

Cancer Rehabilitation and the Role of the Rehabilitation Nurse

A White Paper by the Association of Rehabilitation Nurses

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Background

Cancer survivors represent a unique population of men, women, and children with very specific physical and psychosocial needs. Currently, 15.5 million individuals are living with a cancer diagnosis which represents 4.8% of the US population (American Cancer Society [ACS], 2016); Miller et al., 2016). The projected number of cancer survivors in 2026 is 20.3 million (ACS, 2016) and by 2040, the estimate is 26.1 million. This positive trend in survival is primarily attributed to the advances in early detection and treatment as well as the aging of the US population (Miller et al., 2016). Of the current survivors, 62% are 65 years of age and older and by 2040, 73% of survivors are projected to be in this age range (Bluethmann, Mariotto, & Rowland, 2016). Cancer is a disease associated with aging (Rowland & Bellizi, 2014); thus older cancer survivors are more likely to be deconditioned, have more than one chronic disease, and have poorer physical functioning than younger cancer survivors (Alfano, Cheville, & Mustian, 2016). Thus, in addition to the short- and long-term cancer treatment-related effects incurred by cancer survivors, many are dealing with age-related morbidities. Unfortunately, little is known about the needs and use of rehabilitation in the older cancer survivor population (Pergolotti, Deal, Lavery, Reeve, & Muss, 2015).

Morbidities are associated with the various cancer treatments which include modalities such as surgery, radiation therapy, chemotherapy, and hormonal, immune, and targeted therapies. These modalities can be employed as single treatments or administered in various combinations. Unfortunately, patients incur a myriad of treatment-related morbidities which can significantly impact their quality of life (Mishra et

al., 2015). These morbidities can occur during active therapy or months or years after the completion of treatment (ACS, 2016). Importantly, many of these treatment-related morbidities are amenable to rehabilitation (Alfano et al., 2016). Those which are most amenable to rehabilitation interventions include, but are not limited to, fatigue, cognitive impairment, pain, peripheral neuropathy, sexual dysfunction, balance and gait problems, lymphedema, swallowing and communication difficulties, cardiac problems, and urinary and bowel problems (Alfano et al., 2016, ACS, 2016). With the continued growth of this population, the US health care system is challenged to deliver the rehabilitation care needed by survivors in order to optimize overall functioning, reduce disability, and improve quality of life (Stout et al., 2016). At this time, most delivery models of care do not integrate comprehensive cancer rehabilitation services into the cancer care trajectory.

Description of Cancer Rehabilitation

Definitions

Dietz (1980) was an early proponent of cancer rehabilitation. He described cancer rehabilitation as the “adaptation of the patient to the disabilities and emotional and functional changes that results from the effects of either or both disease and treatment” (p. 3). He believed that, regardless of prognosis, responsive patients are eligible for preventive, restorative, supportive, or palliative rehabilitation. More recently, Silver et al. (2015) defined cancer rehabilitation as “medical care that should be integrated throughout the oncology care continuum and delivered by trained rehabilitation professionals who have it within their scope of practice to 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” (p. 4). A more recent description of cancer rehabilitation revitalizes its link with cancer survivorship and highlights the role of the multidisciplinary team in optimizing the physical, psychological, vocational, and social functions of each cancer survivor within the limits of his or her treatment-related effects and other comorbidities (Alfano, Ganz, Rowland, & Hahn, 2012).

Cancer rehabilitation is, by nature, a coordinated rehabilitation program in which varied disciplines provide assessment, treatment, and support focusing on individuals’ complex medical, psychosocial, functional, and quality of life needs that are directly related to the cancer pathology and cancer treatments (Silver et al., 2015). General rehabilitation programs that are located in a variety of settings may provide care for individuals experiencing acute non-cancer rehabilitation needs (e.g., post-stroke), but who also have a history of cancer. However, when the individual’s primary rehabilitation concerns are related to the cancer or cancer treatment, consultation with a cancer rehabilitation specialist is highly recommended.

Impairment-Driven and Beyond

Initially, the driving force behind cancer rehabilitation as an integral part of the cancer care continuum was cancer- and treatment-related impairments. Qualified rehabilitation professionals could diagnose and treat specific cancer-related cognitive and physical problems (e.g., cognitive changes, lymphedema, peripheral neuropathy, cardiovascular issues, swallowing and speech problems). (ACS, 2016; Silver, Baima, & Mayer, 2013; Alfano et al., 2016). However, rehabilitation experts also have specialized knowledge related to the full scope of functional limitations and disability associated with

cancer- and treatment-related impairments (Stubblefield et al., 2013). Functional limitations and disability are described by The World Health Organization's International Classification of Functioning, Disability, and Health (WHO, 2002) as activity limitations and participation restrictions which are disruptions in an individual's ability to complete daily personal and social activities related to care for self and others such as transferring, walking, performing personal hygiene, shopping, working, and fulfilling family roles.

Few population-based studies exist that cross the spectrum of cancers in addressing the rehabilitation needs of survivors. However, using an institution-based registry that included 159 older cancer survivors, Pergolotti et al. (2014) found that 65.4% experienced some type of functional limitation related to basic or instrumental activities of daily living, and 17% exhibited a disability with regard to social activities such as work. Additionally, using data from the National Health Interview Survey (2000), Hewitt, Rowland, and Yancik (2003) found that adults with a history of cancer and no other chronic disease were significantly more likely to report limitations of activities of daily living (ADL) or instrumental ADL, functional limitations, and, for those under 65 years of age, were unable to work due to their health compared to adults without a cancer or other chronic disease history. Cheville (2005) reported that functional limitations and disability are also associated with significant psychological distress among cancer survivors. Silver et al. (2013) noted that emotional distress is often mitigated when physical dysfunction is addressed.

Cancer Prehabilitation

An emerging focus in cancer rehabilitation is the concept of prehabilitation. Cancer rehabilitation is concerned with existing impairments, functional limitations, and disabilities that result from cancer or cancer treatments, while prehabilitation focuses on preventing treatment-related impairments and resulting functional limitation (Silver & Baima, 2013). Prehabilitation emphasizes interventions that enhance physical functioning before cancer treatment begins (Carli et al., 2010; Gillis et al., 2014). This includes physical and psychosocial assessments to identify existing functional levels and pre-treatment impairments and to initiate a treatment program aimed at promoting physical and psychological health and preventing future impairments (Silver et al., 2013; Silver, 2015). Evidence from clinical trials suggest that prehabilitation interventions including, but not limited to, general conditioning and fitness, impairment reduction exercises, stress reduction interventions, nutrition and psychosocial support, cognitive training, and symptom management can improve postoperative outcomes and lessen postoperative recovery time (Gillis et al, 2014; Silver et al., 2013; Carli, 2010).

Models of Delivery and Regulatory Standards

Ambulatory Cancer Rehabilitation Model

A common model of providing cancer rehabilitation is the ambulatory services and surveillance model in which comprehensive cancer rehabilitation is delivered in the outpatient setting (Stout et al., 2016). An ambulatory surveillance cancer rehabilitation model ideally incorporates regular monitoring for impairments, functional limitations, and disability throughout the cancer care continuum, including at regular follow-up visits (Silver et al., 2013). This model is comparable to the oncology post-treatment model that emphasizes the surveillance of cancer recurrence, secondary cancers, or new

primaries. Key to this model is a proactive approach to identifying rehabilitation needs (Stout et al., 2016) and to identifying the potential for patients to develop future rehabilitation needs. Multidimensional ambulatory surveillance models of cancer rehabilitation prioritize physical as well as psychosocial needs of survivors (Stout et al., 2016) and are congruent with development and implementation of Survivorship Care Plans (SCP) as required by the Commission on Cancer (CoC, 2016).

Cancer Rehabilitation Regulatory Standards

Health care accreditation organizations have recently articulated standards for cancer rehabilitation care. Commission on Cancer (CoC, 2016) and Commission on Accreditation of Rehabilitation Facilities (CARF, 2014) are two such organizations that are responding to the Institute of Medicine (2013) report that highlights a system in crisis and the necessity for delivering a higher quality of care for patients diagnosed with and treated for cancer.

Commission on Cancer (CoC) Standards

The CoC (2016), an accrediting body of the American College of Surgeons that promotes quality cancer care, established standards that address rehabilitation services in cancer facilities. To be accredited, cancer facilities must comply with several standards addressing rehabilitation. Facilities must have policies and procedures in place to ensure that patients have access to rehabilitation services either on-site or by referral. In this context, rehabilitation services include, but are not limited to, lymphedema care, pain management, physical and occupational therapy, weight management programs, reflexology, and exercise therapy. As noted earlier, the CoC (2016) requires SCPs for eligible oncology patients, but these plans are not required to

include the systematic surveillance and treatment of rehabilitation needs nor specific input from rehabilitation professionals.

Ambulatory cancer rehabilitation services are typically not systematically integrated into the survivorship trajectory. Furthermore, little to no standardization exists regarding the services offered; the timing of rehabilitation assessment, surveillance, and intervention; coordination with other health providers; or the availability of an interdisciplinary rehabilitation team (Stout et al., 2016). Finally, no standardization exists that addresses which provider (e.g., advanced practice nurse, nurse navigator, physiatrist, oncologist, etc.) should coordinate rehabilitation care in the ambulatory surveillance model or the amount of specialized oncology training needed by rehabilitation professionals (Stout et al., 2016).

Commission on Accreditation of Rehabilitation Facilities

Commission on Accreditation of Rehabilitation Facilities International ([CARF], 2014) published new standards for accrediting Cancer Rehabilitation Specialty Programs. As the primary accreditation body for rehabilitation facilities, the CARF standards provide a framework for organizing cancer rehabilitation programs that prioritizes a person-centered, interdisciplinary approach to meeting unique needs of persons who have been diagnosed with cancer. A Cancer Rehabilitation Specialty Program may provide services at any point along the cancer care continuum and in a variety of setting (e.g., inpatient, outpatient/community based, and home).

The CARF Cancer Rehabilitation Standards note that cancer rehabilitation “is an integral part of cancer care” (CARF, 2016, p. 7) to ensure optimal outcomes for persons with cancer from the point of cancer diagnosis and throughout the cancer trajectory. In

addition to providing direct care and care coordination, accredited programs are charged with (a) teaching self-advocacy and (b) assisting persons served, their families and support systems to manage their own health, appropriately use and negotiate healthcare systems and services, achieve personal health, wellness and improved quality of life throughout their life span. The standards further stipulate that cancer rehabilitation programs must provide “ongoing access to information, services, and resources to enhance the lives of the person served within their families/support systems, communities, and life roles” (p. 7). In keeping with the CARF philosophy of the ongoing self-empowerment of individuals and their support systems, patients and families are referred to as, “persons served.” CARF Cancer Rehabilitation standards focus on an individualized rehabilitation care plan that addresses the specific needs of each person and his or her support system, with comprehensive treatment provided by the interdisciplinary rehabilitation team. All team members in a Cancer Rehabilitation Specialty Program must regularly demonstrate competent and specialty training in cancer rehabilitation (CARF, 2014).

Role of the Rehabilitation Nurse

Cancer rehabilitation involves a multidisciplinary approach to quality care for the cancer survivor. Essential to providing quality cancer rehabilitation is knowledge of cancer pathologies, the morbidities resulting from cancer treatments, and the cancer- and treatment-related morbidities amenable to rehabilitation. Competency in assessment, decision-making, coordination, and communication skills is a requisite for each discipline and, certainly, nursing. However, nurses who specialize in oncology and rehabilitation nursing are particularly positioned to employ these skills specific to

the care of the cancer survivor. The rehabilitation nurse and the oncology nurse each bring a unique knowledge base and set of skills to the care of cancer survivors and to their rehabilitation needs. Currently, the knowledge and skills of each are typically employed separately in any setting in which cancer survivorship care is provided. However, moving toward a collaborative model of oncology and rehabilitation nursing care is a proposal that warrants consideration. A collaborative model highlights the importance of the two nursing specialties, identifies the shared knowledge and skills needed to provide the highest level of cancer rehabilitation while retaining the uniqueness of each nursing specialty, Identifying the roles of each specialty is a first step toward undertaking the development of a proposed collaborative oncology-rehabilitation nursing care model.

The role of the Rehabilitation Nurse in cancer rehabilitation is similar to the Rehabilitation Nurse's roles for any other population. The rehabilitation nurse provides evidence-based direct care, psychosocial support, patient/family education, care coordination, and health promotion, consistent with the ARN Competency Model (need citation—from ARN website) to all individuals, regardless of diagnosis and across the continuum of care.

Specific operationalization of the oncology rehabilitation nurse role varies based upon the care setting (inpatient, such as Inpatient Rehabilitation Facility or skilled nursing facility; outpatient, such as ambulatory clinic, or home care) and patient/family goals. For example, cancer patients in inpatient rehabilitation may require assistance with activities of daily living (ADLs), medication management, management of pain and other symptoms that interfere with function, and patient/family teaching for activities of

daily living, transfers, locomotion, bowel and bladder management, and a home evaluation. Patients receiving outpatient ambulatory cancer care during and after cancer treatment may require case management, screening and referral to manage impairments such as lymphedema, balance and gait problems, radiation plexopathies, and neurogenic bladder. Rehabilitation nurses are especially qualified to assess the psychosocial and physical functioning of individuals with cancer across the continuum of care. When the rehabilitation nurse identifies impairments, functional limitations, and participation restrictions, appropriate referrals are made for services such as physical therapy or pain management. However, the rehabilitation nurses armamentarium does not typically include a background in functional impairments that are anticipated with specific cancers and particularly with specific cancer treatments. The rehabilitation nurse is best prepared to care for cancer survivors when armed with knowledge of treatment-related morbidities; those that occur during treatment and remain long-term as well as morbidities that occur much later in the survivorship trajectory.

The oncology nurse role specializes in promoting the screening and early detection of cancers, the administration of specific cancer treatments such as chemotherapy, the assessment and collaborative management of the physical and psychosocial morbidities of the disease and related treatments, and the supportive care of patient and caregivers. Knowledge of the types of cancer and designated treatments and the potential treatment-related morbidities is essential to the oncology nurse's armamentarium. The oncology nurse institutes measures to assess and, if possible, prevent anticipated acute, late, and long-term treatment-related morbidities and collaboratively manages such morbidities when they occur. Identified morbidities

amenable to rehabilitation are typically referred to a physiatrist, physical and occupational therapist or speech language pathologist. However, greater knowledge is warranted regarding how best to assess for and identify such morbidities. A full functional evaluation is not typically within the oncology nurse's repertoire and, therefore, developing this type of evaluation skill could be very beneficial in the care of cancer survivors.

Recommendations for the Future

The Collaborative Oncology-Rehabilitation Nursing Model requires a unified approach from the two specialty organizations, the Association of Rehabilitation Nurses and the Oncology Nursing Society. The ARN/ONS collaborative role requires specialized education in both oncology and rehabilitation nursing. The collaborative model recognizes the uniqueness of each specialty while synthesizing the essential knowledge and skill content of each in order to support competent rehabilitation care in the cancer population. A first step is to identify agreed upon content essential to cancer rehabilitation and that address both the rehabilitation and oncology nursing specialties. Determining the venues that this content is presented to each organization's membership is a next step and could become formalized content that is included in both certification examinations.

References

- Alfano, C. M., Ganz, P. A., Rowland, J., & Hahn, E. E. (2012). Cancer survivorship and cancer rehabilitation: Revitalizing the link. *Journal of Clinical Oncology*, 30, 904-906.
- Alfano, C.M., Cheville, A. L., & Mustian, K. (2016). Developing high-quality cancer rehabilitation programs: A timely need. *ASCO Educational Book*, 35, 241-249.
- American Cancer Society. (2016). Cancer treatment and survivorship: Facts and figures 2016-2017. Atlanta, GA: Author.
- Bluethman, S. M., Mariotto, A. B., & Rowland, J. H. (2016). Anticipating the “Silver Tsunami”: Prevalence trajectories and comorbidity burden among older cancer survivors in the United States. *Cancer Epidemiology, Biomarkers & Prevention*, 25, 1029-1036.
- Carli, F., Charlebois, P., Stein, B., Feldman, L., Zavorsky, G., Kim, D. J. . . . Mayo, N. E. (2010). Randomized clinical trial of prehabilitation in colorectal surgery. *British Journal of Surgery*, 97, 1187-1197.
- Cheville, A. (2005). Cancer rehabilitation. *Seminars in Oncology*, 32, 219-224.
- Commission on Accreditation of Rehabilitation Facilities International. (2014). 2014 Medical rehabilitation standards manual. Tucson, AZ: CARF International.
- Dietz, J. H. (1980). Adaptive rehabilitation of the cancer patient. *Current Problems in Cancer*, 5 (5), 1-56.
- Gillis, C., Chao, L., Lee, L., Awasthi, R., Augusting, B., Gamsa, A. . . . Carli, F. (2014). Prehabilitation versus rehabilitation: A randomized control trial in patients undergoing colorectal resection for cancer. *Anesthesiology*, 121, 937-947.

- Hewitt, M., Rowland, J. H., & Yancik, R. (2004). Cancer survivors in the United States: Age, health, and disability. *Journal of Gerontology*, 58, 82-91.
- Institute of Medicine. (2013). *Delivering high-quality cancer care: Charting a new course For a system in crisis*. Washington, D.C.: The National Academies.
- Miller, K.D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H. . . . Jemai, A. (2016). Cancer treatment and survivorship statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66, 271-289.
- Mischra, S. I., Scherer, R. W., Geigle, P. M., Berlanstein, D. R., Topaloglu, O., Gotay, C. C., & Snyder, C. (2012). Exercise interventions on health-related quality of life for cancer survivors. *Cochrane Database of Systematic Reviews*, Issue 8, Art No: CD007566, DOI:10.1002/14651858.CD007566pub2.
- Rowland, J.H. & Belizzi, K.M. (2014). Cancer survivorship issues: Life after treatment and implications for an aging population. *Journal of Clinical Oncology*, 32, 2662-2668.
- Silver, J. K. & Baima, J. (2013). Cancer prehabilitation: An opportunity to decrease treatment-related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. *American Journal of Physical Medicine & Rehabilitation*, 92, 715-727.
- Silver, J. K., Baima, J., & Mayer, S. (2013). Impairment-driven cancer rehabilitation: An essential component of quality care and survivorship. *CA Cancer Journal for Clinicians*, 63, 295-317.
- Stout, N. L., Silver, J. K., Raj, V. S., Rowland, J., Gerber, L., Cheville, A. . . . Chan, L.

(2016). Toward a national initiative in cancer rehabilitation: Recommendations from a subject matter expert group. *Archives of Physical Medicine and Rehabilitation*, 97, 2006-2015.

US Department of Health and Human Services, Centers for Disease Control (2000). *2000 National Health Interview Survey (NHIS) Public Use Data Release, NHIS Survey Description*. Washington, DC, Author.

Vaughn, S., Mauk, K. L., Jacelon, C. S., Larsen, P. D., Rye, J., Wingersgill, W., . . . Dufresne, D. (2016). The competency model for professional rehabilitation nursing. *Rehabilitation Nursing*, 41, 33-44. doi: 10.1002/rnj.225.