Integrating a Prospective Surveillance Model for Rehabilitation Into Breast Cancer Survivorship Care*

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At some point during or after treatment, breast cancer may be considered a chronic illness, presenting many choices for managing the disease, its adverse treatment-related effects, other medical comorbidities as well as the biobehavioral burden of having a lifethreatening disease, even for individuals with potentially curable breast cancer. Health care models, such as the chronic care model, the medical home, and the shared care model, provide a context for building survivorship health care models. Goals and characteristics of recently proposed shared care models for cancer survivorship health care delivery closely align with the goals and concepts of the prospective surveillance model (PSM) proposed elsewhere in this supplement to the journal *Cancer*. Given these similarities, along with the growth and expansion of survivorship care models and impending mandates for delivery, there is merit to considering how implementation of the PSM can be integrated with models of survivorship care delivery. The PSM model will likely face many similar challenges and barriers that have impeded widespread dissemination of other survivorship models of care. There exist opportunities to integrate lessons learned as well as to align efforts to achieve greater impact on the shared goal of improving health outcomes for breast cancer survivors. *Cancer* 2012;118(8 suppl):2201-6. © 2012 American Cancer Society.

KEYWORDS: breast neoplasms, rehabilitation, surveillance, physical function, prospective surveillance.

INTRODUCTION

An important new challenge facing health care professionals, patients, families, and their support networks results from the significant progress made in prolonging survival after breast cancer treatment. At some point during or after treatment, breast cancer may be considered a chronic illness, and this presents many choices for managing the disease, its adverse treatment-related effects, and other medical comorbidities as well as the biobehavioral burden of having a life-threatening disease with chronic implications. The myriad of medical and functional impairments faced by patients during and after treatment can be challenging to manage and requires vigilance and resourcefulness on the part of the patient, family, and provider along with a concomitant network of care to enable breast cancer survivors to return to and continue with the lives they need and wish to live. Ongoing surveillance for local or regional recurrence, as well as for negative functional sequelae of treatment, is of significant concern for patients and health care providers, because these factors are associated with poor overall survival. Models for health care delivery, cancer survivorship care plans, clinical practice guidelines, and consensus on outcomes have been identified as mechanisms that may aid in streamlining a more comprehensive approach to quality care delivery throughout the survivorship period.

In this supplement issue of *Cancer*, a novel prospective surveillance model (PSM) for rehabilitation after breast cancer treatment is introduced. This model proposes a standardized framework for interval assessment from the point of breast cancer diagnosis through survivorship in an effort to promote early identification and intervention for physical impairments that may impede a patient's functional ability. Consideration should be given to integration of the PSM with emerging efforts in cancer survivorship care delivery. The purpose of this article is 3-fold: first, to review several health care models that have informed the burgeoning literature on cancer survivorship care to provide historic context; second, to

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provide a brief overview of current constructs for implementation and delivery of survivorship care plans; and third, to explore a potential mechanism for incorporating prospective surveillance for physical impairments related to breast cancer treatment into these models.

Health Care Models for Managing Complex Chronic Health Issues

The concept of using a health care model for managing complex chronic conditions is not a new idea. Models have evolved as guiding constructs in health care and serve to outline broad concepts and features that are essential to providing comprehensive care for a wide array of disease states. ⁵⁻⁸ The primary features of health care models are to strive to achieve high-quality care as well as to promote health maintenance, effective illness intervention, and enhanced efficiency of care delivery. ^{9,10} Common key elements within a model serve to guide care delivery and include describing which health care providers are involved with care delivery, outlining the operational processes of care delivery, and identifying anticipated clinical outcomes and mechanisms for measuring these outcomes.

In the United States, the concept of the medical home was proposed in the 1960s as an approach to managing the complex health care needs of special needs children. 11 The concept has evolved as an effort to facilitate a partnership with individual patients, their physicians, and families to improve the delivery of health care. 12 The National Committee for Quality Assurance has used the medical home model to identify important tenants of care, including appropriate provider involvement, optimal process for patient-centered care, accurate and relevant data capture, suitable communication strategies between patients and providers, and ideal quality metrics for outcomes assessment. This strategy identifies needed components of care that specifically relate to chronic illness and multisystem management needs. It assumes comprehensiveness, coordination, continuity of care, and ready access. These goals can serve as outcome measures. 13 Although implementation of this model is in its early stages, and demonstrations tend to be focused toward managing a single chronic condition (rarely inclusive of cancer screening or oncology conditions), the medical home model, with adaptation, may offer a construct for comprehensive cancer survivorship care. 14

The chronic care model (CCM), which was introduced by Wagner et al in 1996, is another framework that was designed to improve the management and health outcomes of individuals with chronic illnesses and was derived from the concept of the medical home.⁸ Wagner

et al observed that effective interventions tend to include the following features: the use of a standard protocol; reorganization of practice systems and provider roles to align with the protocol, improve patient education, and increase access to expertise through specialty care providers; and greater availability and sharing of clinical information among providers and patients.9 Services and treatments must be consumer and family centered. Although the CCM was designed to address care at the macrosystem level, this approach has spawned modification of the model to emphasize 1 or another specific aspect(s) of disease management. The CCM was perceived as applicable to healthy aging: It was used as the basis for the active aging model and has been adapted to address mental illness through the behavioral model. 15-17 The broad features of the CCM are generalizable to cancer as a chronic disease and can serve to address survivorship issues. Furthermore, many CCM features are complementary to the key components within the PSM.

Another model that was designed to manage complex health issues is the shared care model. This model relies on joint participation in care management between primary care and specialty care physicians. It is informed by an education program and information exchange that is more robust than simply making referrals to specialists. 18 Through this approach, primary care providers and specialists share joint responsibility for an individual's care and monitoring and freely exchange patient data and share skills and knowledge to facilitate optimal care. It has been used in a wide variety of settings (community, clinic, etc) and diagnostic groups (eg, arthritis, diabetes, mental illness, cancer). 7,19 Shared care models for collaborative cancer care, to date, have been primarily theoretical and have offered little in the way of recommended interventions or strategies for model integration and promotion.⁵

Studies have tested the clinical effectiveness of these macrosystem models on various chronic disease conditions, and most have demonstrated positive clinical outcomes, including enhanced efficiency of care delivery, improved disease management, and improved patient satisfaction 16,20-23; whereas cost-effectiveness studies have demonstrated mixed results. 24,25 However, these health care delivery models can succeed only when health care providers are aware of the model's clinical benefits and are willing to actively collaborate with other providers and enhance the extent of shared clinical duties in an effort to optimize patient care. 26-29 Additional barriers to implementation include insufficient resources, poor infrastructure, and poor or lacking provider incentives to implement that model.

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Currently, to our knowledge, no model for care delivery exists or has been studied related to the chronic functional health issues of cancer survivors. Understanding the evolution and extrapolation of these chronic disease models has relevance to cancer survivorship, because it enables health care providers and patients to contextualize a framework for ongoing surveillance. The PSM takes a first step toward outlining a model for functional assessment and ongoing care for the breast cancer survivor.

Models for Managing Health Issues of Breast Cancer Survivors

Addressing the complexities of health care for long-term cancer survivors is a relatively new phenomenon. In 1986, the National Coalition for Cancer Survivorship was formed as the first organization dedicated to addressing cancer survivors' issues.30 In 1996, the National Cancer Institute established the Office of Cancer Survivorship, providing federal resources to target survivorship initiatives.³¹ Only in the past decade have survivorship issues received widespread attention: The President's Cancer Panel³² was among the first efforts to focus on this period in the cancer care continuum. The seminal 2006 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition, has played a key role in accelerating both research and clinical efforts to understand and improve the quality of care and long-term outcomes for a growing population of cancer survivors, including the development of models of care to meet their needs.² That report was preceded and informed by a 2003 IOM report focused on the needs of childhood cancer survivors.³³ The IOM identified 4 components of survivorship care as "essential": 1) prevention of recurrent and new cancers and other late effects; 2) surveillance for cancer spread, recurrence, second cancers, and other late effects; 3) intervention for consequences of cancer and its treatment; and 4) coordination between care providers to ensure survivor needs are met. A concomitant goal is to eliminate the fragmentation of care and gaps in how these needs are addressed during the post-treatment survivorship period. These goals align closely with those of the PSM and encourage consideration about how such a model can be integrated with survivorship care delivery.

As a result of the IOM report, models of cancer survivorship care delivery have been described in greater detail in the medical literature. These efforts have explored the possibilities of extrapolating both the CCM and the shared care model to the cancer care continuum by outlining cancer-specific, evidence-based interventions, by delineating the support and resources necessary

to assist primary care providers in directing care, and by enabling cancer survivors in self-management and health promotion. By using the shared care model as a template, Oeffinger and McCabe demonstrated how care of the cancer survivor can be shared between the oncology specialist (oncology physician/nurse practitioner/advanced practice provider) and the primary care physician (PCP). The model promotes improved communication between care providers and enhanced use of primary care and other health care professional resources, and it provides a structured mechanism to enable quality monitoring.

The shared care model also potentiates better use of primary care resources for ongoing care. It is anticipated that a projected shortage of oncologists, compounded by a rising demand for oncology services, will shift follow-up cancer care to primary care domains. 37,38 Clear role delineation will be needed for both oncology practitioners and PCPs to streamline follow-up care of cancer survivors and can be realized through the shared care construct. 39,40 Furthermore, given the projected imbalance between physician supply and service demand, it is critical to proactively integrate a wide array of health care professionals into cancer survivorship care. For example, a growing number of centers use nurse practitioner-led models of survivorship care. 10,35,41-43 Not only is it crucial to consider how the PSM will tie into these diverse models of survivorship care, but it is important to recognize that the PSM offers the opportunity to integrate another complement of professionals into the routine delivery of survivorship care: specifically, physical and occupational therapists and other rehabilitation professionals.

Although randomized trials in the setting of breast cancer have demonstrated that PCP-led follow-up care for survivors is equivalent to oncology specialist follow-up care with regard to identifying recurrence-related, serious clinical events and improving health-related quality of life, evidence also highlights disparities between these 2 provider groups regarding the provision of cancer care and adherence to cancer care guidelines. In addition, uncertainty exists about the role of different providers in providing cancer care.

Representing the second of 10 IOM recommendations (Fig. 1),² survivorship care plans (SCPs) have received the most attention,⁴⁸ resource development,⁴⁹⁻⁵¹ and effort toward integration into clinical practice.^{42,43,52-60} SCPs and mechanisms for their dissemination have become a central clinical focus of oncology care providers.^{34,35,40,41,54,57,58,60} The shared care model promotes written and verbal communication from the oncology team to the PCP at a recommended set of specific time points to communicate an SCP.

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IOM Recommendations for Survivorship Care

- Raise awareness of cancer survivorship
- 2. Provide a care plan for survivors
- 3. Develop clinical practice guidelines for cancer survivors
- 4. Define quality health care for cancer survivors
- 5. Overcome health care system challenges
- 6. Address survivorship as a public health concern
- Provide survivorship education and training of health care professionals
- 8. Address employment concerns of cancer survivors of all ages
- 9. Improve access to adequate and affordable health insurance
- 10.Invest in research

Survivorship Care Plan Components

- Prevention of recurrent and new cancers and other late effects
- Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
- 3. Intervention for consequences of cancer and its treatment
- Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met

Figure 1. The Institute of Medicine (IOM) recommendations for developing a survivorship care plan are listed (adapted from: Hewitt M, Greenfield S, Stovall E, eds. Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press; 2006²).

The SCP is a dynamic document intended to provide comprehensive summaries of cancer treatments and their inherent risks to both the primary care provider and the patient, thus guiding follow-up survivorship care and providing a tangible opportunity for integration with the PSM.⁴³

The delivery of SCPs has become a quality cancer care measure, like the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative⁶¹; however, to date, payer and regulatory mandates for such plans are pending. However, the American College of Surgeon's Commission on Cancer, which accredits approximately 80% of cancer centers in the United States, has proposed holding accredited cancer centers accountable for the widespread delivery of survivorship care plans by 2015.⁶² Thus, as clinical implementation of SCPs continues to increase, opportunities for integration of the PSM will grow.

Integrating the Prospective Surveillance Model Into Existing Models of Survivorship Care

The goals and characteristics of survivorship care delivery models closely align with the goals and concepts of the PSM proposed in the accompanying article by Stout et al in this supplement. Given these similarities, along with the growth and expansion of survivorship care needs, increasingly limited resources, and impending mandates for care delivery, it is necessary to consider how the PSM can be integrated with models of survivorship care.

An obvious symbiosis exists between these constructs, because the PSM provides many of the elements

noted as vital in the IOM conclusions, including education regarding the likely course of treatment toxicities, provision of ongoing health maintenance care and guidance for healthy behaviors, description of periodic functional tests and measures, education regarding possible late and long-term effects of treatment, and referrals to specialists as needed. These common elements are synonymous with the preferences for SCP content identified by patients in qualitative studies. ^{56,60,64-67} Furthermore, the goals also meet the needs cited by PCPs for concrete guidance on signs and symptoms of late effects and resources for clinical management. ⁶⁵⁻⁶⁷

The model focuses on identifying symptoms and functional issues amenable to rehabilitation and linking these to interventions. Inclusion of the PSM involves integration of an in-person rehabilitation evaluation and provides a check list of functional tests and measures that should be considered in ongoing patient assessment. This approach enables an individualized plan for ongoing surveillance and management of physical impairments best treated by rehabilitation specialists, and it also incorporates recommendations for physical activity and exercise. In a recent study of SCPs delivered to breast cancer survivors across the LIVE-STRONG Network of Survivorship Centers of Excellence, it was reported that SCPs did not consistently incorporate content on recommended health promotion behaviors, such as exercise, nor were individualized referrals routinely incorporated. 43,68 Integration with the PSM, to a great extent, would help to overcome these deficits by providing ongoing and dynamic assessment and intervention.

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The PSM will face many challenges and barriers similar to those experienced by other health care delivery models, including provider awareness, resource availability, infrastructure needs, and cost considerations, as noted above. There are opportunities to integrate the PSM using lessons learned from the historic perspective of other health care delivery models as well as through aligning efforts with the growing implementation of SCPs to achieve greater impact. Integration of the PSM offers added value to the patient and provider team, because it adds a critical dimension to survivorship care planning that heretofore has been under emphasized.⁶⁹

The model of shared survivorship care offers an obvious platform for prospective surveillance for physical impairments. The PSM functional assessment then becomes an integrated part of the SCP, which is communicated to all members of the medical team and serves to inform and promote follow-up care and communication points between oncologists and primary care providers.³⁴ Current ASCO templates for baseline documentation and communication⁵¹ also easily could be modified to incorporate baseline PSM assessments, interventions, and plans of care.

Summary and Conclusion

Features of the survivorship care models presented here can be aligned with the PSM model for breast cancer rehabilitation toward the goal of improving the overall health of breast cancer survivors. Prospective surveillance for physical impairments needs to be an integrated part of the care plan to enable identification of key clinical signs and symptoms that require evaluation and treatment. The PSM offers specific delineation of the sequelae likely to contribute to functional decline and highlights tests and measures for the identification of physical impairment and recommendations for referral to specialty rehabilitation providers.

Optimal survivorship care constructs are still being crafted and studied, and models of care are only beginning to be developed and tested. Thus, it is an opportune time for proponents of the PSM to collaborate with leaders in survivorship care models to integrate these complementary approaches. Our shared goal is to develop the evidence base to support clinical practice guidelines and improve the medical and functional health of all breast cancer survivors.

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