It's Not the Model that Matters—Still Lost in Transition

By Michael L. Kappel

National Coalition for Cancer Survivorship, Silver Spring, MD

New treatment therapies, new diagnostics, and more targeted approaches mean greater predictability and greater success in fighting many cancers. Despite the dramatic improvement, cancer survivors still find the health care system to be unpredictable, fragmented, and even dangerous. To improve care coordination and integration, new models of organizing and delivering care have evolved. Accountable care organizations and patient-centered medical homes are two examples of care models that reflect the need for more consistent, coordinated care in which incentives for appropriate prevention and treatment are aligned with provider, facility, and payer expectations. A cancer diagnosis strains comprehensive care models as a result of the specialized demands of cancer care. Thus, some oncologists have pioneered a specialty-based medical home for oncology patients: the oncology patient-centered medical home.¹ The quality measures associated with such approaches are impressive, and patients enjoy high levels of coordination and integration within the medical home. However, as patients move through survivorship, oncology concerns may pale compared with concerns about other medical conditions. This problem becomes more acute as patients age. Neeraj Arora, at the National Cancer Institute Office of Cancer Survivorship, found that 25% percent of survivors age 65 to 74 years have five or more comorbidities and see as many as 12 physicians a year.² As a result, cancer survivors are entering and leaving many different care models and experiencing fragmented care. The implications are that cancer survivors often feel that they have no source to turn to when seeking medical care. They are, as Arora described his own experience, “homeless in a world of medical homes.”²

To improve care quality and coordination, cancer survivors need (1) pervasive adoption of patient-centered clinical practice, (2) improved planning tools to facilitate care coordination, and (3) better approaches to capture longitudinal data to support quality research.

Patient-Centered Approaches

In *Crossing the Quality Chasm*, the Institute of Medicine defined the characteristic “patient-centered” as one of its six Aims for Improvement, and almost all of the 10 Rules for Redesign outlined in that publication are expressed in terms of patient needs, values, and engagement with the care process.³ A particular advantage of the patient-centered approach is its ability to transcend primary and specialty care boundaries. Ron Epstein and Richard Street recently wrote in *Annals of Family Medicine* about “The Value and Values of Patient-Centered Care.”⁴ In that article, they distinguished the philosophy of patient-centered care from its outcomes and benefits. The philosophy describes care that respects the individual and acknowledges his

or her unique needs and concerns. The manifestations of a patient-centered approach are the collaboration between patient and care provider, honest communication, shared decision making based on the best available evidence, and the engagement of patients in their own care. Although some consider patient-centered a term best left to primary care, Epstein and Street led an effort at the National Cancer Institute on best practices in applying patient-centered approaches to cancer care.⁵

Although oncology science is moving toward greater personalization in terms of developing targeted therapies, the growing complexity of treatment options may actually be weakening patient-centered approaches to treatment and survivorship planning. Greater complexity in the science means more time required to explain treatment options to patients—putting more strain on open, honest communications. Based on a presentation he made to the National Coalition for Cancer Survivorship (NCCS) in September 2012, Thomas Smith, MD, Director of Palliative Medicine, Johns Hopkins Medical Hospital, spoke of developing a patient-centered communications checklist that can be printed on a simple 3 × 5 index card. The checklist would serve to prompt providers to ask focused questions to reveal a patient’s comprehension of their condition and to support shared decision making based on evidence. This checklist would include questions such as, but not limited to, the following:

- How much would you like to know about your cancer?
- What do you know about your cancer?
- Would you like me to write down the important points?
- What is important to you?
- What are you hoping for?
- Now that we have discussed this, what is your understanding of your situation?
- Who are your other doctors, so that I can communicate with them?

NCCS is working with Smith to promote these communication tools and (as of this writing) is in the process of developing a companion tool for patients. Although a checklist on a 3 × 5 card sounds simplistic, this is a pragmatic first step to ensure that patients understand their diagnosis and their treatment options.

Survivorship care planning. Survivorship care planning is a patient-centered approach that integrates patients’ goals and aspirations with the clinical realities of their diagnosis and treatment. Ideally the planning process is summarized in a survivorship care plan (SCP), which contains a concise treatment summary, a surveillance program with preventative and palliative recommendations, and appropriate health promotion activities. The planning process serves to both document and educate

cancer survivors about potential health concerns and the medical care necessary to ensure effective surveillance while avoiding the risks of unnecessary and potentially dangerous procedures. The resulting document, in paper or electronic form, also provides a powerful communication tool to improve transitions of care—from oncologist to either primary care or other specialists.

Unfortunately, neither survivorship care planning nor the resulting SCP has been widely adopted by oncologists.⁶ Studies show that both cancer survivors and primary care physicians hold favorable views of SCPs, and primary care physicians see SCPs as valuable tools for care coordination.⁷ The impact of survivorship care plans on patient outcomes is not clear. One Canadian study of patients with early-stage breast cancer found no significant differences in patient-reported outcomes between patients receiving SCPs and those receiving a thorough discharge visit to primary care. Oncologists are also concerned about the time and resources required to administer an effective plan, the lack of reimbursement for their efforts, and lack of integration of care planning systems with their electronic health records and registries. Solving these cost and information integration issues is key to broader adoption of care planning. Rather than sort through individual patient charts to develop treatment summaries, improved integration with electronic health records and electronic ordering systems can readily pre-populate the plan with demographic, treatment, and associated patient information. This should allow physicians and their care teams to focus on the planning and delivery processes rather than the research and clerical tasks required to gather the relevant background information.

Despite these obstacles, the Institute of Medicine advocates survivorship care planning for all patients with cancer, and the Commission on Cancer will require care plans as a condition of accreditation of cancer facilities after 2015.⁸ Care planning was considered as a requirement for the stage two criteria for meaningful use under the HITECH incentive program and will almost certainly be considered for inclusion in stage three.⁹

Improving longitudinal data collection. A comprehensive history of a survivor's total health experience is almost impossible to assemble given our fragmented system of care. A survivor's medical history can be scattered across many provider's health records and potentially populate many different disease registries—whether maintained by provider organizations or medical specialties. When measuring quality across the continuum,

it is important to determine how to link these data to better assess the outcomes and late effects of treatment. Some groups, such as the National Quality Registry Network, are now looking at ways to link patient data from multiple quality registries.¹⁰ Retrospective approaches such as linking and data mining can be supplemented by more targeted approaches. SCPs offer the opportunity to improve data flow back to the original treatment provider if possible outcomes, complications, and/or late effects are clearly identified in a survivor's plan. The identification of these potential conditions may prompt the patient or the patient's other providers to alert the treatment provider to subsequent health developments.

Conclusions

In 2005, the Institute of Medicine issued a landmark report titled, *From Cancer Patient to Cancer Survivor—Lost in Transition*.¹¹ I believe cancer survivors are still “lost in transition”—and not just between treatment and survivorship. In order to improve integration of care across the spectrum, oncologists can (1) engage and empower survivors through patient-centered clinical practice, (2) use survivorship care plans as integrative tools to support care coordination, and (3) encourage a new focus on “downstream” data collection by identifying possible complications and late effects and encourage their patients to report them.

Acknowledgment

Presented at the ASCO Quality Care Symposium, San Diego, CA, November 30-December 1, 2012.

Author's Disclosures of Potential Conflicts of Interest

Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a “U” are those for which no compensation was received; those relationships marked with a “C” were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.

Employment or Leadership Position: Michael L. Kappel, National Coalition for Cancer Survivorship (NCCS) (U) **Consultant or Advisory Role:** Michael L. Kappel, NCCS (C) **Stock Ownership:** None **Honoraria:** None **Research Funding:** None **Expert Testimony:** None **Other Remuneration:** None

References

1. Butcher, L: Medical home concept comes to oncology. *Oncology Times*, pp. 45-47, February 25, 2011
2. Arora N: Homeless in a world of medical homes? Presented at the National Cancer Institute Biennial Cancer Survivorship Conference, Arlington, VA, June 16, 2012
3. Institute of Medicine: Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC, National Academies Press, 2001
4. Epstein RM, Street RL Jr: The values and value of patient-centered care. *Ann Fam Med* 9:100-103, 2011
5. Epstein RM, Street RL Jr: Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD, National Cancer Institute, 2007
6. Phillips C: A tough transition: Cancer survivorship plans slow to take hold. *NCI Cancer Bull* 9:5, 2012

7. Shalom MM, Hahn EE, Casillas J, et al: Do survivorship care plans make a difference? A primary care provider perspective. *J Oncol Pract* 7:314-318, 2011
8. American College of Surgeons Commission on Cancer: Cancer program standards 2012: Ensuring patient-centered care, standard 3.3, p. 78. <http://www.facs.org/cancer/coc/cocprogramstandards2012.pdf>
9. Federal Register, Vol. 77, No. 17, 2012, pp 54163-54292, discussion page 54217
10. Richardson, D: National Quality Registry Network. Presented on an open webinar October 12, 2012
11. Institute of Medicine, National Research Council, Hewitt M, et al: *From Cancer Patient to Cancer Survivor—Lost in Transition*. Washington, DC, National Academies Press, 2006

DOI: 10.1200/JOP.2013.001016