

Occupational Therapy's Role in Cancer Survivorship as a Chronic Condition

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Improved medical care has resulted in a documented increase in cancer survivors in the United States. Cancer survivors face challenges in participation across all facets of life as a result of the cancer and subsequent cancer treatments. Long-term and late-term sequelae can result in impairments in neurological systems, decreased stamina, loss of range of motion, and changes in sensation and cognition. These impairments are often long lasting, which categorizes cancer survivorship as a chronic condition. This categorization presents treatment challenges, especially in creating rehabilitation and habilitation service options that support cancer survivors. Occupational therapy provides a unique focus that can benefit cancer survivors as they face limitations in participation in all aspects of daily living. Research, advocacy, and education efforts are needed to focus on the specific rehabilitation and habilitation needs of cancer survivors to increase access to occupational therapy's distinct value.

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In the United States, an estimated 1.7 million new cases of cancer will be reported this year (American Cancer Society, 2016), and as a result of improved medical care, the number of cancer survivors continues to increase (National Cancer Institute [NCI], 2016). According to NCI (2016), cancer survivorship encompasses the period from diagnosis until the end of life. The Centers for Disease Control and Prevention (2016) have defined the *cancer survivor* as a "person who has been diagnosed with cancer, from the time of diagnosis throughout his or her life" (para. 1). The National Coalition for Cancer Survivorship's (2009) definition of *cancer survivorship* is similar and includes family members and caregivers.

Regardless of the definition, cancer survivors are growing in number. Cancer treatments are saving lives, but survivors are often left with residual physical and psychosocial complications that prevent them from fully engaging in their everyday lives and subsequently result in a compromised quality of life. In addition, unique survivor-

ship concerns need to be addressed that go beyond traditional medical interventions and adjuvant therapies.

Lack of survivorship care, including rehabilitation, can exacerbate or prolong the physical, cognitive, and emotional sequelae of cancer and appropriate treatment, thereby impairing function and contributing to limitations in activity and participation during survivorship (Bennion & Molassiotis, 2013; Selamat, Loh, Mackenzie, & Vardy, 2014). These limitations contribute to the survivor's loss of self-efficacy and independence. Activity and participation limitations also include employment or working life, education, finances, and social and family relationships (Alfano, Ganz, Rowland, & Hahn, 2012; Treanor & Donnelly, 2016). Each of these limitations takes a toll on families and caregivers in terms of time, money, lost productivity, and emotional distress. Recently, health care reform has resulted in increased national attention to the specialized needs of cancer survivors, including an appeal to improve efforts to optimize survivors' functioning and counteract the limitations imposed

by the chronic or late effects of cancer and cancer treatment (Alfano et al., 2012; Hewitt, Greenfield, & Stovall, 2006).

Despite the fact that primary cancer treatments can result in unique difficulties, many of the resultant limitations are within the purview of and are amenable to occupational therapy (Hwang, Lokietz, Lozano, & Parke, 2015). Yet, studies have reported an underutilization of occupational therapy services in cancer-related care (Pergolotti, Cutchin, Weinberger, & Meyer, 2014; Thorsen et al., 2011). Pergolotti et al. (2014) found that among an estimated 87% of older cancer survivors who were considered to be in need of occupational therapy, only 32% were treated by occupational therapy within the first 2 yr of the cancer diagnosis.

Several factors contribute to the inconsistent provision of occupational therapy services to cancer survivors. These factors include known disparities in health care access and delivery that have a particular impact on cancer care and affect diagnosis, treatment, and outcome, including cancer survivorship and burden of care (American Society of Clinical Oncology, 2015; Stout et al., 2016) and a lack of awareness on the part of occupational therapy practitioners of the complications and potential limitations that can result from cancer and its treatments.

The purpose of this article is to present information on the effects of cancer and its treatments on function and participation, further articulate the need for better rehabilitation and habilitation for cancer survivors, and present the challenges and tasks that occupational therapy can and should undertake to increase appropriate services for cancer survivors, which will increase function and decrease burden of care. Challenges and tasks include exploring multiple forms of service delivery and legislative advocacy for improved services.

Deleterious Effects of Cancer

Cancer affects the body and the person's functioning through several processes. Some common impairments resulting from cancer or cancer treatments are weakness, fatigue, edema, decreased mobility, and impaired cognition (Burkhardt & Schultz-Krohn, 2013).

Primarily, cancer cells are malignant and invasive and can destroy nearby healthy tissues and organs and subsequently affect a person's physical body, mental processes, and daily functioning.

Multiple medical options are available to prevent the growth and spread of cancer cells, including surgical and nonsurgical treatment. Cancer treatments such as chemotherapy and radiation affect not only the cancer but also the surrounding tissues, including muscles, nerves, and arteries and veins. Alteration of such tissue can also lead to decreased strength and stamina, loss of range of motion, changes in neurological function, changes in sensation, and cognitive impairments (Siddiqui & Gwede, 2012).

Decreases and changes in physical, sensory, and cognitive functioning have been shown to lead to impairments in participation in basic and instrumental activities of daily living (IADLs), including self-care, social engagement, and work. Moreover, some impairments resulting from cancer or cancer treatment can be long lasting and debilitating. For example, cancer-related fatigue (CRF) has been shown to be a significant factor in as many as 60% of people receiving cancer treatment (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007). Therefore, as a result of increased advancements in treatment and increased survival rates, most forms of cancer are now identified as chronic illnesses (Phillips & Currow, 2010).

The ability to work or return to work is a frequent stated concern for cancer survivors and their families (Mehnert, 2011). Additionally, the inability to work has an impact on the burden of care. Factors related to cancer and its treatment have been strongly associated with the ability to work or return to work (Mehnert, 2011; Steiner, Nowels, & Main, 2010; van Muijen et al., 2013). Moreover, family members and caregivers of survivors (also often considered survivors, as mentioned earlier) experience losses in work productivity as they devote time to caring for the cancer survivor. Work disability from cancer may have a societal impact, resulting in economic losses and reduced worker productivity (van Muijen et al., 2013).

Occupational therapy perspectives on other patient groups have shown that the ability to return to work can help the cancer survivor overcome the negative effects of cancer and cancer treatment because work is associated with identity and recovery. For families and caregivers, the survivor's return to work is often the beginning of a return to routines and familiar roles.

Special Needs of Cancer Survivors

In today's health care arena, increasing national attention is paid to the specialized needs of all patients or clients, including cancer survivors (Stout et al., 2016). Stout et al. (2016) indicated that a need exists to improve the general health of cancer survivors and to improve efforts to optimize the physical, psychological, vocational, and social functioning that is limited by the chronic or late effects of cancer and cancer treatment (Alfano et al., 2012; Hewitt et al., 2006; Stout et al., 2016). In addition, there is an increasing focus on the impact of the late and chronic effects of cancer on quality of life, long-term health, and participation in meaningful activities and the ability to resume life occupations during and after cancer care and rehabilitation.

Yet gaps in the care of cancer survivors remain and need to be addressed. Specifically, care delivery models that incorporate cancer rehabilitation services for cancer survivors across the oncology care continuum are lacking (Stout et al., 2016). Recently, a Subject Matter Expert Group was convened by the Rehabilitation Medicine Department of the National Institutes of Health Clinical Center with support from NCI and the National Center for Medical Rehabilitation Research. This group was challenged to review the current information on rehabilitation services for cancer survivors that mitigate functional impairments and prevent disability resulting from cancer and cancer-related treatments. The group was also challenged to identify opportunities and gaps in cancer rehabilitation and make recommendations for future efforts to promote cancer rehabilitation care. The group's recommendations indicate a need for

improved efforts to integrate cancer rehabilitation care models across the care continuum and maximize the functional outcomes and quality of life of cancer survivors (Stout et al., 2016).

Common sequelae 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 difficulties” (Alfano et al., 2012, p. 905). Each sequela affects survivors’ engagement in meaningful activities and the ability to resume life occupations, which often decrease after cancer treatment, resulting in an overall poorer health outcome (Rosenblum, Yurman, Gotfrid, Wolpart, & Binyamin, 2005).

Given the nature of cancer, its many sequelae, and its impact on human performance and participation, habilitation and rehabilitation of impairments is a logical recommendation. Many of the sequelae of cancer treatment, as well as performance and participation impairments, are amenable to rehabilitation interventions. In addition, the increase in the number of cancer survivors increases the possibility that occupational therapy practitioners will work with a cancer survivor at some point in their career. Thus, it is important that the profession of occupational therapy look carefully at the opportunities in cancer-related care and prepare through research and education for an optimal role.

Functional Implications of Cancer Sequelae

By definition, functional skills incorporate physical and psychosocial capacities (Yuen, Gibson, Yau, & Mitcham, 2007). Functional skills are important for recovery, including reducing psychological distress and promoting return to work and roles and routines of daily living, long-term health, and contributions to society. Moreover, these improvements in functional skills lead to a decrease in the economic burden of cancer and cancer treatment on individuals and society in general (Silver, Baima, Newman, Galantino, & Shockney, 2013).

Conversely, unmet functional needs have been significantly associated with decreased quality of life and psychological distress, leading to increased health care utilization and costs (Akechi et al., 2011; Park & Hwang, 2012).

Occupational therapy practitioners have a unique perspective on their clients’ complex functional needs (American Occupational Therapy Association [AOTA], 2014a). Hildenbrand and Lamb (2013) stated that occupational therapy’s perspective on function sets it apart as a distinct and valuable service. In focusing on the functional implications of the sequelae of cancer on occupational performance and participation, occupational therapy practitioners have the potential to address unique needs identified by survivors (Sleight & Duker, 2016). In this section, we address some of the sequelae of cancer and the functional participation limitations that might occur as a result.

Cancer-Related Fatigue

CRF, among the most common sequelae experienced by patients with cancer, varies in frequency from 60% to 90% (Yennu, 2013). More than 30% of patients newly diagnosed with cancer will experience moderate to severe CRF in the first year after diagnosis (Weis & Horneber, 2015). Fatigue has also been reported from diagnosis, during medical treatment, and for a month to years after completion of treatment, which makes it one of the most prevalent and distressing symptoms for cancer survivors (Hofman et al., 2007). CRF can limit occupational performance of activities of daily living (ADLs) and work, leisure, and social activities, in addition to quality of life (Yuen, Mitcham, & Morgan, 2006).

Cancer-Related Cognitive Dysfunction

As many as 75% of cancer patients experience cognitive changes during treatment, and 20%–30% continue to experience cognitive changes after treatment ends (Ahles, Root, & Ryan, 2012). An estimated 4 million cancer survivors have some form of cognitive difficulty (Janelins et al., 2011). Dysfunction may have an impact on survivors’ capacity to return to normal roles and

can influence their own and others’ perceptions of their ability to participate in functional activities (Player, Mackenzie, Willis, & Loh, 2014). In addition, cognitive dysfunction is associated with reduced productivity, social role functioning, and community engagement (Reid-Arndt, Yee, Perry, & Hsieh, 2009).

Cancer-Related Peripheral Neuropathy

Approximately 38% of patients treated with multiple agents develop cancer-related peripheral neuropathy (CRPN), depending on the chemotherapy regimen, duration of exposure, and assessment method (Cavaletti et al., 2013; Stubblefield, McNeely, Alfano, & Mayer, 2012). CRPN can lead to psychosocial and physical impairments as well as balance impairments that put the patient at high risk for falls. In addition to the risk for falls, CRPN can impede most ADLs and participation in occupations (Stubblefield et al., 2012; Tofthagen, 2010).

Cancer-Related Pain

It is estimated that 33%–50% of patients with cancer will experience some level of pain, often intractable pain (Goudas, Bloch, Gialeli-Goudas, Lau, & Carr, 2005). Increased severity of pain that is not controllable has been shown to be correlated with poor performance of ADLs and IADLs (Landi et al., 2009).

Lymphedema

Lymphedema is an abnormal collection of high-protein fluid just beneath the skin. This swelling most commonly occurs in the arm or leg, but it may also occur in other parts of the body, including the breast or trunk, head and neck, or genitals (Foldi & Foldi, 2012). Upper-extremity lymphedema most often occurs after breast cancer; lower-extremity lymphedema most often occurs with uterine cancer, prostate cancer, lymphoma, or melanoma (Meneses & McNeely, 2007). The overall incidence of arm lymphedema is reported to occur within days and ≤ 30 yr after treatment of breast cancer and can range from 8% to 56% at 2 yr postmastectomy (Paskett, Naughton, McCoy, Case, & Abbott, 2007). Eighty percent of patients experience onset of lymphedema within 3 yr of surgery; the remainder develop

edema at a rate of 1% per year (Petrek, Senie, Peters, & Rosen, 2001).

Occupational performance impairments resulting from lymphedema vary from fairly minor changes to significant difficulties in daily activities, depending on the chronicity and severity of involvement (Shigaki, Madsen, Wanchai, Stewart, & Armer, 2013). Activities that can be affected include ADLs such as bathing, dressing, and grooming (Tretbar, Morgan, Lee, Simonian, & Blondeau, 2008) and IADLs such as child care, engagement in leisure activities, grocery shopping and meal preparation, heavy household cleaning, and yard maintenance (Radina & Armer, 2001).

Psychosocial Issues

Psychological stress and distress are pervasive in people diagnosed with cancer, with some estimates as high as 60% (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). The American Cancer Society (2016) has estimated that 1 in 4 people with cancer experience clinical depression. Lasting psychosocial burdens, including anxiety, along with coexisting late effects of treatment, have been found to increase survivors' difficulty reengaging in meaningful occupations such as work, leisure, socialization, sleep, and sexual activity (Breukink & Donovan, 2013; Hwang et al., 2015).

Gaps in Health Care Delivery for Cancer Survivors

Many people in the United States face known disparities in health care access and delivery as a result of race, socioeconomic status, insurance status, and age. Moreover, these disparities have a particular impact on cancer care; they affect prevention, diagnosis, treatment, and outcome, including cancer survivorship and burden of care (American Society of Clinical Oncology, 2015; Smith & Hall, 2015).

For cancer survivors, the disparities and gaps in health care delivery extend to the chronic and late effects of cancer treatment that pertain to occupational performance and overall well-being. For example, although performance deficits have been well documented in the literature (Janelsins et al., 2011), survivors with cognitive dysfunction often go undiagnosed

and unsupported (Mitchell & Turton, 2011). Another study (Palmadottir, 2009) noted that health care professionals are not addressing psychological well-being and participation in meaningful occupations. Survivors report that health care providers often dismiss symptoms of CRPN (Binkley et al., 2012), and those with pain symptoms may not report them out of fear that the cancer has recurred (Smith & Wu, 2012). However, performance issues related to ADLs, IADLs, and work, leisure, and social participation (Silver et al., 2013) that are overlooked during survivorship are amenable to occupational therapy services.

Rehabilitation and Habilitation Mandates

With the adoption of the Patient Protection and Affordable Care Act (ACA; Pub. L. 111–148), mandates require marketplace health plans to cover essential health benefits, including habilitation and rehabilitation services. However, services vary greatly as a result of variations in individual state and federal interpretations of the ACA (AOTA, 2014b; Hooper, 2015). *Habilitation services* are defined by the National Association of Insurance Commissioners as services that help a person keep, learn, or improve skills and functioning for daily living, and they can include occupational, physical, and speech-language pathology. *Rehabilitation services* are defined as services that help a person relearn something after an injury, illness, or disabling condition (AOTA, 2014b).

Ongoing habilitation and rehabilitation occupational therapy services are imperative to cancer survivors for improved performance and engagement in daily routines. For example, cancer survivors' capacity after cancer treatment may differ substantially from their capacity before treatment; habilitation services can enable them to habilitate, or accommodate, to their new permanent status.

A critical habilitation service for managing chronic issues in cancer survivorship is the person's ability to manage his or her own health, or self-management. People with chronic impairments who engage in self-management behaviors improve their health outcomes (Ryan & Sawin, 2009). Although habilitation services are an essential health

benefit included in the ACA (AOTA, 2014b) and approaches to managing and developing healthier behaviors have been called for in the literature (Robinson, Fisher, & Broussard, 2016), barriers to service provision exist. For example, habilitation services vary greatly from state to state; hence, there is a general lack of awareness of how to receive reimbursement for occupational therapy services in survivorship care and, in particular, in nontraditional settings such as the community. However, occupational therapy itself is usually a covered service and is usually medically appropriate to address functional problems; thus, billing can sometimes be appropriate under the basic occupational therapy benefit. This may, however, be an area in which advocacy with insurance and health programs is needed.

Another barrier is that awareness of providers who can deliver these services within the community is lacking; therefore, occupational therapy practitioners must recognize and build their distinct value in these critical emerging survivorship services. An additional barrier is the time it takes to implement habilitation services, including self-management, in a medical model setting to address chronic survivorship issues. The amount of performance deficits coupled with a short inpatient length of stay can be overwhelming.

Self-management needs to be part of routine practice for chronic issues related to cancer survivorship. Self-management tasks critical for practitioners to integrate into practice include medical management of the condition or sequela; maintaining, changing, and creating meaningful behaviors or roles; and dealing with the emotional and psychosocial issues relating to chronic conditions (Lorig & Holman, 2003). Moreover, the area of self-management interventions is one in which advocacy is necessary. Specifically, advocacy for self-management as an intervention strategy should be included as part of health care reform, including payment, reimbursement, quality, and outcome reforms (Robinson et al., 2016).

Occupational Therapy Call to Action

Regardless of cancer survivors' stage of recovery, occupational therapy offers a unique

perspective that facilitates an improved level of functioning and participation in daily living, including self-management across the cancer care continuum (Longpré & Newman, 2011; Vockins, 2004). Therapeutic interventions provided by occupational therapy practitioners are designed to address impairments and improve function and well-being (Burkhardt & Schultz-Krohn, 2013; Radomski, Anheluk, Gabe, Hopkins, & Zola, 2014; Vaughn, 2014). Occupational therapy practitioners bring a distinct holistic approach to promoting independence through engagement in meaningful daily occupations (Crepeau, Schell, & Cohn, 2009). With background knowledge in medical, developmental, and psychological fields, combined with skill in analyzing occupational performance and engagement, occupational therapy practitioners have a unique set of skills that help cancer survivors reintegrate into the myriad routines and roles that make up their daily lives. With an emphasis on collaboration with the client, occupational therapy practitioners also promote opportunities for the cancer survivor to engage in interventions (or daily occupations) that improve well-being and quality of life (Gray, 1998; Wilcock, 2005).

Several models of rehabilitation exist for cancer survivors (Stout et al., 2016). Home care programs and outpatient ambulatory care models offer appropriate services yet vary in the amount, type, timing, and comprehensiveness of services offered. Stout et al. (2016) further indicated that there is little consensus on the core components of comprehensive rehabilitation for cancer survivors. Other models of care that have potential to reach cancer survivors include community health programs and telehealth models of intervention.

As the incidence of cancer and of cancer survivorship increases, occupational therapy practitioners will have more opportunities to encounter and treat clients with cancer or cancer survivors. To prepare new graduates for this likelihood, occupational therapy education should include cancer care and survivorship as a component of the overall educational program. Indeed, more opportunities for fieldwork in cancer care will benefit the profession.

Moreover, as health care reform continues, it is imperative that occupational therapy practitioners advocate on multiple

levels for improved rehabilitation and habilitation for cancer survivors. Occupational therapy research specific to cancer survivors, including application of basic occupational therapy concepts to cancer care, is critical. Advocating for survivors to receive continued postacute care will improve their function, participation, and productivity and thus improve their overall health outcomes, including a reduction in the burden of care. Advocating for legislation that improves access to rehabilitation and habilitation for cancer survivors at the local, state, and national levels is an important piece of improving care for cancer survivors. Advocacy with leaders in the cancer community and with insurers is also needed. Finally, creating new and innovative programs, such as community programs or telehealth programs, for cancer survivors to receive occupational therapy will improve outcomes for survivors and cement a permanent role for occupational therapy in this growing and increasingly important area. ▲

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