

How Do We Encourage Patient Engagement?

Following on the theme from my previous editorial (Mayer, 2014), I want to address another goal identified in *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (Institute of Medicine, 2013): engaged patients. The report identified patient engagement as the number one recommendation. The recommendation states that patients and their families should be given understandable information about their cancer (see Figure 1). But this recommendation is incomplete without including concepts about patient-centered communication, shared decision making, and patient activation. I want to explore each of these and then circle back to how we can encourage patient engagement in cancer care.

Patient-Centered Communication

This communication style is an essential component in delivering quality cancer care (see Figure 2). Epstein and Street (2007) described it as an interaction between the patient and clinician, including

- Eliciting, understanding, and validating the patient's perspective (e.g., concerns, feelings, expectations)
- Understanding the patient within the psychological and social context
- Reaching a shared understanding of the patient's problem and its treatment
- Helping a patient share power by offering meaningful involvement in choices relating to his or her health (shared decision making).

Although this may seem obvious, it is not something that we always do or see in practice. To communicate in this way takes training, skill, and time on the part of the clinician and a conducive environment in which to do it. Most of us

The cancer care team should provide patients and their families with understandable information on cancer prognosis, treatment benefits and harms, palliative care, psychosocial support, and estimates of the total and out-of-pocket costs of cancer care. To accomplish this:

- The National Cancer Institute, the Centers for Medicare and Medicaid Services, the Patient-Centered Outcomes Research Institute, as well as patient advocacy organizations, professional organizations, and other public and private stakeholders should improve the development of this information and decision aids and make them available through print, electronic, and social media.
- Professional educational programs for the cancer care team should provide comprehensive and formal communication training.
- The cancer care team should communicate and personalize this information for patients at key decision points along with the continuum of cancer care, using decision aids when available.
- The cancer care team should collaborate with their patients to develop a care plan that reflects their patients' needs, values, and preferences, and considers palliative care needs and psychosocial support across the cancer care continuum.
- The Centers for Medicare and Medicaid Services and other payers should design, implement, and evaluate innovative payment models that incentivize the cancer care team to discuss this information with their patients and document their discussions in each patient's care plan.

FIGURE 1. Institute of Medicine Recommendation for Delivering High-Quality Cancer Care: Recommendation 1, Engaged Patients

Note. From *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* (pp. 8–9), by Institute of Medicine, 2013, Washington DC: National Academies Press. Copyright 2013 by the Institute of Medicine. Reprinted with permission.

have learned how to communicate with patients and their families by on-the-job experiences and by observing others. But how we communicate is not always helpful (Thorne, 1988). Spend some time thinking about your communication skills, then consider accessing resources that can help us become more effective, including the Epstein and Street (2007) monograph and online programs such as Oncotalk® or the Achieving Communica-

tion Excellence series from MD Anderson (<http://bit.ly/lupupGC>).

Shared Decision Making

The healthcare system has shifted from a paternalistic healthcare system, where patients did what their doctor told them, to more of a shared decision-making process (Informed Medical Decisions Foundation, 2011). This began when

Deborah K. Mayer, PhD, RN, AOCN®, FAAN, is a professor in the School of Nursing at the University of North Carolina (UNC)—Chapel Hill and director of Cancer Survivorship at the UNC Lineberger Comprehensive Cancer Center. The author takes full responsibility for the content of the article. No financial relationships relevant to the content of this article have been disclosed by the editorial staff. Mayer can be reached at CJONEditor@ons.org.

Key words: quality; cancer care; communication

Digital Object Identifier: 10.1188/14.CJON.487-488

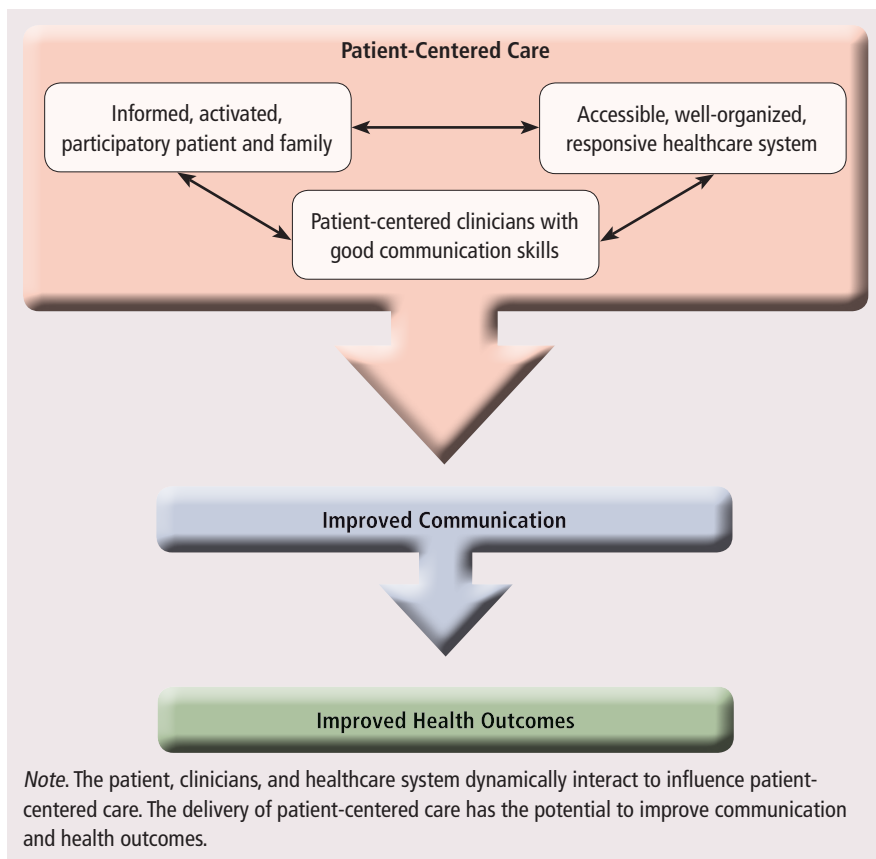


FIGURE 2. The Model of Patient-Centered Care

Note. From *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering* (p. 2), by R.M. Epstein and R.L. Street, 2007, Bethesda, MD: National Cancer Institute. Copyright 2007 by the National Cancer Institute. Reprinted with permission.

patients wanted more information and to have input into their care, particularly around cancer treatments when the outcomes were equivalent (i.e., mastectomy or lumpectomy). Shared decision making is now embedded into the Affordable Care Act and different decision aids have been developed and tested to help in this process. Have you used any? For a few examples of valuable resources in this area, check out the Agency for Healthcare Research and Quality's patient decision aids (<http://1.usa.gov/lupuvhx>).

Patient Activation

Patients need the knowledge, skill, motivation, and confidence to manage their health and participate in their health care (Hibbard & Greene, 2013; Hibbard, Greene, & Overton, 2013; Hibbard, Mahoney, Stock, & Tusler, 2007). The more activated a patient is, the more likely he or she is to have greater self-management skills and is more able to advocate for

themselves leading to better health outcomes (Greene & Hibbard, 2011; Hibbard et al., 2007; Osborn & Squires, 2012). The work on patient activation is intriguing and should be applied and studied in cancer care. As oncology nurses, we routinely educate patients about their diagnosis, treatment, and side effects, but we haven't linked this education to their ability to participate in their care and to improving patient outcomes. I would like to suggest that we need activated patients if we want them to be engaged in their care. We need to learn how we can do that by paying special attention to patients and families who are less activated.

One thing we can do is to help patients figure out what questions to ask. To that end, the Institute of Medicine (2013) report created a *Questions for Patients With Cancer to Ask Their Care Team* document (<http://bit.ly/Yk3yRE>). In addition, the National Coalition for Cancer Survivorship has developed a series of handouts (<http://bit.ly/1AjsaE>).

Patient education has always been an important part of what we do as oncology nurses. It is even more important now that the expectations for patients' participation and engagement have been identified as one of the ways to address the crisis in cancer care.

References

Epstein, R.M., & Street, R.L. (2007). *Patient-centered communication in cancer care: Promoting healing and reducing suffering*. Bethesda, MD: National Cancer Institute.

Greene, J., & Hibbard, J.H. (2011). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine*, 27, 520-526. doi:10.1007/s11606-011-1931-2

Hibbard, J.H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32, 207-214. doi:10.1377/hlthaff.2012.1061

Hibbard, J.H., Greene, J., & Overton V. (2013). Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. *Health Affairs*, 32, 216-222. doi:10.1377/hlthaff.2012.1064

Hibbard, J.H., Mahoney, E.R., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research*, 42, 1443-1463.

Informed Medical Decisions Foundation. (2011). *Patients want to be involved*. Retrieved from http://informedmedicaldecisions.org/wp-content/uploads/2011/05/Perspectives_Patient_Involvement.pdf

Institute of Medicine. (2013). *Delivering high-quality cancer care: Charting a new course for a system in crisis*. Washington, DC: National Academies Press.

Mayer, D.K. (2014). How can we deliver high-quality cancer care in a healthcare system in crisis? *Clinical Journal of Oncology Nursing*, 18, 381-382. doi:10.1188/14.CJON.381-382

Osborn, R., & Squires, D. (2012). International perspectives on patient engagement: Results from the 2011 Commonwealth Fund Survey. *Journal of Ambulatory Care Management*, 35, 118-128.

Thorne, S. (1988). Helpful and unhelpful communications in cancer care: The patients' perspective. *Oncology Nursing Forum*, 15(7), 167-172.