Using Care Plans to Enhance Care Throughout the Cancer Survivorship Trajectory

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The Oncology Nursing Society (ONS) recognizes the importance of cancer survivorship and has launched several initiatives focused on cancer care since 2008. Cancer survivors are those who have been diagnosed with cancer, from the time of diagnosis until death. Recognizing the pivotal role that oncology nurses play in helping patients and their families navigate all phases of the cancer continuum, ONS has partnered with Journey Forward in the development of a survivorship care plan builder.

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One primary goal of the Oncology Nursing Society (ONS) survivorship initiatives are to raise awareness that survivorship care is every nurse’s responsibility. The focus and aim of the initiatives is to (a) identify resources for nurses in all specialties who may be caring for patients who are survivors of adult cancers, (b) address gaps in survivorship care, and (c) develop resources to fill those gaps. ONS has focused on the development of resources for nononcology nurses caring for cancer survivors, with a focus on the late, long-term effects that may be identified and managed by a variety of disciplines. ONS also is launching regional conferences with a focus on survivorship; the goal is to address how nursing can meet the unique needs of cancer survivors across the continuum of their lives and help bridge the gaps in their health care.

Importance of Survivorship Care

Educating patients and families across the trajectory of cancer care is crucial to improving patient care outcomes. Teaching health maintenance, as well as monitoring for long-term complications of malignancy and its treatment, are necessary to meet the basic health needs of survivors and provide the necessary screening and follow-up after treatment (Cooper, Loeb, & Smith, 2010).

The Institute of Medicine report From Cancer Patient to Cancer Survivor: Lost in Transition includes several key recommendations for cancer survivorship care, including (a) building bridges between oncology and primary care providers, (b) developing guidelines to improve quality, (c) providing professional education and training, and (d) creating a survivorship care plan based on the American Society of Clinical Oncology’s surveillance guidelines for long-term and later-term effects of cancer treatment (Hewitt, Greenfield, & Stovall, 2006; Hollowell et al., 2010).

Several organizations, including ONS, recognize that as the number of cancer survivors continues to increase, significant unmet needs still exist for providers and survivors.

Journey Forward

Several survivorship care plans are available. Journey Forward is one solution to providing comprehensive care for cancer survivors. ONS joined the Journey Forward initiative in early 2011. Journey Forward is a survivorship care plan builder that provides a free, downloadable tool that can be used by members of the oncology team to build a care plan for patients. The information that comes in the Journey Forward Toolkit (CD-ROM) includes information on care plans, billing, and resources for physicians and patients, as well as patient resources that aim to empower patients to request a survivorship care plan.

The Journey Forward program is one example of a software program that can be used to create survivorship care plans. Templates are available for planning survivorship care for three cancers, breast, colon, and lymphoma, as well as a generic template that can be tailored to the specific needs of the survivor; more are under development. The template begins with basic patient demographic and contact information of the various healthcare providers participating in the patient’s care. The second page of the template includes detailed information about the tumor pathology and staging. The “Treatment” page provides space for detailed information about treatment regimens, dates, dosages, and patient participation in...
clinical trials. That is followed by the “Treatment Plan and Summary,” which includes total dosages and a record of complications (see Figure 1). The last section is a “Follow-Up Care” plan for use in planning comprehensive care during cancer survivorship. That provides detailed information about the proposed follow-up care and timeline, as well as guidance about which healthcare provider should be giving specific follow-up at designated intervals.

**Strengths, Limitations, and Potential Applications**

Cancer treatment often requires multiple specialists and modalities in the inpatient and outpatient settings. Consequently, a single, integrated medical record seldom exists. Primary care providers often are not included in the management of the patient during active treatment, and it may be months to years after the completion of treatment before the patient returns for regular check-ups with the primary care provider (Ganz, Casillas, & Hahn, 2008). When the patient is ready to begin long-term follow-up, a copy of the entire Journey Forward summary can be printed for the patient to share with other providers. In addition, an extensive survivorship library can be found on the Web site, with many resources on survivorship that can be printed to supplement the material in the survivorship care plan. The detailed treatment record provides a comprehensive summary of completed treatment regimen(s). Data on pre- and post-treatment weights and cardiac function could be important in the long-term follow-up process. The care plan includes sections to record how the patient tolerated the treatment(s), as well as information about potential risks that may require additional surveillance and testing.

Oncology healthcare providers increasingly are interested in creating survivorship care plans. In a survey of 330 Canadian primary care providers, about 50% demonstrated a willingness to assume routine follow-up care of cancer survivors. However, they also detailed specific methods to improve care, referral, and follow-up. The most useful modalities cited by the respondents to the survey were (a) a patient-specific letter from the specialist, (b) printed guidelines, (c) expedited routes of re-referral, and (d) expedited access to investigations for suspected recurrence (Del Giudice, Grunfeld, Harvey, Piliotis, & Verma, 2009).

As many cancer survivors enter the phase of follow-up care, confusion often exists among patients and healthcare providers as to who is coordinating specific aspects of survivorship care, as well as the recommendation for intervals between visits and testing. The Journey Forward care plan is one example of an approach to reduce such confusion. It clearly delineates who should provide specific aspects of follow-up care and at what interval(s). For example, the roles of the gynecologist and primary care provider for female cancer survivors are defined clearly. Another strength of the clinical trials. That is followed by the “Treatment Plan and Summary,” which includes total dosages and a record of complications (see Figure 1). The last section is a “Follow-Up Care” plan for use in planning comprehensive care during cancer survivorship. That provides detailed information about the proposed follow-up care and timeline, as well as guidance about which healthcare provider should be giving specific follow-up at designated intervals.

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### FIGURE 1. Example of a Treatment Plan and Summary

Journey Forward care plan program is that it addresses other areas of primary care, such as recommended screening for other cancers, routine screening tests such as bone densitometry, and promotion of healthy behaviors such as diet and exercise (Toles & Demark-Wahnefried, 2008). Smoking cessation also is recommended, which is very important and often overlooked in survivors (de Moor, Elder, & Emmons, 2008).

Many cancer survivors also seek tangible reading information as they enter the long-term phase of follow-up after cancer treatment. The Journey Forward library provides many well-written resources than can be selected based on the individual needs of the survivor.

Completing cancer survivorship care plans often is a lengthy procedure. Although the Journey Forward template may require some time to complete, it can be approached incrementally as information becomes available. For example, the staging information for a woman with breast cancer could be entered at the time of diagnosis and treatment planning. Once treatment is complete, additional parts of the “Treatment Plan and Summary” section may be completed. The list of all members of the care team in the first section provides a convenient resource for the patient and the care providers. Some patients might benefit from having the page that lists the entire treatment team and phone numbers from the very beginning because everything is on one page. The background information page can serve as a reminder about the pathology and staging of the tumor. Sometimes patients have difficulty remembering all the details, and this summary provides a useful compilation of their diagnosis and treatment.

Collecting family history and information on heredity is somewhat limited on Journey Forward. A drop-down box provides choices about the number of relatives, but does not substitute for a complete assessment for hereditary risk. A notes page provides a place to enter additional information about family history and the results of genetic testing. The final section of the Journey Forward care plan does provide a place to recommend a genetics referral, if indicated.

Another limitation of the Journey Forward care plan is that it does not specifically address psychosocial concerns or risks in cancer survivors. Many long-term survivors are at risk for psychosocial distress, including depression and anxiety, indicating the need for follow-up assessment (Andrykowski, Lykins, & Floyd, 2008). Oncology nurses, aware of the limitations of the care plan, should continue to assess for psychosocial distress and offer appropriate interventions and facilitate referrals.

Implications for Nursing

Journey Forward and the organizations that collaborated to create it—ONS; National Coalition for Cancer Survivorship; University of California, Los Angeles Cancer Survivorship Center; WellPoint, Inc.; and Genentech—are committed to continually evaluating the care plan builder to ensure that it meets the needs of all who are using it. New versions are released when changes have been made. Whether it is used to increase communication among providers or offer patients more portable information about their treatment and follow-up plan, the Journey Forward care plan builder is another tool to create survivorship care plans. Clearly, more research is needed to develop optimal survivorship care plans (Jacobs et al., 2009). Future research should include identifying strategies to enhance outreach efforts for survivors and providers, identify barriers to the implementation of survivorship care plans, evaluate their impact and implement evidence-based practice, expand information availability to include searchable tools for late effects and surveillance guidelines for all types of cancers, and evaluate the satisfaction with and usage of care plans with physicians, nurses, and patients.

References


