Cancer Survivorship: Developing Clinical Practice Guidelines

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Authors' disclosures of potential conflicts of interest are found at the end of this article.

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Abstract

Cancer survivorship is a growing field, and advanced practitioners in both oncology and primary care will likely see an increasing number of cancer survivors in their practices. Despite the numerous recent publications and conferences on survivorship, the specific plan of care for cancer survivors remains unclear; this is especially true in the long-term survivorship phase. Advanced practitioners rely on clinical practice guidelines to provide a standard of care for managing various illnesses. This article describes a step-by-step process for developing a practice guideline for cancer survivors based on a national model of care. An example of the guideline is included.

J Adv Pract Oncol 2010;1:273–278

Cancer survivorship is a growing specialty, aimed at addressing the needs of more than 11 million adult cancer survivors in the United States today (American Cancer Society, 2010). This number is projected to rise as cancer is diagnosed and treated at earlier stages, and as more effective treatments lead to long-term survival. In 2005, an Institute of Medicine (IOM) report identified cancer survivorship as a distinct phase in the cancer care continuum (IOM, 2006). Twenty years earlier, Mullan (1985) identified three seasons or phases of cancer survivorship: acute, extended, and permanent (see Table 1).

The field of cancer survivorship has blossomed since the IOM report, and many publications and conferences have focused on the needs of cancer survivors. Tools and patient resources are published regularly. Organizations such as the American Society of Clinical Oncology and the National Comprehensive Cancer Network provide guidelines for monitoring in the acute and intermediate periods. Many cancer survivors will be followed by their primary care providers, and several recent articles have been written underscoring the importance of a communication process between the oncology clinician and primary care clinician that delineates the plan of care (Jacobs et al., 2009; Landier, 2009; Rabinowitz, 2009).

A plan of care ideally derives from a clinical practice guideline or algorithm that is grounded in evidence, but current guidelines for long-term survivorship are either lacking or are consensus-based. As a result, the frequency and type of surveillance tests and monitoring vary widely for each type

Table 1. **Phases of cancer survivorship**

Acute	Begins with diagnosis, includes testing and treatment
Extended or intermediate	Begins once remission is reached and treatment ceases, and continues through the period in which the risk of recurrence is highest
Permanent or long term	Begins when the highest risk of recurrence passes

Note. The duration of the phases depends upon the type and stage of cancer and the type of treatment given. The focus of this article is the long-term phase. Adapted from Mullan (1985).

of cancer, and the plan of care for the long-term cancer survivor often remains unclear (Cheung et al., 2009; Helwick, 2010; IOM, 2006; Jacobs et al., 2009). Recommendations for surveillance beyond 3 years are inconsistent or lacking, and many fail to address quality-of-life issues and late effects management (IOM, 2006; Jacobsen, 2009). Clinicians in both oncology and primary care settings may be uncertain regarding the exact care needs of their long-term cancer survivors. Clearly, a standard of care is needed to direct the individual plan of care for each patient and to ensure a seamless transition from oncology specialist to primary care provider. Ideally, the standard of care will be evidence-based and comprehensive, with the ultimate goal of improving clinical outcomes.

Given the paucity of data in the long-term survivorship phase and the time required to collect durable data, a dilemma arises: How do we develop a standard of care for this growing population of patients without an applicable body of research? Furthermore, how do we collect data that will drive the standard of care for cancer survivors, when the existing delivery of care is inconsistent? The answer lies in translating the existing research into survivorship guidelines. The guidelines then become the vehicle that drives data collection that can be translated back into clinical care (Earle, 2007; Jacobs et al., 2009; Jacobsen, 2009). Clearly, an urgent need exists for data-driven algorithms to guide decision-making regarding various aspects of cancer survivorship care.

In this article, the author draws from personal experience to describe a process for translating the existing evidence into comprehensive clinical practice guidelines for long-term genitourinary (GU) cancer survivors in a nurse practitioner–led survivorship clinic in a large metropolitan comprehensive cancer center. If you are a nurse practitioner in an oncology setting, this article can assist you in developing practice guidelines as one of the tools needed to cultivate a survivorship practice. If you are a nurse practitioner in a primary care setting, this article can increase your awareness of cancer survivors' needs and provide a template onto which you can customize care for individuals or groups of patients.

Steps for Developing Survivorship Guidelines or Algorithms

IDENTIFY THE TEAM

Before embarking on the labor-intensive task of guideline development, a team of clinical experts must be identified. In the case of the clinic described, the core team consisted of the author (a nurse practitioner), a research librarian, and a small group of GU faculty members who also serve as supervising physicians. Assistance from support staff and management was available as needed during the process.

CREATE OR ADOPT A FRAMEWORK

A framework provides a theoretical foundation from which a comprehensive standard of care is envisioned and actualized. For example, the IOM report (2006) recommends a national strategic plan for survivorship programs based on its framework or model of care. The described program's guidelines derive from a patient-centered and multidisciplinary model of survivorship care, a model that incorporates IOM recommendations (Rodriguez, 2009; see Table 2).

IDENTIFY THE PATIENT POPULATION

Eligibility criteria define the population the guidelines will serve. For example, how many years out from treatment completion must the patient be: 1 year, 3 years, 5 years? Are there any diagnostic criteria that must be met? Do the patients need to be free of disease recurrence? Due to variability in overall prognosis and recurrence

Table 2. Components of the Institute of Medicine's model of care for survivorship visit

Component	Description
Surveillance for disease recurrence:	Addresses the frequency of visits and diagnostic tests
Monitoring for late effects of cancer treatment:	Includes assessment for late effects and implementation of appropriate management strategies
Risk reduction and early detection:	Includes education and counseling related to lifestyle modification and age-appropriate cancer screenings
Psychosocial functioning:	Addresses emotional, financial, and social stressors related to cancer diagnosis and treatment

Note. These four domains become the pillars on which the survivorship clinic visit is built. Adapted from Institute of Medicine (2006) and Rodriguez (2009).

rates among the different types of cancers, the eligibility criteria may vary.

IDENTIFY THE END-USERS

The scope of the end-users should be considered. If a nonphysician provider will be using the guidelines, national and state bylaws governing his or her practice should be considered.

CONDUCT A LITERATURE REVIEW

The most important and time-consuming step in the process is a thorough literature review, which provides a foundation for the guidelines. Access to a large database of publications is essential, and support from a research librarian is helpful. Evidence-based and research-driven recommendations are preferable. For the guidelines to be comprehensive, a separate literature review must be conducted for the various components of care specific to the type of cancer. For example, in the guidelines described, a literature review was conducted for each of the four components or domains of care as follows:

Surveillance: For some cancers, guidelines exist that address the type and frequency of surveillance tests such as imaging and laboratory studies. Canadian and European guidelines should not be overlooked. In general, recommendations are easier to find for the acute and intermediate phases of survivorship and are largely absent for recommendations in the long-term phase of care.

Late effects: The physiological effects of cancer treatment are quite variable, depending on the type of cancer and treatment given. Both long-term and late effects must be considered. Long-term effects occur during treatment, last indefinitely, and require monitoring or management during the long-term phase of survivorship. Late effects differ in that they manifest *after* treatment completion (Aziz & Rowland, 2003). Although the terms "long-term effects" and "late effects" are often used interchangeably, the latter term has evolved to encompass the effects of cancer and its treatment in general.

Health promotion and preventive care: Lifestyle modification has taken a central role in health care as increasingly more studies emphasize the benefits of a healthy lifestyle. A wealth of guidelines and recommendations exist for interventions that promote health and reduce the risk of illness, both as primary and secondary prevention. Recommendations for dietary approaches, exercise, and tobacco cessation abound in the primary prevention literature, and screening and early detection guidelines are available from major organizations such as the American Cancer Society and the United States Preventive Services Task Force.

Quality-of-life and psychosocial issues: These articles may be very specific to the cancer type or treatment, or they may be more general. For example, articles highlighting the late effects of breast and prostate cancer will be easier to locate than those about the ongoing quality of life issues for patients with less common cancers. Several general articles have been published about the psychosocial implications of a cancer diagnosis on the experiences of all cancer survivors, regardless of the specific type.

SUMMARIZE EACH ARTICLE

Read and summarize the findings from each article. Compare any existing recommendations or guidelines, preferably side-by-side in a table. Look for studies on late recurrences, and document both the rates and patterns of recurrence based on stage at diagnosis and type of treatment delivered. Knowledge of these data will be essential in determining the type and frequency of surveillance tests in the long-term phase of survivorship. Additionally, it provides a roadmap for monitoring and management of late effects in your patient population.

DRAFT THE GUIDELINES

Present the summarized articles and discuss the findings with the clinical team. Incorporate the evidence from the literature review into guidelines and submit to a larger physician group for approval. In the case of the GU clinic described, separate guidelines were developed for prostate, testicular, kidney, bladder, and penile cancer, utilizing a standardized institutional survivorship algorithm template.

FINALIZE THE GUIDELINES

Send the guidelines through the appropriate clinical and administrative levels for vetting. For the GU guidelines described, the drafted guidelines were sent to the GU faculty department for final comments and revisions. They were then developed into survivorship algorithms and sent through the executive institutional process for approval. In Figure 1, the guideline for prostate cancer is displayed in the institutional survivorship algorithm format.

TRACK OUTCOMES

By following consistent algorithms for the GU cancers, data can be collected in all four domains. Specifically, recurrences, late effects, second primary cancers, and quality-of-life issues can be tracked and recorded for analysis and publication. As trends surface, the guidelines can be modified, or additional algorithms can be created to reflect management strategies. For example, in the GU cancer survivor population, guidelines can be developed for evaluating and managing hypogonadism in testicular cancer patients, or bone health issues in prostate cancer patients.

Implementation of Guidelines in the GU Survivorship Clinic

After the guidelines were approved, they were posted on the institutional intranet in algorithm format (note that the terms "guideline" and "algorithm" are used here interchangeably). The guidelines for all of the GU cancers were distributed to faculty, midlevel providers, and nurses in the referring clinics. The survivorship nurse practitioner (NP) provided inservices to edu-

Figure 1. Example of prostate cancer survivorship guideline/algorithm and how it is used in the author's GU Survivorship Clinic

1. Patients are referred and eligibility is verified. The majority of prostate cancer referrals are patients with early-stage disease treated definitively with prostatectomy or radiation therapy. Those with higher grade or stage may have additionally received hormonal ablation therapy. Eligible patients must be 5 years out from treatment and cancer-free.

2. Eligible patients are seen by the NP in the survivorship clinic. The concurrent components of the visit guide the assessment and plan of care, and disposition is determined by the outcome of each component. For prostate cancer survivors, details of each component, and possible dispositions, are as follows:

- *Surveillance:* Prostate-specific antigen (PSA) and DRE (digital rectal exam) are used to monitor disease recurrence for all patients, despite type of treatment received. For patients treated with radiation therapy or hormonal ablation, the testosterone level is checked, and if low, annual testosterone level may be monitored for bone health purposes. If the PSA is stable and there is no indication of recurrence, the patient returns in 1 year per the algorithm. Conversely, a rise in PSA or an abnormal DRE may trigger further diagnostic workup or referral back to the treating physician for evaluation and treatment.

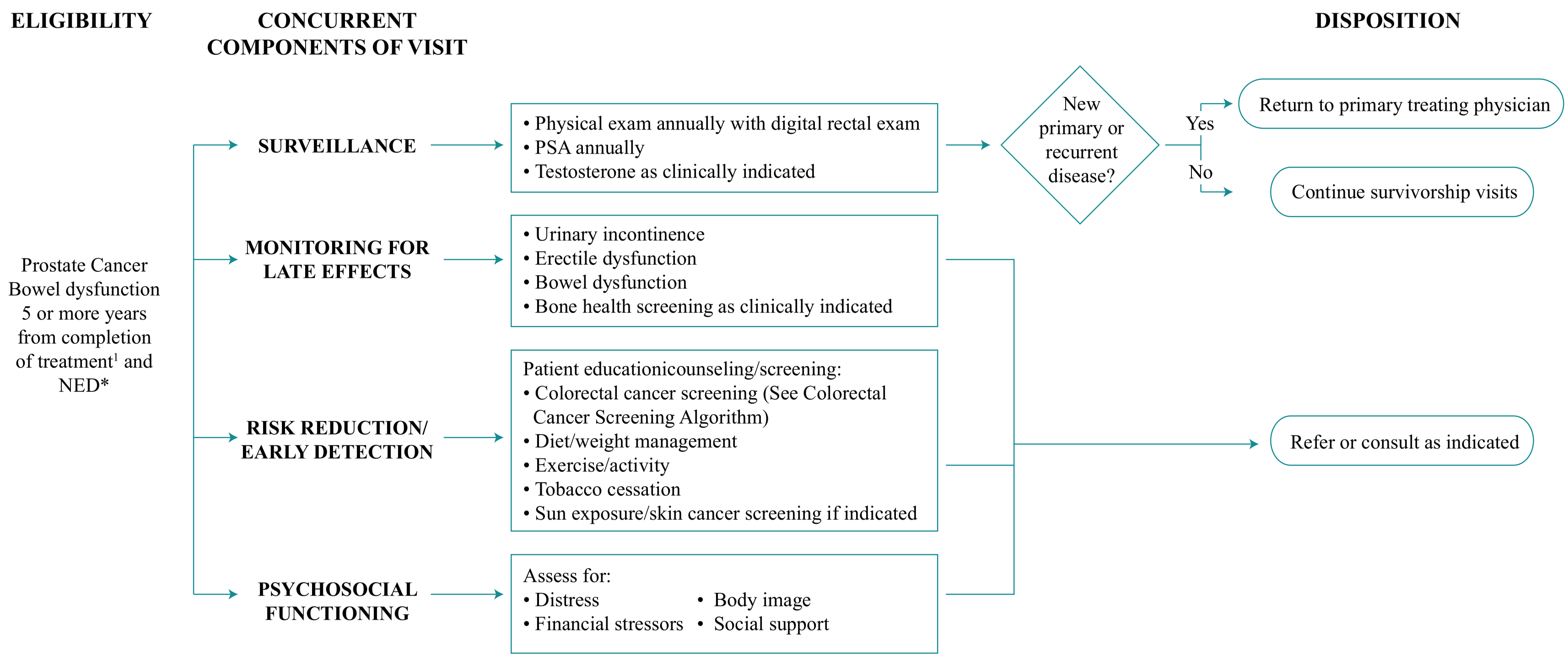
- *Late effects:* These vary based on type of treatment received. Urinary incontinence and erectile dysfunction (ED) are common after both prostatectomy and radiation therapy. Chronic bowel dysfunction can occur with radiation therapy. Bone health is a concern for patients with low testosterone. For problematic urinary incontinence, a referral is made to urology specialist for possible surgical intervention such as artificial urinary sphincter placement. For ED, a referral is made to the ED specialist (a urologist). A bowel nurse specialist is available for relentless diarrhea or constipation. If bone loss is a concern, a referral is made to a rheumatologist or endocrinologist for evaluation and treatment.

- *Risk reduction and early detection:* Colorectal cancer screening is recommended per institutional guidelines, and the patient is referred to a gastroenterologist. Skin screening is recommended based on patient's skin type and risk factors, and a dermatology referral is made as indicated. The patient is informed of the role of diet, exercise, weight management, and smoking cessation in reducing the risk of cancer and other chronic conditions, and a referral is made to the nutritionist or tobacco cessation clinic as needed.

- *Psychosocial functioning:* The patient is assessed for biopsychosocial stressors, and a referral is made to the sexuality counselor, social worker, or mental health practitioner if indicated.

Survivorship - Prostate Cancer

This practice algorithm has been specifically developed for M. D. Anderson using a multidisciplinary approach and taking into consideration circumstances particular to M. D. Anderson, including the following: M. D. Anderson's specific patient population; M. D. Anderson's services and structure; and M. D. Anderson's clinical infonnation. Moreover, this algorithm is not intended to replace the independent medical or professional judgment of physicians or other health care providers.



[1] PSA less than 0.1 for status post prostatectomy and less than 1.0 for status post radiation therapy.

* NED = No Evidence of Disease

Clinical Effectiveness V1
Approved by the Executive Committee of the Medical Staff 02/23/2010

cate staff regarding the referral process, which is as follows: Eligible patients are referred from the Urology Clinic, GU Oncology Clinic, and GU Radiation Oncology Clinic. When a patient is referred to the survivorship clinic, the NP reviews the patient's history to confirm eligibility; the NP uses the guideline or algorithm to determine diagnostic tests, which are ordered and performed prior to the first survivorship visit. Most patients are seen in the survivorship clinic every 6 to 12 months. At each visit, the NP uses the guideline to direct care. If a clinical issue arises that is outside the NP's scope, the NP contacts the supervising physician for assistance with medical decision-making. Figure 1 displays the algorithm used with prostate cancer survivors, with an explanation of how the algorithm assists the NP in the assessment of and plan for each patient.

The development and implementation of a nurse practitioner–led survivorship clinic is influenced by available resources and is driven, in part, by the size and type of practice. The described survivorship clinic is in a comprehensive cancer center, and it benefits from access to interdisciplinary teams. Institutional funding and endorsement from senior leadership were, and continue to be, essential to the success of the program. In the first year, the majority of the NP's time was spent on guideline development and start-up operations. The clinic is now in the second year of a 2-year pilot phase, and over 1,000 patients have been referred. As the practice has grown, the NP role is now predominantly clinical.

Implications for Advanced Practice

Concurrent with the development of cancer survivorship as a subspecialty is the expansion of the advanced practitioner's roles in the changing face of health care. Advanced practitioners will become critical in the impending shortage of primary care providers. In many settings, advanced practitioners are independent clinicians who follow treatment protocols and practice guidelines. Just as clinical practice guidelines exist for chronic illnesses such as hypertension and asthma, they are essential for monitoring and management of the long-term phase of cancer survivorship. Advanced practitioners working with cancer survivors in oncology settings must embrace a primary care philosophy of health promotion and chronic care management, shifting from an illness to a wellness paradigm (Jacobs et al., 2009). Advanced practitioners working in a primary care setting are already familiar with this paradigm, and by accessing survivorship algorithms, can incorporate specific information into the patient's chronic care management.

Conclusion

In summary, cancer survivors face a complex array of health issues that range from physiological to psychological to social. Guidelines serve as a roadmap for both the health-care provider and the patient. Health-care providers feel confident that they are providing comprehensive and appropriate care, while patients feel comforted in knowing their follow-up is based on a plan of care that derives from the current literature. Outcomes can be tracked and measured, and management strategies can be improved. These building blocks are essential to the evolution of the subspecialty called cancer survivorship.

DISCLOSURES

The author has no potential conflicts of interest to disclose.

REFERENCES

American Cancer Society. (2010). *Cancer Facts & Figures 2010*. Atlanta: American Cancer Society.

Aziz, N., & Rowland J. (2003). Trends and advances in cancer survivorship research: challenge and opportunity. *Seminars in Radiation Oncology, 13*(3), 248–266. doi:10.1016/S1053-4296(03)00024-9

Cheung, W. Y., Neville, B. A., Cameron D. B., Cook, E. F., & Earle, C. C. (2009). Comparisons of patients and physician expectations for cancer survivorship care. *Journal of Clinical Oncology, 27*, 2489–2495. doi:10.1200/JCO.2008.20.3232

Earle, C. C. (2007). Cancer survivorship research and guidelines: maybe the cart should be beside the horse. *Journal of Clinical Oncology, 25*(25), 3800–3801. doi:10.1200/JCO.2007.12.2325

Helwick, C. (2010). Primary care providers uneasy on care for cancer survivorship. *The Oncology Report,* Mar/Apr, 41–42.

Institute of Medicine and National Research Council. (2006). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington DC: The National Academies Press.

Jacobs, L., Palmer S., Schwartz , L., DeMichele, A., Mao, J., Carver, J., ...Meadows, A. (2009). Adult cancer survivorship: evolution, research, and planning care. *CA: A Cancer Journal for Clinicians, 59*(6), 391–410. doi:10.3322/caac.20040

Jacobsen, P. B. (2009). Clinical practice guidelines for the psychosocial care of cancer survivors. *Cancer, 115*(18 suppl), 4419–4429. doi:10.1002/cncr.24589

Landier, W. (2009). Survivorship care: essential components and models of delivery. *Oncology Nurse Edition, 23*(4), 46–53.

Mullan. F. (1985). Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine, 313*, 270–273.

Rabinowitz, E. (2009). Written care plans for every cancer patient: a colorectal cancer survivor's new battle. *Oncology Nursing,* Nov, 13–14.

Rodriguez, A. (2009). *Models for multidisciplinary cancer survivorship care.* Podium session presented at the Medical Issues in Cancer Survivors Conference, Houston, Texas.