Cancer Quality Alliance Proceedings: Caring Beyond Cancer

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The May issue of *Journal of Oncology Practice* contained a series of articles arising from the proceedings of the Cancer Quality Alliance. All involved framing communication and coordination of care for survivors of cancer as quality of care issues. The fact that this was a topic for the Cancer Quality Alliance and was published as a special series in *JOP* is a testament to how far we have come in raising awareness about survivorship as a distinct phase in the cancer control continuum. Survivors of cancer, almost regardless of their initial site of disease, are concerned about several crosscutting issues, such as appropriate surveillance for local and distant recurrence; management of long-term and late effects; addressing of noncancer-related medical problems; psychosocial issues involving fears, cosmesis, and relationships; and employment and insurance implications of having a personal history of cancer.

In addition to awareness, our attitudes toward survivorship have evolved in many ways. Physicians traditionally reserved the term “survivor” for those patients who had quite clearly been cured of their cancer, such as those who had lived at least 5 years without evidence of recurrent disease. But it is now understood that survivorship concerns begin long before that time. We do not have to wait 5 years to turn our attention to menopausal symptoms caused by cancer treatment or to address endocrine or sexual issues. The practical definition used by the Institute of Medicine in its 2005 report¹ of the survivorship period beginning at the end of primary treatment and extending to relapse or death is a useful one. However, even this has fuzzy borders, because patient desire for clarity about the follow-up plan and many long-term symptoms can clearly begin before primary treatment ends. Consequently, even more expansive definitions exist, which start at time of diagnosis, end at death, and include friends and family of the patient.

Lack of clarity about what has taken place in the treatment of a survivor's cancer, what should happen going forward, and who is responsible for each element of care (ie, survivorship care planning) is recognized by many as a deficiency in our care delivery system. Cancer survivorship care plans are tools that can potentially facilitate the transfer of follow-up care from cancer clinics to primary care physicians (PCPs), thereby addressing the looming manpower shortage in oncology.² Yet there are several barriers to survivorship planning: time, cost, and a sparse evidence base with resultant lack of buy-in among providers. Most implementations of survivorship care planning to date have involved dedicated staff such as nurses creating documents and having face-to-face meetings to review them with patients. Although some reimbursement is

possible for these visits, it generally does not cover the cost. Electronic medical record vendors are creating systems that can generate treatment summaries with little additional effort. Additional modifications to include semiautomatic generation of disease-specific follow-up plans, information on potential late effects, and contacts for psychosocial resources are promising ways of bringing survivorship care planning into routine practice. A potential lever for making this happen is the inclusion of the treatment summary and care plan as a quality measure in ASCO's Quality Oncology Practice Initiative, which is about to launch a practice accreditation process.

Regarding the evidence base for survivorship care planning, there is a general view that the face validity of survivorship care plans is so strong that rigorous evaluation is not necessary. Nevertheless, as with all aspects of health care, it is important to know whether such plans are truly effective—and if so, at what cost—to determine whether scarce resources should be used. There is one such evaluation currently underway.³ This is a pragmatic, multicenter, randomized, controlled trial involving patients who have completed active treatment for breast cancer and are ready for transition from cancer centers to routine follow-up with their PCPs. This trial is building on previous research demonstrating that follow-up provided by a patient's PCP is a safe alternative to follow-up provided in a cancer specialist clinic.^{4,5} The trial involves nine cancer centers throughout Canada, including two French-speaking centers in Quebec. Patients are randomly selected to receive usual care or a survivorship care and are stratified into two groups: those diagnosed fewer than 24 months before the study and those diagnosed 24 months or more before the study. The care plan used in this study contains the elements recommended in the Institute of Medicine report,¹ including a personalized treatment summary, patient version of follow-up recommendations, summary of what to expect in terms of visits and tests, tailored recommendation (as specified by the patient's oncologist) regarding aromatase inhibitors, and information about local supportive care resources. These documents are compiled and administered to the patient in a 30-minute educational session with a nurse. The patient's PCP receives a copy of the survivorship care plan together with guidelines on follow-up care. Outcomes include psychosocial adjustment, quality of life, patient satisfaction, health service utilization, adherence to follow-up guidelines, and economic evaluation. The study has now enrolled the planned 400 patients. Patients will be observed for 1 year for the primary outcome and 2 years for the secondary outcomes. Hence, results for the primary outcome are anticipated in late 2010 (E. Grunfeld, personal communication, July 2009).

Survivorship care planning has been proposed as the first step in ensuring quality care for survivors of cancer. Supporting this notion with a rigorous evidence base and finding feasible ways to integrate it into daily practice are the challenges we now face.

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