Survivorship Treatment Summary and Care Plan: Tools to Address Patient Safety Issues?

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Improvements in successful cancer therapies and increasing rates of early detection have resulted in more people surviving cancer than ever before. Almost 12 million cancer survivors reside in the United States (Ries et al., 2007). A report by the Institute of Medicine (IOM) concluded that a growing number of patients with cancer are surviving the disease only to face an array of new needs (Hewitt, Greenfield, & Stovall, 2005). Too often, such needs are not met.

When I was discharged after being in the hospital for five weeks having an allogeneic stem cell transplant, I did not want to leave the protection of the unit. I had 24-hour nursing care delivered by experts in their field, and I felt safe; now they want me to go home and figure out what should be done on my own.

This quotation from a cancer survivor is not an uncommon sentiment when treatment is complete; such feelings were the impetus behind the IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition*. The report proposed recommendations for improving the care and quality of life for such individuals, including a survivorship treatment summary and care plan. The report indicated a lack of evidence to support the recommendations, but “some elements of care simply make sense” (Hewitt et al., 2005, p. 154).

It makes more than sense—a survivorship treatment summary and care plan address patient safety issues. The proposed treatment summary and care plan involve communication, chemotherapy, medication reconciliation, review of prior treatment, and a discharge summary with handoff instructions. Each of those issues is addressed by the policies of the Joint Commission.

Given that noncommunication or miscommunication is to blame in many common errors, the central person with whom healthcare providers should communicate—the patient—must be the first priority. Many times, historical information on a patient is incomplete. Collecting such information and consistently reviewing it prior to making treatment decisions allow clinicians to carefully consider potential contraindications and medical concerns (Mansur, 2006).

Although this could have been ripped from the pages of the IOM report regarding the need for a care plan and summary, it was taken verbatim from an online article titled “Enhanced Medication Safety” on the Joint Commission Web site (Mansur, 2006). The article described how medication errors are more likely at times of transition and that constructing a document that contains accurate medication information along with systematic communication with the next provider and the patient are crucial to maintaining patient safety standards.

The Joint Commission has national patient safety goals for communication among caregivers (Joint Commission, 2009). In December 2008, a goal was developed regarding handoff communications between providers. In essence, the goal recommended the development of organizational standards involving how information is communicated at times of transition, uniformly implemented throughout an institution.

The IOM, American Society of Clinical Oncology, and National Comprehensive Cancer Network all endorse that patients completing treatment receive a comprehensive care summary and follow-up plan. They also recommended that such a care plan should summarize critical information such as details of the cancer diagnosis and treatment, recommendations regarding preventive practices and health maintenance, information about legal protections, and availability of psychosocial services (see Figure 1). The IOM report stressed the need for more communication and coordination among providers who treat the diverse health problems described within the report’s pages. The IOM noted that many patients may already have received some of the information during the course of their usual cancer care but that repeating and summarizing such information at the time of transition is important as well. The recommendation should take place at the completion of a survivor’s cancer therapy but, in reality, is a continuation of the informed consent process.

Informed consent is an ongoing process and not the simple act of signing a formal document (American College of Radiology, 2007). The rationale behind the informed consent process is to provide patients enough knowledge of the risks and benefits of cancer therapies to make informed decisions about what is in their own best interest. Although this
process is noble in its intent, numerous studies have shown that patients with cancer often have poor understanding and recall of what doctors tell them and have limited recall of the contents of signed consent forms (Jansen et al., 2008; McPherson, Higginson, & Hearn, 2001). When a patient is on a clinical trial and a new adverse event occurs during the study, the patient is required to sign an updated consent form. This process allows for patients to be informed of any changes that have occurred in the study since their original consent.

The IOM recommendation that every patient completing primary treatment should be provided with a comprehensive care summary and follow-up plan is an opportunity to review the risks and benefits of the administered therapies and would function as an update to the informed consent process. The treatment summary and care plan are also the beginnings of a follow-up process, not just the simple act of handing the patient a static document. The document should be used to inform not only survivors but all providers involved in their care about any medical concerns that might impact the survivors’ current and future health.

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The informed consent process and the Joint Commission have become standard protections for patients; action on the IOM recommendations has only begun to take shape in any uniform manner. A number of cancer centers looking at survivorship as a separate phase of cancer care are taking steps to change the current culture. The Lance Armstrong Foundation and the University of Pennsylvania’s Abramson Cancer Center have partnered in providing a Web-based program called the “Livestrong Care Plan powered by Penn Medicine’s OncoLink,” which allows providers and patients to develop survivorship care plans (www.livestrongcareplan.org). The program provides general guidelines and recommendations and is the first of its kind to be able to reach a nationwide audience. An issue with the OncoLife plan is that it currently does not have the ability to create a care plan that can be individualized for each patient. One attempt to address this is Journey Forward (www.journeyforward.org), a collaboration among the National Coalition for Cancer Survivorship; the University of California, Los Angeles Cancer Survivorship Center; WellPoint, Inc.; and Genentech Inc. The partnership will distribute kits to healthcare providers and patients. The kits will offer tools for providers to generate care plans and interactive tools for patients to participate in the process. The kits are tailored to oncologists, patients, and primary care physicians and will initially focus on survivors of breast and colon cancers (National Coalition for Cancer Survivorship, 2009).

The Dana-Farber Adult Cancer Survivorship Center is also testing the After Cancer Treatment Summary (ACTS), its own Web-based tool that will allow for the generation of individualized treatment summaries and care plans. The goal of an ACTS is to allow for each patient completing primary treatment within the Dana-Farber Cancer Institute to receive a treatment summary and follow-up plan. ACTS documents also are sent to the survivor’s primary care provider to address patient safety concerns involving the important transition point. The Dana-Farber Adult Cancer Survivorship Center also is working with the Massachusetts Department of Public Health to address patient safety concerns statewide. One objective of the partnership is to have all Massachusetts oncology professionals required through licensure to provide a treatment summary and care plan to all survivors completing primary cancer treatment.

If the IOM report is to be taken seriously, it will require more than just good intentions to effect change in the culture and practice of oncology. Many unresolved issues include who will complete treatment summaries and care plans, when and how they will be conveyed to patients and primary care providers, measurement of what differences they make in patient outcomes, and whether the activity will be reimbursable. The

Record of All Care to Be Given to Patient

• Diagnostic tests and results
• Tumor characteristics
• Dates of treatment initiation and completion
• Surgery, chemotherapy, radiotherapy, transplantation, hormonal therapy, and gene or other therapies provided, including agents, regimens, dosages, number and title(s) of clinical trials, indicators of treatment response, and toxicities
• Psychosocial, nutritional, and other supportive services
• Full contact information for treating institutions and key individual providers
• A key point of contact and coordinator of continuing care

Standards of Care to Be Given to Patient and Primary Healthcare Provider

• The likely course of recovery from treatment toxicities, as well as need for ongoing health maintenance or adjuvant therapy
• A description and schedule of recommended screening and periodic testing and examinations
• Information on possible signs of recurrence and second tumors
• Information on the possible effects of cancer on relationships, sexual functioning, work, and parenting, as well as the potential future need for psychosocial support
• Information on the potential insurance, employment, and financial consequences of cancer and possible need for referral to counseling, legal aid, and financial assistance
• Specific recommendations for healthy behaviors
• As appropriate, information on genetic counseling and testing to identify high-risk individuals
• As appropriate, information on known effective chemoprevention strategies for secondary prevention
• Referrals to specific follow-up care providers, support groups, and the patient’s primary care provider
• A listing of cancer-related resources and information

Figure 1. Elements of a Care Plan

Note. Based on information from Institute of Medicine, 2005.
issues must be framed through the eyes of regulating agencies such as the Joint Commission and through legal requirements such as the informed consent process, if improvements in safety concerns for cancer survivors are to be achieved.

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