Prospective Evaluation of Physical Rehabilitation Needs in Breast Cancer Survivors*

A Call to Action

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For most women in developed countries, breast cancer has become a survivable chronic disease. Improved survival has been achieved through steady improvements in early detection and therapy and has contributed to a growing population of breast cancer survivors. However, the natural emphasis on improved survival overshadows the reality that breast cancer survivors face a cascade of post-treatment challenges, principally surveillance for recurrence, but also near-term and long-term, treatment-related medical and psychological sequelae. One set of these sequelae includes physical impairments, such as fatigue, pain, postsurgical and persistent upper-quadrant issues, chemotherapy-induced peripheral neuropathy, lymphedema, cardiotoxic effects of chemotherapy and radiotherapy, weight gain, bone health challenges, and arthralgias. It is known that these impairments, many of which are amenable to rehabilitative and exercise interventions, lead to limitations and restrictions in the performance of common daily activities, including occupational and home activities.

There are multiple barriers to addressing physical impairments secondary to treatment. One barrier is the fractured delivery of health care: Surgery, radiation, chemotherapy, and survivorship follow-up all may occur in separate health care systems.² Other barriers are lack of established relationships between the oncology, general surgery, and plastic surgery professions and the rehabilitation and exercise professions, like what exists between the orthopedic surgery and rehabilitation professions. Furthermore, patients and their health care providers may have a sense that these sequelae are "expected" and normal and that they simply need to be tolerated.³ There is a general lack of understanding of the role that rehabilitation and exercise can have in ameliorating commonly experienced physical impairments after breast cancer. Even when all treatment occurs in the same health system, and even when that health system has electronic medical records, the referral

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The articles in this supplement were commissioned based on presentations and deliberations at a Roundtable Meeting on a Prospective Model of Care for Breast Cancer Rehabilitation held February 24-25, 2011 at the American Cancer Society National Home Office in Atlanta, Georgia.

We gratefully acknowledge the many contributions of roundtable panel members, both at the meeting and subsequently. Their expertise, reflection, and points of difference have helped shape development of the model.

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The views expressed in this article are solely those of the authors and are not necessarily reflective of the official policies or positions of the Department of Navy, Department of Defense, or the United States Government.

The opinions or views expressed in this supplement are those of the authors and do not necessarily reflect the opinions or recommendations of the editors or the American Cancer Society.

*A Prospective Surveillance Model for Rehabilitation for Women with Breast Cancer, Supplement to Cancer

DOI: 10.1002/cncr.27471, **Received:** October 27, 2011; **Accepted:** November 7, 2011, **Published online** April 6, 2012 in Wiley Online Library (wileyonlinelibrary.com)

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of patients to rehabilitation specialists for evaluation and follow-up for treatment-related adverse effects occurs infrequently.²

The number of survivors seen in oncology clinics is growing and is expected to strain available and expected resources in the near future.⁴ Survivorship care research and clinical endeavors are underway to develop creative solutions to meet the unique needs of this growing population, including resources and access issues. Thus far, however, most cancer survivorship care initiatives have been notably inattentive to physical rehabilitation needs and inclusion or capacity to refer patients to rehabilitation specialists (eg, physical medicine and rehabilitation physicians, physical and occupational therapists, and clinical exercise physiologists) during or after treatment.⁵ One objective of this supplement of the journal Cancer is to stimulate discussion in the field of oncology regarding the importance of including rehabilitation specialists, rehabilitation interventions, and exercise in the multidisciplinary survivorship care approaches after breast cancer and to promote steps toward the inclusion of prospective surveillance for rehabilitation needs in survivorship initiatives.

A small planning group, including representatives of the American Cancer Society, organized an international meeting to review the published and clinical practice evidence regarding the physical rehabilitative needs of breast cancer survivors and possible ways to reduce the burden of unmet needs in this growing population. The meeting was held in Atlanta, Georgia, in February 2011. One question that arose—and is addressed in depth in an accompanying piece by Gerber et al.6—is how best to incorporate a prospective evaluation and treatment approach to improve the physical rehabilitation of breast cancer survivors into ongoing efforts to develop multidisciplinary approaches to meeting the health needs of this growing population. This discussion takes place at what may be an opportune time: the American College of Surgeons Committee on Cancer has proposed that all accredited cancer treatment centers will be required to have survivorship care planning as part of standard of care by 2015. Furthermore, the National Institutes of Health has called for the formation of a "blue-ribbon panel" on the overall topic of rehabilitation, which is expected to include attention to cancer rehabilitation. Thus, this is a timely opportunity for discussion of physical rehabilitation and exercise as elements essential to ensuring the health of the growing population of breast cancer survivors.

Although breast cancer survivors face a broad range of disease-related and treatment-related issues, our discus-

sions were purposely focused on treatment effects amenable to physical rehabilitation and exercise interventions, with full acknowledgement that these effects do not encompass the totality of medical and psychosocial needs of breast cancer survivors. The relative merits of this narrower focus versus inclusiveness were debated. The isolation of physical from psychological factors, particularly emotional distress, anxiety, and depression, may seem to fail to acknowledge the contribution of mood disorders to physical impairments, including those listed in the model. Indeed, pain, fatigue, and depression frequently co-occur as a symptom cluster. ^{7,8} We also acknowledge the demonstrated efficacy of exercise interventions to improve psychosocial outcomes in cancer survivors. Thus, our inclusion criteria ultimately were based on the available evidence and relevance to physical rehabilitation interventions for particular sequelae, with full appreciation of the interrelatedness of physical and psychological effects and the importance of psychological assessment and care for breast cancer survivors.

In addition to discussion regarding the specific sequelae for inclusion, there is acknowledgement of the ongoing discussion in the field of oncology regarding the frequency and severity with which any physical impairment occurs and persists after breast cancer treatment. It is noteworthy that the medical, surgical, and radiation oncology literature consistently reports observing fewer breast cancer survivors with physical impairments amenable to rehabilitation and exercise compared with the nursing, physical medicine and rehabilitation, physical therapy, occupational therapy, and exercise physiology literature. The discrepancies in the estimates of the burden of impairments between these fields likely result from differences in timing and type of assessments, thresholds for diagnosis, and length of follow-up. In an accompanying article, this issue is addressed prospectively using data from a cohort of more than 200 survivors who were followed for 6 years. 10 These estimates differ from prior studies in that the primary outcome of interest was the proportion of survivors with 1 or more treatment-related physical impairments at any of the assessment time points. One of the basic tenets of screening and surveillance is that the condition is sufficiently prevalent in the at-risk population to justify testing. The results, although admittedly a preliminary examination of the issue, make a compelling case that there is value to ongoing surveillance for physical impairments, even up to 6 years postdiagnosis; 60% of women had 1 or more treatmentrelated impairments at each time point. 10

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Additional tenets of screening and surveillance include requirements that screened conditions are serious, have a known and acceptable treatment, and that the treatment of these conditions at an earlier stage results in better outcomes than treatment at the point when the disease would be diagnosed based on clinical signs and symptoms. There is also the requirement that the assessment process for early detection should be sensitive, specific, and delivered at reasonable cost and that harms of intervention, if any, do not exceed benefits. Articles in this supplement discuss various aspects of these criteria, although, admittedly, there is further work to be done.

The recommendation that breast cancer survivors should be screened for early indications of treatmentrelated sequelae is somewhat complicated by the observation that some women with positive test results have conditions that are not progressive, will resolve on their own, and would not ever have developed symptoms, ie, the condition would not ever have been detected in the absence of screening. This is an example of over diagnosis. Rates of over diagnosis have been estimated for screening diagnosed breast cancer11 but remain unknown for treatment-related sequelae amenable to rehabilitation and exercise interventions. When early signs of impairment are noted and that impairment has a high probability of worsening if allowed to progress, which ultimately may result in a worse, permanent disability, there is an ethical obligation to treat the condition. At the same time, in advance of screening, there is an ethical obligation to engage patients in a process of shared decision making about the benefits, limitations, and potential harms associated with screening for treatment-related impairments. Discerning the difference between screendetected early signs of impairments that will progress and, thus, may benefit from early detection versus those that are nonprogressive and, thus, result in over treatment is a research challenge that should be a top priority.

The question of whether there is "enough" evidence to warrant proposal of prospective evaluation and treatment of physical impairments that are amenable to rehabilitation and exercise was a topic of discussion before, during, and after the Atlanta meeting. Indeed, it is the central question for any proposed change in clinical care. The evidence presented in the articles in this supplement address this central question. These articles reveal the gaps and uncertainty in the literature side by side with observational evidence that prospective surveillance for specific physical impairments (lymphedema) may result in better outcomes, ¹² compelling evidence for the efficacy of rehabilitation or exercise in the treatment of specific impairments, ¹³⁻¹⁷ and pleas from patients of the reduce avoidable

morbidity and suffering and to commence with identifying and treating physical impairments early.

In addition to resting on an evaluation of the quality of the available scientific evidence and reported patient experience, changing practice likely depends on the cost and complexity of the proposed change in clinical routines. The issues relating to the economic implications of the proposed prospective surveillance model are reviewed in an accompanying article by Cheville et al. ¹⁸

At the meeting in Atlanta and in correspondence while writing the resulting articles, there has been broad agreement that there is a compelling body of evidence that rehabilitative and exercise interventions benefit breast cancer survivors and that establishing better ways of connecting survivors with these interventions is warranted. This is the central objective of the proposed prospective surveillance model. That said, there are honest differences of opinion regarding how best to translate this central goal into practice. One example is the question of whether there is high enough prevalence of any physical impairment to warrant prospective surveillance. There were questions about how best to identify impairments and which types of clinicians have the appropriate training to screen for physical impairments that are amenable to rehabilitative and exercise interventions. Another example was the fear that creation of a prospective surveillance system would impose yet more barriers to exercise in community settings, despite increasing evidence of the safety and broad benefits of exercise among cancer survivors. 19 The uncertainty regarding the best approach to achieving the central objective of the prospective surveillance model (identifying impairments early, connecting survivors with interventions) is resolvable with additional evidence. Research is needed to elucidate the risks, benefits, costs, feasibility, and logistics of early identification of physical impairments as well as dissemination of rehabilitative and exercise interventions into the standard of care for breast cancer survivors. We hope this supplement serves as a call to action to include rehabilitative and exercise expertise in ongoing efforts to devise creative, multidisciplinary solutions to addressing the needs of the growing population of breast cancer survivors.

In the articles that follow, we seek to accurately depict the perspectives of clinicians and researchers of many disciplines. Building consensus on the issues presented herein is an unfolding process that includes finding a common vocabulary. There was lively discussion of the most appropriate terms to use in describing several of the impairments discussed herein. For example, suggested terms to describe the anatomic region affected on the side of treatment included "upper body," "upper quadrant,"

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"upper extremity and trunk," and "upper body quadrant." We allowed authors of the articles that follow some variability in the use of terms, in acknowledgement of differences of the disciplines represented among the author groups. Authors of the articles in this supplement were asked to clarify their use of terms either explicitly or contextually, particularly when it was noted by the editorial committee that a term was being used differently in multiple articles in the supplement.

We believe there is sufficient evidence to warrant the inclusion of rehabilitation and exercise expertise within the multidisciplinary survivorship health care models currently under development. Evidence is mounting that the physical impairments and functional limitations faced by women with breast cancer could be minimized to become minor issues if caught early and treated appropriately. There is compelling evidence that rehabilitative and exercise interventions are beneficial. The overarching objective, for us all, is to improve the quality and quantity of life for all breast cancer survivors. It is to these women that we dedicate the work of creating, writing, editing, and compiling this supplement.

FUNDING SUPPORT

Support for this meeting and supplement was provided by the American Cancer Society through The Longaberger Company®, a direct selling company offering home products including hand-crafted baskets made in Ohio, and the Longaberger Horizon of Hope® Campaign, which provided a grant to the American Cancer Society for breast cancer research and education.

CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

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