benefits, the program was cut.

Yet the savings from such approaches, another participant said, could be substantial by reducing overtesting and inpatient admissions, thanks to a team focus on keeping the patient out of the hospital. In the long run, he said, keeping patients healthier and with their families may, at the very least, help balance out the additional costs resulting from more expensive drugs.

Other "extras," such as the integrative medicine services discussed earlier, are rarely reimbursed. For example, Medicare doesn't cover acupuncture, which "truly does reduce pain," said the director of a mid-Atlantic program. "It enables you to stop taking some medications, it gives you a clearer head, it reduces post-traumatic stress syndrome," he said. "How do we explain that, by this doing, it saves money and it's worth the investment?"

"Unfortunately," said one participant, "we don't hear these kind of comprehensive discussions of cost and the pros and cons of what the cost is versus where the savings are to provide the essential services and treatments necessary to improve the patient's quality experience overall."

The panel also expressed concern about payers restricting provider networks and excluding high-cost providers.²⁰ This only increases the pressure to cut costs, which could affect quality. Nonetheless, one participant concluded, providing the highest quality of care can also reduce costs, which is not often factored into the equation.

Conclusion

The 2014 Institute for the Future of Oncology discussion on communicating quality in cancer care revealed that defining quality in oncology remains challenging, particularly since it differs based on individual patient perceptions, payer needs, and referring physician expectations. This means that quality needs to be communicated differently to different stakeholders.

Participants agreed that for patients, quality care encompasses more than clinical outcomes and includes the environment in which they are treated, their interactions with all members of the cancer care team, and their sense of involvement in decision making.

Participants also agreed that while many organizations are trying to define and develop quality metrics in oncology, none are sufficiently focused on what quality means for patients. They also agreed that the benefits of obtaining numerous quality certifications need to be better defined.

In the discussion on how their programs are defining quality and integrating quality measures, participants agreed that fostering a culture of quality is essential and that communicating quality is something that all cancer program staff is responsible for. Overall, participants concluded that communicating quality and value requires different approaches for each stakeholder, and that the oncology community needs to engage with all stakeholders in refining how quality cancer care is defined and measured.

End Notes

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About the Association of Community Cancer Centers

The Association of Community Cancer Centers (ACCC) serves as the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 20,000 cancer care professionals from approximately 1,900 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. For more information, visit ACCC's website at www.accc-cancer.org. Follow us on Facebook, Twitter, LinkedIn, and read our blog, ACCCBuzz.

About the Institute for the Future of Oncology

The Association of Community Cancer Centers (ACCC) launched the Institute for the Future of Oncology (the Institute) in 2013 because ACCC recognized a gap in knowledge and a need for meaningful discussion on issues unique to the multidisciplinary oncology team. The Institute serves as a clearinghouse of information and knowledge, addressing these issues and offering solutions that can be utilized across the community oncology continuum. For more information, visit www.accc-cancer.org/institute.

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