

Toward a Broader Role for Occupational Therapy in Supportive Oncology Care

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Supportive care in oncology helps people cope with cancer and its psychological, physical, and emotional side effects. However, cancer survivors report dissatisfaction with supportive care and a need for more psychosocial and self-management services. Occupational therapy practitioners represent an integral part of the supportive care team because their scope of practice emphasizes function. Through a focus on function, practitioners address the full spectrum of physical and psychosocial care. Currently, conceptualizations of occupational therapy for cancer survivors often focus solely on physical interventions and, therefore, do not represent the unique involvement of the profession in supportive oncology care. We advocate for a focused framework for occupational therapy practitioners in oncology as experts in function and providers of both physical and psychosocial treatments. Barriers to a focus on function are identified, and strategies are suggested for expanding involvement for the profession in supportive oncology care.

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Approximately 1.5 million adults, 70,000 adolescents and young adults, and 10,000 children are diagnosed with cancer in the United States each year (Centers for Disease Control and Prevention, 2011; National Cancer Institute [NCI], 2015). However, because of more effective diagnosis and treatment methodologies, cancer death rates have plummeted over the past decade (NCI, 2014). In fact, in the absence of other causes of death, 62% of adults diagnosed with cancer can now expect to be alive in 5 yr (Aziz & Rowland, 2003). Likewise, the overall 5-yr survival rate for children and adolescents diagnosed with cancer is currently 80% (NCI, 2014).

As survival rates have increased, awareness has grown regarding the challenges many cancer survivors face, which are numerous. During treatment, people may experience fatigue, pain, nausea and vomiting, weakness, anxiety, fear, and depression (American Cancer Society, 2015). Late effects often develop in the survivorship phase and can include communication impairments, pain, fatigue, joint stiffness and bone pain, reproduction and fertility difficulties, anxiety, depression, posttraumatic

stress symptoms, memory and attention problems, and behavioral difficulties in children (NCI, 2015).

Supportive care in oncology is defined as any treatment or service designed to help people cope with cancer and its psychological, physical, and emotional consequences (Harrison, Young, Price, Butow, & Solomon, 2009). A variety of health care professionals contribute to the multidisciplinary supportive oncology care team. For example, although oncologists treat the disease itself, physical impairments resulting from cancer and its treatment are addressed primarily by physical therapy practitioners, occupational therapy practitioners, and nurses. Psychosocial difficulties are most often addressed by psychologists or social workers, although occupational therapy practitioners and nurses can be involved in these treatments. Cognitive impairments are treated primarily by social workers, psychologists, and various rehabilitation professionals such as occupational and physical therapists (Silver, Baima, Newman, Galantino, & Shockney, 2013; Sleight, 2016).

Despite the wide variety of disciplines involved in supportive oncology care, cancer

survivors report widespread dissatisfaction with these services (Dilworth, Higgins, Parker, Kelly, & Turner, 2014). The most commonly reported unmet supportive care needs of adult cancer survivors involve everyday function, including difficulty coping with emotions such as fear, stress, and anxiety and obtaining education about diagnosis and prognosis, treatment, and self-management of symptoms (Adler & Page, 2008; Sanson-Fisher et al., 2000). Likewise, adolescent and young adult (AYA) cancer survivors report substantial unmet service needs related to everyday function, and younger cancer survivors have been shown to identify a greater number of unmet needs than their older counterparts (Burg et al., 2015). The unmet needs of AYA survivors most often include mental health care and occupational therapy for rehabilitation services (Keegan et al., 2012; Smith et al., 2013).

The side effects of cancer and its treatment can negatively affect quality of life and functional outcomes for survivors (Adcock & Burke, 2014). Functional limitations may then further restrict ability to participate in daily activities including personal care, chores, social activities, employment, and education (Berg & Hayashi, 2013). For example, 50% of young adult survivors of childhood cancer with memory difficulties state that these impairments limit their educational activities (Berg & Hayashi, 2013), and adult cancer survivors with cancer-related cognitive dysfunction report problems with memory, concentration, language, attention, and executive functioning, as well as the ability to manage everyday responsibilities such as paying bills or running errands (Falletti, Sanfilippo, Maruff, Weih, & Phillips, 2005; Sleight, 2016). Because of the variety of functional deficits experienced during treatment and survivorship, many cancer survivors require considerable amounts of supportive care.

Lack of adequate supportive care in oncology can exacerbate and prolong the physical, cognitive, and emotional symptoms of cancer and its treatment that lower quality of life and limit function during survivorship (Park & Hwang, 2012). For example, in the AYA population, unmet needs in the areas of social support, mental health, and occupational and physical

therapy have been strongly associated with decreased emotional functioning, lower health-related quality of life, and reduced functioning at school or work (Smith et al., 2013). In adults, unmet supportive care needs have been significantly associated with decreased quality of life and psychological distress (Akechi et al., 2011). In turn, poor quality of life and increased levels of distress have been associated with increased health care utilization and costs (Park & Hwang, 2012). Accordingly, an international call led by the Institute of Medicine has emerged for a more thorough examination of the supportive care needs of cancer survivors as well as an investigation into the most effective ways of meeting those needs (Hewitt, Greenfield, & Stovall, 2006). Occupational therapy should be at the forefront of the many health care fields responding to this call, especially because our profession contributes unique expertise in maximizing function.

Focus on Function: Untapped Potential for Occupational Therapy in Oncology

Function necessarily encompasses both physical and psychosocial abilities (Yuen, Gibson, Yau, & Mitcham, 2007). Occupational therapy practitioners are experts in evaluating and treating all aspects of the client within his or her context and environment to maximize function. Additionally, occupational therapy practitioners are unique in the value they place on the mind–body–spirit connection, thereby viewing their clients as holistic beings with complex functional needs (American Occupational Therapy Association [AOTA], 2014). The lens of function sets occupational therapy apart as a distinct and valuable service (Hildenbrand & Lamb, 2013) for which a focus on the whole is considered stronger than a focus on isolated parts and that has the potential to positively influence the reported dissatisfaction with the current state of supportive care.

Despite the profession's unique expertise in function and holism, the literature reflects a narrow role for occupational therapy in cancer care, suggesting that occupational therapy provides supportive care primarily for physical issues such as

activities of daily living (ADLs), lymphedema, strength, and range of motion (Silver & Gilchrist, 2011). For example, the seminal and oft-cited article regarding occupational therapy in oncology by Penfold (1996) listed common domains for occupational therapy intervention in cancer care, including motor difficulties, bone fractures, lymphedema, shortness of breath, fatigue, pain, and cognitive and perceptual deficits. Penfold then stated, "Many of the other treatment-related problems do not necessarily fall within the scope of occupational therapy" (pp. 76–77).

Despite the decades elapsed since the publication of Penfold's (1996) article, this limited conceptualization of occupational therapy's role continues to be reflected throughout the oncology and supportive care literature. In fact, a recent systematic review of rehabilitation after cancer treatment noted the various domains in which rehabilitation professionals can provide care to cancer survivors, including physical functioning, fatigue, pain, sexual functioning, cognitive functioning, depression, employment and return to work, nutrition, and participation (Egan et al., 2013); however, despite naming physical therapy, counseling, physiotherapy, acupuncture, and art therapy as appropriate therapeutic modalities, the review contained no mention of occupational therapy as a service provider in any of these domains. Likewise, in the National Comprehensive Cancer Network (NCCN; 2015) Clinical Practice Guidelines in Oncology for distress management, multiple mental health professionals are referenced for possible psychological treatment, including psychiatrists, psychologists, advanced practice clinicians, and social workers, but this document excludes any mention of occupational therapy's role in the evaluation and management of distress.

Given the limited role of occupational therapy described in the literature, it is clear that the profession has the potential to expand its role in supportive oncology care by emphasizing its expertise in function. Because of a remarkably comprehensive professional education, occupational therapy practitioners possess a broad skill set, making them an invaluable part of the supportive care team. In fact, AOTA (2015) has named oncology as one of the key emerging niches

in the field, explicating that occupational therapy interventions can facilitate activity, independence, and quality of life through remediation to restore function, compensation of activities, and adaptation of environments (Longpré & Newman, 2011). AOTA also provides examples of suitable services for cancer survivors, including lifestyle management, sleep and fatigue education, relaxation techniques, cognitive strategies, therapeutic exercise and positioning, and lymphedema management (Longpré & Newman, 2011).

Therefore, the scope of occupational therapy provides a unique emphasis on function by addressing the full spectrum of physical and psychosocial care. In focusing on function, occupational therapy has the potential to encompass all of the specific unmet supportive care needs identified by survivors. For example, stress and anxiety management are two of the most commonly reported unmet needs in supportive cancer care (Adler & Page, 2008). Accordingly, anxiety management and guided relaxation, key intervention approaches capable of ameliorating cancer-related distress, are described in the occupational therapy literature as being appropriate for cancer patients and within the profession's domain of practice (Miller & Hopkinson, 2008).

Likewise, fear about one's health and concerns about loved ones, two additional prominent psychosocial issues reported by cancer survivors (Sanson-Fisher et al., 2000), can be addressed by occupational therapy through the use of cognitive-behavioral approaches, which are within the scope of occupational therapy although not as commonly used (Bruce & Borg, 2002). In fact, occupational therapy professionals are included in a current randomized controlled study investigating the training of various health care professionals to provide psychosocial interventions during routine care to prevent development of significant distress in cancer patients (Turner et al., 2011). Because psychological distress has been associated with impaired physical and emotional functioning in some cancer patients (Ichikura, Yamashita, Sugimoto, Kishimoto, & Matsushima, 2016), occupational therapy intervention addressing both physical and psychosocial impairments

may demonstrate greater impact on functional outcomes.

Education about self-management is also within the scope of practice of occupational therapy and is another common unmet supportive care need reported by cancer patients (Dilworth et al., 2014). Efficacious self-management encompasses the ability to monitor one's own condition and to make changes in the realms of cognition, behavior, and emotion to maintain quality of life (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Access to evidence-based information about self-management of symptoms throughout the continuum of cancer treatment is seen as one of the most essential aspects of supportive care (Harrison et al., 2009). Education about self-management strategies may be particularly important for AYA survivors because this population does not commonly report using long-term follow-up cancer clinics, health professionals, or community resources (Berg & Hayashi, 2013). Baum (2011) has called for a greater focus on self-management strategies in occupational therapy, and research has demonstrated that occupational therapy practitioners are efficacious in teaching self-management in areas such as lifestyle change, coping with low energy, self-advocacy in the health care system, and coping with difficult emotions (Clark et al., 2012).

Barriers to a Focus on Function in Supportive Care

Models of Care, Referral Systems, and Reimbursement Structures

Function involves not only physical but also psychosocial well-being. Current models of care in oncology, in addition to contemporary referral systems and reimbursement structures, can hinder the ability of occupational therapy practitioners to address both physical and psychosocial function in supportive care. In many settings, reimbursement for occupational therapy services requires referral from a physician, and a lack of adequate physician referral has been reported as one of the main barriers to utilization of supportive care services (Eakin & Strycker, 2001; Silver, Baima, & Mayer, 2013).

Physicians may not refer their oncology patients to occupational therapy for a number of reasons. First, today's model of care for cancer treatment typically focuses on disease eradication and monitoring for recurrence (Stout et al., 2012). Although effective, this model lacks systematic attention to functional deficits, resulting in a preponderance of undocumented and untreated function-related issues (Cheville, Beck, Petersen, Marks, & Gamble, 2009; Silver & Gilchrist, 2011; Stubblefield et al., 2013). In fact, the authors of one study evaluating detection and treatment of functional problems in cancer survivors concluded that "functional problems are prevalent among outpatients with cancer and are rarely documented by oncology clinicians" (Cheville et al., 2009, p. 61). However, even when physicians do screen for functional deficits, health care settings often lack adequate systems for referring cancer patients to psychosocial supportive care services (Dilworth et al., 2014).

Newer models of care, such as the Impairment-Driven Cancer Rehabilitation Model (Silver, Baima, & Mayer, 2013) and the Prospective Surveillance Model (Stout et al., 2012), propose screening for functional limitations throughout the continuum of care to maximize quality of life. These newer models suggest an expanded role for rehabilitation services such as occupational therapy from the time of diagnosis and prehabilitation through adjuvant treatment and survivorship (Silver, Baima, & Mayer, 2013; Stout et al., 2012). However, until these models are implemented widely, present-day models of care will continue to deemphasize function and encumber optimal delivery of function-oriented supportive care.

Physicians may also hesitate to engage rehabilitation services for functional problems when anticipating a full recovery in their patients after medical treatment, and this hesitation can be compounded by the gradual, often undetectable, erosion of functionality that can take place in patients during the course of cancer treatment (Cheville, Kornblith, & Basford, 2011). In addition, patients themselves may face stigma surrounding psychosocial issues. Even if physicians inquire about emotional distress, for example, many people refuse

assistance to avoid the label of mental illness (Corrigan, 2004). Finally, physicians cite a lack of insurance coverage and high cost as major barriers to the adequate provision of and referral to psychosocial, function-oriented supportive care services (Dilworth et al., 2014).

Lack of insurance coverage and high cost create particularly challenging barriers to occupational therapy supportive care provision in the United States. The Patient Protection and Affordable Care Act of 2010 (ACA; Pub. L. 111–148) was created to make health care more accessible, less costly, and of a higher caliber of quality and efficiency. However, ACA also requires efficiency, meaning that “unnecessary costs” will result in payment penalties. Unfortunately, what is deemed necessary does not necessarily encompass psychosocial or wellness-based practice. Nonetheless, Medicare does have a history of designating necessary care as encompassing that which increases function (Fisher & Friesema, 2013), and recent scholarship indicates not only that increased function decreases the economic burden of cancer survivorship but also that occupational therapy is an essential part of any multidisciplinary effort to improve function in cancer survivors (Silver, Baima, Newman, et al., 2013). Ultimately, although ACA may complicate efforts to provide holistic, wellness-oriented care, its focus on function also suggests the potential for increased coverage of function-based occupational therapy services.

Barriers Stemming From the Biomechanical Framework

An emphasis on the biomechanical framework in rehabilitation environments (Hooper & Wood, 2002) may inhibit creative, psychosocially oriented treatments that would satisfy the unmet supportive care needs of cancer patients and address function in its entirety. The biomechanical model has been a commonly used framework in occupational therapy. It highlights the use of activity and exercise to limit deficits in occupational performance components and promotes the reduction of deficits to achieve independence in ADLs (Jackson & Schkade, 2001). This framework is applicable to oncology care, given that

many physical side effects of cancer such as lymphedema are, in fact, expressions of problems with underlying structures. However, occupational therapy practitioners in oncology care should not be limited to the biomechanical framework.

Unfortunately, a lack of support for the treatment of emotional and psychosocial concerns has been cited as one of the main barriers faced by health care professionals in oncology (Dilworth et al., 2014). Baum (2011) suggested that to provide the highest quality of care for patients, occupational therapy practitioners must move from the medical model, which entails treating patients to help them recover, to the sociocultural model, which involves treating people to help them function better and participate more fully in their lives. For practitioners working in alignment with the sociocultural model, supportive oncology care focuses not on specific body structures but rather on building client-centered programs that support function and participation in a broader sense. These programs may include family and patient training, social opportunities, return-to-work training, communication building, home assessment, and education about self-management (Baum, 2011).

Education and Research Gaps

Cancer patients have reported that occupational therapy practitioners and other health care providers have provided them with inadequate information about their treatment, care, and self-management options, which can lead to heightened anxiety in the face of diagnosis and treatment (Liao, Chen, Chen, & Chen, 2007). This lack of dissemination of information may stem, first, from the dearth of rigorous research on the needs of cancer survivors, especially in the occupational therapy literature (Holm et al., 2012). Oncology has been emerging in recent years as a popular area of scientific investigation in the rehabilitation sciences, including in occupational science and therapy (Silver & Gilchrist, 2011), so new research will likely continue to emerge in this area.

The shortage of information provision by occupational therapy practitioners may also stem in part from a lack of education in professional curricula about the specific

needs of cancer patients (Silver & Gilchrist, 2011). Occupational therapy practitioners are trained to be generalists, practicing in a wide variety of populations and arenas, and often receive very little specialized training regarding the needs of oncology patients as part of their professional curriculum (Berg et al., 2009). The Institute of Medicine has called for expanded efforts to educate health care providers about the health and quality of life issues facing cancer survivors (Hewitt et al., 2006).

Interdisciplinarity and Contextual Issues

Because of its multifaceted and complex nature, the field of oncology is inherently interdisciplinary. Numerous rehabilitation professionals may contribute throughout the continuum of care, including occupational therapy, physical therapy, nursing, and social work, among others. It is therefore unsurprising that barriers to full, function-oriented occupational therapy involvement in oncology can arise within the team dynamic, including weak interfaces between disciplines (Silver & Gilchrist, 2011); discipline-specific terminology, methods, and measures (Alfano et al., 2014); and concerns about violating scope of practice (Dilworth et al., 2014). Some function-related supportive care services may fall within the scope of practice of more than one discipline, and disputed responsibility has also been cited as a barrier to provision of supportive care (Dilworth et al., 2014). For example, guided relaxation and breathing are used by both occupational therapy and physical therapy practitioners to decrease anxiety and improve quality of life in cancer patients (Jensen et al., 2014). The best possible care for a cancer patient suffering from anxiety would therefore require expert coordination between occupational and physical therapy practitioners.

Other contextual issues may also prevent full involvement in supportive care. For example, cancer psychosocial support services have been shown to appeal primarily to older, White, middle- to upper-middle-class women (Eakin & Strycker, 2001). One study evaluating utilization of occupational therapy services in cancer patients also found that cancer patients using such services are more likely to be

older and female (Pergolotti, Cutchin, Weinberger, & Meyer, 2014). Thus, many people of different genders, races, ethnicities, and ages may not be receiving the full spectrum of physical and psychosocial supportive care.

Moreover, a systematic review of barriers to supportive psychosocial cancer care found that the most common barrier reported by patients is that they do not perceive that they need psychosocial care (Dilworth et al., 2014). Many patients may also be reluctant to report functional limitations or may be unsure of what supportive care services are available (Cheville et al., 2011). In one study, the biggest reported barrier to using more supportive care services was a lack of awareness that the services were offered (Kumar et al., 2012). Ultimately, occupational therapy practitioners may encounter difficulties in providing holistic, function-oriented supportive care when their clients are unaware of or unable to access the full breadth of available care.

Implications for Occupational Therapy Practice

Despite facing barriers to a more expansive position in supportive oncology care, occupational therapy practitioners and researchers can take steps to extend the profession's role. Practitioners can take action in the following ways:

- Advocate for the importance of psychosocial supportive care for cancer survivors. Mental health is essential for function. However, a lack of team support for the treatment of emotional and psychosocial concerns has been cited as one of the main barriers faced by health care professionals working in oncology (Dilworth et al., 2014). This lack of support may inhibit creative, psychosocially oriented treatments that would satisfy the unmet supportive care needs of cancer patients. Advocacy is needed within individual practice settings to broaden accepted definitions of supportive care.
- Develop and test the efficacy of physical and psychosocial function-oriented occupational therapy interventions for the oncology population. High-quality evidence is needed demonstrating that

occupational therapy is efficacious in diverse supportive care roles beyond those involving biomechanical rehabilitation and ADLs. Strong evidence supporting an expanded role for occupational therapy may bolster referrals for a broader array of supportive care needs. Additionally, greater evidence supporting the efficacy of occupational therapy psychosocial interventions may promote the inclusion of occupational therapy in oncology-related practice guidelines such as those provided by the NCCN for distress management, thereby incorporating our profession into documents that determine the standard of care for the oncology population on a national level.

- Continue professional discourse regarding the implementation of an entry-level clinical doctorate in occupational therapy (OTD). Although there is still much debate about the merits of the OTD within the profession (AOTA, 2014; Smith, 2007), an OTD specializing in oncology would certainly provide occupational therapists with a more comprehensive education, enabling them to expand their knowledge as it relates to potential functional impairments in the oncology population; to disseminate more specific, tailored education about self-management to cancer survivors; and to provide appropriate psychosocial interventions.
- Establish supportive care services that are accessible and appealing across genders, ethnicities, and ages. Women cancer survivors have been shown to express more needs and participate more often in rehabilitation activities, whereas older adults with cancer often report more unresolved supportive care needs (Holm et al., 2012). If occupational therapy practitioners are aware of these common disparities, they will be more likely to identify clients who may have difficulty obtaining supportive care.
- Ensure that clients are informed about the full breadth of available occupational therapy services. In a cross-sectional survey of patients with breast, lung, or gastrointestinal cancer, more than half of patients did not use supportive care services simply because they were not aware that the services were available (Kumar

et al., 2012). If a client is unaware of the breadth of an occupational therapy practitioner's scope of practice, the client may neglect to mention functional, psychosocial, or self-management needs. People with cancer need clearer information and communication about the role of function-based care in survivorship and the nature and availability of psychosocial and education-based services provided by occupational therapy practitioners.

- Move toward function-oriented models of care. Recently proposed models of care such as the Impairment-Driven Cancer Rehabilitation Model (Silver, Baima, & Mayer, 2013) and the Prospective Surveillance Model (Stout et al., 2012) suggest that screening for functional limitations should take place throughout the entire care continuum. If these models of care are integrated into contemporary practice settings, occupational therapy's role in supportive care may expand through increased screening and treatment for functional issues.

Conclusion

Cancer survivors report a need for increased psychosocial and education-based supportive care services, and occupational therapy practitioners possess the skills necessary to provide such services. Moreover, occupational therapy practitioners contribute a unique focus on function that enables attention to the full spectrum of physical and psychosocial care necessary for holistic recovery from cancer. However, research suggests that conceptualizations of occupational therapy in oncology focus mainly on physical interventions, limiting the role of the profession in supportive oncology care and underemphasizing its valuable expertise in function. Barriers to a broader role for occupational therapy may stem from models of care, reimbursement structures, referral systems, focus on the biomechanical framework, gaps in research and education, cultural concerns, and issues stemming from interdisciplinarity.

Although the obstacles to achieving an expanded position in supportive oncology care are numerous, it is imperative that occupational therapy practitioners

working in oncology actively take steps to advocate for a greater presence for the field in psychosocial support services. In addition, it is critical that the profession articulate its unique contribution to oncology—namely, its emphasis on function—as it strives to provide comprehensive patient care and establish its unique role in the field of cancer care. Maintaining the status quo not only will indicate a failure to represent the full capabilities of the profession but also will limit the breadth of supportive care, which in turn may perpetuate physical, cognitive, and emotional issues for clients while limiting function, participation, and quality of life. Occupational therapy practitioners can take action by educating themselves about the entire spectrum of clients' supportive care needs, raising awareness about the barriers that may prevent the provision of these services, and advocating for the use of a more expansive, function-oriented occupational therapy skill set in supportive oncology care across both physical and psychosocial domains. ▲

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