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Cancer Survivorship and Cancer Rehabilitation: Revitalizing the Link

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Increasing national attention focuses on the specialized needs of disease-free survivors of cancer.¹⁻⁵ This is a direct reflection of the growing number of survivors of cancer in the US, currently estimated at almost 12 million,⁶ and the many challenges of delivering optimal health care to these individuals. The health system will be further stressed by the aging of the US population during the next 25 years and the corresponding increase in long-term survivors. Most cancers are diagnosed in older adults who have preexisting comorbid conditions that are exacerbated by cancer treatment. The convergence of pre-existing and new chronic conditions in older survivors of cancer is a major challenge for health care policy and delivery. To meet this challenge, we must develop a model of care delivery to maximize the health and well-being of survivors of cancer, focusing on effective symptom management, prevention of late effects, and health promotion. It is time to revitalize the link between cancer survivorship and cancer rehabilitation and investigate a new model of comprehensive cancer rehabilitation, involving a multidisciplinary team of providers that aims to optimize the patient's physical, psychologic, vocational, and social functioning given the limits imposed by the chronic or late effects of cancer treatment and other comorbid conditions.

History of Cancer Rehabilitation in the United States

The National Cancer Act of 1971 launched an ambitious national research program to improve cancer diagnosis, treatment, and care delivery. It funded clinical cancer research centers and demonstration projects in the late 1970s to assess rehabilitation needs and implement and evaluate interventions to address these needs.⁷⁻¹¹ By the early 1980s, several well-established programs throughout the country provided rehabilitation services to patients with cancer.⁹ These services were largely hospital-based, integrated with other rehabilitation services or oncology departments, and involved a multidisciplinary team of providers.⁹

What happened during the past 30 years to change this situation? In the 1980s, most cancer treatment occurred in tertiary, large-volume, specialized centers.¹² A combination of treatment advances, earlier detection, less radical surgery, use of combined-modality therapy, and prolonged outpatient adjuvant endocrine therapy reduced the length of hospital inpatient care; now the vast

majority of oncology care occurs in practices that are physician-owned rather than hospital-based.¹³

The surgical management of breast cancer is illustrative. By the 1980s, the radical mastectomy was no longer being performed, thus reducing its related serious arm and shoulder morbidity. By the 1990s, breast conserving surgery was established as the preferred surgical treatment.¹⁴ Increased diagnosis of small tumors detected by mammography led to even shorter breast surgery hospitalizations and limited or no axillary dissections, moving primary breast surgery to the outpatient arena. Thus, the extensive need for postmastectomy rehabilitation diminished, the opportunity for hospital-based rehabilitation was limited, and systematic delivery of postoperative rehabilitation virtually disappeared. Most women today do not receive the physical^{15,16} and psychosocial³ services that were so integral to those earlier rehabilitation programs. When cancer rehabilitation services are prescribed today, they tend to have a one-dimensional focus rather than comprehensive assessment and treatment of needs. For example, in a study of services offered by National Cancer Institute–designated comprehensive cancer centers, 70% of centers had a lymphedema management program, but no comprehensive cancer rehabilitation programs were reported.¹⁷ In the ≥ 30 years of experience of the authors (P.G. and J.R.), similar patterns have occurred for other common cancers (lung, colorectal, bladder, head and neck, and gynecologic).

Changing Patterns of Cancer Care Delivery

Changes in US cancer care delivery toward a community-based delivery system have exacerbated the disconnect between cancer survivorship and cancer rehabilitation.¹³ With less complex surgical treatments and prolonged adjuvant chemotherapy, traveling long distances to a tertiary center became undesirable, and community cancer centers were established. Community standards for cancer care were established and fostered by the American College of Surgeons and its hospital certification programs.¹⁸ The National Cancer Institute contributed to the decentralization of cancer care by enabling the widening group of community practitioners to offer their patients access to clinical trials through its Community Clinical Oncology Program.^{19,20}

Despite delivering high-quality cancer care in the community, the dissemination of cancer rehabilitation services into this setting has been limited. Poor integration of these services into current tertiary center treatment programs, where trainees lack exposure to rehabilitation services and appreciation of their added value, limits uptake and provision of these services when these oncologists ultimately join community practices or hospitals. Fragmentation of cancer care in the community setting further exacerbates this problem. Although the hospital is a focal point for surgery and radiation, most medical oncology care is delivered in private office settings, and there is no common electronic medical record allowing all providers caring for the patient to communicate about the patient's needs. Finally, as discussed by others, cancer care and rehabilitation care are disconnected even in some institutions that have both services,^{15,21,22} and many community settings lack rehabilitation care altogether.

Financing of Health Care and Rehabilitation Services

Despite the potential benefits of outpatient cancer rehabilitation services, accessing this care entails navigating multiple barriers. The diversity of health insurance coverage with its broad mix of payers and numerous plan types has complicated authorization and reimbursement. Most rehabilitation services are fully or partially covered through the majority of insurance plans. For example, Medicare offers coverage for rehabilitation services such as physical and occupational therapy in the community outpatient setting. However, the limited coverage schedule, funding caps, and strict guidelines for continuation of therapy may mean that some survivors of cancer cannot receive their recommended therapy. Private health insurers are mandated to cover physical and occupational therapy services in some states,²³ but coverage for these services can vary widely and have substantial copays that discourage the financially stressed survivor of cancer. Finally, accessing rehabilitation services is dependent on referral and the ability of providers and administrative staff to understand and work with health insurance plans to obtain services. Providers must be able to ensure timely preauthorizations and prescriptions for continuation of services, locate high-quality in-network providers, understand referral processes, and assist patients in making sense of complex benefit schedules. At present, the existing patchwork of state and federal mandates, complex benefits schedules, and variable patient cost sharing among health insurance plans may be contributing to the underuse of cancer rehabilitation services.

Needs of Survivors of Cancer Today

The multidisciplinary team approach central to comprehensive cancer rehabilitation is ideal for meeting the needs of survivors of cancer. First, it assesses and treats the chronic effects of cancer and prevents or mitigates the effects of late-occurring sequelae. Depending on the specific treatment exposures, survivors of cancer can face numerous adverse consequences of cancer treatment, many of which are amenable to rehabilitation interventions. These include fatigue, depression, anxiety, fear of recurrence, cognitive dysfunction, pain syndromes, peripheral neuropathy, sexual dysfunction, balance and gait problems, upper or lower quadrant mobility issues, lymphedema, bladder and bowel problems, stoma care, problems with swallowing or dysphagia, and communication difficulty.²⁴ Although other models of care assess and treat these problems, the team in the comprehensive rehabilitation model evaluates the sum total of problems that a survivor faces and coordinates treatment. Second, comprehensive cancer rehabilitation can address pre-existing or treatment-related

comorbid conditions. Diabetes, cardiovascular disease, congestive heart failure, bone loss, adverse body composition, and renal disease are common in survivors of cancer¹ and can be managed through rehabilitation interventions including medication, counseling, behavior change and promotion of healthy diets, physical activity, and weight control.²⁴ Third, self-management skills and health promotion interventions provided in the context of comprehensive cancer rehabilitation also have the potential to decrease the risk of additional late effects—for example, the cardiac, pulmonary, endocrine, or bone complications of cancer treatment²⁴ and may even reduce the risk of second malignancies.²⁵⁻³¹ A final benefit is the joint focus on optimizing functional status and quality of life, preserving the ability to remain in the workforce³² and other life roles, and maximizing health and longevity.

A Call to Build a Better Model of Cancer Rehabilitation: Can We Make It Work for Survivors?

The crisis in cancer care presents a challenge and an opportunity. We must identify a new model of survivorship care that is responsive to the needs of the growing number of survivors of cancer and can be effectively delivered within the evolving health care system. We suggest that a coordinated, comprehensive cancer rehabilitation model provides many conceptual advantages including treating chronic and late effects of cancer, managing comorbid conditions, and focusing on prevention. Varied forms of this approach are used in several Nordic and European countries,³³ whereas Italy³⁴ and the United Kingdom³⁵ are currently studying or piloting programs. However, despite the international support for a comprehensive approach, long-term effectiveness data on this model are lacking.³³

In addition to considering these programs from other countries, our efforts to build a better model of comprehensive cancer rehabilitation can be informed by several existing US rehabilitation models. One possibility is to adapt the existing cardiopulmonary rehabilitation model consisting of exercise training and other services as needed, usually coordinated by an exercise specialist, as has been suggested by Schmitz.³⁶ Alternatively, we could adapt the current model of rehabilitation from trauma (eg, spinal cord injury, traumatic brain injury) involving a broader network of multidisciplinary providers and coordinated by a physiatrist. Either of these models would have to be adapted to the needs of survivors of cancer and responsive to survivors with extensive as well as minor rehabilitation needs.

A new comprehensive model needs to be tested against current, fragmented models of cancer rehabilitation services or other hybrid rehabilitation models. Comparative effectiveness studies can test whether a comprehensive cancer rehabilitation program yields improvements in patient, health care system, and cost outcomes. Once an appropriate model of care is identified, risk stratification models will be needed to determine how to identify and effectively refer survivors for rehabilitation services and then how to transition them back to primary care. Implementation research is needed to identify how to best deliver this model of care—for example, rehabilitation could be prescribed as part of survivorship care plans being implemented currently across the country and potentially mandated by the American College of Surgeons for hospital certification in the future. A renewed effort is required to demonstrate the benefit of rehabilitation services by using randomized trials as a step toward incorporating these services into the standard of care. Implementing cancer rehabilitation on a broad scale will require training more cancer rehabilitation providers and educating oncology and primary care providers

about the benefits of these services, including how to identify and refer survivors for this care. Building and implementing a better model of comprehensive cancer rehabilitation will require a coordinated strategic effort of research and policy change. With a sustained integrated approach, we have the potential to significantly enhance the quality and length of survival for current and future survivors of cancer.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

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