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PCPs Seek Identity in Cancer Survivor Care

— Survey: Knowledge gaps, uneasy relations with oncology, no consensus on clinical role

by Charles Bankhead, Senior Editor, MedPage Today
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A professional identity crisis has begun to emerge among primary care clinicians regarding their role in caring for cancer survivors, authors of a survey of physicians, nurses, and physician assistants (PAs) concluded.

Survey participants had widely divergent views regarding primary care's role in cancer survivor care and about the concept of survivorship. A few providers said responsibility for follow-up after acute care belonged entirely to oncology. Alternatively, some respondents

viewed cancer survivors as no different from other patients with chronic conditions.

"In further interpretative analysis, we discovered a deeply ingrained philosophy of whole-person care that creates a professional identity dilemma for primary care clinicians when faced with rapidly changing specialized knowledge," wrote Benjamin F. Crabtree, PhD, of Rutgers Robert Wood Johnson Medical School in New Brunswick, New Jersey, and colleagues in *Annals of Family Medicine*.

"Experts believed cancer survivorship care plans and clinical guidelines would be accepted and used in primary care practices," they added. "As in prior research, however, we found a lack of congruence between clinical guidelines and survivorship knowledge and practices, with no clinician we interviewed articulating best practices in cancer survivorship care as outlined in clinical guidelines. These findings tap into a deeper national discussion concerning the role and identity of primary care."

Growing Patient Population

Advances in treatment and diagnosis of cancer have fueled a rapid growth in the number of cancer survivors. Over the next 20 years, the number of cancer survivors in the U.S. is projected to increase from about 17 million today to more than 26 million. The absolute numbers include many childhood cancer survivors, who are living longer with a comorbidity burden that increases with age, the authors noted. At the same time, the field of cancer care faces a predicted shortage in personnel and services.

Clinical guidelines for cancer survivorship care, including individualized survivorship care plans, evolved with goals that included providing guidance for primary care clinicians. However, no clear direction has emerged with regard to prioritizing and integrating survivorship care into primary care, the authors continued. Moreover, the adoption of varied definitions of cancer survivor has created a "nebulous situation as to when primary care should resume responsibility for these patients."

A previous study by Crabtree and colleagues produced little evidence of systematic care for cancer survivors, despite the availability of resources. Moreover, limited data exist with respect to primary care clinicians' perceptions about their role in providing care for cancer survivors, and the authors' prior study suggested disagreement among primary care clinicians regarding their role in survivorship care.

In an attempt to learn more about primary care clinicians' attitudes and beliefs regarding cancer survivor care, the authors conducted a survey of 38 providers at 14 geographically diverse primary care practices recognized for workforce innovation. Survey participants consisted of 29 physicians, five nurse practitioners (NPs), and four PAs. They represented small, medium, and large practices in urban, suburban, small-city, and rural settings. Participants ranged in age from 20 to 70, and women accounted for 60% of the survey population.

Attitudes, Beliefs

The results showed that most clinicians considered cancer survivorship an appropriate role for primary care. However, many of the providers expressed concerns and described obstacles to their participation in a cancer survivor's care: lack of education about modern cancer therapy and its side effects; lack of understanding about patients' needs and expectations; and an "uneasy relationship" with the field of oncology.

"Historically, oncologists are very possessive of their patients," one physician said. "Once they're an oncology patient, they're an oncology patient." Nonetheless, he said that "if someone 10, 12, 20 years out [from acute cancer treatment] ... we [in primary care] really should be the ones following them."

Five of the 38 clinicians did not consider cancer survivorship care within the purview of primary care. Said one physician, "My presumption is that if [the patients with a history of cancer] have needs, they're going to be hooked in with an oncologist. So, there's a territory or turf issue here." An NP said that incorporating cancer survivorship care would require her practice to decide "that we were going to be some kind of a specialty primary care that made that [cancer survivorship] as our thing."

The clinicians also had divergent views about the needs of cancer survivors. Some considered survivors to be a distinct patient population that would require specialized services and resources within the primary care practice, whereas others considered patients with cancer to be like patients with other chronic conditions.

In parsing the responses, the authors found "a general lack of coherent knowledge about how to care for cancer survivors ... Some clinicians struggled to talk about cancer survivorship at all." Clinicians whose professional identity centered on delivering "whole-

person, comprehensive, coordinated care, appeared to hit a wall of identity confusion when confronted with a swiftly changing highly specialized knowledge base and a highly variable group of patients."

To address the issues raised by the survey responses, the authors suggested "facilitated national conversations might help specialists and primary care develop knowledge translation platforms to support the prioritizing, integrating, and personalizing functions of primary care for patients with highly complicated issues requiring specialized knowledge."

Bridging the Gap

In an ideal setting, the working relationship between oncologists and primary care clinicians would be based on knowledge, education, and good communication, said Anne Blaes, MD, chair of the American Society of Clinical Oncology Survivorship Committee. Knowing what issues to look for during patient follow-up involves knowledge, which is part education and part communication.

"A good working relationship requires communication," said Blaes, of the University of Minnesota in Minneapolis. "Some of the communication is direct, as in phone calls and emails and other interactions between the oncologist and the primary care clinician. But a lot of important communication occurs within the patient's medical record. It also involves being clear about who does what when it comes to a role and taking care of a patient."

As originally conceived by the Institute of Medicine (IOM), an individualized patient survivorship care plan would facilitate both education and communication about surveillance and follow-up, and the role of the oncologist and the primary care clinician in the process. Most plans did not meet all of the goals the IOM set forth as essential to a good continuum of care for patients with cancer, said Blaes.

Last year, the American College of Surgeons Commission on Cancer published revised recommendations for survivorship care to make them more patient-centric and focused on care delivery.

"Survivorship care is not just a piece of paper, it's not just the delivery plan. It's more about instituting comprehensive care," said Blaes.

Primary care clinicians who feel uncomfortable about survivorship care -- in general or specific aspects -- should "embrace" the discomfort and use the resulting energy to learn more, said John W. Ragsdale, MD, a family physician at Duke University in Durham, North Carolina. Begin with the basics.

"Talk to the patient's oncologist. Have lunch with the oncologist. I know that sounds a little basic, but if you're going into a survivorship care plan or handoff plan, find out what you need to know from the oncologist," he told *MedPage Today*. "Just say, 'Listen, this really makes no sense to me. We need to figure out a way to communicate that makes sense.' Let them know that you want to learn more and that you don't want to miss anything, and be open to what they have to say."

The American Cancer Society, the National Cancer Institute, and certain specialty organizations have clinical guidelines that can help educate nonspecialists about current treatments, side effects, essential tests, and other aspects of care that provide a basic education about specific types of cancer. "It's really not brain surgery," said Ragsdale.

By embracing the uncertainty, primary care clinicians can reap the greatest benefit from their relationships with cancer survivors, he added. "Taking care of cancer patients is extraordinarily rewarding work because they're so thankful to be around. I think it sort of gets lost that they are such a wonderful patient population to care for because they've been through a lot and they're just so thankful. It's very rewarding, and I think a lot of people forget that."

Charles Bankhead is senior editor for oncology and also covers urology, dermatology, and ophthalmology. He joined Medpage Today in 2007. Follow

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