ACRM
AMERICAN CONGRESS OF REHABILITATION MEDICINE

Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2016;97:2006-15

SPECIAL COMMUNICATION

Toward a National Initiative in Cancer Rehabilitation: Recommendations From a Subject Matter Expert Group

Nicole L. Stout, DPT, CLT-LANA,[a] Julie K. Silver, MD,[b] Vishwa S. Raj, MD,[c] Julia Rowland, PhD,[d] Lynn Gerber, MD,[a,e] Andrea Cheville, MD, MSCE,[f] Kirsten K. Ness, PT, PhD,[g] Mary Radomski, PhD, OTR/L,[h] Ralph Nitkin, PhD,[i] Michael D. Stubblefield, MD,[j] G. Stephen Morris, PT, PhD,[k] Ana Acevedo, MD,[a] Zavera Brandon, DPT, CBIS,[a] Brent Braveman, PhD, OT,[l] Schuyler Cunningham, MSW, LICSW,[m] Laura Gilchrist, PhD, PT,[n] Lee Jones, PhD,[o] Lynne Padgett, PhD,[p] Timothy Wolf, OTD, MSCI, OTR/L,[q] Kerri Winters-Stone, PhD,[r] Grace Campbell, PhD, CRRN,[s] Jennifer Hendricks, MSW, LCSW-C,[m] Karen Perkin, MEd, CTRS,[a] Leighton Chan, MD[a]

From the [a]Rehabilitation Medicine Department, National Institutes of Health, Clinical Center, Bethesda, MD; [b]Harvard Medical School, Boston, MA; [c]Carolinas Rehabilitation, Levine Cancer Institute, Carolinas HealthCare System, Charlotte, NC; [d]Office of Cancer Survivorship, National Cancer Institute, Rockville, MD; [e]George Mason University, Fairfax, VA; [f]Mayo Clinic-Rochester, Rochester, NY; [g]St Jude Children's Research Hospital, Memphis, TN; [h]Courage Kenny Rehabilitation Institute, Minneapolis, MN; [i]National Center for Medical Rehabilitation Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health, Rockville, MD; [j]Kessler Institute for Rehabilitation Select Medical, West Orange, NJ; [k]Wingate University, Wingate, NC; [l]M.D. Anderson Cancer Center, Houston, TX; [m]Social Work Department, National Institutes of Health Clinical Center, Bethesda, MD; [n]St. Catherine University, St. Paul, MN; [o]Memorial Sloan Kettering Cancer Center, New York, NY; [p]American Cancer Society, Washington, DC; [q]University of Missouri-Columbia, Columbia, MO; [r]Oregon Health and Science University, Portland, OR; and [s]University of Pittsburgh School of Nursing, Pittsburgh, PA.

Abstract

The health care delivery system in the United States is challenged to meet the needs of a growing population of cancer survivors. A pressing need is to optimize overall function and reduce disability in these individuals. Functional impairments and disability affect most patients during and after disease treatment. Rehabilitation health care providers can diagnose and treat patients' physical, psychological, and cognitive impairments in an effort to maintain or restore function, reduce symptom burden, maximize independence and improve quality of life in this medically complex population. However, few care delivery models integrate comprehensive cancer rehabilitation services into the oncology care continuum. The Rehabilitation Medicine Department of the Clinical Center at the National Institutes of Health with support from the National Cancer Institute and the National Center for Medical Rehabilitation Research convened a subject matter expert group to review current literature and practice patterns, identify opportunities and gaps regarding cancer rehabilitation and its support of oncology care, and make recommendations for future efforts that promote quality cancer rehabilitation care. The recommendations suggest stronger efforts toward integrating cancer rehabilitation care models into oncology care from the point of diagnosis, incorporating evidence-based rehabilitation clinical assessment tools, and including rehabilitation professionals in shared decision-making in order to provide comprehensive cancer care and maximize the functional capabilities of cancer

Presented to the Cancer Rehabilitation Symposium at the National Institutes of Health; June 8-9, 2015; Bethesda, MD.

Supported by the Rehabilitation Medicine Department of the Clinical Center at the National Institutes of Health (NIH), the National Cancer Institute, and the Eunice Kennedy Shriver National Institute of Child Health and Human Development National Center for Medical Rehabilitation Research at the NIH.

The opinions expressed in this publication are not an official policy or position of the National Institutes of Health, the Department of Health and Human Services, or the U.S. Government.

Disclosures: none.

http://dx.doi.org/10.1016/j.apmr.2016.05.002

survivors. These recommendations aim to enable future collaborations among a variety of stakeholders to improve the delivery of high-quality cancer care.

Archives of Physical Medicine and Rehabilitation 2016;97:2006-15

Cancer survivors are a growing population in the United States with a unique set of medical and psychosocial needs.[1] These individuals frequently experience functional loss and disability as a result of the side effects of disease and treatment.[2-5] Most individuals experience cancer treatment–related functional morbidity that is amenable to rehabilitation services.[6-12] However, appropriate rehabilitation services that effectively alleviate or mitigate functional impairment and prevent disability are significantly underused in all phases of cancer care.[8,13] The unmet needs of cancer survivors are generally attributed to deficits in comprehensive cancer care delivery and more specifically to the providers' focus on achieving progression-free survival or remission rather than on maintaining function.[14,15]

Historically, the oncology care continuum has had little intersect with rehabilitation outside of severe disability.[16] Recent calls have been made for this relation to be robustly developed to meet the needs of cancer survivors.[17,18] A focus on assessment and management of physical health and function is needed to promote improved health-related quality of life.[19,20] Recommendations and standards from the Institute of Medicine and the American College of Surgeons' Commission on Cancer, among others, provide a framework for alleviating deficits in cancer care and the resulting failures to recognize and manage functional loss and disability.[21-23]

Rehabilitation professionals are an optimal addition to the cancer care team and offer expertise in functional assessment, morbidity management, and disability prevention.[24] Accumulating clinical evidence suggests that rehabilitation interventions are effective before, during, and after cancer treatment to screen for, assess, and treat patients' functional needs.[25-38] Although mounting evidence suggests strong benefit from the integration of rehabilitation into the cancer continuum,[39,40] there is uncertainty around the critical components of a model for cancer rehabilitation. Although functional assessment and measurement frameworks have been described,[41] optimal functional measurement constructs remain undefined. These issues are barriers to the successful integration of rehabilitation services into the cancer care continuum.

Methods

In 2014, an appointed dissemination taskforce of the Rehabilitation Medicine Department of the Clinical Center at the National Institutes of Health (NIH) was charged with identifying an emerging area of rehabilitation practice where the unique resources of the NIH Clinical Center could be leveraged to support practice development. The taskforce identified cancer rehabilitation as the primary area of need and recommended that the NIH Clinical Center Rehabilitation Medicine Department take on a focused effort to scope (1) the evidence base and practice standards supporting clinical aspects of cancer rehabilitation care, (2) gaps and needs for the field, and (3) recommendations that could inform key stakeholders' future planning around national initiatives in cancer rehabilitation. Based on the taskforce's recommendations, the NIH Clinical Center Rehabilitation Medicine Department convened an interdisciplinary group of subject matter experts (SMEs) in cancer rehabilitation from across the United States to participate in this exercise. The SME group included the following: both internal and external NIH participants, researchers and clinical experts in cancer rehabilitation, and representation from the National Cancer Institute and the National Center for Medical Rehabilitation Research of the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

The SME group identified 4 domains germane to understanding the current environment of cancer rehabilitation practice in the United States: (1) cancer rehabilitation clinical models, (2) patient-reported outcomes measures, (3) clinical objective measures of function, and (4) interdisciplinary integration of rehabilitation.

The SME group was divided into 4 smaller work groups based on these topic areas. Individuals self-selected areas of participation based on interest and expertise. The work groups were charged with scoping the existing environment in each domain and identifying relevant gaps in rehabilitation knowledge base and current clinical practice. Systematic reviews were not practical because of the varied focus within each domain and the overall scope of the project.

Each group explored information of relevance to their domain through publications, grey literature, experience, and peer queries. Keywords and phrases were developed and agreed on within groups to identify literature and information of interest. Individuals within each work group conducted literature searches of relevant information sources. Findings were shared among work group members, and consensus was used to identify pertinent information to inform recommendations. Individual work group findings were shared with the full SME group for further synthesis, discussion, and development of overall group recommendations. No specific mechanism for quantitative synthesis was used.

The purpose of this article is to provide the work group findings and SMEs' key recommendations for enhancing the provision of rehabilitation services through the cancer care continuum.

List of abbreviations:

NIH	**National Institutes of Health**
PROM	**patient-reported outcome measure**
SME	**subject matter expert**

Cancer rehabilitation clinical models

Postacute care

Postacute cancer rehabilitation is provided in inpatient rehabilitation facilities, skilled nursing facilities, long-term care hospitals, and hospice facilities. The rehabilitation service conducts a formal functional assessment to identify impairments and provides a range of services (eg, physiatry, physical therapy, occupational therapy, speech therapy, nutrition, psychology, nursing) to assist in optimizing an individual's function.[42] Such programs demonstrate clinically effective care delivery and improved functional